“TMD is completely misunderstood and underestimated by most medical professionals...Dentists and doctors seem to focus on TMJ as just a joint and do not look at the whole body and all of the possible comorbidities. If there were more multidisciplinary collaborations taking place, I feel it would become more transparent that TMD is truly a complex medical condition… I cannot stress enough the fact that comorbidities must be considered and investigated in a comprehensive manner.” - Michelle Reardon, 2019, at the National Academy of Medicine’s Committee on TMDs [1]

“...as my doctor told me not too long ago, “I knew you were really suffering, but I knew nothing about TMD and I didn’t know how to help you. All I could do was help rule out what was not going on.” *To think of all the wasted time, energy, and money spent by countless patients and insurance companies going to dead-end appointments because their doctors don’t know what else to do for us.* Family doctors and dentists need to be educated on the complexities surrounding this disorder.” - Adriana van Ineveld, 2019, at the National Academy of Medicine’s Committee on TMDs [2]

“Two points on [care pathways]. One - *Good training cannot be assumed* and this should be addressed. We’ve heard plenty of evidence for this today….Second point - good/fair is founded on a good diagnosis; TMD is not a diagnosis. A patient may have one or more TMDs and perhaps highly relevant comorbidities, but they can’t just have ‘TMD’.
...*examining TMDs collectively has been useful, but that utility breaks down when you’re attempting to address the needs of an individual patient.*” - Dr. Gregory Ness, 2019, at the National Academy of Medicine’s Committee on TMDs [3]

“It is very important to understand the chronic overlapping pain conditions that these patients suffer from and to get them the care that they need and that’s what we do in an interdisciplinary clinic.” - Dr. Meredith Barad, 2019, at the National Academy of Medicine’s Committee on TMDs [4]

“Therefore, identification of comorbidities is essential in order to select the most effective management approaches.” -Gilles Lavigne, 2016, The Neurobiology of Orofacial pain and Sleep and Their Interactions. [5]

Me:
While making requests for care I get asked by insurance representatives to ‘tell them the disease I have’...well that’s complicated - medical history, comorbidities, how they all interact - basically, the best many TMD patients can do is describe the current systems biology of the issues they experience. In my interactions, insurance representatives will simplify what I relay to them as ‘jaw pain’. The persons performing the reviews for out-of-network adequacies, reconsiderations, and appeals are often asking the wrong questions and do not have a sufficient understanding of TMDs to perform the tasks they are assigned to provide to members.

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A Foreword to the **Medical Director's** of Cigna, Unitedhealthcare, & TennCare:

I will be trying, once again, to get approval for out-of-network adequacies for providers I've delayed attending in-office visits with while working on this medical appeal. I expect these requests to be denied like previous requests were denied. My planned attempt to request these approvals is done solely to document the requests took place prior to seeing the providers. Instead of sitting around and having my health further deteriorate, unable to get closer to answers through accessing competent diagnosis and treatment plans, I will make appointments to see these providers and will attend these appointments without any further delay. I will be expecting the Medical Directors of Cigna, Unitedhealthcare, TennCare, and various team members involved in reviewing my appeal to make it their personal mission, their duty, to overturn these wrongfully denied NAPs and facilitate reimbursement for the associated claims at the rates the clinician charges the patient, even when these claims don't fit easily into existing billing practices. I suggest they advise their colleagues, including the Directors of Policy for one's respective organization, to change how their organization is functioning so that the review process operates with integrity and medically necessary care is accessible to plan members.

I expect an end to the mismanagement of my care. I will not stand-by as Cigna, UnitedHealthcare, and Tenncare bounce responsibility between themselves or wait for their legal departments to find a loop-hole to having to fulfill your ethical and legal obligations. You'll all be doing your jobs with competence and excellence or suffering the consequences of failing to do so, of that I am 100% committed, even if that means I have to die trying.

Appeal Preface:

Before reading the bulk of my appeal I would ask the reader and all those involved in assessing any aspect of my appeal to view recordings of some of the patients who spoke at a committee meeting at the National Academy of Medicine (NAM) titled, “Temporomandibular Disorders: From Research Discoveries to Clinical Treatment” which took place on March 28th-29th, 2019 and is part of a series of meetings taking place throughout 2019 [6]. This is to provide a clearer context of what you are reading with my appeal and to also help the reader realize that the caution and diligence I have engaged in has been done for good reason. Further, that my advocacy for third-party payers to assist in helping myself and other members access appropriate care will, to some extent, require third party payers to go beyond what they have historically perceived as their obligation to do. It is my hope that members will be provided the resources that will enable us to access the physicians and procedures appropriate to our cases.

However, step one in accomplishing that requires first that Cigna and United Healthcare cease acting in bad faith and fulfill what they are, supposedly, obligated to do: one example of many I could provide being, third-party payers are obligated to fairly and competently assess and review claims, network adequacies, appeals, and otherwise interact with members and physicians in a manner which does not place unreasonable burdens upon them; such as forcing someone as myself into a situation which requires one spend years of their life to gather enough information that they can write their own medical appeal rather than using those efforts to seek and receive care for their condition from physicians specialized to meet their needs.

I hope viewing the presentations at the NAM meeting will also make it clearer that my case, and that of many other ‘TMD’ patients, is always far more complicated than a ‘jaw disorder’ and that to claim it is a dental issue is outrageous. That simplifying a complex systems disorder to ‘dental problem’ demonstrates the presence of knowledge gaps I believe indicate that those determining policy and involved in reviewing requests for care tend to be both negligent and incompetent in the performance of their duties.

I hope to make it clear that clinicians must be incentivized to spend the time needed to achieve favorable outcomes in the care of their patients. As a patient I need a primary care physician who is not constrained in their ability to assess and coordinate my care because a service which is necessary is exceedingly difficult or impossible to get approved. It is disconcertingly common to find doctors so discouraged by past interactions with third-party payers they believe efforts to appeal third-party payers to assist them in the care of their patient would be nothing more than a waste of their time that would detract from servicing the needs of their patients. Sadly enough, some of these services that are poorly incentivized in the current reimbursement provided by insurers are things as fundamental as taking the time needed to seek out the educational resources necessary to understand a patient's needs, to communicate with the patient so as to gather a detailed history, or to collaborate with other physicians involved in the patients care so as to better understand or meet patient needs.

I and other TMD patients need to be able to easily consult with and become patients of physicians who are out-of-network as current in-network offerings are extremely deficit or entirely lacking when it comes to the care of Temporomandibular Disorders and Disordered

Breathing. We need to cover these out-of-network providers at in-network rates without having to spend days, weeks, months (or as the current situation is, **years**) trying to get approval or hunting for billing/diagnostic codes and then learning how to navigate third-party payer systems in order to submit successful claims, all while being prohibited from speaking with provider services.

Unlike professionals, I do not have the resources necessary to hire consultants to educate me on how to perform medical billing in the current payer system. As patients, our minds are addled by pain, poor sleep, disturbed digestion, and other burdens. We need to be enabled to get to the bottom of our issues; of what is the most appropriate and efficacious therapy for our medical needs. I and others need to meet with specialists to get multiple treatment plans and then work with physicians to pick the one which seems to provide the best outcome for one's case. The normal machinations of monolithic organizations such as Cigna and UnitedHealthcare have been a frustrating disaster for members by impairing their ability to access even the most basic care for sleep, breathing, TMD, the effects these disorders have on mental health, and other comorbid medical issues.

Failing to take an involved role in helping patients like myself find and access care appropriate to their case has negative consequences to third-party payers, patients, employers, and the communities that they are a part of. It has been tremendously expensive to third-party payers, and has exerted a personal and financial cost to myself, family, and society that dwarfs the cost to payers. The story of Jennifer Feldman and other patients is not uncommon. It is one of many cautionary tales that has made it clear to never trust; always double and triple check and require a provider to validate what they claim even if all they have is a career of case studies. It is imperative for a patient and provider to do everything in one's power to avoid surgical interventions for temporomandibular disorders and, to a lesser extent, it is also preferable to avoid surgeries when treating disordered breathing until a greater portion of orthodontists, oral surgeons, ENTs, and sleep physicians possess a much more robust understanding of the physiology of breathing and respiration, both diurnal and nocturnal.

My ability to work towards accessing care for my medical conditions has been quite limited due to the behavior of Cigna and UnitedHealthcare. My health has declined and I fear for my future, quite often questioning, at this point, if receiving treatment will be sufficient to allow a worthwhile recovery.

So, please, view the video of the patients telling their stories and know my case is different (nearly every TMD case is) and the perspectives and experiences offered are not entirely representative of what needs to occur in my care. What is representative is that the behavior of medical professionals, third party payers, and society have made it difficult, and often impossible, for patients to access appropriate care. And it is with disturbing irony that I observe some of those behaviors and knowledge gaps can be found in the speakers who presented panels to the committee; so if the reader becomes intrigued and views the other panels, know that many of the speakers are missing some spectacularly large puzzle pieces to understanding TMDs that are highly relevant to my case. I would specifically criticize the OPPERA study's methods in assessing breathing and sleep. A self-report questionnaire that relies on patient awareness is far from sufficient to accurately model the prevalence of disordered breathing within the TMD patient population. After reading my appeal, I hope to make such matters clearer to the reader.

The following videos and transcripts are from March 28-29th, 2019, Public Workshop: Temporomandibular Disorders (TMD): From Research Discoveries to Clinical Treatment. This is the second meeting organized by the committee on TMDs working "under the auspices of the National Academies of Sciences, Engineering, and Medicine's Health and Medicine Division".

Youtube video: "Panel 1: Jennifer Feldman" [6]
https://www.youtube.com/watch?v=QLTvPfsmq_M&list=PLGTMA6QkejfgOSMnkgkYgrdqosbuHpO0Z&index=3

See Also: "Panel 1: Discussion" [7]
https://www.youtube.com/watch?v=Mh8WHJeq4UQ&list=PLGTMA6QkejfgOSMnkgkYgrdqosbuHpO0Z&index=6

Excerpts from the meeting worth highlighting:

"Panel 1: Discussion" [7]

6:25-8:10
Dan Clauw?: "I'd like to thank you [J. Feldman] for such a powerful statement. One thing that struck me...is the enormous amount of emotional suffering that occurs….and how that builds over time. I wondered based on your experience what are the things that we can do to identify that suffering early and to reduce it?"
J. Feldman: "...I think we need to make sure patients are taken seriously so that they're not dismissed as lunies because plenty of people looked at me like, 'it's in your head', 'it's psychosomatic', 'it's stress', 'go for some biofeedback', and dismissing somebody is demoralizing and it makes you feel like you're less than deserving of real medical attention."
8:20-10:20
David Deitz: "So Jennifer...you mentioned the difficulty you had with insurance coverage and that's certainly one of the things that can be demoralizing in terms of lack of recognition. ...could we see some of those coverage determination correspondence pieces?"
J. Feldman: "...I happen to be on Medicare. I'm permanently disabled according to the government, so I'm on SSDI. ...So, Medicare denied my last surgery.. They said that...anything that has to do with the teeth and jaws is excluded from the policy and I am happy to provide that letter for anyone to see that it was denied by the government; by Medicare."
15:45-16:30
Sean Mackey: "I want to call out one aspect that really resonated with me and that is the degree of social isolation that you [J. Feldman] experienced. ...I would submit that we frequently give the social aspect short shrift. ...when I was listening to you and hearing the degree of...kind of invalidation of your problem and the impact it's had on you and your family and your friends, that just really struck very strongly. And I see that as a physician scientist who takes care of patients.

I’m focusing more and more on [the social aspects] and when you dive in you see just what a huge impact it’s having on people’s lives.”
16:40-22:45
Sean Mackey: “Dan I want to put you on the spot. Bill followed you so he had a chance to respond to your presentation...and I’m interested in how you’d respond to [Bill’s response]. ...What I’m really looking for is the grand unified theory here; the simple explanation that brings both of [Bills & Dans] models together, if it is at all possible.”
Dan Clauw: “...I think [our] conclusions [are] fairly similar. Probably the only thing I take offense with that Bill says is that he continues to put somatisation into the psychological category. ...what used to be called somatisation...has very strong biological underpinnings. ...study psychological factors separately, because if you look at classic psychological factors such as anxiety, depression, catastrophizing those are only weak predictors of the development of TMD in OPPERA, or weak predictors of the development of fibromyalgia in population based studies...these are very weak. ***Having a sleep disorder in the population is a more powerful predictor of developing pain than having depression or anxiety.”***

“Panel 2: Tricia Kalinowski” [8]

https://www.youtube.com/watch?v=09ZAz9pjjhg&list=PLGTMA6QkejfgOSMnkgkYgrdqosbuHpO0Z&index=8
4:45
T. Kalinowski: “Patients need to stay away from surgery as long as possible and to look for other types of treatment such as physical therapy, cranial sacral therapy, and massage to name a few. ***It takes time and hard work to find a solution and they aren’t likely to be found on facebook or Dr. Google and they are often not covered by most insurance companies.*** Patients can’t rely on FDA approval either. The same rules that allowed the Vitech implant approval [which was recalled and a cause of her problems] is still in place today.”

“I know several patients who have set aside meds that they might need for what they call an “exit plan” should their pain become unbearable. **I know of two suicides within the TMD community in the last six months alone directly related to pain management.”**

“And more importantly how do we [TMD suffers] convince ourselves that even though we had a miserable day and our pain is out of control and insurance has rejected yet another test or procedure, that in spite of it all, it’s still worth waking up again tomorrow? Or do I pray for a terminal illness that has an end date rather than this daily agony so at least my family won’t hate me for giving up.”

“Panel 3: Lisa Schmidt” [9]

https://www.youtube.com/watch?v=3FT5ftunlqY&list=PLGTMA6QkejfgOSMnkgkYgrdqosbuHpO0Z&index=15
0:30
Lisa Schmidt: “It all started in 1999, when the primary care physician sent me to an orthodontist to have a splint made for my migraines. The splint pushed my jaw back causing the disc to go

out of place and I could not open my jaw. Then I was sent to an oral surgeon who recommended I have arthroscopic surgery. After my surgery he suggested we fix my bite which led to a second set of braces and upper and lower jaw surgery. At this point my joints rapidly degenerated and he suggested removing my discs. When the surgery failed my mandible quickly fused to my skull. When I discussed with him that I had gradually worsened through all of these surgeries and asked what his next plan was he told me that my small children and I were the reason for the failed surgeries and said that I needed psychiatric help. That is when I became depressed and began to look for another surgeon to help me."
12:10
Lisa Schmidt: "TMD is a complex medical problem that needs a multidisciplinary approach that is Patient Centered."

"Panel 4: Michelle and Alexandra Reardon" [1]

https://www.youtube.com/watch?v=BAQygFdBaoY&list=PLGTMA6QkejfgOSMnkgkYgrdqosbuHpO0Z&index=25
14:50
Alexandra Reardon: "Pain control for me has been difficult to achieve. Most pain clinics don't even know how to treat TMD. When I went to pain management I was dismissed after mentioning TMJ pain and was viewed as a drug seeker. I now carry a large 3-ring binder with me which contains all of my medical records, reports, and images to appointments just so that I can prove just how significant the damage to my jaw really is."
15:40 "My masseter muscles are in a never-ending tight, clenched position making it difficult at times to open my mouth at all. I avoid lengthy conversations as the reality is I will pay for it later."

"Public Comments and Day 1 Closing". [10]

9:00
Beth Bigge: "I invited Norwalk hospital here, I invited other people to come, I invited some media attention - no one's here. I don't know why….many years ago I was on the board of the TMJ Association and, again, it was difficult to get people to come and give recognition to this disorder. They don't understand the seriousness of some of these caes and the differences. So the education... not just the dentists, but physicians need to be educated. My own physiatrist, because I have arthritis from c1 all the way down to l5 and we're thinking of surgery, but he says there's just too much damage and again my physiatrist won't touch anything from the neck up. *So, I'm left to my own devices.*"

[As an aside, to validate the experience of Beth Bigge (whom I have had no knowledge of until viewing these panels) I will cite observations I made early on and wrote about in 2017 as part of a document draft that was intended for, but never completed and submitted to, Unitedhealthcare. "... the differential diagnosis is often left up to the patient as the opinions of academics, clinicians, and renowned experts are, quite frankly, often in conflict." - Sean Smith, October 2017, "UHC Director Doc", Unpublished work.

Alternatively I wrote in 2018, “Essentially, I have been handed a variety of conflicting opinions and left to perform the differential diagnosis myself; they provide a opinion, a diagnosis even, then a treatment plan, without validating either with the necessary diagnostics.” - Sean Smith via Reddit, 2018 [11].

And to validate both Beth Bigge and myself, here is a quote by Dr. James Guinn, a dentist who spent decades practicing TMD medicine, “Much of the confusion surrounding the TMD field is self-inflicted. As a profession, we have made it confusing because we have failed to reach a consensus on how to diagnose and treat these problems.” “...it is the patient making the differential diagnosis, based on whom they choose to go to for help.” [12].]

36:55
Kimberly Lancaster: “I had doctors tell me from ents to physical medicine that nobody even exposed them to TMD or TMJ training during their residency. They didn’t even know what to do with the TMD/TMJ patient and this is 2019. I see people getting unnecessary surgeries where alternative treatments weren’t offered. I see a lot of greed. I see a lot of engineering of the actual research. If something doesn’t go right they don’t want to report side effects and it really comes down to there has got to be better governing and advocacy and people have to realize that TMD/TMJ is a whole set of things not just muscular.”

37:45
Terry Crowley (founder of TMJ Association): “..I was thinking back to how we started the TMJ patient led round-table, about three years ago, it was interesting because I don’t I have to tell you that this whole area with the complexity of the conditions, of the merry-go-round the patients are on, also leads to distrust of everybody treating them, distrust of the government, they lose their faith, they commit suicide.”
“There is not a lot of patient centeredness nor patient involvement, or I should say, there is none until now, in this condition. And, I actually see it as the only way going forward. We [the patients] have got to be part of the guideline development. These patients [those who spoke to the committee] bring up issues you didn’t even dream up that are important to them, not to you, because you don’t even know, but to them, and they’re the ones that you’re working for.”

“Panel 5: Adriana van Ineveld” [2]

2:40
“At my 6-month follow-up appointment my surgeon declared the surgery a success because my joint was functioning and my opening was acceptable. But when in tears I began to list my new more intense pain and flu-like symptoms, and the fact that pain killers I was taking barely touched the pain, he stopped me mid-sentence and said, “You need to deal with those issues with your family doctor.” In that moment, I felt dismissed and devastated.”
“Now somehow I had to convince my family doctor and the insurance company that I was in more pain than before the surgery, and I would have to do that without the help of the doctor who performed the surgery. But worse than that was that the one doctor qualified to acknowledge my pain, to explain it and possibly treat it, had dismissed me and didn’t want to hear what I was experiencing.”

...."So the patient is left to take the meager amount of research out there to educate their family doctors and negotiate their own treatment and pain management. They have to deal with the fact that every aspect of their life has been affected."

"So who do we turn to for help. You heard Michelle Reardon yesterday list all the specialists that make up her daughters medical team. I was sent to many of the same specialists because, as my doctor told me not too long ago, "I knew you were really suffering, but I knew nothing about TMD and I didn't know how to help you. All I could do was help rule out what was not going on." *To think of all the wasted time, energy, and money spent my countless patients and insurance companies going to dead-end appointments because their doctors don't know what else to do for us.* Family doctors and dentists need to be educated on the complexities surrounding this disorder. ...Family doctors and dentists need to be able to explain to patients, the mechanics of the joint, the nature of the muscles surrounding these joints, and about the major nerve bundles just millimeters away from the joint so that their patients can make sense of the myriad possible symptoms that they're experiencing. Doctors and dentists should be able to suggest self-management options to try first, [and be able to] recommend, hopefully, a truly qualified TMD physiotherapist, and explain that there are no quick fixes."

"...finding a physiotherapist that is truly trained to treat TMJ issues, that didn't just take a weekend workshop, is a challenge."

Excerpts from a letter written by Terrie Crowley to the National Institute of Medicine [13]:

"Fortunately, there has been some progress upon which to build. The TMJ Association Scientific meetings and the OPPERA study have established that unlike the simplistic focus on jaws and teeth, TMD is a complex multisystem disorder with many associated medical co-morbidities. Although we cannot over emphasize the importance of these findings, they also revealed the gaps and many opportunities that exist for cross-Institute collaborations to bring the already existing scientific and clinical expertise in other complex conditions to TMD."

"Another group will develop a plan for identifying all the medical disciplines necessary to include in building the optimal treatment model for TMD patients. A patient in the Round Table put it this way, "the current system (for lack of a better word) for treating TMD is broken and patients are falling through the huge gap between dentistry and medicine; abandoned and alone, and it is in this no man's land that patients find themselves"."

"Now, I have also been asked by the Committee to tell of my experiences with TMD. 33 years ago I started The TMJ Association following my TMJ surgery because my dentist wouldn't even clean my teeth until my jaw was stabilized. Until that surgery, I had no pain and my jaw functioned just fine. This surgery changed my life and not for the better, The surgery triggered years of relentless overall jaw and body pain, jaw dysfunction, excruciating hyperacusis, and years of recovery from the brain injury during the surgery. It was after the surgery that I learned how little was really known about the jaw joint, the most complex joint in the body, the implant that I received, and the resulting problems. It was then that I began meeting and hearing from other TMJ patients far worse off than I and that compelled me to do something about this."

“My years of TMD blur into several areas but the one that consumes me is patients. They are suffering not only from their condition but the dehumanizing actions and attitudes of dentists, physicians, family members, coworkers, friends who cannot understand what “this TMD thing” is and why they don’t get better. When harmed they feel betrayal from the people they sought help from and trusted to “do no harm.” This distrust permeates many aspects of their lives. I see those endless emails that begin or end with the words, please help! I hear of the financial burdens, the bankruptcies, divorces, about the stresses on their loved ones and the guilt the patients feel. They tell of their daily decision to either eat or talk because they can’t do both; the desperation in their voices when they ask us for help after endless treatments which have only lead to more pain and suffering. And yes, deaths and suicides. Margaret’s sister in Pittsburgh called to tell us that Margaret died and that after her 62nd jaw surgery and 11th set of implants. She was 41 years old. And on October 10th at the end of the day I thought I’d make one more call to the patient who emailed me the Friday before. A man answered and I asked to talk to Patty. He said, “She’s not here. Who is this?” I said, “Terrie from TMJ.” He said, “She’s dead.” I said “but she emailed me on Friday, when did she die?” He said, “Saturday.” I asked, “How?” He said, “She shot herself.” The rest of the conversation was a blur but he ended by saying, “She had over 38 surgeries and couldn’t take it anymore. There will be no obituary, no funeral. The past 10 years we haven’t had one person in this house. We never went out with another couple. We couldn’t because Patty couldn’t.”.”.

I think the above information makes it clear the field of TMD medicine is difficult to navigate. That finding a provider who has the expertise to meet one’s needs requires a lot of work. That care needs to be personalized and coordinated. I have been putting in that work to model my medical issues and find providers appropriate to my case. Cigna and UnitedHealthcare have engaged in actions that work against efforts to seek and access appropriate care for TMD and other medical conditions. This increases the burden patients must shoulder - it’s the reason why many of us suffer as much as we do, even to the point of considering or committing suicide.

Sean Smith's Appeal for Medical Care of TMD & Comorbid Conditions:

“The temporomandibular joint is the only joint in the body that is restricted by insurance companies.” - Dr. Jeff Okeson, 2019, in a Presentation to the National Academy of Medicine’s Committee on Temporomandibular Disorders [14]

"Even if you didn't care about the human cost, you should care about the economic cost, treating a disease at its first stage is always going to be much cheaper than treating it at its advanced stage." - Jorge Riopedre, in an interview with National Public Radio [15]

It’s no secret our healthcare system is broken, particularly when it comes to third-party payers, and that the influence payer systems exert on the behaviors of clinicians is having a pervasive, often negative, impact on the care provided to patients [16]. My story, therefore, should really come as no surprise to many healthcare providers, though I find it disturbing the amount of doctors who are complacent to this reality, or even worse, still yet in denial of it.

I’ve struggled with my mental and physical health since childhood and have been disabled my entire adult life. After a lifetime of psychopharmacological intervention aimed at symptom management I found myself in my mid-twenties with a collapse in my ability to function due to intense pain, cognitive deficits, depression, difficulty breathing, and exceptionally poor sleep. For years now I’ve been trying to figure out why this was happening and to get care for these complaints. Early on I was bounced between specialists for four years with negative findings, and those findings being negative in part because the diagnostics used were constrained by what insurers covered and thus what physicians would make me aware of was an option. What treatment was supplied had limited to no efficacy in symptom management and offered practically no substance in regard to an etiological explanation that moved towards achieving a resolution of primary complaints; I observe this trend to be a common story amongst patients with Temporomandibular Disorders (TMDs) and/or disordered breathing [6, 7, 8, 17, 18, 19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 29, 30, 31, 32, 33, 34, 35, 36]. I can provide more references on my last point if the reader so desires.

In fact, instances of patients diagnosed with diseases previously thought to be incurable and difficult to manage have been observed to have those conditions significantly improve or resolve entirely after having their airway and/or TMD treated. Such as cases of refractory epilepsy, orthostatic hypotension, dizziness, syncope, depression, anxiety, complex insomnia, ADHD, cognitive impairment, psoriasis, crohn’s disease, irritable bowel syndrome, hashimoto’s thyroiditis, fibromyalgia, movement disorders such as dystonia and tourette’s, and more. The list of health issues that are directly or indirectly related to breathing, sleep, and TMDs keeps getting longer as more and more cases are being shared. By understanding the systems biology of breathing, sleep, and insults to the trigeminal system and related neurology one is able to comprehend that the referenced cases are far more than mere anecdote. These examples alongside available research evidence demonstrate a profound misunderstanding has been taking place within medicine regarding the etiological factors of chronic diseases and this is in desperate need of revision [37, 38]. As insurers, employers, and citizens we are paying for this - the cost of failing to address these problems is one no party can escape from [39; 13:00:00-18:00:00, 40, 41, 42].

In 2013 the Centers for Disease Control (CDC) described the United States' prevalence of sleep insufficiency as a "public health epidemic" [43]. The CDC partnered with the American Academy of Sleep Medicine in an effort to better address this concern. In partnership these organizations acknowledge that "untreated sleep illness and sleep loss have a cumulative impact on nearly every key public health indicator, increasing the risk of physical and mental health problems, mortality, accidents, injuries, and *disability*." [44]. An article written by a group of medical professionals from different corners of the world proposed insufficient sleep be classified as a "noncommunicable disease" [45].

My health has continued to decline despite enacting many radical changes in lifestyle; my life currently revolves around managing pain, poor sleep, impaired digestion, trying to eat enough, compensating for cognitive deficits, and trying to live with the psychological distress I experience as a result of my situation. By educating myself and engaging with doctors I slowly pieced together that my struggles, although medical issues, would require a dentist to treat them, and that medical doctors would need to be involved in demonstrating this and coordinating my care in an interdisciplinary fashion with the dentist functioning as the 'quarterback'.

I also learned, unfortunately, that most physicians (including specialists) did not have the training to fully understand the complaints I was reporting, let alone how these are medically necessary to treat and which treatment options are the most appropriate to explore. Treating the patient population I am apart of requires looking at the systems biology of what's occurring and addressing each point of dysfunction from a paradigm that focuses on how the growth, development, and function of the craniofacial respiratory-complex (jaws, nose, mouth, head, neck, and the various systems influenced by or attached to this anatomy and related neurology) influences human health. There are few providers who have the knowledge, training, experience, and expertise to provide the level of care required for patients with complex needs. The nature of their work requires that they be able to act in the interest of the patients health to the best of their knowledge and skill.

The tethers third-party payers attach to physicians impede or outright disallow doctors from doing what is necessary to achieve favorable patient outcomes in the TMD population. To be frank, physicians treating this patient population find it difficult to fulfill even their hippocratic oath when it comes to the treatment of patients whose financial status makes them reliant upon medical insurance to access care. Therefore, despite the fact that care is medically necessary, the predominant practice in this field of medicine has been that patients figure out how to pay out of pocket for treatment. This is as much for the practicalities of being in practice as it is the ethical dilemma of avoiding being in a position in which a patient experiences a continued decline in their health because the third-party payer denies coverage; this would place the treating physician in a position in which they would then be unable to fulfill even the most basic standards of care. I would go so far as to state that physicians currently (2019) contracted on an in-network basis to Cigna and UnitedHealthcare are severely constrained in their ability to provide ethical and efficacious care to patients with TMD and disordered breathing in a manner that is sustainable to their medical practice. For pragmatic reasons, financial sustainability often takes precedence over patient outcomes. This reality leaves many basic needs unmet and has been particularly harmful to TMD patients. It is quite disagreeable for Cigna and United Healthcare to claim current in-network physicians can provide comparable care to the physicians I have sought to attain out-of-network adequacies for.

In speaking with multiple healthcare providers in various fields over the past six and a half years (Otolaryngology, Sleep Medicine, Sleep Dentistry, TMD medicine, Psychiatry, Neuropsychology, Physical Therapy, Orthopedics, Critical Care) I have heard a consistent story that the criteria used by third-party payers to determine if a service is medically necessary seems at times arbitrary or in outright bad faith. Over the past three years I have listened to extensive criticism by educators, clinicians, and nurses regarding the review process third party payers use in coverage determinations based upon “medical necessity” for the diagnosis and treatment of disordered breathing and temporomandibular disorders. These reviews of requests for care often dictate what is medically necessary based upon guidelines which are in opposition to established literature and even consensus statements amongst professional organizations and has little bearing on the realities facing doctors in clinical practice - there is a sick patient in need of care.

Dr. Jeff Rouse does a good job explaining in detail [46] enough specifics as it pertains to breathing disorders that it is quite obvious that guidelines dictated by many third-party payers are compromising the ability of our medical system to adequately meet the needs of patients. Dr. Christian Guilleminault (a legend in sleep medicine) has published an extensive amount of literature on the nuance in diagnosing breathing issues that perturb sleep, with 1,010 research items listed on ResearchGate.com. His work, particularly that focused on demonstrating the relevance of non-hypoxic disordered breathing, show a need to provide appropriate care well beyond waiting for the disordered breathing to progress to the point that OSA becomes diagnosable using insensitive scoring criteria and even advises going beyond what we can currently diagnose with in-lab polysomnography [47, 48, 49, 50, 51]. Some of his works document the harm that is done to patients by obfuscating their access to early care [52, 53, 157]. The guidelines utilized by third-party payers can have distinct shortcomings in early detection and effective treatment of disordered breathing [46, 54]. Dr. Guilleminault has even published articles dealing directly with the problem of letting third party payers dictate what constitutes the presence of disease and disorder [55].

In the aforementioned article, the authors state, “Accurate scoring of clinically and biologically relevant respiratory events is a core requirement in sleep medicine.” [55]. This straightforward declaration implies much, including that it is not acceptable to utilize guidelines which fail to respect the physiology of disordered breathing. The authors also point out, “Ignoring all events without desaturation exaggerates the success rate of therapies, by not counting residual non-desaturating events despite persisting sleep fragmentation.” Ironically, most home sleep study systems lack the instrumentation required to track arousals and yet insurers insist on using them more and more. I am certain this practice as it is currently implemented is harmful to plan members and our society in general.

Operator drowsiness or poor decision-making contributes directly to workplace accidents and motor vehicle collisions [56, 57, 58, 59, 60]. “Sleep deprivation, according to the National Sleep Foundation, increases the likelihood of a workplace accident by 70%.” [61]. Insufficient sleep or impaired sleep quality is noted to have a decidedly negative impact on surgical outcomes in our medical system, placing doctors, hospitals, and insurers at increased liability while also being detrimental to employers by the effects these events have on workplace attendance and performance [62]**.** Undetected OSA is also associated with repeated involuntary job loss, suggesting that the financial burden of poor sleep on organizations extends far beyond documented workplace accidents [63]. I would also offer that these studies, particularly the last one, demonstrate that in order for a medicaid program “to help rehabilitate the disabled so that they may return to useful employment” in order to “advance the economic security of the American people.” [64] the program must attend to sleep and breathing with greater diligence, a diligence that fully respects the biology of respiration, breathing, and sleep. Obfuscating access to accurate diagnostics or utilizing criteria that are insensitive contributes to these and other burdens that we collectively share. As one group of authors note:

> “Moreover, most cases of OSA in the population and the workforce remain undiagnosed and thus, untreated. Therefore, excessive daytime sleepiness (EDS) related to OSA has repeatedly been implicated in major transport accidents by the US National Transportation Safety Board.[30,31] OSA has also been demonstrated to have adverse impacts on employees' healthcare costs and workplace productivity.[32] Now, the Garbarino paper demonstrates consistent evidence of about a two-fold excess in the risk of occupational accidents.” [65]

Building from Dr. Guilleminaults work with non-hypoxic disordered breathing is the work of Dr. Avram Gold in linking disordered breathing to functional somatic syndromes [66, 67]. Dr. Gold’s proposition has been a missing piece of the puzzle needed to better explain the relationship between conditions like TMD and Sleep-Related Disordered Breathing (SRDB). It has become an integral part of dental continuing education focused on providing an understanding of how to treat TMDs and a variety of associated comorbidities [68, 69, 70, 71, 72, 73, 74, 75, 76, 77, 78, 79, 80, 81]. This is due, in part, not simply because the foundational knowledge elucidates the necessity an airway centric paradigm, but because improved clinical outcomes are occurring when the provider is competent in assessing the facial anatomy with a knowledge base which allows one to account for the physiology of breathing and respiration. “It is a sea-change in how we see the role of the dentist, orthodontist and all related health care providers. Sleep disordered breathing, Temporomandibular Disorders (TMD), dental crowding, bruxism/clenching, craniofacial distortions, ADHD (Attention Deficit Hyperactivity Disorder), ARCD (Airway Related Craniofacial Dysfunction) and many other medical sequelae are considered signs and symptoms of the deficient airway in the vast majority of cases.” [82]

The way that disordered breathing can act as a perpetuating allostatic challenge which sensitizes the limbic system and HPA-axis is critical to understanding TMD patient populations and the clinical symptoms they present with. It is also important to understanding how facial anatomy that is suggestive of a compromised airway can adversely impact breathing, and thereby disrupt sleep quality, either by fragmenting sleep or altering sleep architecture. It is unfortunate that these topics are a knowledge gap held by the majority of physicians I have encountered. A somewhat common story to be heard in TMD medicine which illustrate this knowledge gap's relevance include how there are clinicians who have had TMD patients who were previously diagnosed with fibromyalgia and after receiving treatment for their TMD they then observe the fibromyalgia symptoms reduce or resolve [29]. Airway patency and its influence on sleep are now beginning to be viewed as critically important to understanding the TMD puzzle as well as other chronic diseases. Research specific to fibromyalgia offer indirect support for these observations made by clinicians in TMD medicine [83]. An excerpt from a book written by Dr. Howard Hindin and Dr. Michael Gelb explains:

> "A study by Harvey Moldofsky, M.D., of the University of Toronto found fibromyalgia patients' sleep lacked restorative qualities. He showed that stage 4 sleep - the second portion of deep sleep - was fragmented in fibromyalgia patients. Stage 4 sleep is key to stress relief since this is the stage where growth hormone and interleukin - a potent immune modulator - are secreted. Moldofsky found that treating fibromyalgia patients with therapeutic interventions that restore their deep sleep also decrease their pain.
>
> To prove this disruption was the cause of the chronic pain and other symptoms, Moldofsky interrupted the stage 4 sleep of healthy patients. In just a few days, these healthy people experienced the same tender muscle points that fibromyalgia patients experience. Moreover, the healthy patients whose deep sleep was disrupted showed brain EEG patterns that were similar to the EEGs of patients with fibromyalgia during sleep.
>
> This study and others show that not only does pain cause sleep disruptions, but also disrupted sleep can literally cause pain [84]." [85]

As part of how respiratory events lead to arousal from sleep, the autonomic nervous system instigates behaviors to compensate for the airway compromise, such as bruxism or posturing the jaw, head, and neck. To support those compensations for breathing the rest of the postural chain will adapt, affecting the thoracic, lumbar, and pelvic regions as well as the legs and feet. For some individuals the consequences of these behaviors and other factors lead to further arousability which fragments sleep and contributes to the development of musculoskeletal issues through multiple physiological and neurobiological pathways. This fragmentation of sleep is known to play a pivotal role in driving central sensitization of the nervous system which is a primary mechanism contributing to the development of a chronic pain condition.

Individuals vary in their vulnerabilities; this variance in individual vulnerability is in large part why it has been so difficult to understand the link between TMD, breathing, sleep, and other comorbidities such as the somatic syndromes and psychiatric diagnoses. There are differences between male and female, between those suffering macrotrauma and those that do not, between those whose onset of disordered breathing is severe in early development and those whose severity remains sub-clinical to an OSA diagnosis until later in adulthood - the amount of variables that have been noted is quite extensive and beyond the scope of even this medical appeal to review.

In my view, only an experienced and knowledgeable physician should be involved in treating complex TMDs if only for this one fact - a failure to accurately and thoroughly model what's going on with a TMD patient will lead to misdiagnosis and inconsistent treatment outcomes. The toll this takes on patients is not simply the biological cost of failed treatment, but the psychosocial stress can even serve as a life-altering trauma [8, 10]. I believe this trauma can and does progress to the point that what is present, in myself and others, seems much like what mental health professionals describe with post-traumatic stress disorder (PTSD). Furthermore, when one understands the neurobiology of TMD and its relationship to sleep and then sees the nearly identical neurobiology described within the psychiatric field on what occurs in PTSD, there is an amazing amount of crossover to the point that they become difficult to separate from one another [66, 67, 86, 87, 88]. More interestingly, one can also explore the links between chronic pain conditions and these neurobiological pathways. One such path is that of alterations in sympathovagal balance [89E], of which interesting observations can be made while reviewing studies showing that vagal stimulation can be effective in treating PTSD [90], Crohn's [91], as well as promising results in refractory depression [92], all of which are disorders known to have comorbidity in persons with disordered breathing. "There is truly no aspect of a human beings wellness that we've been able to discover that isn't eroded by a lack of sleep." [93; 50:00:00]**.**

In listening to the stories patients have shared online and viewing case studies in TMD medicine it is common to hear of patients being bounced between medical specialists for years to then be told by a dentist one has "TMJ". To then spend thousands of dollars out of pocket seeking care from multiple dentists who treat the teeth and jaws without respect to the airway or other aspects of biology only to later find lasting resolution by a dentist or doctor who could recognize and treat their breathing issues appropriately. At times I encounter people where the dentist who 'fixed their TMD' did so in the 'tooth and jaws' paradigm, but the intervention speaks to airway in dramatic ways - such as using braces or an oral appliance to move the mandible forward and down, or using orthognathic surgery to advance and expand the maxilla, or remodeling the maxillary complex non-surgically to fix a crossbite but which also increased tongue space and nasal volume. Dentists at the forefront of an airway centric paradigm and TMD medicine have, during the past several years, been quite interested in the work of Dr. Guilleminault and Dr. Avram Gold. It has proved to be a very important missing piece of information necessary to understand TMD patients and their variety of complaints that both dental and medical professions have struggled to provide care for.

I have also noticed over these past six years an increasingly clear link between oral health and the rest of the body is being evidenced in research findings; issues previously defined to be 'dental' are being understood to medical - that disease of the mouth cannot be segregated from disease in the body; they are often one and the same, or arise from one another in a complicated fashion [94, 95, 96, 97].

Although it has taken me years to become fully aware of all of this, early on I was quite explicitly exposed to the systemic neglect of the medical needs of patients due to the behaviors of third-party payers. In 2014, my psychiatrist wrote an appeal for Repetitive Transcranial Magnetic Stimulation treatment and Cigna denied this request despite extensive evidence and documentation. It was years later that a class action lawsuit made it clear the denials patients received from Cigna were unwarranted, wide-spread, and performed in bad faith [98]. I have also heard repeatedly of instances in which patients have had to contact their employer's human resources department and get them actively involved in order to alter denials by Cigna and other third-party payers, many involving cases in which denial of coverage was perplexingly absurd as the patients case quite plainly qualified as being medically necessary and denying the request for care was not in the financial interests of the employer, employee, nor even the third-party administrator.

One such instance involved a Fedex employee with moderate OSA who was denied treatment and could not work because of this medical condition, thereby receiving disability pay. Fedex contracts Cigna to help provide benefits that enable their workforce and their dependents to stay healthy so that they are able to perform their duties as employee's. Denying coverage of procedures that would prevent disability for employees and their dependents works in opposition to the mandate of Cigna "operating on behalf of Fedex". Denying coverage of procedures that can drastically improve or resolve the medical issues leading to disability is entirely antithetical to the mission statement of Medicaid programs which Unitedhealthcare is meant to uphold: "*to assist the disabled"* [99]. I would also highlight this is a problem endemic to the third-party payer industry and not limited to Cigna or UnitedHealthcare [100, 101].

A former Aetna medical director is on record stating under oath that while he was medical director he did not review patient records but signed off on recommendations provided by nurses. Further that he did not have sufficient training to understand the medical conditions which he was denying coverage to - I find myself wondering if we will find out the same takes place at Cigna and Unitedhealthcare [102]. That so many specialists from various fields are observing the behaviors of third-party payers impede patients access to medically necessary services illustrates this is not an isolated matter subject to the nuances of medical professionals holding differences of opinion. It has become increasingly clear that certain patient populations are not having their needs met primarily due to the behavior of third-party payers and the unwillingness of clinicians to fight with the payer system to facilitate care to those patients in need. This situation harms patients, and in many instances - especially within the population I am apart of - ends up costing third-party payers more in the long-run as patients get sent to one specialist after another having 'covered procedures' performed and reimbursed to physicians which do little to nothing to address the medical issues causing the patient's primary complaints. I'd like to illustrate some of this by relaying some of my own experiences. Please keep in mind I am cutting out quite a lot for the sake of brevity; *do not* view this as a comprehensive patient history.

In 2015 I had a Home Sleep Study (HST) because Cigna would not authorize an in-lab study. The HST came back with only 120 minutes recorded despite my being in bed for over 8 hours. I voiced concern to the sleep medicine practice that the study was not valid and was assured by the nurse over the phone it was and the doctor okayed it so stop fussing - it's good news, your AHI is 0! After continuing to be symptomatic and experiencing a marked decline in overall function I managed to consult with Dr. Melody Barron in the Fall of 2016. She is a dentist whose practice is limited to treating Sleep Breathing and TMD. Note, I was not able to afford to undergo treatment with Dr. Barron largely because of this mess with third-party payers. Even so, I did gain useful insight during the consult, including when Dr. Barron reviewed the 2015 HST and told me it's invalid and needs to be redone. This is later corroborated by an ENT, Dr. Sri Naidu, who refers me to a different sleep physician, Dr. Merrill Wise. In early 2017 I undergo an in-lab sleep study which comes back "borderline" with an AHI of 4.7, but also with over 76 arousals and a REM AHI of 14.7. Dr. Wise says there's nothing he can do because my AHI is 0.3 points away from a clinical diagnosis of OSA, but I should follow up with a sleep dentist. The American Academy of Sleep Medicine's 1B criteria for hypopnea were used to score that study and the relevance of this was not disclosed to me by any of these physicians - more on that later.

Long story short, the sleep dentist I was referred to isn't willing to work with insurance and said I would need to pay him $4,000 out of pocket to undergo treatment with him. I go back to Dr. Wise and ask what can be done and he basically recuses himself from my care and says to ask the sleep dentist if he can work something out. The sleep dentist had said he could not, explaining his presence at the dental college is in private practice and he must be able to pay himself and staff. Further, that due to the sleep study showing "borderline OSA" my primary commercial insurance will not pay for treatment. When I had asked about my secondary insurance, TennCare through Unitedhealthcare, the dentist explains how TennCare's reimbursement is so insufficient that if a clinician were to become in-network they would be unable to deliver the type of care necessary to correctly treat patients.

I go back to Dr. Wise, frustrated, exhausted, tired, in pain, and after asking for options and receiving non-committal responses I ask him, "How do people in my position, people who are on disability and reliant upon insurance, get access to care for their disordered breathing" and he told me "in my experience, they don't." They don't. They don't get care. No willingness to appeal, or to try to work something out, just a collective, 'sorry, but insurers won't make it easy for doctors to treat you; you don't have a problem physicians are willing to acknowledge professionally in their practice because of the payer system'. Despite my attempts to find a way to access care Dr. Wise records in the medical record that "the patient elected not to proceed with an oral appliance.", effectively excusing himself and others. And so, active disease processes are left to fester.

I later learn, as previously mentioned, that the criteria Dr. Wise used to score my hypopneas (1B criteria) lacked the sensitivity of those which are recommended (1A criteria) by the American Academy of Sleep Medicine (AASM). He did this, presumably, because he is in-network with my secondary insurance (UnitedHealthcare: Community Plan). It is still unclear where the mis-communication was - be it billing or the doctor, but it seems that somehow it was believed that the practice would not receive reimbursement from UnitedHealthcare unless utilizing their guidelines despite the fact that Cigna was my primary insurance. In addition, there is a law that if one is an in-network provider with Medicaid one cannot bill patients, therefore I and other recipients of TennCare are not even afforded the opportunity to undergo a sleep study with in-network providers which can accurately assess sleep breathing per AASM standards, let alone those that espouse even greater sensitivity than the AASM standards, such as those practiced at Stanford University and by its many graduates in Sleep Medicine. Nevertheless, the practice got paid, and I got put through...something; it certainly wasn't care prioritizing a favorable patient outcome.

In 2018 I had another home sleep test, ordered by my primary care physician through a sleep clinic. My sleep maintenance insomnia kept me awake most of the night - I estimate about four of the eight hours in bed were spent lying awake. I called and asked if the HST had the ability to detect when I was asleep and when I was awake. I was told it did not, but we could redo the test. I explained that the conditions I need to sleep under for testing aggravate both my breathing issues and chronic pain condition which significantly aggravates the sleep maintenance insomnia. That I really didn't feel I would be up to redoing an HST repeatedly given how it hurts me to sleep under those conditions and that the longer I sleep under those conditions the more my condition deteriorates. The doctor at the sleep clinic offered that he could try to get an in-lab study approved. I inquired if this study would be sensitive enough to detect Upper Airway Resistance Syndrome and/or non-hypoxic respiratory events that lead to arousal. The doctor indicated that insurance doesn't pay for that, so no it would not. I declined pursuing an in-lab study with his practice and opted to try to figure out how I could find a sleep physician who would be able to provide a study with the appropriate sensitivity.

Slightly changing focus, due to the TMD and sleep breathing not being treated my condition continued to get worse. In May of 2018 I was attempting to do jaw exercises, opening and closing the mandible in a slow and controlled manner when I experienced an acute injury. Where before there was pain I now had paresthesia throughout the right side of the face, mouth, nose as well as increased dysfunction, including: increased pain, limited opening, difficulty coordinating my hands, dizziness, difficulty speaking, acute cognitive dysfunction, unilateral nasal inflammation, and more. I called my PCP who was worried of stroke based upon the onset of symptoms, who told me to go to the ER, and the ER physicians did MRIs of the head and neck, instructed me to take NSAIDs, and seek help from other doctors while offering very little insight into which type of doctors would be most appropriate. I sought advice from an orthopedist and had appointments with a physiatrist, a chiropractor, a neurologist, physical therapist, and oral surgeons (residents in training at the University of Tennessee Health Science Center). All in-network physicians.

I never received a solid explanation from these physicians as to what had occurred to cause my condition to progress as it had. The best suggestion was from a neurologist who suggested I consider looking more closely at the upper cervical and cranial nerve V. In the days after the initial injury I would sometimes lose partial control of body movements; I would experience body twitches/tremors/spasms and at one point found myself lose control of my body and spasm on the floor for a few minutes. My primary complaints remained unresolved and at no point did I receive care which was efficacious. I explained to each of these physicians the TMD history, the link to breathing issues that drive poor sleep and compensatory behaviors such as a forward head posture and sleep bruxism. I voiced my opinion that the Trigeminal system seems involved in the paresthesia both due to the conditions preceding the injury and the presentation of symptoms being documented in TMD literature, case studies, and anecdotal reports by patients. I specifically mentioned it seemed plausible the right TMJ became more deranged and this could possibly be affecting the nerves in the retrodiscal tissues which in turn can have adverse impacts in other neurological systems due to how the Trigeminal Nerves feed into the brain stem. I relayed to doctors the existence of the clinical work and research of Dr. Brendan Stack which indicates derangement of the TMJs can influence motor control and other symptoms ascribed to neurological conditions.

I outlined that while there is most definitely involvement of the cervical spine, that there is a host of TMD literature which is quite clear in stating c1/c2 alignment has a strong relationship to the TMJs and orthopedics of the jaws, and that once c1/c2 are negatively impacted the rest of the postural chain compensates - clinical observations and research evidence implicating cervical involvement pointed to an etiology involving the craniofacial-respiratory-complex. I explained I have had limited access to care with appropriate specialists due to the barriers presented by medical insurers and that PCPs and specialists have been either unwilling or unable to provide care or have provided limited assistance to try to help me overcome these barriers erected by third-party payers. My attempts to get help from the physicians I saw for this progression in my TMD, or at least get a deeper understanding of what's going on, were unsuccessful. One doctor advised, 'I don't see anything wrong with your MRI, take some tylenol'. And it is the greatest irony that what's wrong is clearly visible in my facial development; what's wrong is *literally staring doctors in the face!*

A few months after this progression in my musculoskeletal disease I began to have more serious disruptions to my digestion, my stools full of undigested food particles, and I was experiencing uncontrollable weight loss. Disruptions to digestion like this are a known complication of trauma to the head and neck. Digestive complaints are commonly found in TMD patients. I have seen four Gastrointestinal doctors which were unhelpful or of limited assistance and I have had to self-treat my condition via information obtained through the internet. To date I continue to experience digestive issues and seek the advice of medical professionals on the matter. I have experienced 20 pounds of unintentional weight loss since the 2018 injury.

In 2019 I tried once again to get a sleep study with Dr. Merrill Wise, the sleep medicine doctor who had performed the 2017 in-lab polysomnography (PSG) which used the Medicaid criteria for scoring hypopnea. I told Dr. Wise: I know his colleague Dr. John Andrews malpracticed the home-sleep study in 2015, I know the 2017 PSG using Medicaid criteria lacks the sensitivity to rule out OSA and has practically no capacity to accurately assess non-hypoxic respiratory events leading to arousal. I communicated the ongoing findings being made by clinicians, such as those communicated by Jeff Rouse [46], illustrating the failings of the Medicaid/Medicare criteria, but moreover, that when accounted for clinicians are finding their patients with TMD have been provided sleep studies that use the Medicaid/Medicare criteria or use home studies that lack the EEG needed to track arousal and as a result have undiagnosed/misdiagnosed Sleep-Related Disordered Breathing (SRDB). Increasingly, sleep-related disordered breathing of a non-hypoxic nature or mild severity is being found to be an etiologic factor in a patient's TMD onset and progression.

I go over my medical history with Dr. Wise, how I received diagnoses of psychiatric disorders, beginning with ADHD at age 6, only to later be diagnosed with pediatric obstructive sleep apnea at age 17 and undergo a adenotonsillectomy and septoplasty. I relay how I have continually struggled to sleep and breath in the years prior to and since the surgery. That the literature shows these surgeries relapse. That I have a history of rhinitis which does not respond to prescribed corticosteroid or antihistamine nasal sprays, that my septoplasties and turbinate reduction surgeries relapsed, my sleep is disrupted in general but more so when my nose becomes flow limited, that this nasal flow limitation has a relationship with the TMD as well as other medical issues. That the breathing, sleep, and medical issues share as an etiologic factor aberrant facial growth. That I am tired, fatigued, and have notable issues with memory and executive function - daily life is very hard and has been getting harder over my years of struggle.

I communicated to Dr. Wise those and other matters while highlighting the pain and suffering I have endured as a result of having to spend years educating myself to figure out why and how my medical care has not been meeting my needs. I even provide to Dr. Wise a copy of a particularly interesting article on the Trigeminal Cardiac Reflex and its involvement in disordered breathing [103].

That paper not only supports mechanistic links between TMD and disordered breathing, but ties in neatly with research in the field of sleep medicine examining the relationship between facial growth, tonsils, adenoids, and disordered breathing. In one such paper examining this link the authors point out, “Guilleminault et al further propose that the high rate of subclinical, common facial structural variations, including high arched palate, nasal/septal deformity, and small maxilla/mandible are not just co-existing sleep/airway problems, nor are they the end result, but are the primary origin of the problem.42” [104]. Furthermore, such information in sleep medicine ties directly into research in the TMD field, “When the maxilla and mandible do not achieve their genetic potential in length, width, or vertical position, the effects are seen in mal-relationships and dysfunctions in the patient’s tissues, bones, muscles, and nerves. The temporomandibular joint (TMJ) relationship may then become compromised when this occurs, as it compensates for the discrepancies in normal growth and development.” [105]. There is a great deal of data linking sleep and pain, but one well-evidenced finding in TMD literature stands out: “Nonrestorative sleep, as self-reported by the patient, is one of the most powerful predictors of musculoskeletal pain...” “...*reducing orofacial pain and improving sleep need to be targeted together in the management of acute to chronic orofacial pain states in order to improve an orofacial pain patient’s quality of life*, to prevent mood alterations or exacerbation of sleep disorder (e.g., insomnia, sleep-disordered breathing) that can negatively affect their pain, and to promote healing and optimize their health.” [5]. These pieces of information are quite relevant to my own medical history [106; see pages 53-58].

I have been complaining to doctors for some time now that I note direct and indirect links between my nasal inflammation, my jaw disorder, my digestive issues, and my sleep quality. I ask Dr. Wise to help. Don’t stand by as disease consumes my life simply because it is difficult to fight with medical insurers. Work with me to get a sleep study approved using the AASM’s recommended criteria so I can have my breathing and sleep diagnostically quantified in a way that best respects the biology of breathing and respiration during sleep.

I acknowledged in the appointment insurers have been wrongfully denying many of my requests for care and will most likely do so for the sleep study as well; that we will have to fight them to get this study approved. He sends a request for pre-authorization of an in-lab polysomnogram and it is denied by Cigna on July 6th, 2019. After this denial I contact the practice and inquire about next steps, and am informed that typically Dr. Wise will consider performing a peer-to-peer or send in an appeal for reconsideration. As part of a larger effort to model my breathing and sleep issues, I worked with my primary care physician to complete four night's of overnight high-resolution pulse oximetry and provide this to the sleep practice staff who assured me it would be given to Dr. Wise. I do this to assist him in his efforts to argue with insurers that I need a full sleep study. Included with the pulse oximetry is my own analysis of the results. I continued to wait, and call back occasionally asking for an update. I hear nothing from the physician regarding what activities he may or may not be engaged in.

On August 30th, 2019 I receive a letter from Dr. Wise. It's essentially a 'termination letter that isn't a termination letter'. The doctor states he is not going to do a peer-to-peer or apply any further effort to try to get a sleep study approved. He believes that no insurance would approve an in-lab study for my care. He tells a narrative in this letter which does not reflect what was communicated during office visits. To me, it seems like he gives up on me, directing me to find care elsewhere or pay out-of-pocket for the sleep study. How does one pay for a PSG under the financial limitations imposed by a lifetime of disability? I suppose in his mind I will have 'elected' not the have the PSG.

I found it strange that Dr. Wise believes the 2017 polysomnogram is a reason for which insurers would find cause to not approve another polysomnogram. He also states that my "clinical situation" is "essentially unchanged." As previously mentioned, I provided recent pulse oximetry reports as well as my analysis of the data in the reports. In that analysis I stated:

> "June 24, and 25 were done on ketogenic diet. June 24th side sleep with elevation, nasal strips, mouth tape, aqualizer (bruxism guard), breakfast & lunch, but no dinner. June 25th start sleep supine, using aqualizer (bruxism guard). No elevation/strips/tape, breakfast & lunch, but no dinner."
>
> "July 19th and 20th were done after a week of eating carbohydrates. July 19th side sleep with elevation, nasal strips, mouth tape, and aqualizer (bruxism guard). Ate three meals a day. July 20th, start sleep supine, using aqualizer (bruxism guard). No elevation/strips/tape. Ate three meals a day."
>
> "Desaturation and heart rate elevation observed to coincide with instances of patient-reported sleep maintenance insomnia as well as increased pain and dysfunction related to the Temporomandibular Dysfunction."
>
> "The amount of respiratory events involving a 3% or greater desaturation for June 24th (86 events), 25th (164 events) & July 19th (104 events), 20th (141 events) in comparison to pulse oximetry done on January 3rd 2018 (51 events) suggests a progression of the sleep-related disordered breathing has occurred. Moreover, the Jan 3rd 2018 oximetry was a night I forced supine sleep."
>
> "This data suggests that over the past 19 months there has been a 3-fold increase in the incidence of SpO2 desaturations occurring during sleep. It also highlights that for me a supine sleep position significantly increases the severity of sleep-related disordered breathing. These studies also allowed observations which indicate respiratory events are contributing directly to the pain and dysfunction of the Temporomandibular Disorder and that the two conditions are in a complex relationship which contributes to sleep maintenance insomnia and impaired daytime function."

In the 2017 in-lab PSG using the Medicaid/Medicare criteria for scoring hypopnea I experienced 33 desaturations. Overall, these data indicate a trend of increasingly severe SRDB. Further, this increase in severity correlates to the decline I have experienced with my mental and physical health these last few years. In other words, the increased severity of clinical symptoms I have experienced and communicated to physicians correlate to the increase in the incidence of desaturation events observed through the PSG and high-resolution pulse oximetry. How much does someone have to suffer before they can ‘get help’? According to Cigna’s denial for the in-lab PSG they’re waiting until I develop, “seizures during sleep, heart rhythm problems, congestive heart failure, severe lung problems or a neurological disorder.” I suppose Cigna intends to save Fedex money by denying requests for in-lab polysomnograms until people are showing up to the ER with heart attacks.

In November of 2019 I visited with Dr. Mutiah, who specializes in sleep medicine. I felt encouraged in my interaction with Dr. Mutiah and we decided to request another PSG with the understanding it is unlikely it will be approved. My motivation for moving forward was to simply keep trying and documenting the extent to which the misbehavior is occurring. The request was denied for the same reasons provided in the denial letter for the request made by Dr. Wise.

It seems to me that these policies are causing stress to plan members and doctors while also contributing to Fedex’s costs associated with workplace accidents, employee turnover, and mistakes that get written off simply as errors in judgment. When it is this difficult for even motivated patients to undergo effective sleep testing, rest assured the less-inclined will remain undiagnosed or misdiagnosed. More worrisome should be how quite often patients and referring doctors are led to believe the patient does not have OSA based upon the results of a home sleep test - a test which does not possess the sensitivity to determine as much.

Earlier in mid 2017 I had been exceedingly desperate and I asked my parents to go into debt so I could become a patient of Dr. William Mchorris (recommended by a friend) who had practiced TMD medicine for many decades. Dr. Mchorris was very explicit in stating I needed a physical therapist to help manage my condition. Further, that it was imperative I see a physical therapist who was very knowledgeable and experienced. Dr. Mchorris was adamant I needed to make it a priority to see Dr. Jim Hambrick. I saw Dr. Hambrick, who was indeed knowledgeable but he determined that the therapy needed for my case would need even more specialized expertise as it required using dry needling techniques he did not feel comfortably trained to perform. Dr. Hambrick referred me to an associate of his, Dr. Ken Mcmahon.

I saw Dr. Mcmahon twice a week for many months - the deductible and out-of-pocket had been met, that’s the only reason I could access this level of care. It was the first time my pain was significantly impacted by a therapy provided by a physician. Yet, it’s benefits are limited and do not provide lasting relief as it does not directly address the etiology of my TMD, one requiring altering the anatomy to positively influence both breathing as well as the orthopedics and myofascia of the jaws, mouth, neck, and body. Treatment with Dr. Mcmahon has helped me more than anything else, but it’s like treading water. My head bobs above water, but I can still expect to drown absent appropriate intervention.

I had to stop seeing Dr. Mcmahon in January of 2018 because after the deductible turned over I could not afford the out-of-pocket expense and Unitedhealthcare dictated I had to see their in-network physicians because they allege these physicians are able to ‘provide similar services' - which is pretty much the same nonsense as Cigna has done regarding my requests to see doctors specializing in TMD medicine. My TMD steadily got worse, and about a month after having my care with Dr. Mcmahon interrupted is when I developed the facial paresthesia and a worsening of paresthesia in my hands. I was left to locate someone with training by myself despite asking for assistance from Unitedhealthcare representatives on multiple occasions. I cold-called every physical therapist local to my area on the list for the UnitedHealthcare: Community Plan and found one who recently trained with dry needling and said he 'received training in school for TMD.' The appointment I was able to schedule required a long wait.

Even with Dr. Mcmahon's help I had experienced declines in overall function. I had to reduce my physical activity level to manage my pain and fatigue. In the meantime, I suffered the aforementioned injury to the craniofacial region causing paresthesia and increased dysfunction. After that, I found I could not even go on the simple walks I had been doing nor could I do the Yoga or Tai Chi exercises I had found helpful in the past without acutely aggravating the injury. As a consequence of little to no physical activity, my mental health, cognition, and sleep have all quite noticeably deteriorated. The overnight oximetry from January 2018 and June/July of 2019 suggest a connection between these events and the increased severity of my sleep issues.

The PT in-network with TennCare through the UnitedHealthcare Community Plan was not able to help manage my TMD in a worthwhile manner. In fact, after visits the paresthesia and pain would often become worse. I spent about two months trying to work with him over the course of fourteen appointments. There's a big difference between Dr. Mcmahon's expertise and skill with Dry Needling and other modalities compared to that provided by the physical therapist in-network with UnitedHealthcare. They were not at all close to each other in terms of clinical experience and training regarding TMD and chronic pain patients. Yet another waste of time and money for myself and payers, yet the physicians and the practices they are a part of walk away reimbursed and insurers maintain their contracts with employers, medicaid, and medicare without penalty.

Later in the year I met both my deductible and out-of-pocket due to utilizing all the other 'covered services' involved in trying to get some type of help. I was once again able to see Dr. Mcmahon. After a week and a half of treatment with Dr. Mcmahon my pain was much more manageable and the paresthesia improved significantly; yet, I still have recurrence of the paresthesia/injury related to chewing and sleep bruxism. My function is much more limited than it was prior to the injury. For example, my ability to chew, eat, and engage in physical activities are quite impaired in comparison to what I was able to do prior to the injury leading to the paresthesia. I believe this decline would not have occurred had I been able to continue my care with Dr. Mcmahon. Further, I believe if I had been able to access appropriate care for the disordered breathing my overall health would improve and my utilization of healthcare services would be substantially less, perhaps even to the point of no longer requiring Dr. Mcmahon's services. I have heard from multiple providers that it is unusual for someone to require such frequent treatment with dry needling. Usually a few sessions of dry needling alongside patient education will provide substantial and lasting benefits for the myofascial issues and people move on with their life or come back every so often for another session.

Dr. Mcmahon is a physical therapist, who unlike many of his peers, has much more extensive knowledge and training regarding myofascial pain, particularly when it comes to Temporomandibular disorders. He has a remarkable expertise in dry needling (one of only a few physician based therapies I've found effective enough to continue pursuing). Yet, his knowledge has limits and his exceptional skill cannot provide the long-term care that's required to return me to function and address my other complaints. Seeing him helps me like nothing else has. Yet, in the beginning of 2019 I once again had to stop seeing Dr. Mcmahon, just as in 2018, due to the problem with my secondary insurance, Unitedhealthcare, not fulfilling their obligation to pay part of the remainder of what Cigna does not. I requested an out-of-network adequacy (NAP) from Unitedhealthcare for Dr. Mcmahon in November of 2018 in anticipation of my ongoing need for continued care and it was denied [107; see pages 59-63]. The reasons cited in the letter stating the NAP was denied demonstrated more of the same nonsense I'd experienced with previous denials from Cigna.

After the denial I worked with Dr. Mcmahon's billing department to try to get partial reimbursement. Unitedhealthcare representatives had assured me over multiple calls made over a period of several months that they would follow the guidelines of the primary insurance and reimburse claims. I later learn that these representatives all provided false information to me - Unitedhealthcare would not reimburse claims as a secondary insurance; they would not even process claims sent to them from Dr. Mcmahon. As I understand things now, if a member is given false information regarding coverage then the care organization is usually required to honor the information provided to the member through member services. No such accommodation was extended to me when I called in complaining about how I had been misled over the course of several months to believe that Unitedhealthcare would process and reimburse claims as a secondary insurance from providers who are in-network with my primary insurance. Worse yet, even as I was on the phone complaining about this matter representatives would continue to provide me with false information regarding how they function as a secondary insurance.

To further illustrate the necessity and benefit of receiving specialized care, I'll mention a consult I had in early 2019 with Dr. Steve Galella. In February of 2019 I asked my parents to pay for me to consult with a dentist who is highly specialized in treating issues relating to the craniofacial respiratory-complex, such as Temporomandibular Disorders, Dr. Steve Galella. He explained to me how and why TMJs can become deranged and that the MRI of the TMJs I worked six months to get approved (again, Cigna's behavior has impeded access to care quite significantly, an MRI is not this hard to get approved for other orthopedic issues) was not sufficient to examine the TMJs and rule out derangement - radiologists often lack the necessary specialized training (which they are presumed, by referring doctors, to have) and oral surgeons are 'in a different world' when it comes to evaluating the TMJs. The dominant theme I have heard from knowledgeable providers and patients regarding surgical intervention is that outcomes are inconsistent and it's advisable to try just about anything other than surgery, and even once non-surgical options are exhausted, consider if you can find a way to live with the pain and dysfunction rather than elect for surgery. Dr. Galella had insightful answers where other providers had left me with questionable advice such as 'take tylenol and come back if it gets worse'.

There was a great deal that Dr. Galella said which I had been contemplating the possibility of for some time; specifically, that my cervical issues had a relationship to my craniofacial structure in a way that went far beyond the direct link between airway compromise causing a forward head posture. Also of note is that the TMJs can partially displace the meniscus in such a way that most doctors are unable to recognize it due to a lack of knowledge and training. Dr. Galella teaches continuing education to other dentists and from what I gather the nature of his work is far more involved than other dentists practicing TMD medicine. He informed me that in order to properly diagnose me and provide a treatment plan he'd need to spend a month going over everything about me. From what he described, it sounds as if over the years he had expanded his knowledge and scope of his practice to solve the problems his patients were experiencing. His current approach involves working with other medical doctors and allied health professionals to comprehensively diagnose and treat patients.

While my parents can finance a consult, the ability to finance diagnosis and treatment is prohibitively expensive for us. The behavior of Cigna and UnitedHealthcare creates barriers to being able to follow-up with physicians and get clearer answers. That recent events seem to implicate Cigna has been acting in bad faith denying out-of-network adequacies to see specialists, such as Dr. Rice (2018) and Dr. Blumenthal (2018) [107; see pages 63-76], made the prospect of attempting an out of network adequacy for Dr. Galella seem an act of insanity. In fact, I had known of Dr. Galella for nearly two years and would have visited him and many others much sooner had Cigna acted in a manner that allows patients to access diagnosis and treatment with these physicians. Instead, tens of thousands of dollars have been spent on 'covered services' that have provided limited to no benefit. Quite frankly, having my pain and suffering monetized by physicians and my pleas for assistance met with inaction, complacency, and at times discrimination has been traumatizing.

One phone call after another with insurers, explaining everything all over again and again and again and again...and again. Fighting the same battles that never win the war and being instructed to perform tasks that even the doctors refuse to do because they believe them worthless in the long-run. Medical professionals seem to predominantly be of the opinion that the denial of requests for care and reimbursement for procedures by third-party payers is based upon criteria unconcerned with the patients welfare - this is beyond upsetting. It honestly takes a week of purposefully doing my best to ignore matters to get a hold of myself before my mind is in good enough shape to function again. Then a few days of working at the problem, and another break. This is a psychosocial wound with profound effects on my well-being.

> "[If] you're stressed 24/7...you're in the range of where glucocorticoids do exactly the opposite. They decrease oxygen and glucose delivery to the hippocampus, they make neurons less excitable, they disconnect synapses, they cause the processes and neurons to scrivel, they block the birth of new neurons there, they make other insults more damaging to neurons in the hippocampus. ….what we're increasingly realizing is if you're exposed to excessive glucocorticoid levels like on a scale of years to decades you're going to make this part of the brain get older faster." - Robert Sapolsky, PhD, Stanford professor of biology, neurology and neurological sciences [155; 1:00:00]

Beyond the suffering, there have been personality changes and a fracture in my ability to connect to others. As previously mentioned, when I hear medical professionals describe PTSD it sounds much like what I'm experiencing.

It is known that poor sleep contributes to the development of PTSD and that breathing issues contribute to poor sleep and poor sleep plays a role in developing chronic pain and chronic pain contributes to poor sleep and that poor sleep plays a role in experiencing further progression of a chronic pain condition [5, 87, 151, 152]…. From the influence sleep has in maintaining a healthy immune system [108, 109], to how sleep deprivation alters the composition of the gut microbiota [110, 111, 112] which is related to the immune systems role in regulating the composition of the gut microbiome [113, 114], to how the circadian biology of gut microbes can alter organ function and as a result this will reduce the toxicity of exogenous compounds based upon the time of day [115], to how the gut microbiota influence the immune system and its ability to fight cancer [116, 117], to how the immune system plays a role in pain progressing from acute to chronic [118], to the immune systems involvement in keeping tau and amyloid from clumping into tangles [119], to how the glymphatic system is activated during deep sleep to clear out plaques and other byproducts that accumulate in the brain [120, 121, 122], to how sleep-related disordered breathing contributes to sensitization of the HPA-Axis [67], to how "sleep disturbance has been shown to be an independent risk factor for the development and maintenance of [major depressive disorder]" [123], to the similarities between sleep deprivation or fragmentation and their negative impact on immune function and the alterations in immune function observed in persons with depression [124], to the way in which cortical structure is destroyed and dysfunctional neural networks arise due to sleep fragmentation and periodic breathing [88, 125, 126, 127, 128], all of which are contributing to cognitive impairments [128, 129, 130, 131], to the point that one can 'cause' ADHD in healthy controls by shorting sleep [132], and stacked on it all are disruptions to sympathovagal balance [89A-E] and increased permeability of the blood-brain barrier [133], mechanisms implicated in a variety of neurological and psychiatric disorders, and in addition to that research continues to show the vagus nerve plays pivotal roles in our systems biology and systemic diseases [92, 94, 134, 135] - "The adverse consequences of poor sleep on mood, motivation, and cognitive functioning are particularly relevant to bipolar disorder" [153]**.** The mechanisms leading me to present with the issues I have can be mapped if one chooses to do so (any reader with young children should be quite concerned by references 125-127, 132, 133, & 154). Mine is a situation that goes beyond medical necessity, this is foundational biology. The nonsense I and other members are being put through while trying to get care damages us at a physiologic level. The absurdity of this situation...

The foundation of my frustration involves a most unreasonable response to a reasonable plea. I estimate around $60k-80k has been spent (with this number increasing) on covered services that don't fix the problems I have and most of those services did not offer anything close to an efficacious outcome. It seems wise to instead invest in finding the right specialists, accessing needed diagnostics, develop a comprehensive treatment plan, then undergoing treatment that can be efficacious to the point that the outcomes achieved have repeatedly taken people disabled by their problems and returned them to function [21, 29, 34, 136, 137]. I wish I could offer more than mere estimation for these costs, but requests made to representatives at Cigna and UnitedHealthcare for more detailed financial records on how much has been paid to providers since 2012 have so far been unsuccessful.

In addition, my request for a copy of the “cost summary” of how much has been spent processing requests for network adequacies, pre-certification, letters for reconsideration, and other activities are refused and I am told I will need a lawyer to subpoena those records. My requests for the records (calls, notes, requested medical records, etc) generated during reviews of my requests for procedures, adequacies, and reconsiderations were also refused and I was advised I would need a lawyer to subpoena them as well. From what I can gather through conversations with professionals, the cost of reviewing claims and appeals - the administrative costs incurred in an effort to ‘reduce costs’ - would most likely add at least an additional $15k to my estimate, not including what it costs to process this appeal and any future appeals.

What continues to puzzle myself, and others, is why events unfold in this manner when appropriate treatment could be provided at a fraction of the cost. What tortures me, and fellow patients, is that at a time in our life in which we are cognitively impaired and experiencing intense distress we are made to jump through all these hoops instead of accessing care with competent specialists. I’ve requested from Cigna and Unitedhealthcare assistance in writing this medical appeal, as most days I find myself unable to function well enough to work on it. Cigna and UnitedHealthcare both tell me they have no one who can assist me. I am, in essence abandoned to performing a task which my medical issues and disability impair my ability to attend to, and this in turn severely delays my attempts to access care. I think the way their actions lead to delays in my care serve as yet another example of the many ‘cost-saving efficiencies’ medical insurers purposefully use in a misguided attempt to reduce their costs.

This situation in which I and other patients are limited to seeing doctors who are unable to diagnose and treat our primary complaints does not benefit patients, providers, employers, nor medical insurers - Cigna and other insurance companies are flushing money down the toilet by denying patients with TMD, breathing disorders, and other medical complaints related to aberrant growth and development of the craniofacial respiratory-complex access to appropriate care. How much more clearly do matters have to be explained before third-party payers understand there is money to be made in helping patients like myself access the correct physicians and that in order to do so the existing system of pre-certification and coverage determination needs to undergo extensive modification, starting with better policies and educational resources specific to this topic for medical directors and ancillary staff involved in the review process. Educational resources such as those being taught by Dr. Mark A. Cruz (airway mini-residency), Dr. Jeff Rouse (Spear Education Airway Coursework), or Dr. Steve Carstensen (Pankey Institute). My proposal that insurers facilitate appropriate care for patients like myself would hardly be detrimental to themselves or their members. It is, in fact, quite the opposite and has been done successfully in the past [138].

Through my research I’ve learned the etiology of my health issues involves a variety of factors, including multiple physical traumas to the head and a compromised airway since childhood that impairs both daytime and nighttime breathing, and that all of this snowballs into a complex systems biology that can manifest as symptoms that get diagnosed as one or more of the many chronic diseases. Others before me learned of this link decades ago [19]. This airway compromise occurs due to craniofacial underdevelopment. It is an insult that begins in childhood and has been exceptionally disruptive to my life; I've been on disability *my entire adult life.* Underdeveloped craniofacial structure in modern humans is thought by some to be a pandemic in comparison to that found present in our distant ancestors; "What has happened over a period of time is that things which are abnormal and dysfunctional have become so commonplace that people have been led to believe that they are normal. They are not normal, they are commonplace. It is not normal to have 28 teeth. It is not normal to have inflamed tonsils and adenoids." "This planet has 5,432 mammals. Man is the only mammal that sleeps with its mouth open." [38]. It is my observation that patients with these issues can improve dramatically when the compromise to the airway is treated appropriately. Absent treatment patients are often observed to do poorly with increased healthcare costs that place substantial burdens upon families, employers, third-party payers, and our society [18, 52, 139, 140, 141].

Medicine and Dentistry have struggled to model these problems. It has required multiple fields of medicine and fields of study outside of medicine to allow physicians to connect the dots. Today we're at a point that it is possible for treatment to enable patients to get their life back on track, to go from a severely impaired state to almost complete resolution of primary complaints; to even go from being disabled to productive members of society. Treatment can require very specialized care from physicians who have gone far beyond current standards in expanding their knowledge and expertise.

I want it to be clear that as nascent as this field is (treating breathing issues and craniofacial pain that arise as a result of anatomical compromise to the airway/orthopedics of the jaws and understanding the complications in other systems that arise due to these insults, such as that which occurs in temporomandibular disorders) the foundational science supporting it is well-established and continues to expand. That what I am describing isn't limited to obstructive sleep apnea, but goes far beyond it in recognizing the Apnea Hypopnea Index has not been adequate in providing accurate diagnosis demonstrating which patients have breathing issues impacting their health and which do not. Even the Respiratory Disturbance Index has not been a wholly adequate means of quantification [142]. Whether or not a problem with breathing exists begins with how active the autonomic nervous system (ANS) becomes in managing airway patency and the degree to which this activity of the ANS arouses one from sleep or negatively influences sleep architecture. Many sleep labs are not measuring for this primarily because of the difficulties insurers have erected between doctors and patient care. In addition, the complexities of how craniofacial structure influences the orthopedics of the jaw and overall body posture are quite difficult to understand; my grasp of it is limited, but what I understand allows me to comprehend that there's a lot about this subject that remains unsolved or exceptionally difficult to piece together, but nevertheless it must be attended to with diligence in order to seek an etiologic resolution of the TMD.

I have been told and have learned from educational resources I have a problem with my breathing and sleep. That it is a medical problem necessitating treatment. That the reason I am unable to access diagnostics and treatment is because my insurance will not reimburse clinicians to provide the care necessary to meet my medical needs. One might think there's insufficient evidence to demonstrate there is a problem. That the consensus hasn't reached a point in which 'it is understood and known'. Clinicians are slow to change what they think they know. It has taken time, but finally this knowledge is sweeping through dentistry and meandering, at a much slower pace, through medicine. The continuing education materials in dentistry are evidenced to provide clarity where there has been, for decades, confusion when handling certain patient populations, such as those with TMD or Fibromyalgia. And yet, it seems much of this is forgotten knowledge with dentists and doctors having known of the relationship between facial anatomy, breathing, and health over 100 years ago [143, 144, 145, 146, 147, 148].

Recognizing and treating airway issues has become a strong focus within the continuing education materials for dentistry. It is important to note that what instructors first learned and are now teaching in their courses is a not a small incremental change in knowledge, but a radical paradigm shift which is changing both medicine and dentistry. Dr. Mark Cruz was amongst the first dentists to start connecting the dots into a cohesive picture, and began teaching an airway mini-residency in 2014 primarily because there were few to none teaching these things at that time. Dr. Jeff Rouse was another early pioneer and began teaching about this subject at Spear Education in 2017 (he had previously taught some courses as 'airway prosthodontics'). Dr. Dewitt Wilkerson at the Dawson Institute since 2018 and Dr. Steve Carstensen at the Pankey Institute since 2018 are latecomers who learned from the pioneers despite their history of being thought leaders in Sleep Dentistry and TMD medicine throughout their long and well respected careers.

Dr. Carstensen in particular has had a large influence on recent statements and policies declared by the American Dental Association on this topic. Carstensen was instrumental in organizing a conference in 2018 through the ADA, "Children's Airway Health - A Practical Conference". Speakers at this conference included a variety of experts in sleep and breathing. Leaders in sleep medicine such as Dr. Christian Guilleminault (Stanford) and Dr. David Gozal (University of Chicago) presented at the conference. Dr. Cruz was also a speaker as were many other dentists and allied health professionals. A round table conference meeting was held prior to the conference with speakers and experts to discuss the need to treat childrens airways; the dental profession is working hard to figure out how to get this information out to clinicians and it's not clear how to make easy to follow guidelines. Currently, care for this problem requires an extensive amount of training and knowledge that intimidates most healthcare professionals, medical doctor or otherwise. The aforementioned educators and clinicians are involved in action committees within the ADA to work on guidelines and education standards.

The Continuing Education being offered by the major dental institutes is far more than simply including a new course with a new speaker. These professional continuing education institutes have changed core curriculum to reflect our ever-evolving understanding that the airway plays in human health. From diagnosis to treatment planning, how dental CE is teaching clinicians to practice has changed significantly within the last few years; decades of tradition and time-tested methodology is being changed because our current understanding of the airway makes it necessary to do so.

The CE, as far as I can tell, is focused primarily on human health as opposed to being limited to the dentition. This is because it turns out that dentists have the tools to positively impact breathing in a way that is far more significant than anything a medical doctor can currently do. Dentists studying the airway and what they can do for patients are realizing that dentists who can treat the airway will not simply be seen as 'real doctors' but in many ways will become more important than medical doctors to patients interested in doing more than managing disease. People with chronic illnesses medicine has struggled with or outright mismanaged and misunderstood are finding resolution from dentists who treat the airway and the masticatory system.

The behavior of Cigna and other third-party payers has served as an impediment that has obfuscated access to appropriate care for myself and others. This behavior has led to a substantial amount of waste in time and resources. It is bad for patients, it is bad for third-party administrators; it is not conducive to facilitating appropriate care for employees of Fedex and their dependents for whom Cigna is contracted to attend to in good faith. In my observation, the behavior of UnitedHealthcare and TennCare do not at all seem to be geared to trying to rehabilitate people who are disabled by chronic medical conditions.

I would, in fact, go so far as to state that in my view people who are disabled and reliant upon Medicaid are treated like cattle by most medical providers, third-party payers, and by the elected representatives in our state and federal governments who empower and oversee the groups which determine coverage guidelines for Medicaid and it's programs. Disabled persons are, in today's medical system, commodities that fill up offices and allow providers and third-party payers to profit while not meeting the medical needs of those patients, let alone making a genuine attempt to take someone who is disabled by their medical condition and try to provide care which would return them to "useful employment" [64]. Medicaid isn't a program to support and rehabilitate, it's a trap that allows others in society to profit through the exploitation of a vulnerable population in need of assistance.

Whether it is inadequate knowledge on the part of those in pre-certification or who act as medical directors, or organization-wide policies that lead employees of care organizations to act in bad faith, is a question I ponder regularly. What I am sure of is that that my case has been mishandled repeatedly and I have suffered immensely because of this and I hear similar stories from other patients. When I have voiced my unmet needs to representatives of the various organizations involved in this, the response I have grown accustomed to is one that dominates with an inability to facilitate solutions. I have been made to jump through one hoop after another, each hurdle greatly delaying or impeding access to care, at times even preventing access entirely. Some of the representatives I interacted with would understand my situation and from them I would get this sense that they felt powerless to alter the machinations of Cigna's or UnitedHealthcare's approval process - that despite how clearly broken this process was they could offer no recourse. I would go so far as to say the way patients with needs such as mine are handled by third-party payers is so broken that I can easily repeat the outcomes I've described and generate more evidence to corroborate the presence and impact of these problems. At this point, I have full confidence that despite stating this in my appeal nothing will change within these organizations. That, in fact, this appeal will most likely be reviewed with a similar degree of ignorance and inattention to detail that has been present throughout my interactions with Cigna and Unitedhealthcare to get medical diagnostics and treatment approved.

I have been reviewing literature and accessing continuing education materials as it pertains to topics relevant to my situation and learned that very few physicians currently have the knowledge and understanding to comprehend the patient population I am a part of. That few medical doctors or dentists were taught these materials in their schooling and that even specialists for whom one would expect awareness can unfortunately be deficit in their knowledge. The knowledge is old, but the training is new - it is not my job to educate Cigna's staff nor those of any healthcare plan administrator. I am not well situated to do this. I sleep poorly, I have cognitive deficits, and the in-network physicians Cigna and TennCare allow me to see have, predominantly, been unwilling or unable to work directly on my behalf to organize and author an appeal. I am in constant pain that impairs my ability to sit, study, and type - It Hurts Me to Write an Appeal. I am disabled by this problem, it impacts my ability to function significantly, and I have been denied access to the specialized care needed to manage my conditions effectively and then told to write an appeal despite my cognitive impairment and struggle to access physicians which are able to become directly involved in the appeals process. This is discriminatory and abusive.

Unreasonable doesn't begin to describe the situation I and other patients are being placed in. It is also arguably beyond the scope of an appeal to facilitate conveying all of the information necessary to allow a fully informed decision regarding the medical necessity of treatment. For example, CE materials I am aware of which are tailored to this topic take a bare minimum of 12 hours to view. These materials require purchase by professionals. That is simply for a small foundation of knowledge regarding the biology involved. To understand the available treatment options would require further study which I estimate to be at least 20 hours of additional CE. More time would need to be spent through voluntary study reviewing materials and references covered in the CE to truly learn the materials.

How things are 'supposed' to work isn't how they're working. It's a constant consideration that it's quite likely my efforts will be of little consequence and I should get comfortable with the idea that while the health issues disabling me are fixable I won't find a way to access appropriate care. The current medical system, especially third party payers, is so antagonistic to meeting the needs of patients that I honestly wonder if it would be better for me at this point to focus my efforts on determining the value of continuing to exist with this limitation. I really am tired of this circus I'm being put through and one way or another it would be a relief to permanently divorce myself from it. These contemplations have been going on a long time, and are not an ill-conceived consideration - I need help and in the absence of being able to receive that help I have to choose from the options available to me. My thoughts on this matter have been consistent and longstanding [149]. One way or another I will have relief from this disabling existence and intend to ensure that before then those that have contributed to this situation will be held responsible for their behaviors by their fellow citizens.

It is with reticence that I mention what occurs when someone in my situation discloses matters of suicidal ideation over the phone to third-party administrators or in-person to some medical providers. I have mentioned over the phone and in appointments within the recent past that the pain, poor sleep, loss of quality of life, and pscyhological distress I suffer lead me to think about suicide. As upset as I get, as poorly functioning as I often am, I would make it a point to say I have no desire, want, or cognitive drive to commit suicide and am not at acute risk for suicide and simply wished to convey 'things are this bad, and I need help with this, and absent recieving assistence I see suicide as a inevitable outcome due to how my medical issues disable me and continue to become more severe due to a lack of access to needed care.'.

Further, that so much money is spent paying for things that do not help deal with the primary cause of my struggles illustrates that achieving favorable patient outcomes has not been the priority for most physicians, third-party payers, nor the various programs tasked to assist those suffering from medical disabilities. The resources being expended to pay the staff I speak with over the phone at member services, state agencies, doctors offices, etc would likely cover the cost of treatment itself. Yet, the reimbursement provided to physicians for procedures that do not even attempt to deal with my primary complaints has become something truly grotesque. Particularly when it comes to how these parties respond to an honest account of the psychological impact chronic pain, poor sleep, and the other comorbidities have on what gets viewed as 'mental health'.

It seems the moment the word suicide gets used people stop listening and become quite concerned with their percieved 'legal liability'. They call the police, who in turn insist one is assessed by staff at a psychiatric facility. The assessors at intake push everything onto the psychiatrist, who takes days to finally see you, and then proceeds to hold you the maximum they can until they have to present you to a judge, at which point a discharge is expeditiously performed. I explicitly tell the officers, the intake staff, the nurse practitioners, and the psychiatrist:

> "I have a jaw disorder that causes chronic pain, which is aggravated by the disordered breathing during sleep, and managing this takes almost all of my time, and the tools to do that are not accessible to me while being here. Being placed in this facility will worsen my medical issues and endanger my health, and it is that type of mismanagement, that failure to help me with these problems, that leads to the suicidal ideation - my mental health crises are as a result of my medical needs being unmet. My inability to meet these needs is due to the behaviors of members within society failing to fulfill their duties; such behaviors as you are now engaged in. I will not only suffer harm by being placed under the conditions at this facility, but the suicidal ideation will become more severe."

And when my warning is not heeded, events unfold as I stated they would. The psychiatric hospital gets reimbursed thousands of dollars to hold me in conditions that make the problems which lead me to contemplate suicide worse and for good measure my medical issues are ignored with much negligence. I tell them the same things at intake as I do at discharge - they choose to write different things down. At times what they write in charts is entirely fallacious and baffles explanation. For example, the dietitian looking at my chart voiced concern that at intake it was written I had said "I have trouble swallowing and choke on my food"; I did not say this. At intake I said I have sleep breathing issues; that during sleep "I experience the anatomical equivalent of being water-boarded every night of my life" which contribute to the jaw issues which "make it difficult to chew and eat". It is really quite horrendous what goes on in these facilities regarding the opinions of staff overruling anything someone unfortunate enough to become a patient might say. More protections need to be put in place.

Most recently, March 14-22, I was involuntarily committed to Lakeside Behavioral Health System. Police officers were called by TennCare Solutions after I had spent 1 hour and 45 minutes explaining to the representative my situation of which a minute or so involved mentioning that the psychological toll of these untreated medical issues leads to suicidal ideation that is not acute in nature. What happened is a story unto itself, but to highlight, I told the police officer of my medical needs, to which she paid some heed and retrieved from my mother the breathe right strips, micropore tape to seal the mouth, and oral appliance. Yet, overall, it's the same situation of people really not listening and refusing to believe what I state will occur shall occur and through inexperience and ignorance cause harm. The officer doesn't heed my warnings about the suffering I will have to endure.

I arrive about 6 p.m. at Lakeside Behavioral Health Systems and spend eighteen hours at intake. I was unable to sleep both because there is no bed and the constant artificial lighting at night causes me to experience insomnia, but in addition to those issues was fear. Fear that is present because I know if I fall asleep without the oral appliance I get injured and spend weeks with intense pain and dysfunction. Of course, I explain my situation to staff and nothing happens. I get placed on the West ward at 1430 on Friday, and explain to staff "if I fall asleep without this oral appliance I will be injured. I haven't slept in 24 hours. I do not believe I can keep myself awake another night. The oral appliance is downstairs, please get it." I get told to wait, they'll work on it, things will be okay. I check in throughout the day, and find my issues are not communicated between shift changes, the doctor needed to sign orders is no longer available, and no information on when or if the appliance is coming can be obtained. I spend another night without the appliance, and this night I am not entirely successful in preventing sleep. Luckily, I was partially successful and between the lighting disrupting sleep and the effort to stay awake I avoided spending much time in the deeper stages of sleep wherein the disordered breathing becomes more severe and this in turn increases the occurrence of bruxism - I injure myself, but it is not as bad as it could have been. I complain the next day, in pain, to which staff largely ignore my grievance. I eventually find out later that day that LBHS has lost both the oral appliance and the mouth tape, but found the breathe right strips. I finally see the treating physician, who orders the oral appliance, and have my mother bring up a spare, but too little too late.

My diet has become restricted to manage nasal inflammation/congestion, TMD pain, and gut issues; if I neglect this I suffer and lacking the tools I have at home to manage poor outcomes (Afrin, hot baths, wedge pillows at 45 degrees...long list of management tools inaccessible at LBHS) management then requires strict adherence to 'what works'. Their kitchen can't meet these dietary needs. They're simple. Any grocery store can meet them with a short trip. Some avocados, a bag of walnuts/macadamia nuts, kerrygold butter, and canned fish - these are selected to place the least amount of burden on their kitchen staff; no prep, no cooking, it's served in literally minutes. The nuts hurt to eat, but I was trying my best to be accomodating to kitchen staff. There's a Walmart literally less than a few minutes drive from LBHS; it would have taken maybe twenty minutes there and back to get the food required for my entire stay. During my involuntary commitment on February 5th 2019 I received no food for five days - I had very painful muscle cramps due to electrolyte imbalances, and with my caloric intake already a struggle to maintain, lost more body mass.

My involuntary commitment in March was a repeat of what occurred in February, but my parents and I continued to complain and the internal medicine doctor I saw this time took an interest and tried to write an order so my parents could at least bring food, but the order requires an approval from administrators and it took days to get any information on what was happening on their end. I got food after about five days there. Even then, I had to do the best I could with what I was limited to, and could barely get in 1900 calories a day.

The sleep environment was also highly disruptive; bright light causes me to experience sleep onset and sleep maintenance insomnia - they flood the rooms with light every fifteen minutes to do checks. I was acutely sleep deprived my entire stay there. “We show that sleep deprivation enhances pain responsivity within the primary sensing regions of the brain's cortex yet blunts activity in other regions that modulate pain processing, the striatum and insula. We further establish that even subtle night-to-night changes in sleep in a sample of the general population predict consequential day-to-day changes in pain (bidirectionally).” [150]. “Fear induced by pain in human subjects was rated higher for face than for extremities, despite comparable ratings of the pain intensity. fMRI studies further revealed that face pain resulted in higher levels of amygdala activation compared to the same intensity stimulation applied to the hand.” “Our input-output circuit mapping of PB_L-nociceptive neurons revealed many limbic centers that are reciprocally connected with PB_L, providing a circuit basis for understanding closely associated and clinically highly-relevant comorbidities with pathologic trigeminal pain, namely anxiety, depression, disturbance of circadian rhythm and altered intake behavior.” [156]. Sleep, food, pain...very basic needs unmet or neglected, and this is a facility to ‘keep me safe’; to convince me to not engage in suicidal ideation. A facility contracted by TennCare, Unitedhealthcare, and Cigna.

I was having more intense thoughts of suicide throughout my commitments than I had experienced throughout the entire past month. At discharge I viewed suicide as being a more likely outcome than I did at intake. Contempt. Frustration. Trauma. I do need mental health services. Ironically, I need them to figure out how to deal with the trauma of being mistreated by physicians, insurers, officers, and other figures in the community who are ‘supposed to help’ but are instead causing harm to myself and others. Yet, step one of achieving ‘get help’ has been, and remains: fix sleep, fix pain, fix eating and digesting issues, return to exercise - address medical needs, then go talk about the psychological struggles.

Lakeside Behavioral Health System and the employee’s contracted within the facility have profited, and I’m worse off than when I was presented to them. From a physiological standpoint, I’m not sure my body could handle much more sleep deprivation and worsening of my TMD. It surely can’t support any further food restriction without having quite negative effects. Simply to protect my own welfare I will have to learn to lie through my teeth regarding my mental health in the future unless it seems necessary, or safe, to voice otherwise. I feel like I’m endangering my welfare by even communicating what I have through this appeal - without a doubt, this has been traumatizing. Death doesn’t scare me, but somehow I’m afraid of being asked “Are You Safe?” by doctors, police officers, and phone representatives of medical insurers. How do I deal with that?

I think I’m learning what it is to develop hate for others; it honestly terrifies me what might happen if things continue to decline and I finally fully understand what it is to have hate consume one’s thoughts. It feels a little like a Noah’s Flood situation. I tell everyone ‘you do that and this will happen, so instead act in a way that leads to a favorable outcome', and instead of listening, everyone insists on continuing in actions that will lead everyone to drown.

This appeal has been written in spurts in a non-linear fashion, and it should be observed that the next five paragraphs were written weeks after the past several paragraphs. I believe this important to note in order to understand the scope and intensity of this problem I am describing.

These struggles I experience are not isolated to my person; they, in fact, seem quite common. I see this first-hand in online support communities for Temporomandibular Disorders and Sleep Breathing. Quite recently, in fact, one person posted about a member of the support group who they had spoken with for many years. This member had committed suicide recently. The person posting voiced that they'd not realized their friend had been at that point in their considerations. They also admitted that they have been exploring the idea of ending their life for some time as well. This person posted to reach out for support from the only place they knew to find it; a lesson learned intimately by those who experience the abandonment of TMD patients within our medical system; by physicians, insurers, researchers, legislators, etc. I will not reference this group lest it further expose patients to more mistreatment because someone at Cigna, UnitedHealthcare, or any other party decide to pursue actions that might impose penalty or restriction to one of the few havens TMD patients feel they have.

Medical doctors ignore us and/or disqualify our struggles. Insurers deny our pleas for coverage. Our needs remaining chronically unmet has detrimental consequences to our physical health, and if we communicate the mental distress this causes, the impact it wrecks in our lives and those around us, the response we patients have come to expect is to be ignored, blown off, or experience an involuntary commitment to a psychiatric ward in which not only will our medical needs not be met, but our access to the tools we have at home to manage our disease ourselves will be restricted or disallowed, and our overall health will be placed in jeopardy as a result. I have had that happen to myself multiple times. The latest offense was perpetrated by a Licensed Clinical Social Worker who works at Cigna.

I described to this LCSW the plight of TMD patients, some of the comorbidities, the toll it takes, using examples from other patients and intentionally avoided speaking about suicidal ideation in the first-person so that at no point is time was there any admission that I was at acute risk. Nevertheless, I get asked that loaded question that shows someone's concern is focused, whether intentionally or not, upon their liability, "Are you safe?". Even after explaining matters, that the series of events that occur when police get called often leads to an outcome in which the health of patients like me is endangered and can be worsened, that the only means by which to keep someone in this situation safe is to try to address the conditions which are jeopardizing their ability to function, the LCSW still called the police. She did that very thing for which she was informed it would cause harm.

Did she not believe? Did she think she knew better despite clearly lacking in experience? Did she do any due diligence and ask for references to verify the veracity of the claims that were communicated to her person? It's truly equivalent to someone stating "I have a peanut allergy" to another human being and then that person responds by opening up a bag of peanuts and chomping away - it would be outright malicious if the person understood their actions, but the situation is more a mix of negligence, incompetence, and complacency.

However it may be best defined, it's the opposite of what to do to keep someone with these problems safe.

In people who suffer such abuses it instigates in them a response that will worsen their mental health, further aggravating the very thing such hapless people claim to be concerned with, while also potentially, and quite often, causing the individual to be presented to a psychiatric facility in which their physical and mental condition will deteriorate because insurance won't pay the doctors of that facility to meet those needs and, therefore, those needs are ignored even when communicated, and because lawyers need a certain threshold of harm to occur before it becomes financially viable to perform a medical malpractice lawsuit patients have little to no legal recourse and the facility and providers employed are not penalized and, in fact, profit by the manner in which they monetize the pain and suffering of the individual subjected to this abuse - commoditized like cattle. All the while, patients like myself have to put up with the absurd lie that this was all done to keep us 'safe', even though at discharge we are less safe than we were prior to being admitted. Meanwhile, our claims, appeals, and other efforts to find access to care, get ignored and denied because they're not 'medically necessary'. Which is a heinous lie. A vicious display of indifference that shows the health and well-being of fellow human beings lies very low on the list of priorities for medical insurers.

I think that if someone does not understand the outcomes which will occur as a result of an action, then they probably shouldn't be engaging in that action, especially if they are not in a position in which they can stick around to make observations and learn from the outcome. This LCSW clearly didn't comprehend matters but felt perfectly comfortable engaging in actions under conditions she would not have the capacity to observe and insure if something did go wrong she could intervene or at least observe and learn to do better in the future. I have learned, the hard and slow way, that such people are a hazard to work with as they will continually fail to avoid entirely preventable unfavorable outcomes and will find some means by which to excuse their actions in order to believe, "I know I am a good person".

And I would like it noted, I don't normally throw people under the bus - I'm just so sick and tired of being mistreated and placed in jeopardizing situations that I don't know what else to do but to voice my grievances in this appeal with minimal restriction. It's not as if the LCSW's behavior is somehow exceptional in comparison to the other representatives Cigna and other insurers choose to employ. Currently, I don't know what I can do to protect myself from the harms imposed by those people other than outright lie on a continual basis regarding the impact my situation is having on my mental welfare. It seems impossible to get help to fix a problem if it's not safe for me to accurately describe it to others.

A part of me wonders if third-party payers are knowingly engaged in these actions - learned helplessness is a known phenomena and much more likely to occur in persons in these situations. 'Why bother making a request for care, or appeal, or file a claim when the insurance wrongfully denies it anyways'. To claim to prioritize members mental health while purposefully engaging in a business model that compromises their mental health, thereby positioning oneself to utilize their mental anguish as a means to increase profits. I wonder if I can get some academics interested in doing a study on the subject. Actually, I could probably do that study myself if I took the time to organize some TMD patients in these support groups.

I had to put working on this appeal on hold for about five months to deal with pressing health issues. In coming back to it I find myself less able to function, to write as well as I once could, to organize information. My decline continues. If not for the dissociation that protects me I think I would be overcome with a sense of irrevocable loss at the damage that has occurred to my person. I intended to write much more. I intended to do a deeper dive into literature and provide more extensive references. I also intended to have gotten this appeal finished sooner and have been accessing care by June or July of 2019, but here I am in ~~September October~~ November still trying to write an appeal. I am tired. I am feeling exceedingly unwell. I need to take steps to preserve myself and focus on making certain what I've learned is communicated to others.

I want the misbehavior to stop so patients will be able to access medically necessary care. We are entitled to have our requests for care undergo a review process that operates with integrity; a review process that respects the foundational medical science that illustrates a members need is medically necessary. When a plan member's medical conditions lead to chronic pain and impair things as basic as speaking, eating, breathing, and sleep - when their condition attacks Activities of Daily Living and leads to a substantive loss in quality of life - it is contemptible to claim their need is not medically necessary. Insurers and employers have an opportunity to own this problem, fix it, and provide benefit to themselves and their beneficiaries before matters escalate further. Yet, my past experiences breed a cynicism that expects insurers and plan administrators to double-down on committing misdeeds and dig an even deeper hole for themselves rather than trying to turn a new leaf and fix what's broken.

Realizing how people in similar circumstances to my own are being exploited is infuriating. People with intense struggles are presented with an obstacle course that even the most able individuals have a limited ability to navigate. It's wrong. It's wrong in a way that is indefensible. Yet, insurers, employers, and many of their staff are perfectly content to engage in activities which uphold the operation of a system focused on commoditizing the suffering of these vulnerable people. What an awful thing to be remembered for.

Sean: "...what I'm hearing from people who work in this [medical insurance] industry is that it can cost as much as eight thousand dollars to review an appeal and I'm just kind of like, 'that can't be right'. So, I just want to see the numbers for myself and see what's really going on and include that in part of the appeal [that] I'm basically being forced to write on my own."'

Katy: "There's no way to get the information of what it costs for Cigna to pay for people to review appeals and pre-certification requests."

Sean: "What about all the records that are produced in the appeal [process] that would at least be able to corroborate whether or not it was received and read and reviewed with integrity? That they actually sat down, read the whole thing, requested records, actually did their job, and didn't just pick a name and say 'Denied'?"

Katy: "Well I can tell you they don't do that[1], number one, but number two, if you want copies of all those records - as I've told you and many other reps have told you - you will need to get a subpoena and then those records will be sent out to your lawyer and available for you to read."

Sean: "And why does it require a Subpoena?"

Katy: "Because all sorts of notes and documentation that is in Cigna systems are Cigna property and not yours. And in order to get them you do need a subpoena to request those."
"So is there anything else I can help you with today?"

Sean: "I am curious, if people are being forced to get lawyers to be able to get transparency over the review process for, basically, they're medical care organization isn't that a little extreme?"

Katy: "No, because again, it's Cigna property. In order to get that property, all the notations that are put on the account is something that has to go through the legal system…"..."All of the documentation and notation that is put in there is part of Cigna property and that is why the subpoena is required."

Sean: "What I guess I'm trying to understand is, it seems no one is policing Cigna and actually insuring that they are doing their job and from my end it looks like they're violating both their contract with Fedex and violating state and federal laws that are supposed to protect patients. And it seems extreme to me to have to get a subpoena to get something that the Affordable Care Act basically says I have a right to."

Katy: "And as I've explained before Fedex is a self-funded plan - they are the ones who pay all the bills - therefore, they are not required to follow state and federal mandates. If you have concerns or questions about that you need to reach out to Fedex. There is nothing further that I or my reps can do and when you call in and tell them that they are being illegal in their activities, that they're discriminating against you - any of those things - you are now harassing and abusing my reps."
- A phone conversation between myself and Kathleen, a Senior Customer Services Representative at Cigna, October 8th, 2019; reference # 4245.

"As part of this appeal, you or your authorized representative can review, upon request and free of charge, all documents, records and information used to make your benefit decision. For a copy of these documents, send your request to the

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[1] Except, that's exactly what has happened with the denial for Dr. Rice. Similar misbehavior occurred with the denial for Dr. Blumenthal. I had previously explained this to Kathleen and other representatives. See pages 62-75 for more detailed information.

address shown on the denial letter, or call the telephone number shown on the letter. You can include this request as part of your appeal.” - Fedex 2018 Summary Plan Description, page 215

“The people who operate your plan, called “fiduciaries” of the plan, have a duty to do so prudently and in the interest of you and other plan participants and beneficiaries.” - Fedex 2018 Summary Plan Description, page 13

With Regard,
Sean Smith
(901) 573-8610

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    B. https://scholar.google.com/scholar?hl=en&as_sdt=0%2C43&q=sleep+apnea+autonomic+dysfunction&btnG=
    C. https://scholar.google.com/scholar?hl=en&as_sdt=0%2C43&q=sleep+apnea+sympathetic+dominance&btnG=
    D. https://scholar.google.com/scholar?hl=en&as_sdt=0%2C43&q=sleep+fragmentation+sympathovagal&btnG=

   E. See Also: “In fact, we’re writing a paper right now. I think if there is one central pathway through which we can understand almost all aspects of the deleterious impact of insufficient sleep it is through the autonomic nervous system and specifically an excess leaning on the fight or flight branch of the nervous system. Which is to say, that your sympathovagal balance is way off.” - Matthew Walker, The Drive EP48: 16:00:00. https://peterattiamd.com/matthewwalker2/

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Clinical Findings and Self-Reported Observations:

Foreword:

After all I've written I am disinclined to go to further effort with documentation to validate my statements. If the reader does not understand why an anterior and posterior open bite, maxillary hypoplasia, posterior grade 2 tongue-tie, and limited opening are medical issues necessitating care, then I advise you find someone who does, and if you can't then go ahead and call me and I'll explain it, or tell you which individuals you can talk to get an explanation.

Summary:

It's primarily the nighttime and daytime disordered breathing and related posturing of the jaw, cranium, and neck that contributes the most to my TMD (probably most developmental TMD in general). Sleep fragmentation and sensitization contribute as well. As a result of sleeping my muscle bracing, trigger points, and pain get worse. Over time I have experienced a decline in function mentally and physically. I have a variety of medical comorbidities contributing to primary complaints. I need a solution which attends to all of these needs, and one with evidence of good outcomes in adults.

Airway, TMD, and Me:

-ADHD DX age 6, Mild Asthma DX age 6, bed wetting throughout childhood

- A slow gradual change in mood, interests, and athletic ability beginning around age 9. Memories of distress regarding not being able to breathe properly with my mouth closed (not enough tongue space). After a head injury later in the year I had a radical change in my perception of the world - places not the same, hobbies not interesting, difficulty learning - being rudely confronted at age 9 not only by the fact that perception is reality, but that "I" am not the author of what I perceive; I do not control my perception of reality and as a consequence am subject to conditions neither peers, parents, nor mentors comprehend.

-Depression DX Age 9, behavioral issues in school and home

-In hindsight, back/neck pain since age 9, changes in posture/gait, changes in masticatory function, instances of reflux

-Bipolar II DX age 10

-Tinnitus age 10 to date

- First memories of signs of Nocturnal Bruxism and the start of an anterior open bite age 10.

-History of Mouthbreathing and Rhinitis, onset coinciding with a progression of psychiatric symptoms. Worsening 'mental health' Age 14 after a broken nose that went untreated.

-Pediatric Sleep Apnea DX age 17, Tonsil/Adenoid/Septoplasty 2004

- Wisdom teeth extracted surgically. Worsening of TMD symptoms; pain near the right ear, worsening of gait issues, more cognitive difficulties, alterations in mood and perception of the world, etc.

-Treatment Resistant Depression DX as adult, Mood improves somewhat after weight loss and reducing psychotropic medications

-Septoplasty/Turbinite Reduction 2012; continued memory problems, fatigue, depression, poor sleep - TX ADHD and Sleep meds.

- 2013-2015: Worsening health, increased head and neck pain, poor sleep (wake up gasping, dry mouth, loud heartbeat, Nocturia 4-6x a night, nighttime reflux and stuffy nose), constant reports of fatigue, persistent cognitive decline, always tired never sleepy, constantly active stress response, light and smell sensitivity, irritability, cold hands and feet, dissociation, depersonalization, derealization, continual complaints of ‘twisted posture’, orthostatic hypotension. Was going to college for Comp Sci degree, did well academically, but non-functional because of sleep and pain issues and had to drop out.
- May 30, 2014. Sleep onset and maintenance insomnias treated with Trazodone. Induced worsening of orthostatic hypotension. I’d wake up dizzy with a pounding heartbeat. Experienced syncope twice one night while using the bathroom. First fall I wake up right jaw on the floor, blood in my mouth. I get up to try to get help and fall like a tree, hitting the right forehead/eyebrow into the corner of a doorframe - I could’ve lost an eye. Trip to the ER. Heart rate below 40 upon presenting to ER at 0130. Eight stitches, CT, sent home with discharge paperwork suggesting a concussion; lack of instructions for follow-up care. Insomnia went out of control. In the following two weeks, <50 hours sleep. Acute insomnia occurring 2hrs before and 2hrs after time of the head trauma. TMD pain intensified - unable to function because of pain and sleep. RX’d Temazepam - Temazepam led to the worst experience of my life. Since this injury my TMD and cognitive issues are substantially worse - attempts to access care impeded or unsuccessful due to denials for out-of-network adequacies and inability to get procedures covered.
- 2012-2016. Four years of being referred to different places without answers. Told TMD DX by dentist in 2016. Did multiple local consults with TMD providers while doing my own research. What I’ve learned leads me to understand that deficient facial anatomy can lead to airway problems which cause sleep/posture problems which lead to pain, cognitive deficits, and contributes to/drives psych symptoms and other comorbidities through a systems biology that is both omni-directional (interconnected recursive relationships; more than simply uni/bi/multi directional interactions) and multi-dimensional (time, genes-environment, epigenetics, stages of development, etc; i.e. the health effects of disordered breathing on sleep at age 10 is different than at age 30). Multiple head and facial traumas have led to progression of the Temporomandibular Disorder and reduced my capacity for self-care. Development of posterior open bite and progression of TMD pain and dysfunction throughout this time period.
- 2018. Unable to access PT (Dr. McMahon) who has been able to help manage pain. UHC:CP said I had to demonstrate no in-network PTs could provide care. Six weeks later TMD worsened. While opening my jaw I had an acute onset of right-sided facial paresthesia and bilateral loss of coordination of the hands and jaw, body twitches and tremors, and in the week following a few instances of...spasming out of my chair onto the floor due to having brief episodes of impaired control of my body. Still unclear why, a few instances correlated to episodes occurring after tilting my head to look upward. Acute psychological distress experienced in response to these occurrences. I had to give up regular exercise and further restrict my diet to manage the paresthesia and pain - these restrictions continue to date (Oct, 2019).

After a lengthy wait, I finally saw the TennCare PT. Appointments with the PT would worsen pain and paresthesia; 14 appointments, 2 per week. Saw multiple in-network specialists, including an oral surgeon; no answers, no help. Cigna deductible/out-of-pocket met, went back to Dr. McMahon, symptoms improved 70% in two visits. I still struggle with paresthesia. Managing the paresthesia and related functional issues requires a combination of therapies with Dr. McMahon. I attempted an out-of-network adequacy for Dr. McMahon in November of 2018. It was denied by UHC.
- 2019 Attempts to get a sleep-study continue to fail. As explained in the appeal, I’ve been malpracticed, then mismanaged. Sleep physicians engage in these behaviors mostly because they believe the behavior of insurers makes it impossible to get the needed studies approved and treatment provided. This behavior being tolerated also relies upon patient ignorance regarding the care they’re receiving.

My attempts to find a GI doctor that will acknowledge the contribution of my TMD to impaired digestion have been quite difficult. I had requested the physicians acknowledge these medical issues so they can deliver safe diagnostic procedures and treatment plans. Instead I had been told dismissively that I will need to find a jaw doctor; that GI docs only deal with the GastroIntestinal tract.

The jaws are a digestive organ. Mastication is step one of digestion. It's the beginning of the digestive tract. It's hosts a neurology and microbial community which directly influence and regulate the function of the entire body, including the other digestive organs. Yet GI docs ignore it because insurers provide no pathway to allow them to attend to it. Cigna's & UnitedHealthcare's denials obfuscating my access to care for TMD also impedes my efforts to examine my GastroIntestinal complaints. In persons with dysfunction of the jaw, digestive complaints are common and known to be difficult to manage but are regularly observed to improve or resolve with comprehensive treatment of the TMD and related comorbid conditions, such as those affecting sleep. In other words, insurers pay GI docs for diagnostic procedures and ongoing management that costs more than the care which would resolve the complaints, and it's the fault of insurers this model persists as even motivated patients like myself can't get doctors on board 'because insurance won't pay, therefore, why become educated on diagnostics and treatment that cannot be utilized clinically because payers don't reimburse for it.'

-Self-treating has lead to improvements, but not enough to address the disabling nature of my day to day. I require treatment.

Current and Misc Symptoms and Findings:

- Anterior and Posterior Open Bite. Maxillary hypoplasia. Cross bite. High palatal vault. Posterior Tongue tie, Mallampati Class 4, Scalloped tongue [DX Dr. Barron & Dr. Rice], Constricted nasal passages and posteriorly displaced TMJs - from CBCT evaluation: "Inferior nasal concha distance from nasal septum: Right: 0.7mm (markedly reduced); Left: 0.7mm (markedly reduced).", "Right condyle is posteriorly positioned within glenoid fossa with mild flattening. Left condyle is posteriorly-positioned in glenoid fossa with mild flattening."
- REM OSA. UARS. Rhinitis. History of mild snoring since childhood.
- Forward head posture. Twisted posture affecting entire body. Mandible is protruded and pulls posteriorly and distally to the right, which has significant impact on the upper cervical. Entire right side feels pulled down. Body posture twisted. Tongue pulls to right. Hyoid uneven and tender on right. Tight fascia throughout the craniofacial region; focalized throughout the temporalis, TMJs, and occiput. Jaw tightness and forward head posture related to tongue/airway/nasal patency. I think masticatory muscles and head/cervical/thoracic are in a guarded position to protect the airway; relates to lack of tongue-space and nasal constriction. Soft tissue dysfunction and disordered breathing influence facial growth leading to malpositioned jaws which also further contribute to issues with body posture and TMD pain.
- left side weakness and neuropathy. Occasional Bilateral loss of sensation/coordination in arms/hands. Pain near right ear and Cervical/Occipital pain that has occurred longer than I can remember. Since May 2018, paresthesia and loss of sensation on right side of head/face/mouth.

-spend much of my day trying to correct posture and relax muscles. Wake up during sleep with neck postured forward, head is canted up, mandible protruding, and muscles bracing throughout body. Forward posturing affects muscle bracing and trigger points throughout body. Using aqualizer for bruxism seems to contribute negatively (TMD/cervical pain, jaw position) and positively (reduce tooth pain, sleep quality)

- When nose is flow limited my sleep quality, cognitive function, and mood suffer substantially.
- I think nose is congested because of maxillary underdevelopment, soft tissue dysfunction and neurological issues due to the TMD, oral microbial issues, gut issues, and airborne irritants. My nose gets more inflamed/congested as I sleep during the night - TMD directly contributes. Possible that additional factors are involved, especially those occurring during sleep, such as increased airflow resistance irritating the mucosa, or vacuum forces and inflammation related to respiratory events. My nose will usually clear up some if I stay awake at least 30 minutes and work on relaxing my face/head/neck

muscles. On nights in which things are more severe, it takes longer to clear up, or sometimes it won't clear up and my sleep maintenance insomnia will be really bad.

- There is some tongue-tie, but also simple tissue restriction. I notice tight/contracted muscles near the frenulum. Definitely not enough room for the tongue in my mouth, so it drops into the throat. Not sure how much of my tongue-tie needs surgical intervention, and how much is fascia/restriction/myofunctional.
-Digestive issues. I have struggled for years with digestion, usually constipation/low stool motility. I used to be obese, but have been a normal weight since 2015. I almost never feel hungry. Occasionally I feel nauseous with no clear reason why. I struggle to eat because chewing leads to pain and paresthesia. My diet has become increasingly limited and repetitive to avoid chewing. Eating certain foods reduces postprandial salivary flow.

Four months after the injury in early 2018 that caused the facial paresthesia and related complications I experienced unexplained weight loss of about 14 pounds in less than four weeks. Stools were loose, undigested food particles present, color was 'pale blond' instead of brown or green; weight loss stabilized using a ketogenic diet as did the ability to digest food, though digestive issues continue to be a problem I struggle with. I used to skip breakfast to manage jaw pain in the morning, but have changed that. I tried skipping dinner to manage disordered breathing. I make sure breakfast doesn't involve chewing. Though in order to avoid bone density loss and soft tissue atrophy within the structures of the masticatory system I force myself to eat something somewhat chewy every so often; it hurts and the pain makes it very difficult to get anything done the rest of that day. Despite my efforts I have experienced wasting of the masticatory muscles, especially the temporalis.

I had to discontinue the ketogenic diet because constipation was causing rectal bleeding. My stools are once again loose with undigested food particles. Sleep quality is worse. Cognitive capacity poorer. While on a low-carb and ketogenic diet stools were solid and initially I experienced slight constipation, but over time stools became hard, compacted, and constipated (passed every 48-72hrs). Returning to carbohydrates stools are loose, with undigested food particles (potato skins, bits of carrot, etc), smells like vomit, and pass once or twice a day. I continue to have to supplement with minerals, especially magnesium, to manage some symptoms that get progressively worse the longer I abstain from taking the mineral supplements - given the consistency of stools, some degree of nutrient malabsorption seems a given.

- Gum irritation and thick Saliva. I notice a correlation between irritated gums and nasal congestion. I also notice a correlation between irritated gums and issues with cognition and mood. What I eat seems to affect how irritated the gums can get. When I fasted for 9 days my mouth became constantly acidic as if I had chewed vitamin C tablets. The sourness would come from the gumline and in-between teeth. This occurs on additional fasts, more intensive oral hygiene has little to no impact on it. I would experience nausea alongside the increased oral acidity. I suspect a systemic connection between digestive/gut issues and what is occurring in the gums.
- In 2017 and 2018 I tried flonase over three times. Each trial was separated from others by 6 weeks to 3 months or longer. Each time on day 4-5 my nose would get stuffed up so bad I'd have to use Afrin to sleep and then discontinue trying to use Flonase. Tried Azelastine, which had no effect. Eating a low-carb diet leads to improved nasal patency, but I am still congested and flow limited. Facial paresthesia alters patency of the right nasal passage. Tight muscles in the face and jaw alter patency of both nasal passages; facial muscles get 'scrunched up'.
- Orthostatic hypotensive events. It's not as bad as it was in the past, but still a problem. Sometimes when I get out of the car I'll feel weak and dizzy and have to lean back into the car for a few seconds. After going for a walk I'll sit on the floor, take off my shoes, lie back and rest. When I get up I'll be dizzy sometimes. Sometimes when the TMD pain is bad and I turn my head the wrong way I'll get...not dizzy but feel faint, and have to 'grab the ground' to avoid falling. Occasionally when I get out of my car I'll have to lean on the car due to feeling faint. More recently I have experienced events that when walking lead me

to ‘fall’ into a wall. I’m having to spend more and more time managing my TMD in order to minimize the incidence of these events.

-Cognitive Deficits and Decline. Difficulty recalling information I know I should have command of. Difficulty focusing. Ongoing dissociation that varies in intensity. A persistent sense of unreality. Cognitively fatigued. Difficulty organizing information. Difficulty finding words while writing or speaking. Almost always struggle to communicate verbally. Cannot respond dynamically very well; I have to prepare beforehand and even then I forget to cover some basics. Difficulty remembering names, directions, and other simple tasks. Months ago, a class-mate from middle-school/high-school saw me, recognized me, and knew my name. When I saw her, I could tell I should be able to recognize this person, but could only muster the faintest ability to discern the face was familiar. She told me her name more than once in our conversation before I could remember it.. I think...it was Tabitha...I forget her last name even though I know I should remember it; I know I wrote it down. I’m distrubed by my cognitive decline. I’m a shadow of what I was and I’m a shadow that is fading into an indistinct blur. I don’t have access to my past in the way others do. Who I am...was?... I am losing “I”. I would be terrified if it was not for the dissociation and depersonalization that limits my experience of emotion and sense of ‘things really happening’.

- More complaints could be listed, but I will refrain.

Self-Treatment:

-Positive pressure saline or Xlear as needed ~1hr before bed.

-antimicrobial rinses and herbal teas ameliorate some issues with nasal congestion.

- I’ve tried a variety of dietary interventions and noticed there are dietary influences on my sleep and breathing. I limit or avoid certain foods that provoke nasal congestion/inflammation. I don’t overeat hard to digest foods and eat dinner ~3hrs prior to bed.
- I would use a wedge pillow first half of the night for managing reflux and keeping nose clear, then side sleep during the second half. I have discontinued the wedge because of TMD pain. I side sleep with pillows used to elevate my body.
- At night I use breathe right strips, place an aqualizer in my mouth to manage bruxism, and tape my mouth closed to force nasal breathing.
- I have learned to avoid strenuous physical exertion as it sets off muscle issues. Tight muscles in the neck/jaw/face somehow provoke nasal inflammation and congestion - it is most often unilateral, though occasionally bilateral. Lack of strenuous exercise has led to muscle atrophy and has had cognitive drawbacks.
- I manually distract my jaw. When I do this regularly I feel better overall, but it takes too much time and I neglect it. After a period of not having distracted my TMJs, when I then perform a manual distraction I’ll experience body tremors/spasms from head to pelvis, with bracing through the body relaxing, and I’ll feel a pronounced change in my gut - relief/calm
- I massage and stretch soft tissues every day throughout the day.
- Hot baths seems to influence many symptoms. It’s complicated, but in short, gut motility acutely increases, nasal inflammation clears up, cognition improves. The positive effects of this last about 3-4 hours.
- Betaine HCL taken before meals and after meals seems to alleviate some of the stomach issues. Lugols Iodine seems to help as well. Something is going on with my digestion and I suspect it involves some form of microbial activity and/or neurology governing the function of these organs; antimicrobial actions and/or extra stimulus to the organs to increase function are the mechanisms I’ve been entertaining.
- Again, more can be listed but I will refrain to maintain some brevity.

Treatment with Providers:

-too numerous to comprehensively list, but over the last six years, seven PCPs (family med, internists, RNPs), a chiropractor, three orthopedists, one physiatrist, seven physical therapists, two neurologists, multiple consults with Dentists claiming to treat TMD (orthodontists, TMD & Sleep Dentists, General Dentists), Diagnostics with two TMD ‘specialists’(Barron, Mchorris), treatment with one local TMD ‘guru’ (Mchorris), three sleep physicians, three ENTs (Dr. Naidu 2004-2017, Dr. Lazar 2018, Dr. Gillespie 2018), two allergists, four Gastroenterologists, two podiatrists, three psychiatrist, five psychotherapists.

Medical Records:

- I have purposefully had a limited focus on medical records within the main body of my appeal because making sense of those records requires first understanding what’s going on with my care. Many of the records are incomplete or misleading. My appeal and the referenced materials should, hopefully, facilitate a good understanding. To some extent, using medical records to corroborate my account is superfluous. In the event someone feels that they are required I am attaching some records I collated in the past. This medical appeal and the collated records will be provided as digital files contained on a CD-R inside the envelope delivered via certified mail, the folder directory will be: Sean Smith’s Medical Appeal and Medical Records/Medical Records. There will be 30 items contained in the Medical Records folder. Items 1-28 are medical records. Item 0 supplemental information. A readme.txt is included.

Denials for Out-of-Network Adequacies, Diagnostics, and Procedures:

Contents:

Introduction:

I will not cover each and every instance of wrongful denial or jumping through hoops that have delayed care and caused harm. I will recount in detail a few instances that illustrate how medical insurers are wrongfully denying coverage, at times not even following their own rules.

There are many other instances that have occurred and are occurring right now. Six months of constant effort to get an MRI of the TMJs approved, in which after the initial denial I assembled, authored, and faxed in a letter for reconsideration which was 60-pages in length, and still got denied. Somehow when the resident physician gets on the phone for a peer-to-peer it's approved in under 48 hours. Having requests for sleep studies denied. Primary Care Physicians that stop trying to figure out what's wrong and how to fix it because they believe insurance won't approve the diagnostics. After being told by quite a few doctors I should go to Mayo Clinic, Cleveland Clinic, and other major medical centers for help I asked Cigna/UnitedHealthcare if requests for care at these locations would be more likely to be approved or if I'd be experiencing the same series of denials as I do now. The answer was to talk with those centers. The centers were non-committal as well. It's a simple question - is the same misbehavior occurring here locally going to occur with requests for care from acclaimed institutions such as Mayo? I have my answer, but I had to hear it from third parties in closed discussions - some providers at Mayo are unable to see patients because the denials are so bad. I hear in some cases they can't even get office appointments to see patients approved.

I told Cigna and UnitedHealthcare over the phone about how doctors have left me to figure out how to write appeals and get insurers to cover procedures. I said I needed help. I said my medical issues were overwhelming and I have lost so much function that I find myself too cognitively impaired to work on an appeal most days and that this impairment is getting worse. Neither Cigna nor UnitedHealthcare would provide me any assistance or put me in contact with someone who would. They could not even guarantee me that my appeal would be read by a doctor nor that the materials from past denials had been read by the doctors who denied the request.

I've spent too much time on the phone trying to find a way to work with medical insurers. Think this appeal is long? Try reading transcripts of my phone calls. The amount of information that's been conveyed...your organizations have had all the data required to know that I need care and that the requests I have been making are medically necessary.

United Healthcare and its denial of an out-of-network adequacy for Dr. McMahon:

Finding a physical therapist trained in TMD medicine has been very difficult. I tried working with six other physical therapists between 2013-2017 and none of them provided any benefit to my pain and dysfunction. I had finally found one in late 2017 who proved able to help. I communicated this over the phone to the representative in much the same way as it is covered in my medical appeal, "Dr. Mchorris was very explicit in stating I needed a physical therapist to help manage my condition. Further, that it was imperative I see a physical therapist who was very knowledgeable and experienced. Dr. Mchorris was adamant I needed to make it a priority to see Dr. Jim Hambrick. I saw Dr. Hambrick, who was indeed knowledgeable but he determined that the therapy needed for my case would need even more specialized expertise as it required using dry needling techniques he did not feel comfortably trained to perform. Dr. Hambrick referred me to an associate of his, Dr. Ken McMahon." (2019, Sean Smith's Appeal for Medical Care).

In early 2018 the deductible for my primary insurance turned over and the cost of care with Dr. McMahon become too much. I contacted UnitedHealthcare and asked how I could get a network adequacy performed so that they would reimburse for office visits as a secondary so that the cost to me was manageable. I explained how hard it was to find Dr. McMahon and the idea that their in-network providers would have the necessary expertise to be improbable. Further, that it would take up my time, delaying my care, and cost UnitedHealthcare more money in the long-run to insist I screen through all of their in-network providers. My care was ongoing and requires specialized knowledge that few physical therapists possess - Dr. McMahon the only one I have found locally after years of searching. Despite this explanation I was told I'd have to show in-network providers cannot provide similar services.

So, I cold-called every provider on Unitedhealthcare's list of in-network physical therapists and found one physical therapist who did not have specialized training specific to Temporomandibular Disorders but had recently taken a course on dry needling. I scheduled an appointment. Unitedhealthcare had declined to help me maintain my access to care with Dr. McMahon and because of that I suffered an injury related to my unmanaged Temporomandibular Disorder. I spent weeks searching through their in-network providers and more weeks spent waiting for an appointment and throughout this time my TMD was not only entirely unmanaged but was being actively provoked due to the time I was having to spend sorting through the list of providers over the phone, through e-mail, and the stress this causes also contributes to worsening the pain condition. The injury was not small and I have never been the same since. The acute nature of the injury was very concerning and my Primary Care Physician instructed me to go immediately to the Emergency Room and the ER physicians instructed that I needed to follow-up with specialists for further diagnostics and care.

I then go through multiple appointments with doctors trying to diagnose this complication (without success) while also attending the appointments with the physical therapist in-network with Unitedhealthcare. The in-network physical therapists attempt to help with my complaints would often make my condition worse. After a few months we both acknowledge care has not been able to meet my needs. The deductible and out-of-pocket are both met by now because of the costs associated with trying to diagnose and manage the injury causing paresthesia of my face, jaws, and hands. I return to seeing Dr. McMahon and within two weeks my pain is under noticeably better control and the paresthesia is less severe.

In anticipation of the deductible turning over for 2019 I called Unitedhealthcare and outlined the events of 2018 to the Unitedhealthcare representative and insisted on performing an out-of-network adequacy. The request for an out-of-network adequacy for Dr. McMahon was denied. The reason for the denial, per the letter sent to me:

“Based on your health plan rules your care must be sought with providers in the plan. The request for services from a non-plan provider is not approved. In plan providers are available to provide care. Care with a non-plan provider can be covered if:

- It is an emergency
- You are receiving care and it cannot be interrupted.
- There is not an in-plan provider to give needed care

You can also call your primary care doctor with questions.”

Honestly, it’s as if nothing I said to the representative was acknowledged. Based upon what I had communicated over the phone in my request for an out-of-network adequacy each of those reasons for covering a non-plan provider were met.

For reason one: *Due to lack of access to care I experienced a medical emergency earlier in the year. It would be unreasonable to expect this might not occur again.*
For reason two: *I was receiving care, and interrupting that care led to the injury which required emergency services - past events have proved it is unsafe to interrupt my ongoing care with Dr. McMahon. Yet, my request was still denied by UHC:CP.*
For reason three: *I was unable to locate a competent in-plan provider in Feb-May 2018; when I called the providers listed on the denial these proved unsuitable, some of them egregiously so.*

As I have covered, I described to Unitedhealthcare during the phone call in November of 2018 that not only did they not have in-network physicians able to meet my needs, but that because of the events in early 2018 which interrupted my care I was injured. Three providers were listed on the denial letter dated Dec 11, 2018.

The first provider listed, Department of Intellectual and Development, only accepts patients who have wheelchairs; their office will not see someone not in a wheelchair; if the patient is not in a wheelchair this office is not going to see the patient.
Second to this, even if one were in a wheelchair they don't treat jaw disorders.
Third, even if one somehow convinced a provider at this office to see a patient not in a wheelchair and to treat a Temporomandibular Disorder, they do not perform dry needling.
Fourth, even if you handed them the needles they are not trained and certified to use this modality to manage Temporomandibular disorders. Performing dry needling as a physical therapist without the necessary training and certification is against state law. Performing dry needling without adequate training on managing TMD is negligent.
So….Please, Do Explain Why This Office Was Listed. I'm serious. I want Unitedhealthcare to **EXPLAIN!** I also want an explanation as to why UHC's customer service representatives (call Ref# 19G011685154; Nov 6, 2019, Representatives: Kayla and Tiffany) state they are not allowed to disclose to me the name of the reviewer and medical director who made the coverage determination for this request.

The second office said they don't do dry needling.

The third office claimed they treated TMDs and knew how to dry needle. I asked if I could speak with the PT that treats TMD with dry needling. They said the PT wasn't there. I asked the name of the PT and when they would be available. They said they don't give out that information. Perplexed by this, I offered to provide my contact details and they could contact me. Their response was that they don't give out the names of their on-staff physicians over the phone and aren't going to get on the phone unless you're a patient. I was told I could schedule for an appointment. This behavior seemed unusual and suspicious. I'm expected to schedule an appointment with a physician whom they will not provide me even the persons name let alone any means by which to confirm this person has the necessary certification to perform dry needling?

As a consequence of having my needs once again remain unmet for the beginning of 2019 I experienced increased pain, paresthesia, and dysfunction. I experienced intense psychological distress and markedly more severe suicidal ideation because of my unmanaged Temporomandibular Disorder, sleep issues, as well as the abuse and discrimination I'm being subjected to. I tried to communicate my needs to representatives over the phone at Cigna and Unitedhealthcare multiple times throughout the early part of 2019 asking them for assistance so I could access care and was told I'd have to write a medical appeal. I explained my health was such that doing so would be exceedingly difficult for me and that it would also delay access to care, further endangering my health and safety. I told them that their in-network doctors were unwilling to write a medical appeal for care on my behalf. That...well the medical appeal that I've been forced to write covers much of this.

It covers the phone calls, the police showing up to my home, the inappropriate involuntary psychiatric commitments - the circus ride. For 2018 and 2019 Unitedhealthcare and Cigna paid quite handsomely for services that don't help or which actually made my condition worse until finally the deductible and out-of-pocket is met for Cigna and I can see Dr. McMahon.

Wrongful denial of care doesn't even begin to describe this mess. Apparently for Cigna and Unitedhealthcare interacting with members and trying to meet their needs in a rational and humane manner "is **not covered**". My health has been on a downward spiral since 2018, getting worse in 2019. I wonder what's going to happen in 2020?

Cigna and Its Denial of an Out-of-Network Adequacy for Dr. Kellye Rice and Dr. Herbert Blumenthal:

To communicate what occured in my request for an out-of-network adequacy for Dr. Rice I will include the entire body of the document I sent in to the reconsideration department. This document can be found on pages 64-67**.** It will cover what I told to Cigna over the phone during the request for pre-authorization, outlining in detail the reasons I needed care and why in-network doctors were unable to provide this care. After the first denial I sent in the aforementioned letter for reconsideration and the denial was maintained. It was a case worker who got the denial overturned because the original denial didn't followed Cigna's own rules for denying a request for care. They needed to list two providers able to provide similar services and only listed one. So, technically, Dr. Rice was never approved, just that Cigna's negligence in reviewing the request for approval was so egregious their review team didn't even follow basic rules - I doubt they even reviewed any of the documentation I sent in.

After experiencing these events I decided to document this failure and reached out again to the providers listed on the denial of the network adequacy for Dr. Rice. It was my hope that the provider, Dr. Nicholas Gerard, would be willing to write a letter in his own words confirming the information I received from his staff that he does not provide the services I was seeking. Over the phone I asked his staff if I could speak with Dr. Gerard or send him an e-mail and was informed the only way to communicate with Dr. Gerard would be by making an appointment. So that's what I did. In summary, Dr. Gerard refused to listen at the appointment. I was not afforded the opportunity to communicate even the purpose of my visit to him. He would continually interrupt me and refused to read the documentation I had brought. This left me with few options to document what had occurred, and I elected to file a complaint against Dr. Gerard. I will include the complaint in full on pages 68-75.

My request to have an out-of-network adequacy performed to see Dr. Blumenthal was also denied. As memory serves, I communicated to the pre-cert representative I needed a second opinion on my MRI study of Temporomandibular Joints (TMJs) from a provider who treats Temporomandibular Disorders (TMDs) non-surgically, regularly uses MRI's to assess the TMJs to plan and deliver non-surgical care, and has an intimate understanding of TMD that extends beyond the TMJs. I needed to specifically see Dr. Blumenthal to get his opinion on my case, especially regarding my facial paresthesia. I communicated that Dr. Blumenthal's attachment to the Pankey Institute and decades of practice in the TMD field would provide valuable insight into my case and also allow me to network with physicians more likely to meet my needs. Dr. Blumenthal has developed relationships during his many years of practicing and teaching TMD medicine and from that standpoint alone he has a unique ability to direct patients to clinicians able to assist in their care. Moreover, over three medical providers had referred me to Dr. Blumenthal over the course of the past two years.

The physicians listed on the denial for Dr. Blumenthal which Cigna claim are able to provide "similar services" were Dr. Phillip Hathcote and Dr. Steven Zambrano.

I called Dr. Hathcote's office and spoke with Judy in January of 2019. I explained my request for an out-of-network adequacy, the denial, what my needs were, and asked if Dr. Hathcote could indeed provide similar services. Judy stated Dr. Hathcote's practice is generalized and does not specialize in TMDs. That his experience with treating TMD is limited to simple cases, usually some minor bruxism. That paresthesia and numbness is well outside his practice. I recall her stating to this effect, 'Your needs are so far outside of what Dr. Hathcote practices I wouldn't feel comfortable scheduling you for a consult.'

I called Dr. Zambrano's office as well in January of 2019 and explained much as I did to Dr. Hathcote's office. The staff at the front desk replied that Dr. Zambrano only does surgeries for the TMJs. They provide no conservative treatment. In the staff members words, "I don't want you to waste your time coming here for what we don't do."

Months later, while working on this appeal I attempted to get in contact with Dr. Zambrano and Dr. Hathcote and ask each of them write a letter to corroborate in their own words what their staff had communicated to me. Dr. Hathcote had unfortunately passed away. I had tried to get in contact with Dr. Zambrano via phone message and e-mail for weeks, and finally got a reply via e-mail. He stated he wouldn't write a letter for me. He instructed me to write it myself and he would "look and edit as needed and we can go from there.". So I ghostwrote a letter and provided it to him to review. Long story short, Dr. Zambrano has not yet taken the time to send a copy back and I have not been able to find a way to get in contact with him. I have tried multiple times, leaving messages through his staff and sending a few e-mails since August of 2019. Whatever the reason for his lack of response, the claim that Cigna's in-network physicians are able to provide comparable services is laughable. I can't even get a letter from them to assist in fighting wrongful denials. Even when I ghostwrite the letter myself. I guess he's a busy guy. Ironically, he is probably too busy jumping through the hurdles Cigna puts in front of him to have the spare time to assist in this matter.

Very clearly, the review team did not do their job. Their claims that these physicians can provide comparable services is fallacious. In my experience, this level of incompetence is to be expected from Cigna and Unitedhealthcare. The review process lacks integrity and patients suffer complications as a result of delays in accessing care and or an inability to access care. I expect more wrongful denials to occur and I'll be going to the trouble of extensively documenting each and every one.

[A letter for reconsideration I sent to Cigna regarding the denial of network adequacy for Dr. Rice]

ATTENTION: To Reconsideration Department

August, 29th, 2018

To whom it may concern,

On August 17th 2018 I, Sean Smith (patient), called to have an out-of-network adequacy performed so that I could make an appointment with Dr. Kellye Rice (DMD). I explained to the agent in the pre-cert department that I would be seeing Dr. Rice for treatment of a Temporomandibular Disorder that is occurring due to a compromised airway.

I brought it to the attention of the pre-cert agent that this is a long-standing issue. I spent over four years being bounced between medical specialists before being advised to look into TMDs. I then spent two years doing research and consulting with local physicians to try to diagnose and treat my presentation of symptoms. I mentioned to the pre-cert agent I have previously had an out-of-network adequacy approved twice for this issue, once with Dr. Melody Barron in 2016 (DDS) and once with Dr. William Mchorris in 2017 (DDS), because there are no in-network physicians capable of conservatively and non-surgically treating my TMD in the Memphis area.

In addition to working with Dr. Barron (who performed diagnostics and proposed a treatment plan) and Dr. Mchorris (diagnostics and delivered treatment), between 2016-2018 I have consulted with over five different physicians who practice TMD medicine, four different physical therapists seeking treatment specific to TMD, and worked with the UTHSC Oral Surgery department to perform an MRI of the TMJs to rule out internal derangement of the TM Joint, which itself became necessary due to the conflicting diagnosis and treatment plans I had been provided. I have been repeatedly advised by Sleep Doctors (MD and DDS) that I should seek care for my disordered breathing, but due to the barriers Cigna has presented, and the unwillingness of physicians to spend the time needed to argue for medical necessity, I have been left without access to efficacious therapy.

I have done little else other than perform research into TMDs, Airway, and Sleep seeking to determine which path to treatment is most appropriate and how to access that treatment. Repeatedly, access to basic diagnostics and skilled physicians has been obfuscated by Cigna and my physical and mental health has suffered a great deal as a result of this. A consequence of Cigna's behavior is that I have had been admitted to the Emergency Room of local hospitals three times for complications directly related to a compromised airway and inadequately managed disordered breathing. Further, all medical care I have sought since 2012 is directly related to this as well.

The latest example of this struggle to receive care is the denial of the out-of-network adequacy for Dr. Kellye Rice. By now it should be clear I would not request an out-of-network adequacy were it not necessary. But, for the sake of thoroughness I will demonstrate this to an absurdity.

I was informed by Victoria M. in pre-cert that my request for an out-of-network adequacy for Dr. Kellye Rice was denied because the ‘search team’ determined Dr. Nicholas Gerard was an in-network physician who could provide the services I was seeking. In April of 2017 I consulted with Dr. Cooper Sandusky (Orthodontist) who advised I treat my airway and TMD with 18 months of braces followed by bi-maxillary surgery. He referred me to a Maxillofacial Surgeon, Dr. Nicholas Gerard. I sought out second opinions, third opinions, forth opinions, and was advised by multiple physicians and academic literature to first seek out conservative treatment. I inquired of Dr. Gerards office if they would first perform conservative treatment prior to moving to a surgical intervention, and was told ‘Dr. Gerard only performs surgery, he does not offer any non-surgical treatment.’ In an effort to better understand which physicians I might seek care from I sorted through the disciplinary action reports for dental providers going back ten years. Dr. Nicholas Gerard’s name came up in those reports for malpractice, and further, Dr. Gerard seems to have then decided to move his practice from, as memory serves me, Franklin, Tennessee to Memphis - I would not deign to commit to going under the care of Dr. Gerard for major orthognathic surgery without a frank conversation regarding that DAR and his reason for relocating his practice. To be thorough, and leave no doubt, I called Dr. Gerard’s office again, on 8.28.2018 and confirmed Dr. Gerards practice remains limited to surgical intervention. I believe the ‘search team’ did not perform their assigned tasks with the diligence necessary to meet even the most basic need for ANY patient with needs similar to my own.

I have continued to consult physicians and educate myself on matters. What I have learned leads me to believe that most of the physicians in the Memphis area are currently undereducated on the airway and its role in health, and this remains so almost entirely due to the reimbursement model of insurers, especially Cigna, limiting the scope of their practice (i.e. not reimbursing for a diagnosis of UARS means they never develop the clinical experience gained from investigating and diagnosing UARS). That those who do have an appreciation of matters have knowledge gaps that limit their capability to provide patient care. That the treatment plan Dr. Sandusky proposed is incomplete (f.ex it does not acknowledge my tongue-tie, nasal flow limitation, or the involvement of the autonomic nervous system in managing nocturnal respiratory events) and as a result is inappropriate for the treatment of disordered breathing. My attempts to engage with Dr. Sandusky to receive clarification and determine the accuracy of my assessment regarding his treatment plan have not been successful. As yet I have been waiting for ‘his call’ for over six weeks. In any event, considerations for surgical intervention are, to me, merely a back-up plan in the event that non-surgically remodeling of the upper airway via biomimetic oral appliance therapy does not lead to sufficient resolution of my compromised airway. Even in that scenario, the capacity of the the Vivos appliance to remodel the maxilla and improve the function of the upper airway necessitates that, for an optimal outcome, even surgical treatment of the airway start first with this appliance therapy.

There has been a community of physicians that have been vocal in the Sleep and TMD communities that the airway is the culprit behind many somatic disorders and chronic diseases. Within this community are well-known and respected physicians such as Dr. Christian Guilleminault from Stanford, Dr. David Gozal from the University of Chicago, Dr. Avram Gold of Stony Brook University, Dr. Bertrand De Silva of St. Jude Medical Center, Dr. Stephen Park of

Montefiore Medical Center, Dr. Ron Harper of UCLA, and Dr. Mark A. Cruz who operates an Airway Mini-Residency which is, in my opinion, at the bleeding edge of how airway relates to health. On the 24th of August 2018, Dr. Guilleminault, Dr. Gozal, and Dr. Cruz were amongst many other speakers presenting at the American Dental Associations CE Live event, “Children’s Airway Health - A Practical Conference”. The ADA is changing policies and adopting new positions which reflect what this community of physicians has, for over a decade, been vocal advocates for.

There is no way for me to adequately summarize those views within the context of this letter, but needless to say, this conference and the ADAs change in stance marks the beginning of major changes in Dentistry and Medicine. Such changes include, but are not limited to: recognizing that AHI is a inadequate method of assessing a patient's need for care; that there are many patients with AHI’s below 5 that quite obviously benefit from treatment - “...to treat symptoms, not numbers”. That OSA is the end-stage of the illness of disordered breathing, and physicians need to diagnose and treat patients prior to the development of OSA, preferably intervening prenatally or before the age of 6. That TMD patients are predominantly airway patients, and to treat TMD effectively one must treat the compromise in the airway.

Dr. David G. Singh is among that community of aforementioned physicians focused on and advocating for airway health. I have sought out Dr. Kellye Rice because she is trained to deliver an appliance therapy developed by Dr. David G. Singh which can non-surgically remodel the upper airway [1] [2], and in multiple case studies this has resulted in significantly improving and even resolving mild, moderate, and severe sleep apnea [3][4][5][6].

I am not even certain Dr. Kellye Rice has the training needed to meet all of my needs as determining that requires an in-office visit for diagnostics and treatment planning. However, she is one of three physicians with the training to deliver this appliance therapy within a 200 mile radius and none of these physicians are in-network with Cigna. This is nascent science that has taken two decades to develop and it is set to play a substantial role in the standard of care for airway patients during the next three to five years. I would like to be very clear, that this therapy does not ‘move teeth’; it is not *ortho-dontic*. It remodels the upper airway and can correct compromises within the airway; this treatment aims to treat the etiology of my symptoms; qualifying that statement would require a review of literature and continuing education materials in excess of thirty-hours. Nevertheless, I will include citations to research and resources should the reader require more information on this subject [7].

Furthermore, to avoid a common misconception I will be explicit in saying that what I have been describing is a <u>medical</u> issue in which aberrant craniofacial growth impairs the form and function of breathing and respiration, nocturnally and diurnally, and that this is a problem for which dentistry will play a pivotal role in both prevention and treatment. This, is, not, a dental problem. It is, however, a medical problem that has significant attrition to the dentition, thus it has provoked the interest of dentistry in such a way that they aim to reorient their entire field to an airway centric paradigm.

Sincerely,
Sean Smith

(901) 573-8610
6402 Baird lane, Bartlett TN, 38135

References

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3. Heit TC, Sebastian J, Singh GD (2016) A Novel Combined Protocol for the Resolution of Severe Obstructive Sleep Apnea. J Sleep Disord Ther 5:251. doi:10.4172/2167-0277.1000251 https://www.omicsonline.org/open-access/a-novel-combined-protocol-for-the-resolution-of-severe-obstructive-sleepapnea-2167-0277-1000251.php?aid=80799

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6. Singh GD, Cress SE (2017) Biomimetic Oral Appliance Therapy in Adults with Mild to Moderate Obstructive Sleep Apnea Using Combined Maxillo-Mandibular Correction. J Sleep Disord Manag 3:014. https://clinmedjournals.org/articles/jsdm/journal-of-sleep-disorders-and-management-jsdm-3-014.php?jid=jsdm

7. Additional Resources

Dr. Mark Cruz’s Airway Mini-Residency References:
https://docs.google.com/document/d/1BbCln3G0T1g2JSFmIKpF9HPObSJyixISXFtdAieIRiE/edit?usp=sharing

Dr. Tom Colquitt’s presentation to the American Academy of Restorative Dentistry Projected Clinic. It demonstrates the capacity to remodel the upper airway in a 70 year old male and the subsequent clinic outcome:
Tom Colquitt. “AARD Projected Clinic Movie”. YouTube. YouTube, 20 April 2016. Web.
https://www.youtube.com/watch?v=R5S5AZ50pAE&t=419s

A presentation by Dr. David Singh. It goes into more depth regarding the capabilities of BOAT to treat patients:
VivosLife. “Dr Singh Keynote”. YouTube. YouTube, 25 August 2017. Web.
https://www.youtube.com/watch?v=-wAPhcECbMU

[A complaint I sent to various organizations regarding a provider listed on Cigna's denial letter]
A formal complaint regarding my office appointment with Dr. Nicholas O. Gerard:

Aforementioned appointment took place on April 30th, 2019
At address 1650 Bonnie Ln #101, Cordova, TN 38016
Phone # (901) 275-8159
Practice name, Mid-South Oral Surgery

Over the past six years of struggling to figure out what is causing my chronic pain, poor sleep, and other health issues I have had a variety of encounters with healthcare professionals. Occasionally I would think about how to find a way to voice my dissatisfaction regarding my experience and a few times I asked for advice regarding malpractice lawsuit, but feared repercussions that would further limit my healthcare options, and pursued neither, telling myself it would be better to just move on and try to find a way to access care and thereafter be well enough to return to living life. Yet, to date, I've not even bothered to provide online reviews of healthcare professionals. I, in essence, have kept things to myself and limited interactions to online forums in order to focus my attention towards finding solutions, with any reviews or communications of dissatisfaction to be a task to be documented and then later attended to after I've been able to meet my needs by accessing treatment. It so happens, that that motivation to access care and the perceived need to file a complaint have now crossed paths and it has become necessary, as part of writing my own medical appeal, to document what occurred in my encounter with Dr. Nicholas Gerard through a formal complaint.

In August of 2018 I received a letter from Cigna indicating they were denying my request for an out-of-network adequacy (NAP) for Dr. Kelly Rice, stating that "similar services are available from in-network healthcare professionals, and no compelling reason has been given as to why an exception should be made and this request approved." Dr. Gerard was listed as the in-network physician able to provide those 'similar services'. I believe I gave 'compelling reasons', plural, with quite a lot of detail, but nevertheless my first call after reading the denial letter was to Dr. Gerards office to ask if he provided the services for the 'compelling reasons' I'd outlined to Cigna over the phone. The office said they did not provide those services. I called and complained to Cigna, and the denial got reversed at a much later date due to the efforts of a medical case manager who looked into the matter. The grounds for the reversal of the decision to deny the NAP was solely because the person reviewing the claim didn't follow their own internal rules for denying NAPs - they must provide the names of two in-network providers as grounds for denial - a technicality showing a certain amount of inattention was demonstrably present during the review process. And long story - a very long story - short, I basically have to write my own medical appeal to find a way to get specialists approved and seen, because whoever is reviewing NAPs is evidently incompetent, negligent, or purposefully working in bad faith. So, I'm writing that appeal, and as part of writing it I am documenting, among many observations, the behaviors I encounter which serve as barriers to patients in need of care, especially those undertaken by third-party payers. Currently, in those efforts to write this medical appeal and demonstrate the presence of such behavior, I'm working on the NAP denials, which is why I reached out once again to Dr. Gerard's office.

On April 25th, 2019 I contacted Dr. Gerard's office and explained over the phone the situation with the NAP denial, my medical appeal, and my interest in getting Dr. Gerard to write a letter, in his own words, acknowledging that his private practice does not include providing the services I communicated to Cigna over the phone I was in need of. I asked if I could send Dr. Gerard an e-mail, or speak with him over the phone, but was told that I would be required to attend an in-office appointment for me to have any communication with Dr. Gerard. Due to the financial constraints imposed on me by being on disability paying out-of-pocket for such an appointment seemed unnecessarily burdensome to my situation. I then proposed that perhaps the person I was speaking with could simply write a letter on behalf of Dr. Gerards office saying that I requested Dr. Gerard's assistance and that in order to receive his attention with this matter I would be required to attend and pay for an in-office appointment. The woman on the phone said okay, and I offered to stop by their office so they could see the NAP denial and we could communicate face-to-face.

While on the way there that day I recalled I had met my out-of-pocket costs this year, so technically I could attend an in-office appointment at no cost to myself. So when I arrived I offered that perhaps we could schedule an appointment if they believed insurance would approve a claim for an in-office visit that didn't involved medical diagnosis or treatment. An appointment focused on providing assistance with my medical appeal by addressing the NAP denial, doing this by writing a letter acknowledging Dr. Gerard does not provide the services that I had communicated to Cigna I was in need of and for which I had become aware, after many years of seeking to find such a local provider who did, that no in-network providers could provide these services. I was told this would be okay. They copied my insurance cards and I learned they also were in-network with United Healthcare: Community Plan, my secondary. I received paperwork and completed it at home.

At my appointment a few days later I waited in the lobby, and the staff called me and requested I undergo an x-ray. I was taken a back as I had very explicitly made it clear I was not here for diagnostics, but just to cover the NAP denial and get a letter from Dr. Gerard about it to assist in my medical appeal; I needed the doctors help with a medical appeal not a diagnosis. The staff were insistent, so I asked what type of x-ray. They said it was a panogram. I informed the staff:

> I already have such records available as well as a recent CBCT [3d Xray of the entire head] which provides greater diagnostic capacity, and would have been happy to have brought these records if this was truly necessary. However, I did not come to this appointment for Dr. Gerards medical diagnostics and treatment plans - though I voiced it would be quite agreeable to have a discussion with Dr. Gerard to assess if it would seem worthwhile to schedule another appointment for diagnostics and treatment planning sometime in the future - and, moreover, a pangogram would not be diagnostic for my case and I was not interested in undergoing any more unnecessary procedures from

> providers. I would just like to sit and consult with Dr. Gerard about the issues I scheduled the appointment for.

So that's what we did, or tried to do.

I saw Dr. Gerard and when prompted attempted to convey what was going on. I got a sentence and half out when he interrupted, indicating what he wanted me to provide different information. So I tried again, and again he interrupted expressing dissatisfaction. And again, and again, each time getting out little more than a sentence or two. We're less than a minute into our meeting and I'm already finding myself having to pause and use deep breaths to try to quell the negative impact on cognition that develops from the frustration of being repeatedly interrupted and dismissed; failure to manage this increase in activity within the sympathetic nervous system also leads to increased pain related to the TMD - the autonomic nervous system and limbic system are quite burdened by chronic pain and disordered breathing, which quite often leads to cognitive deficits and takes a toll on one's mental well-being. I am going to have to abbreviate matters, as due to pain and stress and very poor sleep my ability to recall fine details regarding these events is impaired when it comes to what exactly was stated, but essentially Dr. Gerard spent a lot of time explaining he doesn't understand what my needs are and won't unless he has an x-ray and other records. That I would need to submit to doing things his way in order to become a patient. That outside of me becoming a patient he is not willing, or believes himself unable, to assist me. At no point in time was I able to explain the full situation with my appeal, the denials of the NAPs, my medical history...the reason I declined the xray... In short, I Was Not Heard because someone was not listening.

Among my many efforts to access information I have spent quite a lot of time listening to healthcare professionals in videos and podcasts. In one podcast produced by a group of physical therapists who spend a lot of time managing chronic pain patients - the intended listening audience being their peers, fellow physiotherapists - one of the many things stated in the podcast, which I found useful to hear, is that they've learned in their practice that with new patients it's beneficial to just ask, 'tell me about why you're here today?', and to then sit and listen for at least two minutes, because in the majority of cases the patient will provide almost all of the information you're looking for in that two minutes, and if they don't, then, no big deal, you can interrupt them and direct them to provide more relevant information. In five minutes, by listening, one can pretty much have a rather clear understanding of why someone is in their office and what they, as healthcare providers, might be able to offer assistance with. This podcast episode has stuck me not because it was personally insightful, but because it was integral to understanding what type of behaviors are engaged in by healthcare providers who understand how to appropriately manage patients experiencing pain and dysfunction. The first thing one needs to do is *Listen.* When it comes to TMD patients, more especially so is this a priority given the pain is not only chronic but the standards of care perceived to exist for this disorder by most doctors are, as outlined in the recent (2019, March 28th-29th) panel presentations at the National Academy of Medicine's Committee meeting on TMDs, quite lacking which is a big problem for patients as the disorder can be quite complicated to diagnosis and treat properly. A point I intend to outline in the medical appeal. And in pursuit of writing that appeal it seems beneficial to provide some form of documentation of my encounter with Dr.

Gerard to serve as a substitute for the brief letter I was there to request he write for me - I'm making some lemonade from this lemon.

While my memory of events during my conversation with him is not as clear as I would wish, and will probably require some time for me to sort through events, one thing stuck with me. I do remember him specifically stating this because it was so disturbing to hear from someone claiming he 'treats TMJ' and implied his role as a physician necessitates patients submit to him the moment they step in the office.

He said, and I paraphrase due to not having a direct recording, 'You don't have a say in what happens to you at the doctors office', to which I interdicted, 'excuse me, I believe I have full autonomy in deciding what happens to me here', to which he elaborated his view that patients are to submit to what the doctor decides needs to be done diagnostically, with no say-so in that process, and then the doctor provides the patient a treatment plan. The patient can either accept it or not. Which, is...well I wasn't there for diagnosis or treatment planning. I was there, from the get-go, to explain to him I just need a letter acknowledging your practice doesn't offer these services that Cigna claims you can provide.

He refused to read the paper with the paragraph long, bullet-pointed list of services I had communicated to Cigna were what I was seeking. Which, for the sake of accuracy, I timed how long it takes me to read: 28.17 seconds to read. I'm including a scanned copy of this in case the reader wishes to see this document and attempt to corroborate this [1]. He refused to look at the denial letter as well, which would have taken a similarly miniscule amount of time as most of the text is superfluous - one denial letter is much the same as another with small differences. In essence, I would've required little more than perhaps five minutes of Dr. Gerards undivided attention, without interruption, to fully communicate why I was there. He wouldn't hear me out. He kept insisting he can't do anything for me if I don't let him take x-rays and do diagnostics. That I will not be a patient of his without submitting to this and that therefore he has no obligation to attend to any need I present to him. Dr. Gerard seemed very insistent I submit to doing things his way and only his way and seemed to have no interest in stopping to listen and comprehend even the basics of why I had presented myself to him in his office.

At one point, I interrupted Dr. Gerard and tried to make it clear I felt he wasn't able to understand why I was here and what I was trying to do because he just wasn't affording me the opportunity to explain by exercising the patience to listen, and that, furthermore, this is part of the reason TMD patients have such a difficult struggle in the current medical system. So, he provided about thirty seconds of pause, in which I was able to say I was looking for 'non-surgical remodeling of the frontonasal complex', before he interrupted again to tell me how, 'Any non-surgical expansion of the maxilla at my age is just tipping teeth'. I tried to express, but again was not afforded adequate opportunity to do so fully, that's not what I have seen in published literature, case studies, and presentations by clinicians, as well as evidences from other patients, which is why I'm requesting to see those clinicians who are more focused in the area of non-surgical care; those whose practice specializes in seeking non-surgical intervention; those who are not surgeons, and are, therefore, much more attentive to determining what is achievable through non-surgical interventions. He was dismissive, so I asked him what did he think of Won Moon's work out of UCLA? He got up then, making no comment about Won Moon.

Perhaps he's not familiar that Won Moon has published articles in which he expanded the maxilla of adults well into their fourth and fifth decades of life, with no teeth tipping. That Won Moon has resolved class three skeletal relationships in adults over the age of 25 using facial protraction rather than highly invasive - and also quite costly to insurers and patients - Lefort procedures (Jaw surgery)… perhaps he is aware, and his response was more about just being disinterested in having the discussion go down this path of 'debate' and to end the appointment since I had made an attempt to move the conversation in that direction. I don't know. And I think my willingness to admit as much is the key difference between someone like myself and Dr. Gerard - the ability to recognize and be comfortable admitting when one doesn't know and, from each and every opportunity, attempt to learn so that one can know better in the future. And it is that behavior, first and foremost, that seems to be the hallmark of excellence in providers specializing in treating chronic pain, especially TMDs - 'I don't know, and will therefore go take the time to find answers wherever they are and from whomever may be in possession of these answers and is willing to divulge that information'. Such people, such attitudes, lead to providers that learn just as well from listening to their patients as they do from fellow professionals.

I wasn't asked to leave at this point, but it was implied by his affect and body language, so I get up and exit with Dr. Gerard while he continues to talk dismissively in a manner clearly intended to end all further conversation. On the way out he says something, I forget what, which I remember finding quite provocative and consequently feeling a desire to voice as much. I turn around before crossing the threshold of the doorway to the waiting area to tell Dr. Gerard that 'the National Academy of Medicine is currently engaged in Committee meetings on Temporomandibular Disorders and patients have presented panels. These patient presentations in these meetings paint a decidedly negative picture regarding their experiences with most dentists and medical providers, oral surgeons in particular.' And that these patients made it abundantly clear that behaviors like those Dr. Gerard engaged in at this appointment plays a large part in the many hazards patients have to navigate through and that I think he should take the time to listen to those patients who presented at the NAM meeting on TMDs. Furthermore, the academic presenters mirror the patient experience - they reiterate many times that clinicians are undertrained, non-surgical care is often inadequate or inaccessible, unnecessary surgeries continue to take place, that many such surgeries can and have failed and when they do patients learn this the hard way, so much so, that many become more knowledgeable experts on TMDs than their doctors are. It took me less than a minute to say these things. Dr. Gerard responded to this attempt to communicate by threatening to call the police if I don't leave the office.

So I exit to the lobby, and stop at the front desk to inform the front desk that I advise they don't try to file a claim to my insurance for whatever it is that just happened at this office as I would fight that claim - the idea Dr. Gerard would be reimbursed for what just happened would be contemptible. Dr. Gerard continues to threaten to call police, even as I am clearly moving to exit the building and less than a minute of time has passed since his last threat, and in fact escalates matters promptly by saying he thinks he should take a photo. He then takes out his phone, to which I stop at the doorway which exits the office to tell him I think his behavior here has been inexcusable. I say - my demeanor having become clearly agitated showing I was in distress - 'Sir, I think I should inform you I intend to file complaints regarding your behavior here today with both the major medical insurers you are in-network with and any other agency it seems relevant to, and that I think I will call the police simply as a preventative measure for my own well-being.' and I pause in the doorway for him to take his picture, with his phone, then leave, get in the car, and call the police department to inquire as to if I should be afraid of Dr. Gerard filing a police report which falsely represents events and if he does so how can I protect myself from that? I am informed that there is nothing I can do to protect myself from that occurrence. I voice grave concern to the police staff on the phone, and am so distressed from the threat of police action by Dr. Gerard that I break down emotionally - an event which is highly irregular for me; I have a very flat affect - as being someone who has experienced abuses from medical providers in the past, only to learn that lawyers are not interested in the case because it wouldn't be sufficiently profitable to pay the costs associated with a malpractice lawsuit, and being on disability I don't have the resources to afford legal representative, how would I protect myself from someone licensed to practice medicine, perceived per his degree as 'doctor', with the resources granted from private practice, who might wish to use the legal system to 'squash out a potential problem to his perceived self-interest'.

I admit, to some extent, this can be rightly viewed as catastrophizing. That's not how doctors are 'supposed' to behave, so why expect it? Well, the stories I have heard first hand or read online from other patients with chronic pain would be unbelievable if the stories weren't so consistent and at times, documented in court, in blogs, or by the very primary care physicians and dentists who have to somehow help these patients salvage their health from the mess the previous physicians abandoned the patient to. That these stories are so common to hear, from dentists and patients, in this patient community is my cause for concern. Furthermore, Dr. Gerard is, honestly, the first provider I've dealt with who behaved in a manner that seems to be what I have heard so often described by other TMD patients mistreated and/or abused by physicians, specifically, oral surgeons and/or neurologists - there's something about those two specialities and TMD patients where things can go quite negatively for patients. Although, I have had plenty of other encounters with physicians that have been unfavorable, I believe I was afforded an opportunity to be heard by those physicians, just, perhaps, not taken seriously due to bias, knowledge gaps, or some other reason. However, due to hearing those stories from other patients I made it a point to stay away from oral surgeons - I have heard very little in favor of oral surgeons when it comes to TMD outside of situations in which a dentist specializing in TMD medicine refers a patient to a very specific surgeon for specific procedures as part of a larger treatment plan. Recognizing that this is the type of behavior patients have been describing is what leads me to take such great offense to it, but more, it also indicates to me that it would be wise to give up on the prospect that any further interaction with Dr. Gerard or his practice, outside of a third-party offering some form of arbitration, would be, in my view, inadvisable and expectedly unproductive.

My efforts to communicate with Dr. Gerard were unsuccessful. I was unable to communicate my desire for him to write a letter acknowledging his office does not provide the services I am seeking, let alone why I am seeking those services. As such, my ability to document that Dr. Gerard's office does not provide these services requires an alternative approach. Given the poor quality of the encounter with Dr. Gerard and my need to demonstrate to insurer's why it was inappropriate to deny requests for the network adequacy by listing Dr.

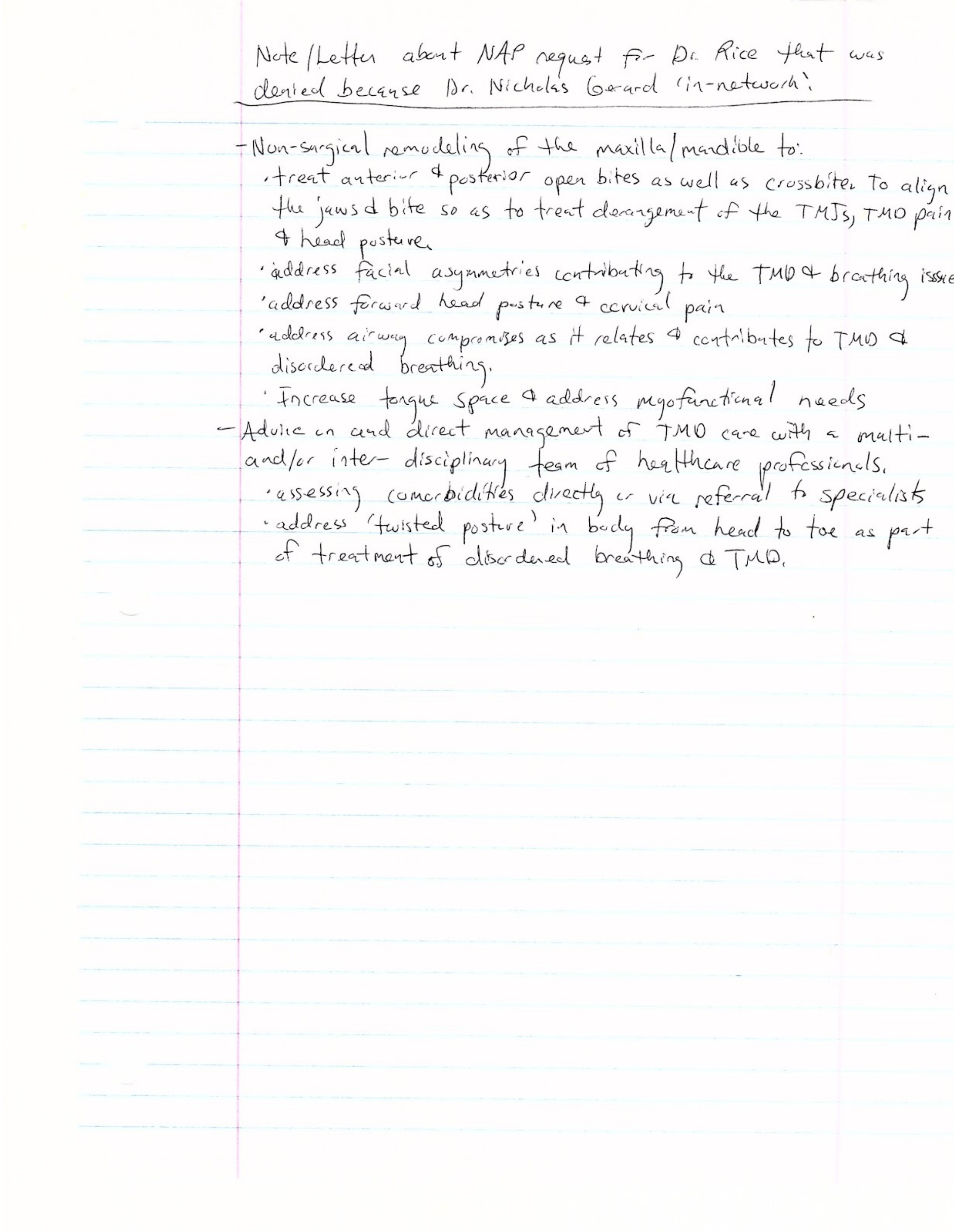
Gerard and other providers as being suitable, outlining the encounter in a formal complaint seemed the next best option afforded to me. On top of this, I'm just tired of providers like Dr. Gerard treating patients like they're objects to have things done to them with billing and procedure codes instead of acknowledging patients with chronic pain as people who are immensely burdened and will remain so until their healthcare professionals prioritize the patients needs rather than what they can commoditize - the first step to achieving that is to listen to those needs! My decision to file a complaint is as much a personal grievance as it is aimed at being a public service.

Feel free to contact me to request any additional information or details. I have records of the phone call setting up the appointment. I would be willing to sign whatever you need to request records of the call to the police department. I could provide direct references to the materials I mentioned if so desired.

Sincerely,
Sean Smith
(901) 573-8610

References:

1.



Note/Letter about NAP request for Dr. Rice that was denied because Dr. Nicholas Gerard 'in-network':

- Non-surgical remodeling of the maxilla/mandible to:
  - treat anterior & posterior open bites as well as crossbites to align the jaws & bite so as to treat derangement of the TMJs, TMD pain & head posture.
  - address facial asymmetries contributing to the TMD & breathing issue
  - address forward head posture & cervical pain
  - address airway compromises as it relates & contributes to TMD & disordered breathing.
  - Increase tongue space & address myofunctional needs
- Advice on and direct management of TMD care with a multi- and/or inter-disciplinary team of healthcare professionals.
  - assessing comorbidities directly or via referral to specialists
  - address 'twisted posture' in body from head to toe as part of treatment of disordered breathing & TMD.