



The TMJ Association, Ltd.

Issue 7, 2018

National Academy of Medicine to Conduct a Study on Temporomandibular Disorders

We want you to be among the first to know that because of the advocacy efforts of **The TMJ Association, the National Academy of Medicine (NAM) will conduct a first-ever study on Temporomandibular Disorders (TMD)**. The Academy is the nation's prestigious non-government organization whose elected members represent the most distinguished leaders in health and medicine in the country. NAM's mission is to improve health for all, accelerating health equity and providing independent, authoritative and trusted advice nationally and globally.

Why is this important for TMJ Patients? First, that the NAM sees the need to undertake a study of TMD is itself significant. Second, NAM studies are highly valued. They enlist experts in collecting evidence-based data and analyses to generate comprehensive reports with policy advice and recommendations. The NAM report will provide decision makers with the information needed to change regulation or policy and to other influential groups who can change behavior--having a large impact on the health of the nation and the world.

In the case of TMD they will explore all aspects of these conditions including how many people are affected and how they pay for care (What are current insurance practices? How much do patients pay out of pocket?) They will examine the safety and efficacy of current treatments, review promising research approaches as well as identify major gaps that need to be filled. Importantly, they will note, how health care professionals are educated about TMD, and even more importantly, examine the evidence-base for defining chronic TMD as a complex multi-system medical disorder that necessitates multidisciplinary research and interventions.

Your support is needed, now more than ever! As exciting as this news is, we are currently experiencing a low point in our fundraising. ***We desperately need your financial support*** so that we can continue to address the goals of our mission - advocacy for patients' needs, education, and patient support. **Please support The TMJ Association's work [with a gift today](#). Every donation, no matter the size, is valued and appreciated.** Together we are changing the face of TMJ!

TMJA Advocacy At Work: Report Language

For 25 years, The TMJ Association's advocacy efforts have resulted in congressional report language in which funding committees communicate to federal agencies, such as the National Institutes of Health (NIH), that our elected officials are concerned about the plight of TMD patients and propose initiatives needed to improve their health care and lives. These directives have a powerful influence on the decisions made by government agencies. In the case of TMD we are talking primarily about, the components of the NIH.

We have established personal contacts with congressional staff and elected representatives and garnered their support by reporting regularly on the state of TMD research and letting them know what we, the patients, need. It is gratifying to report that Congress responds to the needs of TMD patients and tracks the progress the NIH has made on their behalf.

Report Language appearing in the FY2019 Appropriations Bills:

Temporomandibular Disorders [National Institute of Dental and Craniofacial Research]. The Committee is concerned that over 36,000,000 people, primarily women in their childbearing years, are affected physically, financially, and emotionally by TMD. The Committee is aware that TMD are primarily a multisystem disorder with overlapping conditions influenced by multiple biological and environmental factors rather than solely an orofacial pain condition. Therefore, the Committee urges NIDCR to support multidisciplinary research and attract scientists across other disciplines to this research. At the same time, the Committee is encouraged by the scientific meetings between NIDCR, several Institutes and Centers as well as Temporomandibular Joint [TMJ] patient groups on an integrated systems approach of precision medicine related to cellular-molecular-genetic-epigenetic mechanisms related to diagnosis and treatment of TMD and its comorbid conditions. The Committee requests an update on initiatives that resulted from the recommendations that came forth from these meetings. Further, it applauds NIDCR's involvement in the TMJ Patient RoundTable to advance collaboration to work toward the common end of providing safe and effective treatments that improve patient's quality of life. The Committee encourages continued collaboration with governmental agencies and other stakeholders in the project.

Temporomandibular Disorders [Office of the Director]. The Committee understands that NIH-funded research has demonstrated that TMD are primarily a multisystem disorder with overlapping conditions influenced by multiple biological and environmental factors rather than solely an orofacial pain condition. However, diagnosis and care of patients have not changed to reflect this major paradigm shift, with many patients continuing to receive treatments solely focused on teeth and jaws. Moreover, the medical community lacks education regarding the complexity and systemic aspects of TMD as well as its many comorbid medical conditions. Patients are treated by a multitude of practitioners across numerous disciplines with treatments that have the potential to cause harm. The Committee is encouraged that NIH, led by NIDCR and in coordination with OD is leading an effort to provide to the Committee recommendations for a plan to most effectively study the state of TMD science, TMD education, examine the safety and efficacy of current clinical treatments of TMD, the burden and costs associated with TMD, develop policies related to the future scientific and clinical management of TMD patients. The Committee directs NIH to provide an update on development of such plan no later than 180 days after enactment.

Chronic Overlapping Pain Conditions [Office of the Director]. The Committee is concerned with the lack of progress in advancing a comprehensive initiative on Chronic Overlapping Pain Conditions, especially in light of recent findings from major studies funded by the agency demonstrating the significant prevalence and cost of Chronic Overlapping Pain Conditions, as well as the associated disability and detrimental health and quality of life outcomes for those with these debilitating disorders. The Committee strongly encourages the Director to continue to assess the state of science on Chronic Overlapping Pain Conditions and use the findings to continue to advance the scientific understanding of Chronic Overlapping Pain Conditions, as well as the development and discovery of safe and effective treatments

What is the National Institutes of Health (NIH)? Why is it Important to TMJ Patients?

The NIH, one of 10 federal agencies under the direction of the U.S. Department of Health and Human Services, is the primary federal agency that conducts and supports medical research. With the support of the American people, the NIH annually invests over \$30

billion in medical research. The NIH is comprised of 27 Institutes and Centers. It provides leadership and financial support to researchers in every state, and at selected sites throughout the world. Helping to lead the way toward important medical discoveries that improve people's health and save lives, NIH scientists investigate ways to prevent disease, work to determine causes, and establish treatments, and even cures for common and rare diseases. One of those 27 components is the National Institute of Dental and Craniofacial Research (NIDCR), which supports the bulk of research on TMD. Now that scientific understanding has uncovered the neurological and other complexities of Temporomandibular Disorders (TMD), an increasing number of components of the NIH are recognizing that they have a significant role in solving the puzzle of TMD by also providing funding for integral research programs.

TMJA Provides Patient Perspectives on TMJ Implants

The University of Maryland in partnership with the Food and Drug Administration (FDA) held a workshop in Baltimore, Maryland, on September 12th on *Medical Devices - Patient Engagement in Real World Evidence: Lessons Learned and Best Practices*, hearing testimony from your TMJA.

The meeting's objectives were to detail lessons learned and best practices for engagement with patients from the patients themselves and the groups they represent. The discussion centered around the need and use of "real world" evidence for many stakeholders.

The meeting opened with a session on *Framing the Challenge* with remarks by Dr. Natalie Eddington, Dean and Professor at the University of Maryland School of Pharmacy, and remarks by Dr. Jeffrey Shuren, Director of the FDA's Center for Devices and Radiological Health.

Terrie Cowley, TMJA President and Co-Founder, provided the patients' perspective by reviewing the history of TMJ implant devices and noting that patients still feel betrayed by all parties involved and by the lack of accountability. She spoke about a new patient-led initiative which the TMJA has pioneered and is the first of its kind at the FDA: The MDEpiNet TMJ Patient-Led RoundTable. She said, "There are so many questions and concerns we still need answers to! We need a device registry to help us set a gold standard of information for patients and health care professionals." [Click here to read Terrie's talk \(.pdf\)](#).

Speakers throughout the day described building the necessary infrastructure and case studies with audience members participating in an afternoon breakout session to continue discussions. The meeting was attended by representatives of academia, government officials, researchers and patient advocates.

Meet Raven



I am 27 years old and have been dealing with TMD for over 10 years. When I was younger, I didn't experience pain related to the condition. The only thing that would happen was the constant cracking of my jaw. I would actually purposefully crack my jaw because it felt like it provided some relief. In addition, when I was younger I had never heard of TMD nor inquired about it. When I entered my early 20s, I started getting headaches often. I have food allergies so I attributed the headaches to foods I was eating. I started being conscious of what I ate, trying to detect what may be triggering the headaches.

I started teaching when I was 23, so you can imagine how often I'd have to speak. I remember going home feeling exhausted every day. Teaching is already exhausting, but I'd be experiencing headaches and speaking felt awkward. I didn't know what was going on. I thought I may have just been overwhelmed and stressed. So I started practicing techniques to help me relax.

In 2017, I got Invisalign because I was told that if I align my teeth then it would help my jaw. They actually seemed to make the pain worse after about 2 months. That said, I discontinued using them...money wasted. I've tried Botox... no relief. I've tried acupuncture...definitely calming and I can honestly say it seemed to help for a few days but the results weren't remarkable. (I may have to just be consistent with the acupuncture, but that's an out-of-pocket expense for something I'm not sure will work.) I recently traveled to Georgia to get treatment. In Georgia I underwent TENSing which is a process that's supposed to relax the muscles, and it allegedly erases the muscle memory. They also created an orthotic for me that I've now been wearing for approximately 2 months. I have to be honest the orthotic does seem to be helping, but the pain is still a daily struggle.

It has gotten to the point where I can't even teach because the constant speaking causes so much discomfort. I am blessed to work with an administration that has made accommodations for me and has still allowed me to work for the school by doing office work. Though this does allow me the opportunity to rest my jaw, I still feel the discomfort every day. It's amazing how an issue can show you the small things that you take for granted. Laughing, eating, smiling, speaking, swallowing, and existing have honestly become a struggle.

I was on pain medication that made me feel sedated. I stopped taking the medication because I honestly became suicidal, and I felt myself becoming dependent on them. So, now I push through the pain without the medications. Sometimes I'm tempted to pop a pill or two or three or four, but at this point the medication doesn't even seem to work. It just makes me feel sleepy, but I still feel the pain. Regular ibuprofen doesn't work. Only the strong stuff works....Valium.

I am thankful that TMD isn't life-threatening; however, it does threaten a person's quality of life. Socializing causes me so much anxiety now. Trust me; I was never an anxious person. I used to be much more outgoing than I am now. I don't want to do anything anymore. I go to work, come home, and most days I cry because I feel so helpless. I'm so used to being able to figure out a way to solve my problems. However, being in pain every single day from doing things that you need to sustain well-being (like eating, swallowing, speaking) takes a toll on a person. Family and friends don't understand what I'm going through and I don't want them to. I wouldn't want for any of my loved ones to experience what I'm dealing with. When you do TMJ research many sites will tell you that it's caused by stress. I don't think the stress precedes the TMJ. I think the TMJ causes stress and enhances it. On a brighter note, the TMD has strengthened my connection with spirituality. This experience has humbled me and caused me to become so much

more compassionate. Often-times we see people and we may think, "Why do they look so unhappy, they need to relax"...truth is, we never know what someone is going through. I've now been on the receiving end of feeling like people are looking at me like, "she just needs to cheer up," and in my mind I'm thinking "these people don't even know that I'm in pain right now, and not regular pain, my FACE is literally in pain."

I am grateful for The TMJ Association's website. All of you who have shared your stories give me strength. For those of you who read my story, I don't want you to feel like I feel defeated. This TMD has shifted my consciousness in ways that I could've never even imagined. Without the dependency on meds, I've had to dig deep within myself to combat the constant discomfort. I probably could become more in tune with my inner being without the TMD, but it has forced me to utilize my mind and spirit to help my body heal.

For those of you suffering from TMD, I encourage you to immerse yourself in peace and positivity. Of course, you will come into contact with events and individuals that may not promote the peace that you're trying to achieve. However, you can't control everything that happens. What you can control is how you respond to people and events. Challenge yourself to always respond from a place of love and compassion. Just like you may have expressed yourself in harsh ways due to your pain, you never know what pain others may be going through that's buried deep within them. Don't take anything personally; just work on strengthening your character; don't allow the pain in your body to cause you to become weak mentally and spiritually. I will pray for all of you when I pray for myself. Thank you for reading my post.

With Love,
Raven

In Memorium

Patricia "Patty" Meinhart of Pennsylvania. Patty was a Vitek implant recipient following an auto accident at the age of 22. She had over 38 TMJ surgeries throughout the years and multiple TMJ implants. She is survived by her husband, Larry and their son, Joshua. She will be missed dearly by all her TMJ friends!

Mark Parkin of Florida. Mark passed away this month unexpectedly from pancreatic cancer. He was the loving and supportive husband to Linda Parkin, a TMJ implant patient. Lin's story is featured on our website, [Making TMJ Fashionable](#), and we invite you to read it. We send our deepest sympathies to Linda at this difficult time.

Patrick Kilcoyne of Washington D.C. Patrick was a friend of the TMJA for over 18 years after he developed TMD when he had a crown placed at a local dental school. He informed us that he never had TMJ problems before this treatment. Patrick was a staunch supporter of the TMJA and believed in the need for advancing scientific research for TMD. He was always excited when we held our TMJA scientific meetings in the nearby Washington DC area.

Dentists in Distress

by Sophia Stone, TMJA contributing author

Fear of the dentist is practically a rite of passage in youth. Growing up, I wasn't exactly afraid of the dentist; rather, any excuse to leave school early was a powerful incentive. These days, I have a more complicated relationship with dentistry: I go to get answers and try to feel better, but I always pop a prophylactic ibuprofen or two in case my jaw protests from the oral gymnastics.

But we the patients rarely get a glimpse into the psyche of the dental provider. The paper, [*Dentist's distress in the management of chronic pain control: The example of TMD pain in a dental practice-based research network*](#) by Yokoyama et al. (2018) gives us a rare glimpse into the minds of dentists who treat TMD. The study examines which aspects of TMD management are most distressing to dentists. Spoiler alert: patients aren't the only ones losing sleep over TMD.

Despite the prevalence of TMD in the general population [1], prior studies have shown that about half the dentists in practice are not confident in their ability to diagnose and treat TMD [2]. Frankly, this statistic is alarming. Imagine if half of primary care physicians weren't comfortable treating diabetes, which is similarly prevalent among about 10% of the population [3] [4]. Then imagine that these providers recommended dubious, expensive, irreversible, or potentially harmful therapies that haven't been proven effective. In the case of dentistry, even though clinical practice guidelines* advise *against* occlusal adjustment as a treatment for TMD (because it's irreversible and probably doesn't work), a whopping 64% of US dentists do it anyway [5].

A major motivation for this study was to understand barriers and misperceptions that hinder TMD care and result in variable treatment recommendations and outcomes from practice to practice. It was the authors' hope that addressing dentists' distress around providing TMD care would bridge the gap between what is known about TMD and what dentists actually *do*. [Click here to read full article.](#)

Systemic Disease and Other Painful Conditions in Patients with TMD and Migraine

Abstract: Temporomandibular disorders (TMD) are a highly prevalent, painful musculoskeletal condition affecting the masticatory system, and are frequently associated with migraines (M) and other diseases. This study aimed to investigate the association between painful TMD and Migraine with other painful conditions and systemic diseases, such as cervicalgia, body pain (BP), ear-nose-throat disorders, musculoskeletal disorders, diabetes, cardiopulmonary diseases and gastritis/peptic ulcer.

Methods: This was a cross-sectional study conducted in a sample of 352 individuals. Participants were stratified into three groups according to the presence of painful TMD and Migraine: controls [individuals free of TMD and any headache (HA)]; TMD only (presence of painful TMD, but free of any Headache); and TMD+Migraine (presence of painful TMD and Migraine). TMD was classified according to the Research Diagnostic Criteria for Temporomandibular Disorders (RDC/TMD) - Axis I. Nonspecific physical symptoms (NSPS) were assessed by RDC/TMD - Axis II. The International Classification of Headache Disorders - II criteria, second edition, were applied to identify and classify primary headache. Other painful conditions and systemic diseases were assessed by volunteers' self-report. The prevalence of all assessed conditions was higher in the TMD+Migraine group. Multiple regression models showed that cervicalgia was associated with the TMD only group ($p < 0.05$), whereas gender ($p < 0.05$), cervicalgia ($p < 0.05$), Body Pain ($p < 0.05$) and NSPS ($p < 0.05$) were significantly associated with the TMD+Migraine group.

Our results suggest that individuals with a comorbidity (TMD associated with Migraine) have a more severe condition than those presenting only painful TMD.

Article available online at: <http://www.scielo.br/pdf/bor/v32/1807-3107-bor-32-e077.pdf>

TMJ Patients Needed for an Important Study on Botox

Treatments

We were recently informed by the researchers that they are still looking for more TMJ patients to participate in an important observational study looking at Botox injections for the treatment of Temporomandibular Disorders (TMD) pain. Enrollment in this study will be ending in December.

Please consider participating if you reside in the New York City, Los Angeles, or Boston areas and have:

- received Botox injections as a TMD treatment or
- considered Botox injections for TMD but have not had this treatment.

To learn more about this study go to: <http://www.tmj.org/site/page?pagelid=372>

Identifying and Prioritizing Patient-Centered Outcomes for Comparative Effectiveness Research

In the era of patient-centeredness, what YOU, the patient, wants is becoming more important by the day. The TMJ Association hears from many patients experiencing adverse effects from medications and other treatments. It is helpful for scientists, clinicians, pharmaceutical manufacturers, and device manufacturers to know what you want and what you DON'T want from their products.

For these reasons, The TMJ Association agreed to work with the Johns Hopkins Bloomberg School of Public Health to identify what health outcomes matter to people with pain. **We thank the many TMJ patients who participated in the 2015 online study for their help.** The study was recently published and we're pleased to provide you with a link to the article:

<https://pilotfeasibilitystudies.biomedcentral.com/track/pdf/10.1186/s40814-018-0284-6>

Young Investigator Initiative Grant Mentoring and Career Development Program

The TMJA is a member of the United States Bone and Joint initiative. We were asked to post the following announcement on an opportunity for young investigators.

The United States Bone and Joint Initiative (USBJI) and Bone and Joint Canada are dedicated to increasing research of musculoskeletal diseases. To keep pace with the high and increasing burden of these diseases, a higher level of research performed by young investigators in the musculoskeletal diseases is required, and future levels of research assured. This is particularly important given the current environment for research funding, and academic careers. In response, the Young Investigator Initiative is a grant mentoring program providing early-career investigators an opportunity to work with experienced researchers in our field to assist them in securing funding and other survival skills required for pursuing an academic career.

To date 245 participants (60%) have successfully obtained \$421 million in grants for 1,492 new musculoskeletal research studies. Participants consider this program instrumental to their success. They rate highly the one-on-one mentoring with experienced researchers, the opportunity for inter-disciplinary and peer-to-peer exchange, and collaborations established during workshops.

This grant mentoring program and career development program is open to promising

junior faculty, senior fellows or post-doctoral researchers nominated by their department or division chairs seeking to pursue a career in clinical or basic research. It is also open to senior fellows or residents that are doing research and have a faculty appointment in place or confirmed. Basic and clinical investigators, without or with training awards, are invited to apply. Investigators selected to take part in the program attend two workshops, 12-18 months apart, and work with faculty between workshops to develop their grant applications. **The Spring 2019 workshop is scheduled to take place on April 26-28, 2019, in Rosemont, IL (Chicago).** The unique aspect of this program is the opportunity for attendees to maintain a relationship with a mentor until their application is funded.

For more about the program and detailed application instructions, please refer to <https://www.usbji.org/programs/yi>. **Deadline for application submissions is January 15, 2019.**

NIH Funding Opportunities

Basic and Clinical Research

In an effort to promote greater understanding of TMD and to develop safe and effective evidence-based diagnostics and treatments, The TMJ Association promotes and encourages basic and clinical research on Temporomandibular Disorders. [Click here to view the latest National Institutes of Health \(NIH\) funding opportunities for scientists interested in advancing TMJ research.](#) The following NIH research opportunities are currently available:

- (NEW) Research on Chronic Overlapping Pain Conditions (R01)(R21)
- (NEW) Analytical and/or Clinical Validation of a Candidate Biomarker for Pain (R61/R33)
- (NEW) Discover and Validation of Novel Targets for Safe and Effective Pain Treatment (R01)(R21)
- Clinical Validation of Candidate Biomarkers for Neurological Diseases (U01 Clinical Trial Optional)
- Factors Underlying Differences in Female and Male Presentation for Dental, Oral, and Craniofacial Diseases and Conditions (R01) (R21)
- NIDCR Small Research Grants for Secondary Analysis of FaceBase Data (R03)
- Tailoring Dental Treatment for Individuals with Systemic Diseases that Compromise Oral Health (R01) (R21)
- Personalized Strategies to Manage Symptoms of Chronic Illness (R15) (R01) (R21)
- Research on the Mechanisms and/or Behavioral Outcomes of Multisensory Processing (R01)
- Blueprint Neurotherapeutics Network (BPN): Small Molecule Drug Discovery and Development for Disorders of the Nervous System (UH2/UH3) (U44)
- Population Health Interventions: Integrating Individual and Group Level Evidence (R01)
- Family-Centered Self-Management of Chronic Conditions (R21) (R01)
- mHealth Tools for Individuals with Chronic Conditions to Promote Effective Patient-Provider Communication, Adherence to Treatment and Self-Management (R01) (R21)
- The Biomarkers Consortium
- Blueprint Neurotherapeutic Network Applications Directed at Small Molecule Drug Discovery and Development of Disorders of the Nervous System



**“Sometimes a TMJ patient needs
inspiration just to
get through each day.”**

- The TMJ Association, Ltd.

**Connect with others who understand in the
new TMJ Cafe Support Community**

Visit TMJ.Inspire.com

Research E-Newsletter

Cutting Edge - COPCs Research Advances, is an electronic newsletter published by the Chronic Pain Research Alliance, an initiative of The TMJ Association. Developed to keep the medical-scientific community abreast of

recent research advances, this publication contains abstracts of recently published studies on the epidemiology, pathophysiology and clinical management of Chronic Overlapping Pain Conditions. These conditions include **temporomandibular disorders**, chronic low back pain, chronic migraine and tension-type headache, endometriosis, myalgic encephalomyelitis/chronic fatigue syndrome, fibromyalgia, vulvodynia, irritable bowel syndrome and interstitial cystitis/painful bladder syndrome.



CUTTING EDGE a publication of 
COPCs Research Advances

The most current issues are now available for your review at:

http://www.cpralliance.org/New_Findings. If you would like to receive future issues of *COPCs Research Advances*, [click here to register](#).

Educational Brochures on Chronic Overlapping Pain Conditions

This brochure addresses Chronic Overlapping Pain Conditions (COPCs), how COPCs are diagnosed, the complexity of the chronic pain experience, and how to work with your health care provider to develop a treatment plan. It is available by [postal mail](#) or as a [PDF on our website](#).

Educational Brochures on TMD

Your Guides for Temporomandibular Disorders - This brochure, written by the TMJA, is a straightforward, easy-to-read booklet that guides patients in how to make health care decisions. It is available [by mail](#) or as a [PDF on our website](#) and we encourage you to share it with your friends, health care professionals and family members.

TMJ Disorders - This brochure is produced and distributed by the National Institute of Dental and Craniofacial Research in partnership with the Office of Research on Women's Health, components of the National Institutes of Health (NIH) in Bethesda, Maryland. Part of the U.S. Department of Health and Human Services, NIH is one of the world's foremost medical research centers and the federal focal point for medical research in the United States. This booklet is available in English and Spanish at: <https://www.nidcr.nih.gov/OralHealth/Topics/TMJ/TMJDisorders.htm>.

Dental Care Guide

Temporomandibular Disorders, Dental Care and You

The TMJ Association developed this guide to provide you with oral hygiene self-care tips that you can do at home, as well as suggestions for future dental appointments. Routine maintenance of your teeth and gums should reduce the risk of dental disease and the need for invasive dental treatments. [Click here to view on our website](#).

TMJ Science Journal

Our latest issue of *TMJ Science*, which includes the summary and recommendations from our 8th scientific meeting-*How Can Precision Medicine Be Applied to Temporomandibular Disorders and Its Comorbidities*---is now available. We hope you're impressed with how far the science of Temporomandibular Disorders has come. [We invite you to read this new publication which is available in the publication section of our website as a pdf file.](#)

Support Our Work

The TMJ Association (TMJA) is the only patient advocacy organization fighting for the best science that will lead to a greater understanding of Temporomandibular and related disorders, as well as safe and effective treatments. We cannot *change the face of TMJ* without YOU.

[Click HERE to make a tax-deductible online contribution today!](#)



About The TMJ Association

Changing the Face of TMJ

The TMJ Association, Ltd. is a nonprofit, patient advocacy organization whose mission is to improve the quality of health care and lives of everyone affected by Temporomandibular Disorders (TMD). For over 25 years, we have shared reliable information on TMD with people like you. We invite you to visit our website, www.tmj.org.

- If you're not currently receiving *TMJ News Bites* and would like to [be on our mailing list, sign up here.](#)
- [Read Past issues of TMJ News Bites](#) available on our website.

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