



TMJ News Bites

Issue 1 2020

On behalf of all of us at The TMJ Association (TMJA) and those we serve, we thank everyone who contributed to our end-of-year fundraising campaign. We are so very grateful for your financial support. Please know it is instrumental in bringing about changes in the way Temporomandibular Disorders (TMD) are perceived and researched. **Together we are changing the face of TMJ!**



TMJ Patient Advocates in Action

TMJ Patients, caregivers, and your TMJ Association participated in a group discussion with staff in the FDA's Office of Health Technology at the Center for Devices and Radiological Health on January 27, 2020 in Silver Spring, Maryland.



Participants shared their TMJ treatment experiences, perspectives and concerns during this meeting with FDA staff. After the patient presentations, FDA staff outlined the next steps for developing a patient-reported outcomes measurement that can be used in the future to advance the development and monitoring of TMJ devices. The TMJ Association appreciates the time and effort of all those who participated in this meeting; **together we are changing the face of TMJ!**

Meet Bernard...

His TMJ story is both common and unique. Common, because he shares in the suffering, both emotional and physical, that many others afflicted with this disease endure. Unique, because of his life situation.

Who is Bernard? He is a twenty-nine year old who is in prison. His TMJ story began in 2013 when he was prescribed a medication that he took for less than three months. The medication permanently locked his jaws. Of course, in 2013 no one in the institution had

the knowledge to make a diagnosis of what was actually causing Bernard's unremitting pain. It wasn't until the end of 2019 that he was finally told he had TMD. That's when he contacted The TMJ Association and started a dialogue with Terrie and Deanne.

So, what are the experiences that Bernard, in his unique situation, has in common with the vast majority of TMJ patients? Let's look at them and use Bernard's own words to describe them.

Effects of the locking and the pain: "It's an unending stress from the things it forces me to do, like holding my hand underneath my chin to yawn with a closed mouth. My mouth comfortably opens only a quarter inch, but can be forced to about a half. I feel ashamed eating around others. Even if my mouth could fully open, I would still be self-conscious, because it has no lateral movement. It is embarrassing to cover your mouth and tell others to not look while you are eating, because your food is always falling out." Imagine always having to take your meals in a room full with others, especially fellow inmates, who may not be inclined to be empathetic. Bernard also mentioned that he often cannot finish his meals in the allotted time, because he must eat so slowly.

In addition to the physical effects, Bernard, as is true of many others with TMD, has little emotional support, either from family, other relatives, or the medical staff that he deals with. He writes: "When it comes to family, my dad is the only one supportive. We may only talk a few times a month, but I really love him."

In terms of treatment, the only option that has been offered to Bernard is radical surgery. The doctors want to "cut my face open, remove a section of my jaw bone, replace the bone and joint with titanium and insert nine screws into each jaw." They cannot predict how well it will heal, or how long the surgery would alleviate his pain, so that the surgery may someday have to be repeated.

Many TMJ patients can relate to these common realities. Bernard, however, has additional challenges. An inmate cannot choose when, or even if, medical appointments will occur. "On the days I have appointments, it is always a surprise, because we are never told until we have to get ready. On the morning of appointments, staff will wake me up at 4:15 and we leave shortly after 7 AM. While it is a relief to be away from prison, I cannot rid myself of the thoughts that I would rather be anywhere than where we are going." The last doctor's visit he had scheduled was refused because he wanted to bring his notes with questions for the doctors, because he like many, gets nervous and didn't want to forget the questions he wanted to ask.

Unlike most TMJ patients, Bernard does not have access to treatments that could alleviate his pain, such as hot or cold compresses, an extra pillow or a soft diet. He says: "They [The TMJA] actually sent me a caddy head wrap [hot/cold pack] that was confiscated a couple months later. My selection of food is limited. Every day, I eat beans, oatmeal or peanut butter." He has to get special permission to receive ibuprofen.

Being in prison brings other risks. "Every year I go through spells of depression and sometimes become easily angered. What if I lose my temper and someone punches me in the face so hard that my jaw unhinges, then what? Emergency surgery?"

All patients worry about surgery, but in Bernard's case, with the radical jaw surgery that

the doctors want him to undergo, there is a significant probability that there could be facial scarring. Bernard asked about this, and was shown an internet site depicting how people could possibly look after surgery. There were no black people among those examples. “I knew African-Americans are prone to keloids, and, since no black people were shown, it means that the surgery probably healed in an undesirable way. At that moment, every positive thought disappeared.”

Now, you have met Bernard. Although his life situation is a unique one, he shares the experiences, frustrations and anxieties of many of his fellow TMJ sufferers. His closing paragraph is worth noting: “The TMJ Association is my main source of support and information. Deanne and Terrie have been something special. I am deeply appreciative of everything they have done. These are the words of a prisoner serving twenty-six years, starting at age twenty-two. I thank you all for devoting your time to reading my life.”

Bernard has indicated that he would welcome cards or notes of encouragement. If you would like to send him one, you can direct it to **The TMJ Association, C/O Bernard, P.O. Box 26770, Milwaukee, WI 53226** and we'll see that he receives it.

Your Association Hard at Work...

2020 Congressional Report Language

Each year for 27 years, The TMJ Association's advocacy efforts have resulted in congressional report language. This report language lets the National Institutes of Health (NIH) know that elected officials are concerned that the research needs of TMJ patients should be addressed. These directives should have a powerful influence on the decisions made by government agencies. It is gratifying to report that Congress responds to the needs of TMJ patients and tracks the progress the NIH has made on their behalf.

NATIONAL INSTITUTE OF DENTAL AND CRANIOFACIAL RESEARCH (NIDCR)

NIDCR is encouraged to continue collaboration with governmental agencies and other stakeholders in the project entitled Temporomandibular Disorders: From Research Discoveries to Clinical Treatment and to increase funding to expand the science base in this field.

OFFICE OF THE DIRECTOR

For the first time, the nation's leaders in health and medicine are enlisting experts to review all aspects of TMD, generating recommendations for research, regulation, and policy. To continue to build on advances in coordinated research and treatment, the agreement asks the Office of the Director, as it continues to work with the National Academy of Science on the study, to explore the creation of an NIH inter-Institute TMD working group and to report to the Committees within 90 days following the publication of the final report.

TMJ Patient-Led RoundTable

The RoundTable is the first patient-led project under the auspices of the Medical Device Epidemiological Network (MDEpiNet), a public-private partnership developed to bring real

world data and patient experiences together with a broad array of experts to conduct studies aimed at improving outcomes for implant patients worldwide.

The following reports have resulted from the activities of the RoundTable Working Groups:

- [WhitePaper - The TMJ Patient-Led RoundTable: A History and Summary of Work](#)
- [TMD Research Plan](#)
- [TMD and Nutrition Summary](#)
- [TMD Treatments: Review of Meta-Analyses & Systematic Review](#)
- [Update: Dental Education \(Working Group 3\)](#)
- [Summary TMJ Components and Repair](#)

More information is also available on the MDEpiNet's website: <http://mdepinet.org/tmj-patient-led-roundtable-crn/>.

Oral Splints for Patients with TMD or Bruxism: A Systematic Review and Economic Evaluation

Health Technology Assessment, No. 24.7., Riley P, Glenny AM, Worthington HV, et al., Southampton (UK): NIHR Journals Library; 2020 Feb.

Treatment options for people experiencing temporomandibular disorders (pain and/or restricted movement in and around the jaw joint) include splints, which are removable appliances, often similar to a mouthguard. They are provided to patients to help ease pain in the mouth, face or jaws. They are also used to manage the symptoms of temporomandibular disorders, such as frequent headaches/migraines, clicking jaws, restricted mouth-opening or tooth wear from the grinding of teeth (bruxism). There are many types of splints.

This research looked at the evidence addressing the primary question of whether or not splints reduce the pain in reducing the pain associated with temporomandibular disorders and/or tooth wear, and if they offered value for money, regardless of the type of splint. Patients were involved in the research to ensure that the question and the outcomes that were measured were appropriate.

A systematic review of the literature was undertaken to find all randomised controlled trials including patients with temporomandibular disorders or bruxism. Online databases of research publications were searched, and these searches were checked to identify relevant trials. All stages of the review process were undertaken with the highest standards by two people, independently and in duplicate, using well-respected and recognised Cochrane methods. We conducted a value-for-money assessment, comparing the trial data with the costs of splints to see if splints are a cost-effective use of National Health Service* funding.

There was no evidence that splints reduced pain when compared with not wearing

a splint or when compared with a minimal treatment (like jaw exercises, advice or education) in patients with temporomandibular disorders. The evidence was assessed as being of very low quality. Therefore, it remains unclear whether or not splints are good value for money, or if they should be paid for by the National Health Service.

This research showed that more well-conducted trials on temporomandibular disorder patients are needed.

**The National Health Service is the publicly funded healthcare system of the United Kingdom. It is made up of four separate systems: The National Health Service in England, NHS Scotland, NHS Wales, and Health and Social Care in Northern Ireland.*

Source: <https://www.ncbi.nlm.nih.gov/books/NBK553651/>

Prevalence of First-onset Temporomandibular Disorders in Low Back Pain and Associated Risk Factors

A nationwide population-based cohort study with a 15-year follow-up

Lee, Kuei-Chen MS; Wu, Yung-Tsan MD; Chien, Wu-Chien PhD; Chung, Chi-Hsiang PhD; Chen, Liang-Cheng MD; Shieh, Yi-Shing PhD, Section Editor(s): Enix., Dennis

Abstract

The coexistence of low back pain (LBP) and temporomandibular disorder (TMD) has often been noted clinically. However, studies of the association between these two conditions involving a large population with longitudinal evidences are lacking. Therefore, the study aimed to investigate the association between LBP and TMD in a nationwide-matched cohort population with a 15-year follow-up.

Data of 65,121 patients newly diagnosed with LBP were analyzed, along with those of 195,363 (1:3) sex- and age-matched controls. Multivariate Cox regression analysis was used to determine TMD risk between the LBP and non-LBP groups. Kaplan-Meier method was used for determining the cumulative risk of first-onset TMD between groups, with a 15-year follow-up.

The LBP group was more likely to develop first-onset TMD (adjusted hazards ratio (HR) = 1.561, $P < .001$), after adjusting for demographic variables and comorbidities. The risk factors for TMD were LBP, young age, higher insured premium, and osteoporosis. In the subgroup analysis, the LBP group had a higher risk of TMD than the non-LBP group in all stratifications.

Low Back Pain is the risk factor contributing to the development of first-onset TMD. Therefore, clinicians should be reminded to manage Low Back Pain disorders concurrently when treating TMD.

Read full article at: <https://journals.lww.com/md->

Have You Seen the Film *Dark Waters*?

The Film. [Dark Waters](#) is about attorney Robert Billott's real-life 20 year legal battle against DuPont chemical for releasing toxic waste - perfluorooctanoic acid, or PFOA - into Parkersburg, West Virginia's water supply, with devastating health effects on the townspeople and livestock. PFOA, also known as C8, is a man-made chemical. It is used in the process of making Teflon and similar chemicals known as fluorotelomers.

Vitek Implants. In the 1970s, Vitek Inc. created Teflon sheeting using DuPont's Teflon FEP film, laminated to a porous composite material made from polytetrafluoroethylene (PTFE). These implants, usually no larger than a thumbnail, were manufactured individually or custom cut from sheets in the operating room by the surgeon and then sutured to the TMJ fossa or condyle. Unfortunately, no clinical research has been conducted to date on TMJ implant patients who received the Vitek devices to assess the relationship between the material and the many devastating health effects that have resulted in the death of patients and caused continued suffering in others.

Attorney Robert Billott. Co-Founder and President, Terrie Cowley contacted Mr. Robert Billott after reading an article in the NY Times on this issue. Mr. Billott thanked her for reaching out to him and sending information on the Vitek implants. He said he was generally familiar with the issue, but was not aware of the extent of the patient's battle with these devices.

If you are Vitek implant patient you'll no doubt find this film interesting.

Additional Resources.

- [Orthopedic Network News, April 1995](#)
 - [MedPage Today article on Dark Waters](#)
 - [TMJ Association website information on the Vitek device](#)
 - [Cancer.org -Teflon and PFOA](#)
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**Connect anonymously with
others who understand what
you're going through!**

- The TMJ Association, Ltd.

**Join 1,000+ members in the TMJ
Cafe Support Community**

Visit TMJ.Inspire.com

Researchers Need You! Several Research Opportunities

Online Survey Study on Fibromyalgia, Chronic Migraine, Chronic Orofacial Pain, and TMD

The Pain Research Lab at Cincinnati Children's Hospital Medical Center is currently conducting a study to learn more about social and psychological functioning in young adults (ages 18-30) with fibromyalgia, chronic migraine, or chronic orofacial pain or temporomandibular disorder. The study will be done entirely online and consists of completing online surveys for approximately one hour. Participants will be compensated via a gift card for \$15 to Target for their participation. If you are interested, please email: chronicpainstudy@cchmc.org.

University of North Carolina, Duke and University of Los Angeles Study on Chronic Vaginal Pain

Recruiting participants in the Vestibulodynia (VBD) UPDATe Study. In order to identify the most effective treatments for women with chronic vaginal pain, researchers at Duke University, The University of California, Los Angeles, and The University of North Carolina at Chapel Hill are performing a randomized placebo-controlled blinded clinical trial. This trial hopes to better understand how women experience vestibulodynia pain, in order to determine what treatments work best for

different women. English-literate women between the ages of 18-50 years are eligible for immediate enrollment if they have VBD and meet certain study criteria. To learn more about the study, meet the research team, and enroll, please visit the [UPDATE Study](#) website.

University of California San Diego Chronic Low Back Pain Studies

The Brain Mechanisms of Pain and Health Laboratory at University of California San Diego (UCSD) is conducting a National Institutes of Health (NIH) Clinical trial examining the effects of meditation on chronic low back pain. They are looking for patients between 18-65 years of age who have been suffering from chronic low back pain for at least three months. The study requires seven days of patient involvement, with one month to complete the study. Patients will be compensated \$400 for completion of the study. For additional information, including a complete description of the study at the Altman Clinical and Translational Research Institute at UCSD, please feel free to contact us at zeidanlab@ucsd.edu or call (858) 246-2028.

UCSD is conducting an additional NIH clinical trial examining the effects of meditation on chronic low back pain. They are looking for individuals with chronic low back pain who are 18-65 years of age. This study is a 16-part study that may take up to 48 days to complete. Participants will undergo bodily maneuvers, noxious heat, brain imaging, meditation interventions, and cognitive testing. Brain imaging will take place in a magnetic resonance imaging (MRI) scanner located at the UCSD campus. Participants will be compensated \$780 for successfully completing the study. The study is located in the San Diego County region. In order to participate, individuals must contact us at zeidanlab@ucsd.edu and/or call (858) 246-2028.

CME on Chronic Overlapping Pain Conditions

The Chronic Pain Research Alliance, an initiative of The TMJ Association, in partnership with the International Pelvic Pain Society, is pleased to announce the release of our newly developed Continuing Medical Education (CME) program on Chronic Overlapping Pain Conditions (COPCs) titled, "[A Biopsychosocial Approach to the Clinical Management of Chronic Overlapping Pain Conditions.](#)"

This activity - hosted by the International Association for the Study of Pain (IASP) - is designated for 1 AMA PRA Category 1 Credit. If you are not a current IASP member, or do not have IASP login credentials, please follow the instructions below to access the course free of charge by registering as a non-member. To access the program, visit: <https://www.pathlms.com/iasp/courses/11652>.

If you are interested in obtaining a copy of the course's PowerPoint slide set and corresponding slide notes for teaching purposes, please contact CPRA's Director, Christin Veasley by email (cveasley@cpralliance.org).

Meeting Announcement – 9th Institute of Biomaterials Tribocorrosion and Nanomedicine

The TMJ Association was contacted by the organizer to share the following meeting announcement with our readers.

The University of Illinois Chicago Dental School is hosting the 9th Institute of Biomaterials Tribocorrosion and Nanomedicine (IBTN) meeting on Monday, April 20, 2020. More details can be found at: <https://sites.google.com/view/ibtn-conference/home>

Topics: Regenerative Medicine, Biomaterials, Implants, Medical devices, Tissue Engineering, Nano-medicine, Surface modifications, Cell-material integrations, Total Joint Replacements, Tribology, Tribocorrosion, Biosensors, Bio-mineralization, In-Situ liquid-TEM Bio-imaging, 3D printing, and Computational modeling

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 Funding Opportunities

- NIDCR Administrative Supplement for Collaborative Science (Notice of Special Interest)
- Notice of Special Interest of NIDCR in Supporting Discovery, Characterization, and Mechanistic Study of Genetic Variants Underlying Dental, Oral, and Craniofacial Diseases and Conditions
- The Intersection of Sex and Gender Influences on Health and Disease (R01)

Additional Funding Opportunities

- Achieving Tissue Robustness Through Harnessing Immune System Plasticity (R21)(R01)
- HEAL Initiative: Translational Development of Devices to Treat Pain (U18)
- HEAL Initiative: Translational Devices to Treat Pain (UG3/UH3)
- HEAL Initiative Translational Devices to Treat Pain (U44I)
- HEAL Initiative: Clinical Devices to Treat Pain (UH3)
- HEAL Initiative: Stimulating Peripheral Activity to Relieve Conditions (SPARC):
- Global Brain and Nervous System Disorders Research Across the Lifespan (R21)
- Research on Chronic Overlapping Pain Conditions (R01)(R21)
- Analytical and/or Clinical Validation of a Candidate Biomarker for Pain (R61/R33)
- Clinical Validation of Candidate Biomarkers for Neurological Diseases (U01)
- Blueprint Neurotherapeutics Network (BPN): Small Molecule Drug Discovery and Development for Disorders of the Nervous System (UH2/UH3) (U44)
- Family-Centered Self-Management of Chronic Conditions (R01)(R21)

- 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 Neurotherapeutics Network (BPN): Small Molecule Drug Discovery and Development of Disorders of the Nervous System (UG3/UH3) (U44)
- Mechanisms Underlying the Contribution of Sleep Disturbances to Pain (R01)(R21)

Educational Publications

E-Newsletters

TMJ News Bites

[Read Past issues of TMJ News Bites](#) available on our website.

If you're not currently receiving TMJ News Bites and would like to [be on our mailing list, sign up here.](#)

Cutting Edge - COPCs Research Advances

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.

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.](#)



CUTTING EDGE a publication of CHRONIC PAIN Research Alliance
COPCs Research Advances

Chronic Overlapping Pain Conditions Brochure

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.](#)

Your Guide to Temporomandibular Disorders Booklet

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 [postal mail](#) or as a [PDF on our website.](#) and we encourage you to share it with your friends, health care professionals, and family members.

NIH Brochure on 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

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.](#)

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.](#)

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 30 years, we have shared reliable information on TMD with people like you. We invite you to visit our website, www.tmj.org.



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