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TMJA

The TMJ Association, Ltd.

Issue 6 - June/July 2016

At Last We Got Everyone Around the TMJ Patient RoundTable!

It's taken persistence and too much time, but on June 16th of this year your TMJ Association, working with the Food and Drug Administration (FDA), led the first-ever RoundTable bringing together all those concerned with TMJ implants: patients, providers, manufacturers, regulators, researchers, and policymakers. The meeting was held under the auspices of MDEpiNet – a Public-Private partnership working to improve patient-centered outcomes for medical devices, wherever they are used in the world, through better data gathering and analysis, the use of appropriate methodologies, and by conducting research studies.

The meeting was hosted by the FDA's Center for Devices and Radiological Health at FDA headquarters in Maryland.

The Background

The need for the RoundTable grew out of conflicting reports on TMJ implants. Device manufacturers and surgeons have claimed that patients get better after receiving implants. But comments from FDA's MedWatch system, as well as what has been circulating on social media and what we hear at The TMJ Association tell a different story. Many patients say their pain and jaw dysfunction has gotten worse; some developed infections and sensitivity to metals or other materials. Often patients have



required additional surgeries or other treatments. There have also been reports of systemic problems that have developed, such as autoimmune disorders. In more than a few cases, patients have been rendered totally disabled.

Unfortunately, at this stage of TMJ science there are no telltale tests or specific kinds of patient data to indicate who will benefit from an implant and who will not. Further, when patients do experience adverse events following implant placement, the news is seldom reported in the published professional literature. ([Click here to read the background](#))

After Terrie Cowley, TMJA President and a member of MDEpiNet, brought this background information to MDEpiNet colleagues, plans for a TMJ Patient RoundTable were born. And, interestingly, this time the response from all stakeholders was dramatic: "[We were overwhelmed by the numbers and stature of professionals who expressed enthusiasm about participating](#)," Cowley said.

The Meeting Itself

At the outset of the June 16th meeting three long-term goals were announced ([click here to view detailed goals](#)):

1. Develop outcome assessment and reporting tools based on patient input.
2. Explore the multidisciplinary intersection of patient biology, anatomy, genetics, and physiology with TMJ medical devices and clinical patient-centered outcomes in order to better target therapies toward the patients most likely to benefit from them.
3. Develop evidence to incorporate patient-centered data into clinical care.

As co-chair of the RoundTable, Cowley welcomed participants explaining how the idea for the RoundTable had developed, but has now expanded. Not only would the project examine issues with regard to jaw implants, the RoundTable would also explore the evidence underlying other TMD treatments and decisions that lead to implant surgery. These studies will necessarily encompass research to understand the role of genetics, physiology, sex, biology and behavior in the development of TMD in pre- and post-implant patients. It will even include the state of TMD professional education, protocols, and standards-of-care among the health professions.

Following Cowley's introduction, co-chair Dr. Benjamin Eloff, Senior Scientific Program Manager, Division of Epidemiology at FDA, discussed the format and structure of the meeting. He remarked that since everyone in the room could lay claim to being a TMJ expert; all titles were to be left at the door. [Click here to continue to full article.](#)

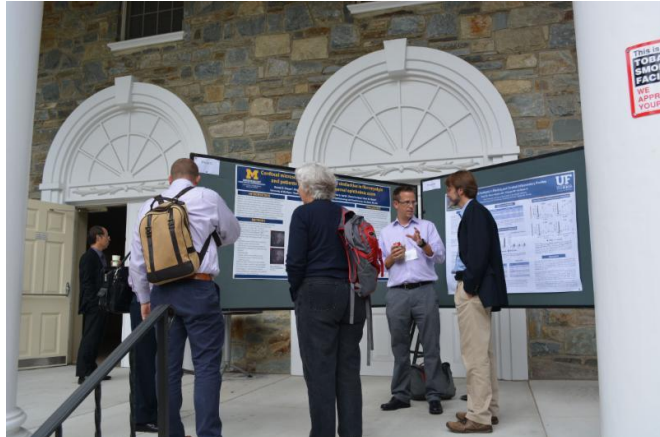
Eighth Scientific Meeting of The TMJ Association

How Can Precision Medicine Be Applied to Temporomandibular Disorders and its Comorbidities?

The TMJ Association's eighth scientific meeting, Sept. 11-13, 2016 in Bethesda Maryland, will focus on how methods of Precision Medicine can improve the treatment of

temporomandibular disorders (TMD) and the associated comorbid conditions. These conditions include vulvodynia, chronic tension-type and migraine headaches, myalgic encephalomyelitis/chronic fatigue syndrome, fibromyalgia, irritable bowel syndrome, interstitial cystitis/bladder pain syndrome, chronic low back pain and endometriosis.

Current diagnostics and treatments do not reflect recent findings in the state of the science and fall short in meeting the needs of patients. Successful application of Precision Medicine technology to TMD and its comorbidities will enable providers to classify TMD patients into subgroups according to specific diagnostic criteria and lead to tailored, more effective treatments to relieve their pain and suffering.



Presentations and discussions will focus on the challenges of obtaining precise molecular and phenotypic measurements from thousands of patients, repeatedly and efficiently. These challenges include development of methods to analyze and integrate large data sets from multiple modalities such as clinical measurements, imaging data, DNA sequence variants, and epigenetic profiles. The meeting will engage key scientific leaders, National Institutes of Health representatives and patient advocates and will yield recommendations to advance research in the field. [Click here to view the meeting agenda.](#)

Call for Posters

The TMJ Association's Scientific Advisory Board Program Committee invites the submission of abstracts for a poster session to be held in conjunction with the eighth scientific meeting of The TMJ Association. Students and research fellows are especially encouraged to submit abstracts for this session and to apply for travel awards. Up to six awards will be given. Abstracts submitted by students and fellows seeking travel awards will be judged by the TMJA's scientific advisors. The registration fee for award recipients will also be waived. Additionally, accepted poster abstracts will be published in the journal, *Molecular Pain*. **Poster abstract submission deadline is August 1, 2016.**

Who Should Attend?

Clinical and basic scientists, physicians, dentists and other health professionals, federal agency officials, patients and loved ones, and patient advocates for the comorbid conditions are encouraged to participate.

Additional Meeting Information

<http://www.tmj.org/site/content/2016TMJAScienceMeeting>

URGENT!

Action Item: Sign and Share the White House Petition Urging

Implementation of the National Pain Strategy

The TMJ Association is a member of the Consumer Pain Advocacy Task Force (CPATF). The CPATF started a White House Petition to urge the implementation and funding of the National Pain Strategy (NPS). The NPS is a federal blueprint for a better future for people with chronic conditions to increase discovery research for new treatments, pain education, and insurance coverage and to recognize chronic pain as a disease. Currently, the NPS is housed at the Department of Health & Human Services, but the Administration has not implemented or funded it.

There is a chance that the NPS could be ignored and not funded, which is why we need YOUR help! In order to ensure this petition is presented to President Obama, we have until **August 12th** to get 100,000 signatures, and we need your support.

[Sign the White House Petition at: bit.ly/whp-nps](http://bit.ly/whp-nps). Signing is a two-step process. After signing, check the email account you used to sign the petition. The White House will send an email asking you to confirm your signature.

Learn more about the #ISpeakForPain campaign supporting the National Pain Strategy at <http://yourvoicematters.info/ispeakforpain-blitz>

Meet Michele

From Terrie Cowley, TMJA's President & Co-Founder about Michele:

"I am pleased to announce that Michele Kasetta has accepted our invitation to Chair a newly formed Patient Advisory Committee of The TMJ Association. I first heard from Michele around 18 years ago when she was experiencing the frustrations TMD patients know so well. We've been in touch since then and a while back she said she was interested in becoming more active in TMJA as a patient advocate. At the time, we discussed the need for a safe place where patients could express their feelings, ask questions, and give and receive support. In response, she developed two private online boards - one for implant patients and one for non-implant TMD patients-and recruited other patients to monitor the posts and offer support. Michele and her colleagues have since heard from hundreds of TMD patients, many who then come to the TMJA for more advice. In turn, we refer patients to her boards for support and camaraderie. We collaborate in offering credible and evidence-based information to patients, especially providing support and understanding to patients upset by the chaotic and controversial treatment environment. Michele will strengthen our advocacy efforts and bring TMD patients together to ensure that their needs and concerns get heard in the right places."



Michelle replies:

"I have known Terrie Cowley for many years. She was the only person fighting for research and demanding TMD treatments are backed by scientific research. Terrie has been my rock and has been a great support as I struggled with infected implants. She has been a driving force in my desire to create the online support boards. I am excited to forge this new relationship with the Association, working on projects that are moving TMD to the front lines of neuroscience research. Science tells us that TMD is a complex disease that often overlaps with other painful conditions. As patients, that information alone demands new approaches to diagnosis, treatment and prevention. We deserve far better than what the current TMJ/TMD treatment environment has to offer - especially TMJ implant patients."

Patients in Los Angeles or New York City Needed for Clinical Study - Comparative Study of Women Considering or Currently Receiving Botox® Injections for TMJ Pain

Are you a woman with TMJ pain in facial muscles, who has either:

- a. recently had Botox® injections for your pain or
- b. not had Botox® for your pain but has thought about such treatment?

If either is true for you, you may qualify for an observational research study centrally administered by the New York University College of Dentistry. It is funded by the National Institutes of Health (NIH). The purpose of this study is to understand potential health risks that may be caused by treating "TMJ pain" with Botox® injections. Potentially eligible women must first complete a brief interview via telephone to confirm eligibility. [Click here for further study information and details.](#)

Patients Needed for Research Study in Baltimore MD

Researchers at Johns Hopkins School of Medicine and the University of Maryland Dental School are looking for volunteers with widespread pain that includes jaw pain (TMD) to participate in a research study to investigate the effect of three different non-drug treatments on pain and sleep symptoms. If you live in the in the Baltimore, MD area and are interested in further information, please read through the [study information brochure](#) and [patient consent form](#) for further details.

FDA Safety Alert: Over-the-Counter Antacid Products Containing Aspirin - Serious Bleeding Risk

The FDA is warning consumers about the risk of serious bleeding when using nonprescription, also known as over-the-counter or OTC, aspirin-containing antacid

products to treat heartburn, sour stomach, acid indigestion, or upset stomach. Many other products for these conditions are available that do not contain aspirin. These widely used products already contain warnings about this bleeding risk on their labels; however, we are continuing to receive reports of this serious safety issue. As a result, we will continue to evaluate this safety concern and plan to convene an advisory committee of external experts to provide input regarding whether additional FDA actions are needed. [Click here to read the full article.](#)

FDA Safety Alert: Migraine Patch - Risk of Burns and Scars

TMJ patients may experience migraines and/or headaches, therefore we are sharing this safety alert with our readers.

The Food and Drug Administration is investigating the risk of serious burns and potential permanent scarring with the use of Zecuity (sumatriptan iontophoretic transdermal system) patch for migraine headaches. Since marketing of the Zecuity patch began in September 2015, a large number of patients have reported they experienced burns or scars on the skin where the patch was worn. The reports included descriptions of severe redness, pain, skin discoloration, blistering, and cracked skin. As a result, FDA is investigating these serious adverse events to determine whether future regulatory action is needed, and will update the public with new information when the FDA review is complete. [Click here to read this MedWatch safety alert.](#)

FDA Safety Alert: Loperamide (Imodium) - Serious Heart Problems With High Doses From Abuse and Misuse

FDA is warning that taking higher than recommended doses of the common over-the-counter (OTC) and prescription diarrhea medicine loperamide (Imodium), including through abuse or misuse of the product, can cause serious heart problems that can lead to death. The risk of these serious heart problems, including abnormal heart rhythms, may also be increased when high doses of loperamide are taken with several kinds of medicines that interact with loperamide (see Examples of Drugs that Can Potentially Interact with Loperamide, in the [FDA Drug Safety Communication](#)).

The majority of reported serious heart problems occurred in individuals who were intentionally misusing and abusing high doses of loperamide in attempts to self-treat opioid withdrawal symptoms or to achieve a feeling of euphoria. FDA continues to evaluate this safety issue and will determine if additional FDA actions are needed. [Click here to read the full MedWatch safety alert.](#)

Avoid a TMD Misdiagnosis - Watch Out for Lyme Disease

Lyme disease is caused by the bacterium *Borrelia burgdorferi* and is transmitted to humans through the bite of infected blacklegged ticks. Typical symptoms include fever, headache, fatigue, and a characteristic skin rash called erythema migrans. If left untreated, infection can spread to joints (including the jaw), the heart, and the nervous system. Symptoms also can present differently in men and women. For example, women with Lyme disease significantly reported more joint pain, muscle pain, headache, back pain, heart palpitations, nausea, vomiting, anxiety, numbness and tingling, and changes in vision. Patients treated with appropriate antibiotics in the early stages of Lyme disease usually recover rapidly and completely.

Since many symptoms of Lyme disease are similar to Temporomandibular Disorders (TMD) it's easy for a misdiagnosis to occur. **If you think you suffer from TMD, it's very important to see your medical doctor to rule out any other medical conditions** such as Lyme disease that could be causing your symptoms.

We invite you to [read John Benjamin's story](#) which appears on our website. John initially thought his symptoms were caused by TMD and spent thousands of dollars on treatments and suffering for many years before he was properly diagnosed and treated for Lyme disease.

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. [We invite you to view a listing of the latest National Institutes of Health \(NIH\) funding opportunities for scientists interested in advancing TMJ research.](#)

The following are the newest NIH requests for information and funding announcements:

- [Request for Information: Increasing the Varieties of Marijuana and Marijuana products for Research \(NOT-DA-16-034\)](#)

National Institute on Drug Abuse

The National Institute on Drug Abuse (NIDA) supports the production of research grade marijuana and marijuana products (i.e. extracts, purified cannabinoids, etc.) for research.

- [Factors Underlying Differences in Female and Male Presentation for Dental, Oral, and Craniofacial Diseases and Conditions \(R01\)](#)
National Institute of Dental and Craniofacial Research
National Institute on Aging
Office of Research on Women's Health

- [Factors Underlying Differences in Female and Male Presentation for Dental, Oral, and Craniofacial Diseases and Conditions \(R21\)](#)

National Institute of Dental and Craniofacial Research
National Institute on Aging
Office of Research on Women's Health

The purpose of this funding opportunity announcement is to encourage exploratory/developmental research on mechanisms underlying the manifestations of sex-based differences in Dental, Oral, and Craniofacial (DOC)-related diseases and conditions. Specifically, this initiative encourages studies aimed at understanding immune reactivity, genetic variation, environmental triggers, aging, and hormonal changes as they affect sex-based differences in DOC-related diseases and conditions including, but not limited to, Sjögren's Syndrome (SS), orofacial pain, **temporomandibular joint (TMJ) disorder (TMD)**, salivary gland tumors, and human papillomavirus (HPV)-associated oropharyngeal cancers.

Professional Opportunity

The University of North Carolina at Chapel Hill, School of Dentistry seeks to appoint a full-time, tenure-track position at the rank of Assistant Professor in the Department of Endodontics and in the Center for Pain Research and Innovation. The candidate must have a successful history of acquiring peer-reviewed competitive funding to support research into TMJ/orofacial pain and related pain conditions. The position requires a PhD, Doctor of Dental Surgery (DDS), Medical Doctor (MD) or equivalent degree. [Click here to read the complete announcement.](#)

TMD Nutritional Guide

TMD Nutrition and You

TMD Nutrition and You, was specifically developed to help those with compromised oral function maintain a diet of good nutrition despite their oral disability, and also provide guidance on making dental appointments as comfortable as possible. [Click here to download a free copy of our booklet.](#)

Research E-Newsletter

Cutting Edge - COPCs Research Advances

Cutting Edge - COPCs Research Advances, is a new 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 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 Brochure on TMD

A Resource Guide for Temporomandibular Disorders

This brochure 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.

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](#).

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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!](#)

"My daughter lost some of her childhood to TMD. She went undiagnosed for so long. The doctors judged her and us. It seems that most doctors don't understand how debilitating this syndrome can be. They need to be educated. This contribution is in honor of our little girl who had no voice" - Michelle, New York

"The TMJA is a great organization. I am impressed by your objectivity and transparency. Thank you for your hard work." - Lisa, Pennsylvania



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](#).
- [Past issues of *TMJ News Bites*](#) are also available on our website.

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