Advocacy Work

After President Obama submits his budget to Congress, the work of Representatives and Senators begins. It is at this time that we tell our elected officials what YOU, TMJ patients, need to have addressed.

The past two months have been busy ones outside our office. On February 23rd we visited the offices of Wisconsin Senators Tammy Baldwin, Ron Johnson, and Representative James Sensenbrenner while attending the American Association for Dental Research and Friends of the National Institute of Dental and Craniofacial Research Advocacy Day event on Capitol Hill. On March 8th we visited nine Senate and House Offices. During our Hill meetings with staff and Senators we discussed:

- **Research on TMD pain:** As always, our number one request is for research. Since 2006, the National Institute of Dental and Craniofacial Research has supported OPPERA, the *Orofacial Pain Prospective Evaluation and Risk Assessment* project, which has been the leading research program not only in deciphering the intricacies of TMD pain, but also that of a number of conditions that often coexist with TMD. **We want this kind of research to expand.**

- **The temporomandibular joint:** Research on the TM joint still lags behind research on other major joints in the body. **This has to change.** In 2013, the National Institutes of Dental and Craniofacial Research, Biomedical Imaging and Bioengineering, and Arthritis and Musculoskeletal and Skin Diseases convened a Round Table meeting, notably highlighting the absence of solid information on the jaw joint. We are working to remedy that situation.
Pain research: If patients are not able to receive opioids for severe and chronic pain, what are their options for safe and effective alternatives? Over-the-counter medications may not "touch" the pain and can have severe consequences on the liver, kidneys, heart, stomach, and esophagus. Other complementary or behavioral therapies take time that a person in pain who is employed may not have. Nor will the costs necessarily be covered by insurance. We need to intensify research aimed at finding safe and effective alternatives to opioids to relieve the chronic pain of millions of Americans.

We also visited with Food and Drug Administration staff to discuss the development of the first TMJ Implant Round Table.

It is clear that research on all aspects of Temporomandibular Disorders and our overlapping pain conditions are needed. Please send that message to your own Senators and Congress person! They need to hear from you now.

Scientific News: Sleep and TMD
Dr. Anne Sanders was kind enough to write the following synopsis of a recent study on sleep and TMD.

A recent study of the OPPERA group reported in The Journal of Pain, sheds new light on the understanding of poor sleep in relation to painful Temporomandibular Disorders (TMD). OPPERA, an acronym for "Orofacial Pain: Prospective Evaluation and Risk Assessment," is an NIDCR-sponsored community-based, multi-site project that for the past 10 years has been investigating risk factors for the onset and persistence of painful TMD. Although scientists have long known that pain and poor sleep often coexist, only recently has science combined evidence from experimental and longitudinal studies to determine which direction matters most: does pain lead to poor sleep; or is poor sleep a stronger predictor of pain? Those reviews concluded the latter—that poor sleep is a stronger and more reliable predictor of pain onset.

This finding is consistent with OPPERA findings from 2013. In its prospective cohort study, OPPERA enrolled 2,722 men and women who were clinically free of painful TMD and who had no lifetime experience of TMD. At enrollment, these study participants completed the Pittsburgh Sleep Quality Index—a questionnaire that evaluated their sleep quality. The OPPERA investigators then followed them for a median 2.8 years to observe who developed TMD and who did not. Dr. Sanders and colleagues found that the rate of first-onset TMD was 50% higher in participants whose sleep quality at enrollment was poor compared to those with good sleep quality.[1]

The 2013 findings were informative, but still fell short in providing a full picture of what happens to sleep quality in the window between enrollment and TMD development, which often occurs many months or years later. By analyzing participants’ questionnaire responses (sent every three months throughout the entire study), OPPERA investigators found no change in sleep quality in those who did not develop TMD; however, in participants who developed painful TMD, sleep quality worsened progressively over
time. Not only did those who went on to develop TMD have worse sleep quality at enrollment, but their sleep quality continued to worsen. Most intriguing was that sleep quality deteriorated before these participants developed symptoms that alerted OPPERA investigators to recall them for a follow-up clinical examination. Furthermore, the statistical analytic approach determined that worsening sleep quality was independent of psychological stress, somatic awareness and other major predictors of TMD found in the OPPERA study.

The OPPERA team recognizes the importance of these findings in the comprehensive management of TMD pain and related symptoms, and is now planning a six-to-eight week pilot study to determine the feasibility of monitoring sleep duration and staging while chronic TMD patients receive treatment. Promising findings may lead to a more definitive study to identify new treatment for painful TMD.


New Safety Warnings Added to Prescription Opioid Drugs

Opioids are a class of powerful narcotic pain medicines that are used to treat moderate to severe pain that may not respond well to other pain medicines. They can help manage pain when other treatments and medicines are not able to provide enough pain relief, but they also have serious risks including misuse and abuse, addiction, overdose, and death.

The U.S. Food and Drug Administration (FDA) has issued a consumer warning regarding several safety issues with the entire class of opioid pain medicines. The new safety risks include potentially harmful interactions with numerous other medications, problems with the adrenal glands, and decreased sex hormone levels. The FDA is requiring companies to make changes to the opioid medication labels warning consumers of these risks as described below. To view full FDA safety alert, click here.

**Label change #1:** Opioids can interact with antidepressants and migraine medicines to cause a serious central nervous system reaction called serotonin syndrome, in which toxic levels of the neurotransmitter serotonin build up in the brain.

Cases of serotonin syndrome in the FDA Adverse Event Reporting System (FAERS) database were reported more frequently with the opioids fentanyl and methadone used at the recommended doses. Therefore, the FDA is requiring a new statement in the
Warnings and Precautions section to be added to these drug labels. Some opioids, including tramadol, tapentadol, and meperidine, already have warnings about serotonin syndrome. Cases were also reported with other opioids, so the labels of all these drugs will be updated to include information about serotonin syndrome in the Drug Interactions and Adverse Reactions sections.

Patients taking an opioid along with a serotonergic medicine should seek medical attention immediately if they develop symptoms such as agitation; hallucinations; rapid heart rate; fever; excessive sweating; shivering or shaking; muscle twitching or stiffness; trouble with coordination; and/or nausea, vomiting, or diarrhea. Symptoms generally start within several hours to a few days of taking an opioid with another medicine that increases the effects of serotonin in the brain, but symptoms may occur later, particularly after a dose increase.

**Label change #2:** Taking opioids may lead to a rare, but serious condition in which the adrenal glands do not produce adequate amounts of the hormone cortisol. Cortisol helps the body respond to stress.

**Label change #3:** Long-term use of opioids may be associated with decreased sex hormone levels and symptoms such as reduced interest in sex, impotence, or infertility.

### NSAIDs, Acetaminophen Potential Dangers Often Go Unrecognized

The following is from *Pain Medicine News*, Survey: Potential Dangers of NSAIDs, Acetaminophen Often Ignored, Unrecognized.

"A new survey conducted by the American Gastroenterological Association (AGA) has revealed some problematic beliefs that patients have about acetaminophen and nonsteroidal anti-inflammatory drugs (NSAIDs). For example, over 40% of surveyed patients said they see over-the-counter (OTC) label use instructions as "just suggestions," and some did not even consider OTC drugs to be medications.

Each year, for every 1 million Americans, 35 die from acetaminophen (Tylenol) overdose, 64 succumb to ibuprofen (Advil) overdose and 118 die from naproxen sodium (Aleve) overdose (Adv Pharmacoepidemiol Drug Saf 2013;2:1-5). Besides the risk for death, NSAIDs can cause gastrointestinal bleeding and damage to the esophagus and small intestine, while improper use of acetaminophen is associated with liver damage and liver failure, said Anne Larson, MD, clinical professor of medicine at Northwest Hospital/University of Washington Medicine Liver Clinic, in Seattle, during a recent webinar when she and others presented findings from the AGA’s survey..." [Read more.](#)

### National Pain Study Released

*Terrie Cowley, the TMJA’s President and Co-founder of the Chronic Pain Research Alliance, Christin Veasley, Director and Co-founder of the Chronic Pain Research*
The Office of the Assistant Secretary for Health at the U.S. Department of Health and Human Services recently released the National Pain Strategy, outlining the federal government's first coordinated plan for reducing the burden of chronic pain that affects millions of Americans. Developed by a diverse team of experts from around the nation, the National Pain Strategy is a roadmap toward achieving a system of care in which all people receive appropriate, high quality and evidence-based care for pain.

"Chronic pain is a significant public health problem, affecting millions of Americans and incurring significant economic costs to our society," said Karen B. DeSalvo, M.D., M.P.H., M.Sc., HHS acting assistant secretary for health. "This report identifies the key steps we can take to improve how we prevent, assess and treat pain in this country."

In 2011, in recognition of the public health problem of pain in America, the Institute of Medicine called for a coordinated, national effort of public and private organizations to transform how the nation understands and approaches pain management and prevention. In response, HHS tasked the Interagency Pain Research Coordinating Committee (IPRCC), a group of representatives from the Department of Defense, Department of Veterans Affairs, Agency for Healthcare Research and Quality, Centers for Disease Control and Prevention, Food and Drug Administration, National Institutes of Health and members of the public, including scientists and patient advocates, with developing a National Pain Strategy that recognizes access to safe and effective care for people suffering from pain as a public health priority. The final Strategy being released today makes recommendations for improving overall pain care in America in six key areas: population research; prevention and care; disparities; service delivery and payment; professional education and training; and public education and communication.

More specifically, the Strategy calls for:

- Developing methods and metrics to monitor and improve the prevention and management of pain.
- Supporting the development of a system of patient-centered integrated pain management practices based on a biopsychosocial model of care that enables providers and patients to access the full spectrum of pain treatment options.
- Taking steps to reduce barriers to pain care and improve the quality of pain care for vulnerable, stigmatized and underserved populations.
- Increasing public awareness of pain, increasing patient knowledge of treatment options and risks, and helping to develop a better informed health care workforce with regard to pain management.

"Of the millions of people who suffer from chronic pain, too many find that it affects many or all aspects of their lives," said Linda Porter, Ph.D., director, NIH's Office of Pain Policy and co-chair of the IPRCC working group that helped to develop the report. "We
need to ensure that people with pain get appropriate care and that means defining how we can best manage pain care in this country."

The IPRCC engaged with a broad range of experts, including pain care providers, scientists, insurers, patient advocates, accreditation boards, professional societies and government officials to develop the Strategy. Upon the release of the Strategy, the Office of the Assistant Secretary for Health, in conjunction with other HHS operating and staff divisions, will consider the recommendations included in the Strategy and develop an implementation and evaluation plan based on this process. In addition, the IPRCC is creating a research agenda to advance pain-related research in an effort to realize the goals of the Strategy.

"Pain can affect all aspects of a patient's life, so we wanted to hear from everyone," said Sean Mackey, M.D., Ph.D., chief, Division of Pain Medicine, Stanford University, and a co-chair of the IPRCC working group that helped to develop the report. "Similarly, to achieve the goals in this report, we will need everyone working together to create the cultural transformation in pain prevention, care and education that is desperately needed by the American public."

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.

TMJ patients often struggle with basic dental care due to limited mouth opening and associated pain. This new NIH funding opportunity addresses this critical need by tailoring dental treatment for those patients with compromised oral health.

- Tailoring Dental Treatment for Individuals with Systemic Diseases that Compromise Oral Health (R01) [PAR-16-154] National Institute of Dental and Craniofacial Research (NIDCR)
- Tailoring Dental Treatment for Individuals with Systemic Diseases that Compromise Oral Health (R21) [PAR-16-153] National Institute of Dental and Craniofacial Research (NIDCR)

The following are related to vulvodynia, one of the conditions that often coexists with TMD.

- Multidisciplinary Research in Vulvodynia (R21) [PA-16-100] Eunice Kennedy Shriver National Institute of Child Health and Human Development
Application Receipt/Submission Date(s): Multiple dates, see announcement.

- Multidisciplinary Research in Vulvodynia (R03)  [PA-16-101]
  Eunice Kennedy Shriver National Institute of Child Health and Human Development
  Application Receipt/Submission Date(s): Multiple dates, see announcement.

- Multidisciplinary Research in Vulvodynia (R01)  [PA-16-102]
  Eunice Kennedy Shriver National Institute of Child Health and Human Development
  Application Receipt/Submission Date(s): Multiple dates, see announcement.

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**TMD Nutritional Guide**

*TMD Nutrition and You*

Did you know March is National Nutrition Month®? A nutrition education and information campaign by the Academy of Nutrition and Dietetics aims to bring attention to the importance of informed food choices and developing sound eating and physical activity habits. In honor of this campaign, we encourage you to get our free nutritional guide!

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

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**New 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 January and March issues are now available for your review at: http://www.cpralliance.org/New_Findings. If you would like to receive future issues of
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 maintaining 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.

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!

"I am glad your organization exists. I could not find a similar one here in Canada. I appreciate your informative website...I would like my contribution to go toward promoting scientific research so probably the 2016 TMJA science meeting is the best way to use my donation. Since TMD affects so many people it's surprising that not more research has been done. Diseases that affect quality of life just do not get adequate funding in my opinion." John, Canada

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