

The TMJ Association, Ltd.

2013 Annual Report



P.O. Box 26770, Milwaukee, WI 53226 ♦ www.tmj.org

Message from the President

The TMJ Association continues to strive toward its goal: the development of universal standards for safe and effective evidence-based diagnostics and treatments. Our advocacy efforts in 2013 continued to yield results that bode well for all TMD patients. In a 2013 survey of our website visitors, 80 percent of respondents want more scientific research on TMD. This priority was echoed by the scientists and policy makers whom we interviewed. We are convinced that promoting and advocating for scientific research must remain the TMJA's number one priority.



Association Roles

The TMJA is currently the only national, nonprofit health advocacy organization working exclusively to encourage research for therapies to relieve the jaw pain and dysfunction experienced by TMD patients. Through its website, the TMJA also extends its reach globally, receiving and responding to inquiries from TMD patients around the world.

While there are no physicians on the TMJA staff, the organization has excellent physician representation on its Scientific Advisory Board. The small staff at the TMJA includes the President, Terrie Cowley; Association Administrator, Deanne Clare; and volunteers who carry out various responsibilities. The primary functions of the Association are to foster scientific research, advocate for TMD patients, serve as a resource and provide a support network.

Foster Scientific Research

The TMJA encourages research through its efforts to influence, support, collaborate, organize, or directly participate in TMJ-related and pain-related research projects, surveys and conferences.

Advocate for TMD Patients

The TMJA advocates for TMD patients by raising awareness of their problems and needs with health care policymakers in organizations such as the National Institutes of Health (NIH).

Serve as a Resource and Provide a Support Network

The TMJA reports on TMD and related research activities and findings in the U.S. and abroad. The Association also acts as a hub for the collection and dissemination of TMJ-related information and provides a support network for patients. Through its network of reporting and sharing information, the TMJA educates patients, health care providers and the general public about TMD

Since its inception the organization had gained the respect of elected officials, policymakers, government agencies, and the research and health care communities. In that regard we continue to promote the organization and its mission.

Sincerely,

A handwritten signature in cursive script that reads "Terrie Cowley". The ink is dark and the signature is fluid and legible.

2013 Achievements

...in Fostering Scientific Research

- **Exploring the Temporomandibular Joint: NIH Sponsors Round Table**

For many years the TMJA has asked agencies of the National Institutes of Health (NIH) to convene a meeting to assess what we know about the TM joint and to determine gaps in our knowledge. On May 3, 2013, the NIH held a scientific round table of experts to do just that. Three agencies of the NIH—the National Institute of Dental and Craniofacial Research (NIDCR), the National Institute of Arthritis and Musculoskeletal and Skin Diseases, and the National Institute of Biomedical Imaging and Bioengineering sponsored the workshop.

Discussion topics included factors important in the onset and transition to chronic TMJ pain, specific molecular biomarkers of disease, new methods of measuring joint function, and future research directions. The recommendations that resulted from this meeting were developed into an initiative (of the National Institute of Dental and Craniofacial Research (NIDCR)) that will guide future research on the jaw joint – quality research so desperately needed by TMJ patients. Studying the many aspects of the TM joint will bring scientifically based knowledge to the field that will guide health professionals in diagnostics and treatments of this joint.

- **TMD and Overlapping Pain Conditions**

The TMJA is a member of the Chronic Pain Research Alliance (CPRA), which worked to encourage the National Institutes of Health (NIH) to convene the first federal scientific meeting focused solely on overlapping pain conditions. CPRA is the first and only collaborative advocacy effort dedicated to advancing research efforts on nine prevalent but longtime neglected disorders that frequently co-occur in women (chronic fatigue syndrome, chronic headache, endometriosis, fibromyalgia, interstitial cystitis, irritable bowel syndrome, low back pain, vulvodynia and TMD).

Among recommendations for advancing research in these conditions are to:

1. Develop standardized ways to classify patients with overlapping pain conditions.
2. Search for common mechanisms of disease.
3. Define risk factors for the course of disease (onset, progression, exacerbation, etc.).
4. Develop research diagnostics and outcome measures.

- **TMJA Advisory Board Member Heads Research Team on Orofacial Pain**

Dr. William Maixner, Director of the University of North Carolina at Chapel Hill, Regional Center for Neurosensory Disorders, and also a member of the Scientific Advisory Board of the TMJA, recently completed the first stage of a clinical study titled “Orofacial Pain: Prospective Evaluation and Risk Assessment”, (OPPERA). This multi-site research project has been exploring the relationship between temporomandibular disorders and other chronic pain conditions and recently published two sets of papers of their findings in *The Journal of Pain*. TMJA is pleased that the OPPERA study is moving forward with the next stage of its trials and will continue to support Dr. Maixner and his team in their research.



- **TMJA Board Member Appointed Dental School Dean at Columbia University**

Dr. Christian S. Stohler, a member of the TMJA's Board of Directors and a Scientific Advisory Board member since 1996, was named Dean of the College of Dental Medicine at Columbia University in New York, effective August 1, 2013. Dr. Stohler, a well-regarded expert on pain management and jaw disorders, will serve as Dean and Senior Vice President at the Columbia University Medical Center. This appointment follows a decade in which he served as Dean of the University of Maryland School of Dentistry in Baltimore.



Columbia University President Lee C. Bollinger noted that Dr. Stohler is “deeply committed to advancing dental care through research” and has led pain studies funded by the National Institutes of Health focused on patients with TMD.

...in Advocating for TMD Patients

- **The TMJA Keeps U.S. Congress Aware of TMD Patient Needs**

The TMJA has the support of the Senate Subcommittee responsible for funding the National Institutes of Health (NIH) and regularly keeps members informed. Subcommittee support is important because it brings Congressional attention to the issues and its members hold the Directors of NIH accountable.

- **The TMJA Cited Failure of Compliance by TMJ Device Manufacturers**

The TMJA continued to meet and voice concerns with the FDA regarding the lack of compliance by manufacturers to submit protocols regarding the safety of their devices. The most recent order was issued to manufacturers two years ago.

- **TMJA and Dear Doctor Join Forces**

The TMJA entered into a new partnership with *Dear Doctor – Dentistry & Oral Health* magazine, a leading source of dental health care advice for consumers. This opportunity to join forces with *Dear Doctor* enhances our mission to educate the public and dental professionals about the realities of TMJ disorders as well as provide the latest scientific knowledge.



- **TMJA's Advocacy Efforts Cited in New York Times**

The *New York Times* Sunday opinion piece by Laurie Edwards titled, "The Gender Gap in Pain" cited the Campaign to End Pain in Women and the Institute of Medicine reports. Both reports discuss the inadequate care women with pain often receive. The TMJA is one of the founding members of the Chronic Pain Research Alliance, which launched the *Campaign to End Pain in Women* in 2010.

...as a Resource and Support Network for TMD Patients

The TMJA communicates with patients and educates professionals and the general public on TMD topics through a variety of resources including website, electronic and printed publications, and social media.

- **Reports on Current Research and Related Findings**

Some of the topics that the TMJA covered in its publications during 2013 included:

- Identification of metal hypersensitivity to TMJ implant materials.
- Evidence that disc displacement is common in the general population.
- Continuing research on the question: “Does estrogen increase or diminish TMD pain?” The jury is still out.
- Using electric stimulation of the brain to relieve pain.
- A recent study published in the journal *Pain Practice* confirmed the importance of Central Sensitization Syndrome (CSS) in mediating pain in some TMD patients.
- Establishment of a new brain initiative at the National Institutes of Health (NIH), **Brain Research through Advancing Innovative Neurotechnologies (BRAIN)**, whose focus is aimed at revolutionizing our understanding of the human brain.
- A revised view of the role of sleep bruxism and sleep chewing muscle activity in TMJ muscle pain. A large study published in the *Journal of the American Dental Association* found that this belief was simply not supported by evidence.
- Both the diagnosis and treatment of TMD and other musculoskeletal pain conditions would benefit if health care providers conducted a number of physiological and psychological test on patients to determine their “pain profile”.
- Evidence that your brain may be “hardwired” for chronic pain. It plays a critical role in chronic pain, a concept that may lead to changes in the way doctors treat patients.
- Researchers determine that bacteria trigger nerve cells to cause pain.
- Stabilization splints may worsen obstructive sleep apnea.
- Using hot and cold packs is the most effective therapy for reducing TMD pain.
- There is no connection between TMD, body posture and dental occlusion.
- A Michigan study by Dr. Barbara Reed, looks at the relationship among coexisting pain conditions.
- Scientists can now “see” your pain through using magnetic resonance imaging. (MRI)
- Orofacial Pain Prospective Evaluation and Risk Assessment (OPPERA) researchers have determined that, in terms of TMD, stop looking at the teeth, the muscles of mastication and the jaws as the be-and-end-all of TMD chronic pain and dysfunction, and see what else is going on in the body.

- **Provides a Support Network for TMD Patients**

The TMJA serves as a central source to collect and share information with patients, government agencies, elected officials, and the health care and research communities. In addition to communicating through its publications, the TMJA carries out its role through:

- One-on-one telephone patient support.
- The *TMJ Exchange*, an online TMJ implant patient communication center that provides an avenue for patients to share experiences.
- Facebook, Twitter, and LinkedIn accounts where the TMJA can share urgent news as well as provide for the sharing of personal experiences.



- **Alerts Readers of Concerns**

The TMJA publications include tips and alerts about TMJ-related topics. In 2013, topics included:

- Don't be fooled by false claims. Health fraud scams can do more than waste your money. They can cause serious injury or even death.
- Safety concerns: Potential drug interactions – even interactions of natural products with drugs.
- Don't double up on acetaminophen.
- It's important that you use NSAIDs while under a medical doctor's supervision. Aspirin, naproxen (Aleve) and ibuprofen (Advil, Motrin) are examples of over-the-counter NSAIDs.
- Watch out for Lyme disease. 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.
- Acupuncture helps TMD? Maybe.....
- Warning: "Diagnostic Tools" Proven to be Inaccurate. Tools such as electromyography (EMG) of the jaw muscles and kinesiographic (KG) recordings have been shown to be inaccurate and can provide false positives – indicating that you have a TMD problem, when you actually do not.

...in Promoting the Organization

The visibility of the TMJA staff in addition to Scientific Advisory Board members increases awareness of the needs of TMD patients and creates opportunities that draw attention to the need for more research and funding.

- **Representation**

Terrie Cowley, Co-founder and President, represented the TMJA in the following:

- Participated in talk show radio – *In Short Order* – discussing the topic of TMJ Disorders and Lyme Disease
- Attended a meeting in Washington DC: "How Can Healthcare be Improved with Comparative Effectiveness Research?"
- Patient Registries Technical Expert Panel Participant, American Institutes for Research Community Forum

- Friends of NIDCR Board Member, Rockville, MD
- National Pain Strategy Task Force on the Interagency Pain Research Coordinating Committee of the National Institutes of Health, Bethesda, MD
- Panel Member, *Management of Cough: American College of Chest Physicians Evidence-based Guidelines and Expert Panel Report*, Guidelines Oversight Committee of the American College of Chest Physicians, Northbrook, IL.
- Special FDA Government Employee, Center for Devices and Radiological Health
- Public Education Committee member on the Interagency Pain Research Coordinating Committee of the National Institutes of Health, Bethesda, MD
- Oversight Committee member on the Interagency Pain Research Coordinating Committee of the National Institutes of Health, Bethesda, MD

**Statement of Activities and Changes in Net Assets
For the Year Ended December 31, 2013**

Summary of Revenue & Support

Contributions	\$98,134
Grants	20,000
Scientific Meeting	8,553
Special event	0
Dividend and interest	480
Unrealized gain on investment	0
Realized (loss) on investment	0
Other	177
Total revenue and support	\$127,344

Summary of Expenses

Program	\$75,188
Administrative	6,826
Fundraising & Related Expenses	5,121
Total expenses	\$87,135
Change in net assets	40,209
Net assets, beginning of year	238,796
Net assets, end of year	\$279,005

The TMJ Association is a non-profit tax exempt organization. A copy of the annual financial report of The TMJ Association can be obtained by contacting: Mr. David Hilker, CPA, Hilker Associates, 300 W. Walnut Street, Milwaukee, WI 53212.