

**The TMJ Association, Ltd.**

**2014 Annual Report**



P.O. Box 26770, Milwaukee, WI 53226 ♦ [www.tmj.org](http://www.tmj.org)

## ***Message from the President***

Year's end is the time we reflect upon the past and look to the future. We are grateful for your moral and financial support that resulted in several impressive accomplishments in 2014.

The highlight of the year was our seventh scientific meeting, *Genetic, Epigenetic, and Mechanistic Studies of Temporomandibular Disorders and Overlapping Pain Conditions*. The meeting was cosponsored by agencies of the National Institutes of Health (NIH). The recommendations from this high-caliber scientific meeting will direct future research on Temporomandibular Disorders (TMD) and overlapping pain conditions. The [meeting report](#) and [abstracts](#) have been published in the journal, *Molecular Pain*.



Another result of our advocacy efforts is the NIH funding opportunity for comprehensive research on the [Biology of the Temporomandibular Joint](#), which will lead to a better understanding of total joint structure and mechanics, including the interactions of the skeletal, muscular, nervous, immune, and circulatory systems, using new in vivo and in vitro models. An expected outcome is new knowledge that will provide a basis for developing novel approaches to prevent, diagnose, assess risk, and treat TMD.

The TMJ Association has been at the forefront in highlighting the fact that over 85% of TMD patients have other chronic pain conditions. The TMJA joined forces with several patient advocacy organizations to form the Chronic Pain Research Alliance (CPRA), the country's first and only research-led collaborative advocacy effort dedicated to addressing chronic overlapping pain conditions. In June, the NIH posted a funding opportunity to encourage research that will increase our [understanding of multiple chronic pain conditions](#) (including TMD) for people with pain.

In 2015 we will continue our advocacy, information dissemination, patient support and education efforts on TMD and those conditions that coexist with TMD. Over the past 10 years, we have moved TMJ science from the doldrums to the cutting edge. TMD is no longer merely about teeth and jaws, but rather a complex disease with many contributing factors, including painful conditions in other parts of the body – even throughout the whole body. This new knowledge will be a game-changer in how TMD is diagnosed and treated. However, patients continue to be harmed, because this science has been translated neither to their primary care physician's office, nor to their dentist's. Our next step is to explore ways to bring the science to health care providers.

Sincerely,

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

## 2014 Achievements

### ...in Fostering Scientific Research

- **NIH Funding Announcements**

The NIH convened a round-table meeting to assess what we know about the TMJ joint and to determine gaps in our knowledge. This meeting was a result of years of advocacy efforts by The TMJ Association to call attention to the jaw joint. As a result of these efforts, the National Institutes of Health released two new funding opportunities for the ***Biology of the Temporomandibular Joint in Health and Disease***, supported by the National Institute of Dental and Craniofacial Research and the National Institute of Biomedical Imaging and Bioengineering. The intent is to support scientific research that will provide a better understanding of total joint structure and mechanics, including how the skeletal, muscular, nervous, immune, and circulatory systems, which function together, can go awry in disease.

The TMJ Association has been at the forefront in highlighting the fact that up to 85% of TMD patients have other chronic pain conditions. The TMJA joined forces with several patient advocacy organizations to form the [Chronic Pain Research Alliance \(CPRA\)](http://www.chronicpainresearchalliance.org), the country's first and only research-led collaborative advocacy effort dedicated to addressing chronic overlapping pain conditions. CPRA's advocacy has resulted in two new NIH research opportunities: ***Research on Chronic Overlapping Pain Conditions***, (R01) <http://grants.nih.gov/grants/guide/pa-files/PA-14-244.html> and (R21) <http://grants.nih.gov/grants/guide/pa-files/PA-14-243.html>

- **Seventh Scientific Meeting of The TMJ Association**

On September 7-9, 2014 in Bethesda, Maryland, scientists, clinicians, and patients took part in the TMJA's Seventh Scientific Meeting, *Genetic, Epigenetic, and Mechanistic Studies of Temporomandibular Disorders and Overlapping Pain Conditions*. The meeting, which was co-sponsored by the National Institute of Dental and Craniofacial Research, the National Institute of Neurological Disorders and Stroke, and the Office of Research on Women's Health, explored the molecular and genomic basis of Temporomandibular and related chronic pain disorders. The meeting was supported by grant number 1U13DE024691-01 from the National Institute of Dental and Craniofacial Research.

- **Young Investigator Travel Awardees**

Our science meeting is not only designed to bring together scientists and clinicians knowledgeable about TMD and its complex presentations, but also to invite young investigators to participate and stimulate their career commitments to TMD and related research. This year the TMJA received abstracts from 12 investigators. The abstracts were judged by our scientific advisory board and six young investigators were selected and received \$1,000 travel award to attend our meeting, present their poster and give a brief description.



## 2014 TMJA Science Meeting Travel Awardees:

**Yong Chen, Ph.D.**, Duke University, Durham, NC  
Poster: *TRPV4-mediated trigeminal pain: behavior assessments and mechanisms*  
Mentor: Dr. Wolfgang Liedtke

**Daniel E. Harper, Ph.D.**, University of Michigan, Ann Arbor, MI  
Poster: *Confocal microscopy reveals nerve fiber similarities in fibromyalgia and patients with dry eyes with a normal ophthalmic exam*  
Mentors: Drs. Daniel Clauw and Richard Harris

**Christopher D. King, Ph.D.**, University of Florida, Gainesville, FL  
Poster: *Case-control analysis in resting and evoked inflammatory profiles*  
Mentors: Drs. Roger Fillingim and Joe Riley III

**James Sciote, D.D.S, M.S., Ph.D.**, Temple University, Philadelphia, PA  
Poster: *Associations between ACTN3 and OPPERA pain-related genes in malocclusion*

**Shad B. Smith, Ph.D.**, University of North Carolina at Chapel Hill, Chapel Hill, NC  
Poster: *Association between INADL genetic variant and the subgroup with high risk for TMD in the OPPERA study*  
Mentors: Drs. Luda Diatchenko and William Maixner

**Roi Treister, Ph.D.**, Massachusetts General Hospital & Harvard Medical School, Boston, MA  
Poster: *Repetitive transcranial magnetic stimulation (rTMS) of the primary motor cortex for treating facial neuropathic pain - preliminary results of a randomized, sham-controlled, cross-over study*  
Mentor: Dr. Anne Louise Oaklander

## ...in Advocating for TMD Patients

- **Submitted Guideline Proposal for Treatment of TMD**  
The TMJA sent in a topic submission form to Associated Medical Conditions to American Academy of Otolaryngology – Head & Neck Surgery Foundation to include guidelines for TMD. The new guidelines would become the basis for large scale clinical effectiveness trials that will yield evidence-based treatments for patients with TMD and related conditions.
- **Obtained Senators Support in Advocating for TMJ Implant Patients**  
The TMJA was able to gain the support of elected officials in the United States Senate. Senators Tom Harkin (IA) and Tammy Baldwin (WI) of the United States Committee on Health Education, Labor, and Pensions regarding the problems associated with TMJ implants. The Senators sent a letter to Commissioner Margaret Hamburg, United States Food and Drug Administration, voicing these concerns.

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

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

Some of the topics that the TMJA covered in its publications during 2014 included:

- **OPPERA II Summary of Newly Published Articles**  
This study was designed to build on the findings of OPPERA I and deepen the understanding of risk factors and genetic markers for chronic pain conditions like TMD, headaches, irritable bowel syndrome, low back pain and chronic widespread pain.
- **Introduction to Adult Stem Cell Research**  
Scientists are using stem cells to grow grafts of bone in the shape of the TM joint. This research will someday help patients who have had TMJ implants or may be contemplating implant surgery down the road.
- **Let's hear it for Mindfulness Meditation!**  
The National Institutes of Health re-established a cross-institute Pain Consortium about a decade ago to increase pain research and promote inter-institute collaboration.
- **TMJ Disc Displacement without Reduction Management: A Systematic Review**  
Various interventions have been used for the management of patients with temporomandibular joint (TMJ) disc displacement without reduction (DDwoR), but their clinical effectiveness remains unclear. This systematic review investigated the effects of these interventions.
- **Study Looks at Arthrocentesis in the Treatment of Juvenile Idiopathic Arthritis**  
Authors suggested that arthrocentesis in the TMJ treatment of patients with JIA may be beneficial, as steroids had no additional effect.

- **Educational Information & Alerts Readers of Concerns**

The TMJA publishes educational topics that provide patients with guidance and support. The following topics were addressed in our newsletter and website in 2014:

- **TMJA Video**  
A new awareness video was premiered at the TMJA's Seventh Scientific Meeting. Audience members included research scientists, NIH officials, health care providers, and patient advocates. This video is also available on the TMJA's website home page as a tool to help bring about more awareness of Temporomandibular Disorders.
- **TMD Patient Stories**  
*A series of stories from readers who are willing to share TMD experiences with our readers*
- **TMD and Sexual Intimacy**  
An inherent problem experienced by people with TMJ pain and dysfunction is the effect the illness has on the sex lives of both the patient and the partner.
- **Social Security Disability Benefits and Temporomandibular Disorders**  
Those who suffer from TMD may find it impossible to maintain the responsibilities associated with full-time work activity. Fortunately, in some cases, Social

Security Disability benefits can help alleviate some of the financial strain associated with this condition.

- **Understanding Medical Research**

Sometimes one study seems to disagree with the results of another study. It's important to be critical when reading or listening to reports of new medical findings.

- **New TMJA Educational Brochure: A Resource Guide for Temporomandibular Disorders**

This brochure is a straightforward, easy-to-read guide for patients making health care decisions.

- **NIH Primer's for Women's Health: Learn About Your Body in 52 Weeks**

The National Institutes of Health's Office of Research on Women's Health has developed a tool to promote healthy lifestyles by offering practical guidelines and strategies women can use every day to reduce the risk of developing illnesses or conditions affecting quality of life.

- **A Nation in Pain: America's Hidden Epidemic**

Judy Foreman, an award winning journalist and a former nationally syndicated health columnist, documents her struggle with chronic neck pain and the experience she had going from doctor to doctor seek relief in her article, *A Nation in Pain: Healing Our Biggest Health Problem*.

- **Cobalt Poisoning and Metal-on-Metal Implants**

Doctors reported case studies of patients with severe heart failure who had metal-on-metal hip implants. FDA approved a TMJ implant device that is metal-on-metal and still on the market.

- **Who Owns YOUR TMJ Implant?**

A number of TMJ implant patients who were having their implants removed reported that they were told by their surgeon that the devices **MUST** be returned to the manufacturer. The TMJA forwarded this information to the Senate Health, Education, Labor and Pensions Committee for clarification and the FDA response.

- **Is Botox Safe and Effective for TMD?**

As TMJ patients search for alternative treatments to manage their pain, a doctor may have suggested the possibility of trying Botox injections directly into the chewing (masseter and temporalis) muscles to relax these muscles.

- **It's Tick Season!**

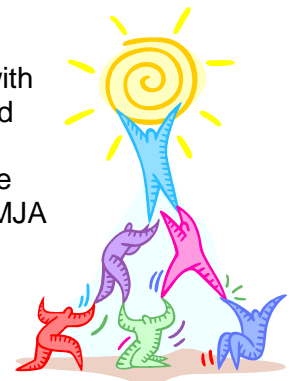
Many symptoms of Lyme disease are similar to Temporomandibular Disorders (TMD) so a misdiagnosis may occur.

- **DePuy Synthes Craniomaxillofacial Distraction System**

DePuy Synthes recalled certain lots of the Craniomaxillofacial Distraction System, because the device may reverse direction and lose the desired distraction distance after surgery.

- **Provides a Support & Guidance**

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. Facebook, Twitter, and LinkedIn accounts where the TMJA can share urgent news as well as provide for the sharing of personal experiences.



## *...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 attended PAINS annual meeting in Washington D.C., January 26-28, 2014
- Terrie Cowley was a participant in the NIH Overlapping Pain Conditions, IPRCC Meeting, February 4, 2014 in Bethesda, MD
- Terrie Cowley attended the American Pain Society Annual Scientific Meeting, April 30, 2014, Tampa, FL.
- Terrie Cowley participated in the meeting at the American Association for the Advancement of Science, *What Evidence is Essential for New Medical Products. Implications for Patients and Health Policy*, Washington, D.C., June 13, 2014
- The Seventh Scientific Meeting of The TMJ Association, *Genetic, Epigenetic, and Mechanistic Studies of Temporomandibular Disorders and Overlapping Pain Conditions.*, September 7-9, 2014, in Bethesda, MD.
- Terrie Cowley was a participant in the NIH Overlapping Pain Conditions, IPRCC Meeting, September 24, 2014 in Bethesda, MD
- Dr. Robert Bilkovsky gave a presentation on TMD at the Eastern Pain Society in New York, NY, October 25, 2014
- Terrie Cowley participated as a patient advocate at the Cough Panel Meeting at CHEST 2014, Dallas, TX October 27, 2014

**Statement of Activities and Changes in Net Assets  
For the Year Ended December 31, 2014**

**Summary of Revenue & Support**

Contributions	\$70,484
Grants	48,443
Scientific Meeting	19,640
Dividend and interest	322
Other	163
<b>Total revenue and support</b>	<b>\$139,052</b>

**Summary of Expenses**

Program	\$106,093
Administrative	7,694
Fundraising & Related Expenses	4,869
<b>Total expenses</b>	<b>\$118,656</b>
Change in net assets	20,396
Net assets, beginning of year	279,005
<b>Net assets, end of year</b>	<b>\$299,401</b>

*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.*