

# The TMJ Association's 2012 Annual Report



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

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

2012 witnessed the continuation of the paradigm shift in the scientific community, which now views TMD as one of a family of disorders that can co-occur and interact with other painful conditions in the body. It is not just a matter of teeth and/or jaw problems. Today, scientists are conducting an increasing number of research studies and sharing their findings, and in turn, generating more attention and greater interest among other scientists.

Note: The format and content of this year's annual report is changed to emphasize the TMJ Association's roles and how efforts and achievements aligned with those roles over the year.



## ***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 as follows: foster scientific research, advocate for TMD patients, serve as a resource and provide a support network, and promote the organization and its mission.

### ***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 the world. 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.

### ***Promote the Organization and Its Mission***

Through greater recognition, the TMJA is better able to present its agenda to the public, elected officials, policymakers, government agencies, and the research and health care communities.

Sincerely,

A handwritten signature in cursive script that reads "Terrie Cowley". The signature is written in dark ink and is positioned below the typed name "Terrie Cowley".

## 2012 Achievements

### *...in Fostering Scientific Research*

- **NIH Workshop on 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. The goals of the workshop were to:

- Determine the state of science in chronic overlapping pain conditions.
- Develop a coordinated research strategy.
- Improve and develop new strategies to identify risk factors and outcome measures.

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).



The workshop, held in August 2012, concluded with the following major recommendations to:

- Create standardized terminology and definitions for chronic overlapping pain conditions to ensure a common language.
- Coordinate clinical research right from the start so what is being studied in the laboratory setting is applicable to the clinical population and vice versa.
- Design long-term studies to understand how overlapping pain conditions develop and persist.

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

William Maixner, D.D. S., Ph.D., Director of the Regional Center for Neurosensory Disorders, and also a member of the Scientific Advisory Board of the TMJA, completed the first stage of a clinical study titled “Orofacial Pain: Prospective Evaluation and Risk Assessment” (OPPERA). OPPERA explores risk factors for the development of temporomandibular disorders and the relationship between TMD and other chronic pain conditions. The study aims to provide doctors, researchers and patients with valuable information about the causes of TMD and identify new treatments. The study follows patients for a period of three to five years. The research team has made impressive progress, and the TMJA will continue to support their important research.

- **New Engineering Initiative at Cornell University**

The TMJA entered into an agreement with Jonathan Black, Ph.D., FBSE, Cornell University, to provide advice and support on a new education and research program focusing on developing engineering strategies to restore function to diseased or damaged temporomandibular (TM) joints. Several design projects are underway with the goal that good ideas become the bases for new business ventures.

## *...in Fostering Scientific Research (Continued)*

- **TMJ Bioengineering Conference Validates the TMJA's Position**

Kyriacos Athanasiou, Ph.D., P.E., a member of the TMJA Scientific Advisory Board, was one of the organizers of a conference whose goals were to:

- Advance the field of TMJ research.
- Review current therapies.
- Assess the progress of TMD research.

Presentation topics included surgical approaches to restore joint function and the role of stem cells and tissue engineering in developing therapies. The results of the conference validate the TMJA's long-held position on the need for additional research and funding in the field of bioengineering.

- **The TMJA Ranks as Finalist in Sanofi US Challenge**

The TMJA, in conjunction with two other Chronic Pain Research Alliance (CPRA) members, submitted a research proposal to a competition sponsored by the international pharmaceutical firm, Sanofi. The CPRA group was one of four finalists among 280 participating organizations in the Collaborate/Activate Innovation Challenge designed to encourage ideas that foster collaboration among health care groups in an effort to spur innovation. Though the CPRA group did not win the competition, the experience was invaluable in making contacts with other organizations and publicizing the mission and goals of the TMJA.



## *...in Advocating for TMD Patients*

- **First Collaborative NIH Workshop on TM Joint to be Held in May 2013**  
For many years, the TMJA has pressed the Directors of three National Institutes of Health – the Arthritis and Musculoskeletal and Skin Diseases, Biomedical Imaging and Bioengineering, and Dental and Craniofacial Research – to combine their intellectual and scientific resources toward a greater understanding of the TM joint. In May 2013, representatives from the three institutes along with multidisciplinary scientists will meet for the first time to assess the state of science of the TM joint and identify research priorities.
- **FDA-Sponsored, Patient-Focused Drug Development Initiative**  
The TMJA requested the FDA to include TMD on its list of 20 disease areas needing research and the development of treatment options. An appearance on this list will showcase the need for research and garner the attention of drug companies.
- **CPRA Catalyst for U.S. Senate Hearing on Chronic Pain**  
The Chronic Pain Research Alliance (CPRA) was the catalyst for the Senate hearing on pain on February 14, 2012. A founding member of CPRA presented testimony on the need for pain research. The TMJA, also a founding CPRA member, was represented by the President, Terrie Cowley; Association Administrator, Deanne Clare; and Scientific Advisors. The TMJ Association also submitted a statement on behalf of the TMJA.
- **The TMJA Keeps U.S. Congress Aware of TMJ 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 cause 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.



## *...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 2012 included:

- Work to develop a replacement for the TM disc using tissue composed of extracellular matrix material tissue.
- Development of tissue-engineered replacements for components of the TM joint.
- The role of female hormones in TMD.
- The use of stem cells to grow grafts of bone in the shape of the TM joint.
- The role of genetics in development of TMJ.
- Intensity of chronic orofacial pain compared to headaches and backaches.
- Smoking and allergies associated with TMD.
- Altered brain anatomy and dizziness associated with TMD.
- Immunity-suppressing drugs that can help relieve pain.

- **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 and Twitter 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 2012, topics included:

- Safety alerts regarding Celexa, topical pain relievers and magnesium supplements.
- The similarity in symptoms between TMD and Lyme disease.
- The accessibility of MedWatch, an online service that can be utilized to report adverse affects of TMJ devices.
- How pets can be good medicine for people living with pain.
- Clinical trial opportunities for TMD patients.
- Tips to avoid medical problems and errors.

## *...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 at Major Events**

Terrie Cowley, Co-founder and President, represented the TMJA at several 2012 events. Accomplishments included:

- Receiving the 2011 Outstanding Public Advocacy Award from the Friends of NIDCR (National Institute of Dental and Craniofacial Research) in January 2012.
- Selection to serve on the new Interagency Pain Research Coordinating Committee (IPRCC), a federal advisory committee created by the Department of Health and Human Services (HHS) to enhance pain research efforts and promote collaboration across the government with the ultimate goals of advancing fundamental understanding of pain and improving pain-related treatment strategies.
- Serving as a panel member for design teams of students at Cornell University who, under the direction of Jonathan Black, Ph.D., FBSE, were addressing issues associated with the restoration of function and management of pain in the TM joint.
- Participating as a member of the Chronic Pain Research Alliance (CPRA) charged with the mission to see that research is directed to the conditions that overlap with TMD.
- Attending the University of North Carolina School of Dentistry Symposium on the OPERA study.
- Moderating a panel at the Conference on Medical Device Safety featuring FDA spokespersons.
- Attending meetings of the NIH Pain Consortium and FDA Assessment of Analgesic Treatment of Chronic Pain.
- Serving as a panel member at the Annual Meeting of the Consumers United for Evidence-based Healthcare (CUE).
- Appearing in a video by the American Society of Anesthesiologists (ASA) on the self-management of pain.
- Serving as a Patient Advocate for the 2014–2019 NIDCR Strategic Planning Session.
- Presenting a paper on the Patient's Perspective at the European Academy of Craniomandibular Disorders (EACD) Meeting in Paris, France.

**Statement of Activities and Changes in Net Assets  
For the Year Ended December 31, 2012**

**Summary of Revenue & Support**

Contributions	\$66,651
Grants	30,000
Scientific Meeting	10,553
Special event	0
Dividend and interest	898
Unrealized gain on investment	2,316
Realized (loss) on investment	(2,355)
Other	155
<b>Total revenue and support</b>	<b>\$108,218</b>

**Summary of Expenses**

Program	\$75,961
Administrative	6,289
Fundraising & Related Expenses	4,769
<b>Total expenses</b>	<b>\$87,019</b>
Change in net assets	21,199
Net assets, beginning of year	217,597
<b>Net assets, end of year</b>	<b>\$238,796</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.*