

The TMJ Association, Ltd.
2016 Annual Report



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

Message from the President & Co-Founder

We are grateful for your moral and financial support which has enabled several impressive accomplishments in 2016.

TMJ Roundtable. In June, TMJA, in collaboration with the U.S. Food and Drug Administration, led the first-ever Roundtable on TMJ implants. Stakeholder groups representing manufacturers, health care providers, patients and others, engaged in lively discussions, shared challenges, and committed to working collaboratively to rebuild trust and improve the care of TMD patients. Since the June event, several work groups have been formed to implement the goals of this project, which include generating scientific evidence to guide clinicians in determining which treatments are safe and appropriate for different subgroups of TMD patients. They will also develop treatment outcome measures that patients deem meaningful and useful.



Eighth Scientific Meeting. In September, TMJA, with components of the National Institutes of Health, held its Eighth Scientific Meeting, *How Can Precision Medicine Be Applied to Temporomandibular Disorders and its Comorbidities? The goal was to explore how scientific advances in precision medicine can inform TMD treatment* so that it aligns with the unique characteristics of each patient in terms of genetic, environmental, behavioral and other factors. The meeting's recommendations and summary will be included in the Association's *TMJ Science* journal in early 2017.

Chronic Pain Research Alliance (CPRA) Initiative. Because TMD patients frequently suffer from other pain conditions, such as migraines, fibromyalgia or irritable bowel syndrome, TMJA worked collaboratively to establish CPRA, with the intent of advancing scientific, educational and clinical efforts on chronic overlapping pain conditions (COPCs). Toward that end, CPRA launched a new publication, *COPCs Research Advances*, which contains summaries of research articles on COPCs that have appeared in the scientific literature to update the scientific community on the latest findings. CPRA goals for 2017 include securing funding for a continuing medical education program for primary care providers on the diagnosis and treatment of COPCs and establishing startup funding to support future research on COPCs.

In 2017, we will continue our advocacy, information dissemination, patient support and education efforts on TMD and its coexisting conditions.

With deepest gratitude,

A handwritten signature in cursive script that reads "Terrie Cowley".

Terrie Cowley
President & Co-founder

2016 Achievements

...in Fostering Scientific Research

- The TMJ Association led the first-ever RoundTable, working with the FDA, bringing together all stakeholders concerned with TMJ implants
- The TMJ Association sponsored its 8th scientific meeting focused on how precision medicine can improve the treatment of TMD and the associated comorbid conditions.
- **NIH Funding Announcements**
 - Tailoring dental treatment for individuals with systemic diseases that compromise oral health (R01) PAR-16-154 and (R21) PAR-16-153, National Institute of Dental and Craniofacial Research
 - Multidisciplinary research in vulvodynia (R21) (PA-16-100) and (R03) (PA-16-101), Eunice Kennedy Shriver National Institute of Child Health and Human Development
 - Development multidisciplinary research in vulvodynia (R01) (PA-16-102), Eunice Kennedy Shriver National Institute of Child Health and Human Development
 - Establishment of resource centers for dental, oral and craniofacial tissue regeneration consortium (U24) RFA-DE-17-001, Administrative Supplements for Research
 - Administrative supplements for research on sleep disturbances and impact on chronic pain (NOT-NS-16-020) PA-16-164
 - Increasing the varieties of marijuana and marijuana products for research (NOT-DA-16-034)
 - Factors underlying differences in female and male presentation for dental, oral and craniofacial diseases and conditions (RO1)(R21)
 - Small research grant for secondary analysis of FaceBase Data (R03), National Institute of Dental and Craniofacial Research
 - Implementation science research to improve dental, oral and craniofacial health (U01)
 - Stimulating peripheral activity to relieve conditions (SPARC): pre-clinical development of existing market-approved devices to support new market indications (U18)

...in Advocating for TMD Patients

- The TMJ Association's advocacy work has resulted in Senate report language for 2017 for temporomandibular disorders and chronic overlapping pain conditions.
- *Painful Truth about Opioid Abuse*, a blog post published in the Capitol Hill newspaper, *The Hill*, February 2016.
- Participated in Friends of the National Institute of Dental and Craniofacial Research Advocacy Day event on Capitol Hill, February 2016.
- Over the course of the year, The TMJ Association impressed upon federal representatives the need for increased scientific research.

...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 2016 included:

- Risk factors for chronic facial pains. Investigating the role of increased levels of the pro-inflammatory proteins Calcitonin Gene-Related Peptide (CGRP) and Protein Kinase A (PKA) in a model of TMD.
- Steroids may ease jaw pain in juvenile idiopathic arthritis, but not totally and not for everyone.
- CGRP antibodies for migraine? Drug companies think so.
- Blocking a stress-related gene relieves chronic pain.
- Unclear results of botulinum toxin therapy for TMD pain.
- Scientific news: Sleep and TMD.
- National Pain Study released.
- Multimodal assessment of body pain in orofacial pain patients.
- TMD is a complex disease.
- How accurate are dental websites when it comes to TMD?
- How does a parent's chronic pain affect children?
- Emerging research on orofacial pain.
- Painful TMD: Decade of Discovery from OPPERA Studies.
- Should the FDA rush approvals when patients demand it?
- Genes associated with risk for fibromyalgia found.
- Estrogen plunge before menstruation linked to migraine.
- Dopamine in plasma: a biomarker for myofascial TMD pain?
- Bioengineers grow living bone for facial reconstruction.
- Smoking marijuana provides more pain relief for men than women.
- Are TMD patients more pain sensitive? Maybe. But it's complicated.
- From functional pains to central sensitivity syndromes.

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

The TMJA publishes on educational topics that provide patients with guidance and support. The following topics were addressed in our newsletter and website in 2016:

- The neuroscience of pain, a free webinar on translating science to the patient on BrainFacts.org.
- TMJ Nutrition guide, *TMD Nutrition and You*, developed for those with compromised oral function to help them maintain a healthy diet in spite of their oral disability.
- Dental Care Guide, *Temporomandibular Disorders, Dental Care and You*, developed to provide patients with oral hygiene self-care tips, as well as suggestions for future dental appointments.
- *TMJ Science*, which includes the summary and recommendations from our 7th scientific meeting--*Genetic, Epigenetic, and Mechanistic Studies of Temporomandibular Disorders and Overlapping Pain Conditions*.

- A white paper on Chronic Overlapping Pain Conditions, *Impact of Chronic Overlapping Pain Conditions on Public Health and the Urgent Need for Safe and Effective Treatment – 2015 Analysis and Policy Recommendations*.
 - Cutting Edge - Chronic Overlapping Pain Conditions Research Advances, e-newsletter.
 - Taking Control: Learn more about accessing your health information by Dr. Francis Collins, NIH Director.
 - New FDA safety warnings added to prescription opioid drugs.
 - Clinical study opportunity in New York and Los Angeles for TMJ pain
 - TMJ patients needed for research study in Baltimore, MD: Biobehavioral pain management in TMD.
 - Clinical study: Genetics of facial, jaw and headache pain.
 - Implementation of the National Pain Strategy petition.
 - United States Bone and Joint Initiative, Career development & grant mentoring program call for applications.
 - Postdoc fellow and junior faculty funding opportunity.
 - NSAIDS, acetaminophen potential dangers often go unrecognized.
 - Gut check: Know your medicines.
 - National prescription drug take-back day.
 - IBS awareness.
 - Scientists figure out how NSAIDs can harm the heart.
 - MedWatch mobile app.
 - FDA safety alert: Over-the-Counter antacid products containing aspirin.
 - FDA safety alert: Migraine patch risk of burns and scars.
 - FDA safety alert: Lopermaide/Imodium.
 - Avoid a TMD misdiagnosis: watch out for Lyme disease.
 - FDA Safety alert: Opioid pain or cough medicines combined with benzodiazepines.
 - Acetaminophen safety awareness.
 - Antidepressants: rise in off-label prescriptions.
 - Musculoskeletal inflammation and natural products.
 - TMJA survey results: here is what you told us.
- **Provides 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, YouTube, 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 presence of the TMJA staff, in addition to the involvement of the Scientific Advisory Board members, increases awareness of the needs of TMD patients and creates opportunities to draw attention to the need for more research and funding.

- **Representation**

- Friends of National Institute of Dental and Craniofacial Research Advocacy Day, February 23, 2016, Washington, DC; attended by Terrie Cowley and Deanne Clare.
- Patient-Centered Outcomes Research Institute stakeholder workshop, March 7, 2016, Washington, DC; attended by Terrie Cowley and Christin Veasley.
- MDEpiNet TMJ Patient RoundTable at FDA campus, June 16, 2016, Silver Spring MD; attended by TMJA staff and several board members.
- Eighth Scientific Meeting of The TMJ Association, Sept. 11-13, 2016, Bethesda, MD; attended by TMJA staff and several board members.

2016 Contributors

\$1-\$49

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Mary and Len Boczkowski
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David Wood – *in honor of Alexandra Reardon*
Hai Yao

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William Maixner
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Quotient
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\$5,000+

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American Association for Dental Research
Sheila Moore
National Institutes of Health/National Institute of Dental and Craniofacial Research
Purdue Pharma, L.P.

United Way/Combined Federal Campaign

(exact amount donated unknown)
Amber Mann
Lena Najarian

**Statement of Activities and Changes in Net Assets
For the Year Ended December 31, 2016**

Summary of Revenue & Support

Contributions	\$93,986
Grants	20,000
Scientific Meeting	45,377
Dividend and interest	540
Other	175
Total revenue and support	\$160,078

Summary of Expenses

Program	\$132,029
Administrative	9,090
Fundraising & Related Expenses	5,574
Total expenses	\$ 146,693
Change in net assets	13,385
Net assets, beginning of year	268,576
Net assets, end of year	\$281,961

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.