

**The TMJ Association, Ltd.**

**2018 Annual Report**



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

## *Message from Our President...*

Looking back over the years and reviewing the progress made in the TMJ area, it is clear that every major step forward was the result of the advocacy efforts of The TMJ Association and science brought by our scientific meetings. The first important accomplishment was triggering the 1992 congressional investigation of TMJ implants and the most recent the National Academy of Medicine study on Temporomandibular Disorders which recently started. Our efforts have resulted in a paradigm shift moving the condition from one of teeth and jaws to a complex multisystem disorder with comorbidities and is influenced by genetic and environmental factors. TMD now demonstrates a paradigm shift towards multidisciplinary research and treatment.

The NAM study will have a major impact because it will analyze *every* aspect of what is happening to TMJ patients—from determining how many people are affected by TMD, to evaluating insurance reimbursement practices and patient out-of-pocket expenses, to identifying new research discoveries as well as major gaps that need to be addressed, to assessing the safety and effectiveness of TMD treatments, to understanding how health care professionals are educated about TMD, and much more.

Importantly, NAM will also examine the evidence-base for defining chronic TMD as a complex multi-system medical disorder that necessitates multidisciplinary research and interventions. We look forward to the NAM study and will keep you informed, as your help will be invaluable to this project.

We continue our advocacy and support, keeping patients and the public informed of progress in the field along with our other major project, The TMJ Patient-Led RoundTable.

Sincerely,

Terrie Cowley  
President & Co-Founder

## 2018 Achievements

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

- The TMJ Association continues to lead the first-ever TMJ Patient RoundTable project, working with the FDA, bringing together all stakeholders concerned with not only TMJ implants, but all therapies. TMJ patients are members of the steering committee, the working groups and are also co-chairs of the working groups. The project began in 2016 and will continue its work in the coming years.
- **NIH Funding Announcements**
  - Research on Chronic Overlapping Pain Conditions (R01)(R21)
  - (Analytical and/or Clinical Validation of a Candidate Biomarker for Pain (R61/R33)
  - Discover and Validation of Novel Targets for Safe and Effective Pain Treatment (R01)(R21)
  - HEAL Initiative: Translational Development of Devices to Treat Pain (U18)
  - HEAL Initiative: Translational Devices to Treat Pain (UG3/UH3)
  - HEAL Initiative Translational Devices to Treat Pain (U44I)
  - HEAL Initiative: Clinical Devices to Treat Pain (UH3)
  - HEAL Initiative: Stimulating Peripheral Activity to Relieve Conditions (SPARC):
    - Anatomical and Functional Mapping of Pain-Related Visceral Organ Neural Circuitry (U01)
    - Promoting Research on Music and Health: Fundamentals and Applications (R01) (R21)
    - Mechanisms, Models, Measurement, and Management in Pain Research (R01) (R21)
    - Global Brain and Nervous System Disorders Research Across the Lifespan (R21)
    - Specialized Centers of Research Excellence (SCORE) on Sex Differences (U54)
    - Research on the Health of Women of Understudied, Underrepresented and Underreported (U3) Populations An ORWH FY18 Administrative Supplement
    - Clinical Validation of Candidate Biomarkers for Neurological Diseases (U01)
    - Factors Underlying Differences in Female and Male Presentation for Dental, Oral, and Craniofacial Diseases and Conditions (RO1) (R21)
    - NIDCR Small Research Grants for Secondary Analysis of FaceBase Data (RO3)
    - Tailoring Dental Treatment for Individuals with Systemic Diseases that Compromise Oral Health (R01) (R21)
    - Personalized Strategies to Manage Symptoms of Chronic Illness (R15) (R01) (R21)
    - Research on the Mechanisms and/or Behavioral Outcomes of Multisensory Processing (R01)
    - MAPP Network Basic/Translational Science Blueprint Neurotherapeutics Network (BPN): Small Molecule Drug Discovery and Development for Disorders of the Nervous System (UH2/UH3) (U44)

- Building Genetics and Genomic Knowledge about Dental, Oral, and Craniofacial Diseases/Disorders (RO1)
- Population Health Interventions: Integrating Individual and Group Level Evidence (R01)
- Family-Centered Self-Management of Chronic Conditions (R21) (R01)
- mHealth Tools for Individuals with Chronic Conditions to Promote Effective
- Patient-Provider Communication, Adherence to Treatment and Self-Management (R01) (R21)
- The Biomarkers Consortium
- Notice of National Institute of Neurological Disorders and Stroke (NINDS) and National Institute on Drug Abuse (NIDA) Interest in Blueprint Neurotherapeutic Network Applications Directed at Small Molecule Non-Addictive Pain Therapies
- **Patient Clinical Study Opportunities**
  - *All of Us* Research Program
  - Comparative Study of Women Considering or Currently Receiving Botox Injections for TMJ Pain
  - Young investigators seeking research funding urged to apply for USBJI Career Development and Grant Mentoring Program
  - Digital Signals in Chronic Pain Study Seeks Participants

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

- *Cutting Edge – COPCs Research Advances* is an electronic newsletter published by the Chronic Pain Research Alliance, an initiative of the TMJ Association. It was developed to keep the medical-scientific community abreast of recent research advances.
- On February 26, 2018, TMJA staff and others participated in the Friends of the National Institute of Dental and Craniofacial Research (NIDCR) American Association of Dental Research Advocacy Day on Capitol Hill.
- TMJA advocacy work resulted in a donation from John Lucas, owner of Face Caddy, of 10 free face caddy wraps to be given to TMA patients, plus a discount for those who go to the website to purchase a caddy for themselves or a loved one.
- 2018 NIH Report Language – for over 25 years the TMJA's advocacy efforts have resulted in congressional report language in which funding committees communicate to federal agencies, such as the National Institutes of Health, that our elected officials are concerned about the plight of TMD patients and propose initiatives needed to improve their health care and lives.

### *...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 2018 included:
  - Hyperreactive Brain Networks May Be Cause of Chronic Pain in Fibromyalgia, Study Suggests
  - Dry Eye Linked to Chronic Overlapping Pain in Veteran Population

- Pain in Your Head Hurts More Than Elsewhere in the Body
- Stem Cells Study of Jaw Development Could Offer Insight Into Craniofacial Flaws
- TMD and Burning Mouth Syndrome
- Study Links Lack of Sleep to Pain Sensitivity
- Centralized Pain in TMD: Is it All in the Head?
- Tissue-engineering Advance Grows Superior Cartilage for Joint Repairs
- Prevalence of TMD in Sjogren Syndrome Patients
- Early Molecular Response and Microanatomical Changes in the Masseter Muscle and Mandibular Head After Botulinum Toxin Intervention in Adult Mice
- Sustained and Repeated Mouth Opening Leads to Development of Painful Temporomandibular Disorders Involving Macrophage/Microglia Activation in Mice
- The Scoop on TMD Pharmaceuticals
- Future NIH Research Initiative on TMD: 218<sup>th</sup> NIDCR Council Meeting
- NIH Study Explains Why Opioid Therapy May Not Always Work Well for Chronic Pain
- Patients Front and Center at the 2018 TMJ Patient-Led RoundTable
- Brain Fog
- TMJ Researcher Spotlight: Yong Chen, Ph.D.
- Changes of TM Joint in Patients With and Without TMD Complaints
- Tissue Engineering the TM Joint
- A Small Cause of Big Pain
- Fibromyalgia and TMD: What's the Connection Between these Painful Conditions?
- Long-term Changes in Biopsychosocial Characteristics Related to TMD: Findings from the OPPERA study
- Researchers Uncover Link Between Migraines and Cochlear Disorders
- Relationships Between Temporomandibular Disorders, MSD Conditions, and Mental Health Comorbidities: Findings from the Veterans Musculoskeletal Disorders Cohort
- National Academy of Medicine to Conduct a Study on Temporomandibular Disorders
- TMJA Provides Patient Perspectives on TMJ Implants
- Dentists in Distress
- Systemic Disease and Other Painful Conditions in Patients with TMD and Migraine
- TMJ Patients Needed for an Important Study on Botox Treatments
- Identifying and Prioritizing Patient-Centered Outcomes for Comparative Effectiveness Research

- **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 2018:

- 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 8th scientific meeting—*How Can Precision Medicine be Applied to Temporomandibular Disorders and its Co-Morbidities?*
- A whitepaper 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.
- *Your Guide for Temporomandibular Disorders* – a brochure written by the TMJA is a straightforward, easy-to-read booklet that guides patients in making health care decisions.
- *TMJ Disorders* – a brochure distributed by the National Institute of Dental and Craniofacial Research in partnership with the Office of Research on Women's Health.
- *TMD Nutrition and You*, designed to help those with compromised oral function to maintain healthy nutrition despite their oral disability.
- *Temporomandibular Disorders, Dental Care and You* – a guide developed by the TMJA to provide patients with oral hygiene self-care tips that can be done at home, along with suggestions for future dental appointments.
- *Know the Science About Drug-Supplement Interactions*
- *TMJ Patient Featured in U.S. News & World Report Article*
- *Beware of Ticks and Lyme Disease*
- *Francis Collins: We Can't Forget the People with Chronic Pain in Fight Against Opioid Abuse*
- *Opportunity to Voice Your Opinion: U.S. Government Officials Want To Hear from Patients with Pain*
- *FDA Approved Devices and the Patient Perspective: A Netflix Documentary*
- *TMJ Tips for the Holidays*
- *Healing After Harm: Addressing the Emotional Toll of Harmful Medical Events*

- **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. Inspire, Facebook, Twitter, YouTube, and LinkedIn accounts, where the



TMJA can share urgent news, as well as provide for the sharing of personal experiences.

The TMJA partnered with *Inspire* and together are providing TMJ patients with a free, anonymous, online support network discussion community. Over 500 patients joined TMJ Café in 2018.

### *...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**

- MDEpiNet TMJ Patient-Led RoundTable Meeting, May 11, 2018
- Medical Devices Patient Engagement in Real World Evidence: Lessons Learned and Best Practices, Baltimore, MD September 12, 2018, presentation by Terrie Cowley and attended by Deanne Clare
- Consumers United for Evidence-based Healthcare Annual Membership Meeting, July 13, 2018 attended by Terrie Cowley
- MDEpiNet Annual Meeting, October 23-34, 2018, Silver Spring, MD; presentation by Terrie Cowley

## 2018 Contributors

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**Statement of Activities and Changes in Net Assets  
For the Year Ended December 31, 2018**

**Summary of Revenue & Support**

Contributions	\$78,408
Grants	0
Scientific Meeting	0
Dividend and interest	1476
Other	4078
<b>Total revenue and support</b>	<b>\$83,962</b>

**Summary of Expenses**

Program	\$102,463
Administrative	9,241
Fundraising & Related Expenses	5,538
<b>Total expenses</b>	<b>\$117,242</b>
Change in net assets	(33,280)
Net assets, beginning of year	270,087
<b>Net assets, end of year</b>	<b>\$236,807</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.*