

The TMJ Association, Ltd.

2019 Annual Report



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

Message from Our President...

When we began The TMJ Association (TMJA) over 30 years ago, scientific understanding of Temporomandibular Disorders (TMD) was limited in scope. Many thought TMD was simply an isolated problem of the teeth and jaws. Today, we understand that TMD represents a highly complex family of disorders that involve the nervous, immune and endocrine systems and are affected by one's genetic makeup, the environment and a host of other factors. We also know TMD patients are more likely to suffer from other painful conditions, such as chronic headache, irritable bowel syndrome and fibromyalgia, as well as non-painful conditions, including sleep disorders, mitral valve prolapse, connective tissue disorders, and hearing loss. Research has shifted from looking for clues in the end organs where pain is experienced—the jaw, head, intestine—to the nervous system where pain is processed, to understand how and why selected nerve centers and pathways become hypersensitive to pain. This shift informs how research will be conducted, as well as how TMD should be treated.

In response, The TMJ Association has worked collaboratively to establish the Chronic Pain Research Alliance to advocate for the scientific, educational and treatment needs of TMD patients who experience other painful and non-painful conditions. This year, we participated in the National Academy of Medicine's (NAM) Study on Temporomandibular Disorders public meetings. Also, we continue to work to address concerns about TMJ implants, by working collaboratively with many stakeholders through the MDEpiNet TMJ Patient-Led RoundTable. The aim of the RoundTable is to generate the scientific evidence to determine which treatments, implants or otherwise, are safe and appropriate for different subgroups of TMD patients. Both the RoundTable and CPRA initiatives put TMD patients front and center in the process, incorporating their input and feedback on what is most important to them.

As we move into 2020, with the release of the NAM report on TMD, we remain committed to advancing these and other initiatives to improve the health and quality of life of TMD patients. Our intent is to ensure that patients' voices are heard and play a central role in any measures aimed at improving how TMD is diagnosed and treated.

Sincerely,

Terrie Cowley
President & Co-Founder

2019 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 critical work.
- **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)
 - NIDCR Small Research Grants for Secondary Analysis of FaceBase Data (RO3)
 - NIDCR Small Research Grants for Data Analysis and Statistical Methodology Applied to Genome-wide Data (RO3)
 - NIDCR Administrative Supplement for Collaborative Science (Notice of Special Interest)
 - Notice of Special Interest of NIDCR in Supporting Discovery, Characterization, and Mechanistic Study of Genetic Variants Underlying Dental, Oral and Craniofacial Diseases and Conditions
 - Mechanisms Underlying the Contribution of Sleep Disturbances to Pain (R01)(R21)
 - Research on the Health of Women of Understudied, Underrepresented and Underreported (U3) Populations n ORWHFY19 Administrative Supplement
 - Tailoring Dental Treatment for Individuals with Systemic Diseases that Compromise Oral Health (R01) (R21)
 - Factors Underlying Differences in Female and Male Presentation for Dental, Oral, and Craniofacial Diseases and Conditions (R01)(R21)
 - Blueprint Neurotherapeutics Network (BPN): Small Molecule Drug Discovery and Development for Disorders of the Nervous System (UH2/UH3) (U44)

- 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
- Limited Competition: Dental, Oral and Craniofacial Tissue Regeneration Consortium (U24 Clinical Trial Not Allowed)
- Request for Information (RFI): Identification of Potentially High Value Biomarkers for Predicting Acute to Chronic Pain Transition and Resilience
- Achieving Tissue Robustness Through Harnessing Immune System Plasticity (R21)(R01)
- Clinical Validation of Candidate Biomarkers for Neurological Diseases (U01)
- Discover and Validation of Novel Targets for Safe and Effective Pain Treatment (R01)(R21)
- **Patient Clinical Study Opportunities**
 - *All of Us* Research Program
 - Career Development and Grant Mentoring Program
 - Digital Signals in Chronic Pain Study Seeks Participants
 - A research study on the effects of temporomandibular disorders on the diet of sufferers. A questionnaire, followed by a three day diet history.
 - Online survey study on Fibromyalgia, Chronic Migraine, Chronic Orofacial Pain, and TMD – the Pain Research Lab at Cincinnati Children’s Hospital Medical Center
 - University of Minnesota Study on Jaw Pain
 - University of Michigan Study of the Brain and TMD
 - University of North Carolina, Duke and University of Los Angeles Study on Chronic Vaginal Pain
 - University of California San Diego Study on Chronic Low Back Pain

Professional Educational Opportunities

- Young Investigator Initiative Grant Mentoring and Career Development Program
- New CME on Chronic Overlapping Pain Conditions

...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.
- 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.
- 2019 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.
- The following have resulted from the activities of the RoundTable Working Groups:
 - WhitePaper, *The TMJ Patient-Led RoundTable: A History and Summary of Work*
 - TMD Research Plan
 - TMD and Nutrition Summary
 - TMD Treatments: Review of Meta-Analyses & Systematic Review
 - Dental Education

...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 2019 included:
 - Predicting Pain that Persists: Clinical clues may foretell chronic temporomandibular disorder
 - Serotonin Linked to Somatic Awareness, A Condition Long Thought to be Imaginary: New research suggests serotonin could be involved in a condition where patients experience physical discomforts for which there is no physiological explanation
 - Researchers Grow Bone at Rib to Restore Facial Bone
 - Drug Induced Bruxism
- **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 2019:
 - The National Academy of Medicine (NAM) Study on Temporomandibular Disorders (TMD) is well underway. Everyone affected by TMD is strongly encouraged to write to the NAM committee, letting them know what it is like to live with TMD and experiences you've had with getting care.
 - 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.
- *Article on Dental Tribune: Self-care Treatments or Temporomandibular Disorders Most Beneficial, Study finds*
- *“Genetic Differences Contributing to TMD Susceptibility in Males”*, a summary of a new publication written by Dr. Shad Smith in the Department of Anesthesiology, Center for Translational Pain Medicine, Duke University, Durham, North Carolina
- You, Your Esophagus and TMD: Patients and Caregivers should be aware of the gastrointestinal implications for patients with TMD – and vice versa
- Press Release: University of California, Irvine – UCI engineers aim to pioneer tissue-engineering approach to TMJ disorders. Solutions have been hampered by past failures, proximity of jaw joint to brain. Source article: Donahue, Ryan P., Hu, Jerry C., and Athanasiou, Kyriacos A. (2019) Remaining Hurdles for Tissue-Engineering the Temporomandibular Joint Disc. *Trends in Molecular Medicine.* 25(3), Pg.241-256.
- What does blood pressure have to do with chronic pain?, Sophia Stone, TMJA contributing author. Source: Herberito Suarez-Roca, Rebecca Y. Klinger, Jihai V. Podgoreanu, Ru-Rong Ji, Martin I. Sigurdsson, Nathan Waldron, Joseph P. Mathew, William Maixner; Contribution of Baroreceptor Function to Pain Perception and Pre-operative Outcomes. *Anesthesiology*, 2019; 130(4)
- Cervical Muscle Tenderness in Temporomandibular Disorders and Its Associations with Diagnosis, Disease-Related Outcomes, and Comorbid

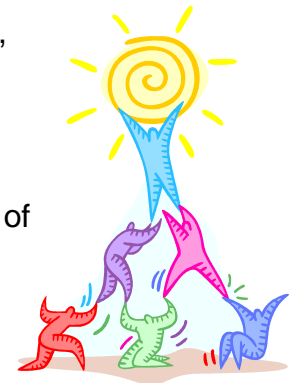
Pain Conditions: The evidence is mounting for the inclusion of medical disciplines into TMD diagnostics and treatment

- Fibromyalgia Linked to Gut Bacteria for the First Time: Article source: [McGill University Health Centre](#)
- Premorbid and Concurrent Predictors of TMD Onset and Persistence: TMD onset appears to represent the cumulative effect of multiple system dysregulation
- Brain Responses in CFS and TMD to Autonomic Challenges: An Exploratory fMRI Study
- General Medical Practitioners' Knowledge of Assessment and Management of TMD in the UK: Respondent GMPs demonstrated limited knowledge of TMD and most lacked confidence in contemporary management
- A Functional Substitution in the L-aromatic Amino Acid Decarboxylase Enzyme Worsens Somatic Symptoms via a Serotonergic Pathway

- **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 1,700 patients have joined TMJ Café.



...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**

- National Academy of Medicine Study on Temporomandibular Disorders: From Research Discoveries to Clinical Treatment, January 29, 2019
- National Academy of Sciences, Washington, D.C. Presentation by Terrie Cowley
- National Academy of Medicine, second meeting focused on TMD, March 28-29. Presentation by Dr. Allen Cowley, attended by Terrie Cowley and patients from the TMJA

- Transition from acute to chronic painful temporomandibular disorders: exploratory paths. Terrie Cowley participated in this workshop on June 27, 2019 in Quebec, Canada.
- Patient and Caregiver Connection Town Hall. On June 18, Dr. Jeffrey Shuren, the Center Director of the Food and Drug Administration Center for Devices and Radiological Health (CDRH) welcomed participating organizations (14) to introduce the new Patient and Caregiver Connection Pilot Program. The TMJA was represented by Deanne Clare, the TMJ Association's Administrator.
- 10th MDEpiNet Annual meeting, Addressing Challenges in National and Global Health Technology Research and Surveillance, October 21-23, 2019 in Silver Spring Maryland. Deanne Clare and Terrie Cowley attended and Terrie gave a presentation on behalf of the TMJ Patient-Led RoundTable project.

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**Statement of Activities and Changes in Net Assets
For the Year Ended December 31, 2019**

Summary of Revenue & Support

Contributions	\$63,801
Grants	0
Scientific Meeting	0
Dividend and interest	2,365
Other	64
Total revenue and support	\$66,230

Summary of Expenses

Program	\$97,955
Administrative	9,538
Fundraising & Related Expenses	6,530
Total expenses	\$114,023
Change in net assets	(47,793)
Net assets, beginning of year	236,807
Net assets, end of year	\$189,104

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.