

The TMJ Association, Ltd.

2021 Annual Report



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

A Message from Our President...

The past several years has been especially challenging, however our commitment to *changing the face of TMJ* remains strong. We serve patients like Jennifer.

“Like many patients who have chased after a cure for many years, I have undergone 18 jaw surgeries. I am so thankful for the work of The TMJ Association to raise awareness on Capitol Hill, at the NIH, FDA, and other government agencies. The community of patients constantly seeking verified information on the subject of TMJ, go to the TMJA for comprehensive and credible research updates. When I can’t speak because I am in too much pain or my jaw is literally wired shut, The TMJ Association is my voice. If The TMJ Association wasn’t fighting for us, who would?”- Jennifer

We continue to inform and educate health care professionals, policy makers, scientists, the public about the hard road tread by TMJ patients. In November, we joined IMD Health Global to extend our outreach to patients and medical professionals to provide TMJ resources via [our IMD TMJ platform](#).

We are also collaborating with government officials and TMJ stakeholders in developing the first Patient Powered TMJ registry to compile information about patients’ journeys from initial treatments to their current state. We are working with international scientists on several projects— all with TMJ patient leadership —,with the goal of improving patient care.

Sincerely,

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

Terrie Cowley
President & Co-Founder

TMJA pursues its mission essentially by

- **Serving TMJ Patients**
 - Being there for them, communicating, listening, educating
- **Educating Multiple Audiences**
 - Patients, health professionals, policy makers, scientists, the general public
- **Promoting Scientific Research**
 - Regularly meeting with funding agencies, creating data-gathering entities, holding scientific meetings



SEVERING TMJ PATIENTS

Providing Support & Guidance

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 website and publications, TMJA carries out its role through one-on-one telephone and email patient support. *Inspire*, *Facebook*, *Twitter*, *YouTube*, and *LinkedIn* accounts provide forums where the TMJA can share urgent news, as well as invite members to share personal experiences.

TMJA has partnered with *Inspire* to provide TMJ patients with a free, anonymous, online support network/discussion community. Over 3,000 patients have joined TMJ Café.



Inspire
together we're better™

TMJA
The TMJ Association, Ltd.

**“Sometimes a TMJ patient needs
inspiration just to
get through each day.”**

- The TMJ Association, Ltd.

Connect with others who understand in the
new TMJ Cafe Support Community

Visit TMJ.Inspire.com

In March 2021, the TMJA launched a new website, www.tmj.org, to replace one that was no longer user friendly, especially on mobile devices. Our intent was to continue providing the most comprehensive and credible information on temporomandibular disorders (TMJ) to anyone wanting to learn about this condition. Since the site’s launch, The TMJ Association’s monthly visitors have increased to over 20,000 a month, with respondents from 153 countries. A sample of the messages received from our website visitors:

“I just wanted to thank you for the information on your website regarding various TMJ treatments. I was better prepared for my appointment with a “TMJ specialist” as a result and was able to ask the right questions, which made me realize I needed to continue seeking opinions before deciding which route to take. Thank you for providing this resource to patients trying to figure out the best path for treatment. It’s much appreciated.” Jennifer

“I appreciate all the information, especially the links to studies that the website provides. Thank you for existing!” Chris

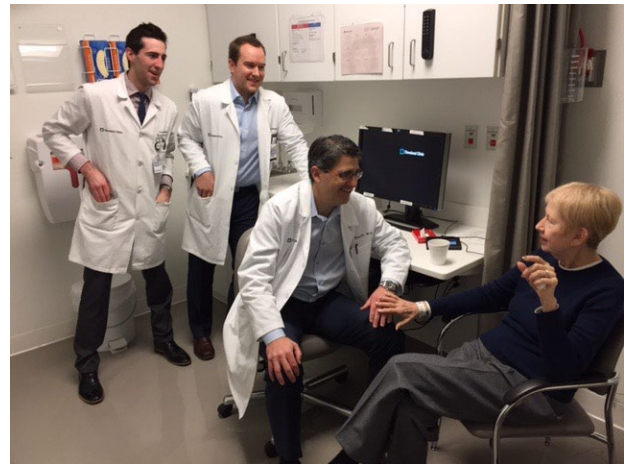
Listing Opportunities to Volunteer for Clinical Studies

- NIH *All of Us* Research Program
- On-line Research Survey Opportunity: Cannabinoid use for Chronic Pain: Understanding the Perspectives of Individuals with Chronic Pain

EDUCATING MULTIPLE AUDIENCES – PATIENTS, PROFESSIONALS & THE PUBLIC

Articles & Alerts to Readers of Concerns

- Transitioning to Chronic TMD Pain: A Combination of Patient Vulnerabilities and Iatrogenesis.
- Long-term evaluation of temporomandibular disorders in association with cytokine and autoantibody status in young women
- Parathyroid hormone attenuates osteoarthritis pain by remodeling subchondral bone in mice
- Do sex hormone imbalances contribute to idiopathic condylar resorption?
- Transcriptomes in peripheral blood of young females with temporomandibular joint osteoarthritis
- Proteomic expression profile in human temporomandibular joint dysfunction
- Temporomandibular Disorders and Dietary Changes: A Cross-sectional Survey
- Exploring mental health experience in individuals with temporomandibular joint pain
- Can Physical Therapies for Chronic Temporomandibular Disorders Cause the Wind-Up of Nociceptive Neurons in the Trigeminal Subnucleus Caudalis?
- Experimental Pain Sensitivity in Subjects with Temporomandibular Disorders and Multiple Other Chronic Pain Conditions: The OPPERA Prospective Cohort Study
- Self-reported symptoms of temporomandibular pain and jaw dysfunction in adolescents is associated with exposure to violence
- Quality of life in young and middle age adult temporomandibular disorders patients and asymptomatic subjects: A systematic review
- Frequency of Involvement of Different Head and Neck Sites in Referred Otalgia
- Animal Models of Temporomandibular Disorder
- Clinical, psychological, and sensory characteristics associated with headache attributed to temporomandibular disorder in people with chronic myogenous temporomandibular disorder and primary headaches
- Temporomandibular Disorders and Fibromyalgia: A Narrative Review
- Treating temporomandibular disorders in the 21st century: Can we finally eliminate the “third pathway”?
- Arthrocentesis of the temporomandibular joint: systematic review and clinical implications of research findings
- A preliminary analysis of the wear pathways of sliding contacts on temporomandibular joint total joint replacement prostheses
- Healthcare burden and associated adverse events from total alloplastic temporomandibular joint replacement: a national United States perspective



- Prosthetic temporomandibular joint reconstruction in a cohort of adolescent females with juvenile idiopathic arthritis
- Temporomandibular Disorders Slow Down the Regeneration Process of Masticatory Muscles: Transcriptomic Analysis
- Pain Management for Dental Medicine in 2021: Opioids, Coronavirus and Beyond
- “Catastrophizing: A Form of Pain Shaming” is from a blog post by Gwenn Hermann on the U.S. Pain Foundation website that we thought would resonate with TMJ patients.
- The “Problematic Patient”: What is the Problem? This article by Dr. Jens C. Turp at the Clinic for Oral Health & Medicine, University Center for Dentistry, Basel, Switzerland.
- The U.S. Food and Drug Administration (FDA) updated its information for patients and health care providers on TMD and TMJ Implants.

Professional Educational Opportunities

- New CME on Chronic Overlapping Pain Conditions

Promoting Scientific Research

- For over 25 years 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.
- TMJA encourages the National Institute of Dental and Cranial Research (NIDCR) to increase funding to expand the science base for the project: Tempo mandibular Disorders: From Research Discoveries to Clinical Treatment.
- Supports the creation of an NIH inter-institute TMD working group
- The TMJ Association continues to lead the first-ever TMJ Patient RoundTable project, working with the FDA, bringing together all stakeholders concerned not only with 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 continues its critical work.
- The RoundTable is developing a framework for the first-ever TMJ patient registry in collaboration with the FDA, other federal agencies and stakeholders. The goal of the registry is to establish a scientifically valid roadmap that can reliably predict treatment outcomes for individual patients.
- Other RoundTable projects include developing: Patient Reported Outcomes (PROs) for the TMJ registry using patient focus groups and Core Data Elements: a list of specific information collected from patients, health care providers, and electronic health records.
A New Treatment Model of Care for TMJ Patients
- *Cutting Edge*: the Chronic Pain Research Alliance, an initiative of the TMJ Association publishes *COPCs Research Advances*, an electronic newsletter It was developed to keep the medical-scientific community abreast of recent research advances.



NIH Funding Announcements

- 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 (U441)
- HEAL Initiative: Clinical Devices to Treat Pain (UH3)

- HEAL Initiative: Stimulating Peripheral Activity to Relieve Conditions (SPARC)
- Notice of Special Interest of NIDCR in Supporting Discovery, Characterization, and Mechanistic Study of Genetic Variants Underlying Dental, Oral, and Craniofacial Diseases and Conditions
- The Intersection of Sex and Gender Influences on Health and Disease (R01)
- Clinical Validation of Candidate Biomarkers for Neurological Diseases (U01)
- Blueprint Neurotherapeutics Network (BPN): Small Molecule Drug Discovery and Development for Disorders of the Nervous System (UH2/UH3) (U44)
- Achieving Tissue Robustness Through Harnessing Immune System Plasticity (R21)(R01)
- Family-Centered Self-Management of Chronic Conditions (R01)(R21)
- Mechanisms Underlying the Contribution of Sleep Disturbances to Pain (R01)(R21)
- Notice of Special Interest (NOSI): Research on the Health of Women of Understudied, Underrepresented and Underreported (U3) Populations
- Notice of Intent to Publish a Funding Opportunity Announcement for HEAL Initiative: Advancing Health Equity in Pain and Comorbidities
- Notice of Intent to Publish a Funding Opportunity Announcement for HEAL Initiative: Restoring Joint Health and Function to Reduce Pain Consortium (RE-JOIN)

Promoting The TMJ Association

The presence of the TMJA staff, and their presentations at meetings, in addition to the involvement of the Scientific Advisory Board members, increases awareness of the needs of TMJ patients and creates opportunities to draw attention to the need for more research and funding.

Representations

- TMJ Patient-Led RoundTable project with FDA and MDEpiNet
- Northwestern Medicine annual review meeting – Center for Chronic Pain and Drug Abuse
- Practical Pain Management: Chronic Pain Facebook live event
- American Medical Women’s Association
- IMG Health Global, Canada



The TMJA is grateful for our many contributors in 2021

\$10,000+	Sean Mackey <i>in memory of William Maixner</i>
Terrie and Allen W. Cowley, Jr.	Felecia McBride
Christin and Melvin Veasley	Glenn Nead <i>in memory of Catherine E. Loranger-Nead</i>
	Neurotech Network
\$1,000-\$5,000	Beverly and Gary Nyhuis <i>in honor of Marsha Love</i>
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Antonio Wilfredo	Tina Ziolkowski
\$1-\$49	Combined Federal Campaign (Amount not disclosed)
Anonymous	Garris Green

**Statement of Activities and Changes in Net Assets
For the Year Ended December 31, 2021**

Summary of Revenue & Support

Contributions	\$68,034
Grants	
Scientific Meeting	
Dividend and interest	1,944
Other	
Total revenue and support	\$69,978

Summary of Expenses

Program	\$90,647
Administrative	9,064
Fundraising & Related Expenses	7,154
Total expenses	\$106,865
Change in net assets	(36,887)
Net assets, beginning of year	164,308
Net assets, end of year	\$127,421

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: Krause & Associates, SC, 1214 Bridge Street, Grafton, WI 53024