

The TMJ Association, Ltd.

2023 Annual Report



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

A Message from Our President...

Dear Members and Supporters,

As we contemplate the strides we've made together in advancing the understanding and treatment of temporomandibular disorders (TMD), it becomes clear that our dedication to educating diverse audiences—patients, professionals, and the general public—is paramount. Our core mission revolves around championing scientific research that enhances patient outcomes and embraces evidence-based healthcare practices.

Our commitment to nurturing collaboration among dental and medical students stands as a testament to our commitment to progress in education and the promotion of a comprehensive approach to patient well-being.

Moreover, our advocacy endeavors continue to bear fruit, with tangible support from congressional representatives for initiatives aimed at advancing TMJ research and patient care. Through initiatives like the TMJ Patient-Led RoundTable, we empower patients to shape the trajectory of future treatment and outcomes.

Looking forward, our resolve remains steadfast in our mission to champion scientific inquiry, advocate for patient-centric care, and elevate awareness of TMD. Together, we possess the collective power to effect transformative change in the lives of those impacted by temporomandibular disorders.

Warm regards,

Sincerely,

A handwritten signature in cursive script that reads "Terrie Cowley". The signature is written in black ink and is positioned above the printed name and title.

Terrie Cowley
President & Co-Founder

The TMJ Association is the ONLY patient advocacy organization fighting for the best science that will lead to a greater understanding of Temporomandibular and related disorders, which will result in treatments that will help and not harm patients.

We pursue this mission by:

- Providing Support and Guidance to Patients
- Serving as a Source of Current Research and Related Findings
- Educating Multiple Audiences: Patients, Professionals, Decision-Makers and the Public
- Promoting and Advocating for Biomedical Research



SERVING TMJ PATIENTS

Providing Support & Guidance

The TMJ Association (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*, *X*, *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 4,000 patients have joined TMJ Café.

Our website, www.tmj.org, is always available for those seeking information and support. We keep it updated with the latest research findings, alerts, and patient questions and concerns. Here are some examples of messages we received:

“I am so grateful to you and your organization for helping people like me. I owe my life to anyone who can figure this out and how to treat it. I am optimistic for the first time in a long time. THANK YOU FOR WHAT YOU ARE DOING!!!!”
Mark

“I appreciate all your support. I wouldn't be this far in life had I not found your website and resources.” Kim

“I just want to thank you so very much for your help today...I'm currently trying to process everything we spoke about today. It was so wonderful and overwhelming to finally have some validation. With so much gratitude.” Karen

“Thank you so much for all of this information, it has really helped me decide what is best for me. It has been difficult to find specific information online.”
Alec

Listing Opportunities to Volunteer for Clinical Studies

- **Impact of Daily Physical Activity and Chronic Musculoskeletal Pain Survey**

The graphic features the *Inspire* logo (with the tagline 'together we're better') and the *TMJA* logo (The TMJ Association, Ltd.) at the top. The background shows several coffee cups. The central text reads: “Sometimes a TMJ patient needs inspiration just to get through each day.” followed by “- The TMJ Association, Ltd.”. A pink banner at the bottom contains the text: “Connect with others who understand in the new TMJ Café Support Community”. At the very bottom, it says “Visit TMJ.Inspire.com”.

A research team from the Faculty of Rehabilitation Sciences of Hasselt University in Belgium is investigating the relationship between the intensity of daily physical activity and chronic musculoskeletal pain. They will be looking at fibromyalgia, chronic temporomandibular disorder, osteoarthritis, chronic neck pain, chronic shoulder pain, and chronic low back pain. The study involves an online survey which will take approx.. 50 minutes to complete.

http://ygassekt.qualtrics.com/jfe/form///SV_etk78e58y2YeYDQ

- **Central and Peripheral Factors in Temporomandibular Disorder (TMD)**

Researchers at Emory University in Atlanta need TMJ patients to participate in their study. They are investigating people who experience chronic pain in the head and/or face in everyday life. They are using unique tests to find out how the brain processes chronic and acute pain messages

and will observe patients to see how pain and sensory processing differ in TMD.

Contact Daniel Harper, PhD (Principal Investigator) at Daniel.harper@emory.edu with any questions and to participate.



- **Experiences with Jaw Stretching Devices**

Johathan Huang, a junior at Washington University in St. Louis, Missouri, is currently in the process of developing a new jaw-stretcher device. Eager to make the device accessible to multiple patient populations, he is hoping to gain some perspective from TMJ patients who currently use jaw stretchers. If you would like to offer your thoughts on such devices, contact: huang.j.j@wustl.edu.

- **TMJ Patients Needed for In-Person Study at the University of Minnesota**

For those in the Twin Cities, Duluth, Rochester, or nearby areas, a researcher working with the University of Minnesota is looking for participants to collect data as an early step toward development of a new medical device. There is one brief in-person meeting required, but the researcher can travel around those areas to meet you if you are interested. Please see below for details.

"Have you been diagnosed with TMD/TMJ Pain, Chronic Low Back Pain, and/or Painful Peripheral Neuropathy? Has your pain lasted for more than 3 months with an average daily pain intensity in the past week of $\geq 3/10$ and at least one instance of pain $\geq 6/10$ in the past week? If so, please contact groenke@umn.edu for more information regarding possible participation in an ongoing, at-home research study seeking to learn more about how the body responds to different pain levels. There is a \$20 gratuity payment following successful completion of the study."

Serving as a Source of Current Research and Related Findings

Some of the topics covered in the TMJA's publications in 2023 included:

- Description of Grant for Next Stage Testing of Tissue-Engineered Material for TMJ Disc Complex
- An International Collaborative Effort to Develop a Guide to Help Dental Professionals Effectively Treat Patients with TMDs
- Ehlers Danlos Syndrome and TMD
- The Invisible Podcast: A Collaboration Initiated by the TMJA to Connect Patients with the Chronic Pain Research Alliance. Listen on Spotify and Apple Podcasts
- New Understanding of Our Body's Defense System Could Lead to Better, Safer Implants: an article on the website of the *National Institute of Biomedical Imaging and Bioengineering* sheds new light on medical devices, including TMJ implants.



EDUCATING MULTIPLE AUDIENCES – PATIENTS, PROFESSIONALS & THE PUBLIC

Articles & Alerts of Concern to Patients

- **TMJ Device Causing Patient Harm**

CBS News and Kaiser Health News recently investigated one of the many temporomandibular disorder treatments that are on the market and sold routinely to patients without evidence of safety and efficacy. It was found that the device had not been reviewed by the FDA and allegedly left a trail of mangled mouths in patients with TMDs. You can follow the CBS investigation and also read the Kaiser Health News article available at: <https://khn.org/news/article/dental-device-lawsuits-displaced-teeth-agga-steve=galella/>. Should you be experiencing ANY type of TMD device problem, including splints, it is important to report these issues to the FDA through their MedWatch system.



- **Evaluation of Safety Concerns with Certain Dental Devices Used on Adults – FDA Safety Communication**

<https://www.fda.gov/medical-devices/safety-communications/evaluation-safety-concerns-certain-dental-devices-used-adults-fda-safety-communication>

The FDA is evaluating safety concerns with the use of certain dental devices that are **fixed** (non-removable) palatal expanders used on adults to remodel the jaw or to treat conditions. The devices of concern include AGGA, FAGGA, ARA, FARA, FOR A, and any other similar device types. **Device Description:** Palatal expanders are dental devices typically used to widen the roof of the mouth (palate) to make room for crowded teeth. The safety and effectiveness of fixed (non-removable) palatal expanders being used to treat conditions such as OSA and TMD, or to remodel the jaw in adults have not been established and these devices have not been cleared or approved by the FDA.

- **New Understanding of Our Body’s Defense System Could Lead to Better, Safer Implants:** An article on the website of the *National Institute of Biomedical Imaging and Bioengineering*, stated that “by closely examining the immune system’s responses to two different materials implanted in mice, researchers have identified key driving factors for implant-induced regeneration vs. damage. The authors suggest that their findings, published in *Nature Materials* help set the table for the design of new medical devices that influence the immune system to help, rather than harm, the body.

- **Bringing Dental and Medical Students Together to Learn About TMD**

On January 30, 2023, second-year dental students from Marquette University Dental School in Milwaukee joined first-year medical students from the Medical College of Wisconsin (MCW) in the *first* combined TMD educational session which was held at MCW. The session was designed as an interprofessional activity to increase understanding of TMD and the need for collaboration in providing effective clinical care.

- The medical and dental students enjoyed their interactions with each other, which is encouraging for future planning and understanding between the two professions.
- The students greatly appreciated the presence of the TMJA representatives (Terrie Cowley, Deanne Clare, Laurie Friedrich). They showed keen interest and asked many questions. They were sensitive to the plight of TMD patients. These informal interactions should be incorporated into their schedules in the future.
- Evidence of the value of this first meeting has resulted in the scheduling of the second meeting of these two groups on February 8, 2024.



Promoting and Advocating for Scientific Research

- For over 35 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 Craniofacial Research to increase funding to expand the science base for the project: Temporomandibular Disorders: From Research Discoveries to Clinical Treatment.



- **July 25 and 26, 2023 Understanding and Restoring Whole Joint in Pain Management: An NIH HEAL Initiative (Virtual) Workshop**
The purpose of this Helping to End Addiction Long-term Initiative, or NIH HEAL workshop was to examine the current literature on joint pain research and identify critical knowledge gaps to gain a comprehensive understanding of the whole joint, including the contributions of various articular and periarticular tissue pathologies that lead to pain in different types of joints. In addition, the workshop explored manipulations and interventions that may help to restore whole joint health. Workshop participants examined the relationships and interactions among the different tissue components of joints, including myofascial tissues, and their contributions to and impact on reducing pain by preserving and restoring joint health and function.
- The TMJ Association continues to lead the first-ever **TMJ Patient-Led RoundTable project**, working with the FDA, bringing together all stakeholders concerned not only with TMJ implants but all therapies. TMD patients are members of the steering committee, and 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 compendium of data that can reliably predict treatment outcomes for individual patients.
 - Other RoundTable projects include developing Patient Reported Outcomes for the TMJ registry using patient focus groups and Core Data Elements:
 - a list of specific data collected from patients, health care providers, and electronic health records.

- a new treatment model of care for TMJ patients
- Up-date on the **Development of Patient Reported Outcome Measures (PROMS)**
 The RoundTable focus groups identified 52 distinct concepts across six domains: somatic, physical, social, sexual, affective, and sleep. Findings support PROM item development for TMDs, including selecting existing PROMs or developing new ones that reflect patients' lived experiences, priorities, and preferred terminology. Such measures are needed to increase understanding of TMDs, promote accurate diagnoses and effective treatment, and help advance research on TMDs.
- The **TMJ Association's International Scientific Advisory Council's (TMJA-ISAC)** major goal is to advocate for high-quality biomedical research directed toward Temporomandibular Disorders and comorbidities that overlap with TMD. To address this goal, TMJA-ISAC will provide advice and strategic direction to enhance this mission by creating and implementing an overall agenda for biomedical research. TMJA-ISAC will assist the TMJA in identifying resources among governmental, academic, industry, professional organizations and charitable foundations to support activities that will lead to scientifically based precision treatments for TMJ patients. Advisors are listed at: <https://tmj.org/about-the-tmj-association/our-team/scientific-advisors/>
- **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.
- The TMJA promoted **TMJ Awareness Month** and kicked off a social media campaign to bring awareness and education to this issue during the entire month of November.

NIH Funding Announcements and Research Grant Opportunities

- **HEAL Initiative: Toward Developing Quantitative Imaging and Other Relevant Biomarkers of Myofascial Tissues for Clinical Pain Management (R61/R33, Clinical Trial Required)**
 This notice of a funding opportunity (NOFO) seeks research applications that will develop quantitative measures to facilitate the development of future biomarkers of myofascial tissues and assess their management interventions, manipulations, or therapies.
- **Planning for the TMD Collaborative for Improving Patient-Centered Translational Research (TMD IMPACT) (R34 Clinical Trial Not Allowed)**
 The Purpose of the TMD IMPACT is to be a national, interdisciplinary. Patient-centered temporomandibular disorders (TMD) research collaborative that will advance TMD-related basic and clinical research, research training, and translation to evidence-based treatments and improved clinical care. The planning grants are intended to enable institutions to develop partnerships, infrastructure, and capabilities needed to address the major goals of future collaborative and develop a collaborative-wide research framework and

strategies to support coordination among studies, research projects, and sites and thereby enhance competitiveness for future participation in the TMD IMPACT Collaborative.

Promoting The TMJ Association

The TMJ Association staff and their presentations at meetings, in addition to the involvement of the Scientific Advisory Board members, increase awareness of the needs of TMJ patients and create opportunities to draw attention to the necessity for more research and funding.

Representations

- TMD Patient-led RoundTable monthly meetings. Co-chairs, Terrie Cowley and John Kusiak, committee members Allen Cowley, Lisa Schmidt, and Michelle Reardon.
- TMJ Bioengineering meeting at the University of Pittsburgh, May 2023 (virtual attendance).
- Research!America event, March 2023. Attended by Terrie Cowley and Allen Cowley
- Friends of NIDCR (AAODCR) meeting on November 17th. Participants Terrie Cowley and Deanne Clare.
- The TMJA marked TMJ Awareness Month (November) by sharing updates on research and content that shed light on the reality of TMJ conditions.
- The TMJ highlighted the TMJA Store to both support the cause and continue to raise awareness of TMJ conditions. The TMJA can be found on Facebook, Instagram, LinkedIn, and X.
- National Academies of Sciences, Engineering, and Medicine Forum on TMD, December 11, 2023. Members Allen Cowley, Terrie Cowley, and Christin Veasley.

The TMJA is Grateful for our Many Contributors in 2023

\$10,000+

Alexandra Alger
Christian Blessing Fund - Mr. and Mrs. John Burkhalter
Terrie and Allen Cowley, Jr.
NIH Heal Connections
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\$1,000-\$5,000

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Combined Federal Gifts (amount not disclosed)

Stephen Moretto

**Statement of Activities and Changes in Net Assets
For the Year Ended December 31, 2023**

Summary of Revenue & Support

Contributions	\$89,629
Dividend and interest	446
Other	1021
Program earned income	30,212
Total revenue and support	\$121,308

Summary of Expenses

Program	\$84,203
Administrative	8825
Fundraising & Related Expenses	6988
Total expenses	\$100,016
Change in net assets	21,292
Net assets, beginning of year	166,583
Net assets, end of year	\$187,875

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