

**The TMJ Association, Ltd.**

**2022 Annual Report**



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

## A Message from Our President...

A compelling focus of The TMJ Association is on improving the understanding and treatment of Temporomandibular Disorders (TMD). One major project in 2022 involved educating both dental and medical students on the complexities of TMDs, ensuring that they become better-informed practitioners. We reached out to the Medical College of Wisconsin to share the recommendations of the National Academies of Sciences, Engineering and Medicine on their report on TMD. The result was a collaboration between the Medical College of Wisconsin and Marquette University School of Dentistry and us. Together we developed a TMD education program offered to first-year medical students and second-year dental students. Included was a TMJA video in which a caregiver describes her experiences and advocates for interprofessional education. We hope this initial project will serve as a model for other academic institutions to emulate in coming years.

The TMJ Association also dedicated much time in 2022 working with government officials and TMJ stakeholders to develop patient-reported outcome measures and common data elements which will be included in the first international patient-powered TMJ registry. The registry will provide a more comprehensive picture of what TMD patients experience in their journey from initial treatment to their present physical condition.

The TMJ Association continues its essential role of advocating for patients with policy makers and research funding agencies while providing indirect support and guidance to patients and their loved ones. As well, through our e-newsletters, our website, news articles, and social media posts we have been able to extend our reach to a wider range of professional and non-professional contacts who can be enlisted to help “change the face of TMJ”.

Sincerely,

A handwritten signature in cursive script that reads "Terrie Cowley". The signature is written in a dark ink and is positioned below the word "Sincerely,".

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 3,800 patients have joined TMJ Café.

Our website, [www.tmj.org](http://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:

This patient wrote to us following a special issue of *News Bites*:

*“I pray and hope that someday there will be a cure or a definitive answer for treatment. Until then, we suffer, often in silence, with recognition that no one will truly understand the distress and suffering, unless, unfortunately, they live with it as well.”* Norine

And, from a dental professional:

*“To my mind, the NASEM TMD Report is an exceptionally good and accurate statement of the problem, and your summary very nicely captures the impact this condition has on patients”.*

From another patient, seeking advice on the website:

*“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

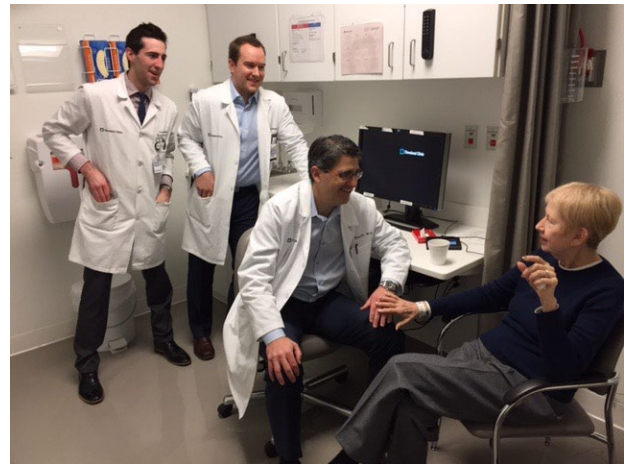
The graphic features the *Inspire* logo (with the tagline 'together we're better') and the TMJA logo (The TMJ Association, Ltd.) at the top. The background shows faint outlines of coffee cups. The central text reads: "Sometimes a TMJ patient needs inspiration just to get through each day." followed by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



## EDUCATING MULTIPLE AUDIENCES – PATIENTS, PROFESSIONALS & THE PUBLIC

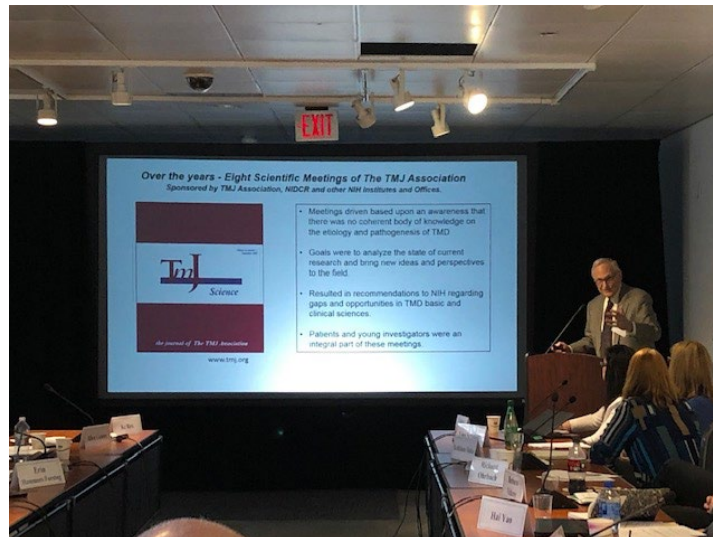
### Articles & Alerts of Concern to Patients

- Anti-Inflammatory Drugs Associated with Increased Risk of Persistent Pain: a recent research article in *Science Translational Medicine* by an international team of researchers.
- *The National Academies of Sciences, Engineering, and Medicine Consensus Study Report on Temporomandibular Disorders – Priorities for Research and Care*. The report explored a broad range of issues relevant to improving the health and well-being of individuals with TMD.
- The TMJA encourages patients to share all of their conditions, including TMD, and symptoms with their primary care physician or internist, even if they don't think they are relevant or related. Doing so will help rule out any conditions that mimic TMD symptoms, such as giant cell arteritis, which can be a missed diagnosis. An article published by MedPage Today, *Giant Cell Arteritis Growing More Lethal*, described this condition.
- An article on TMD was published in a bulletin of The American Academy of Otolaryngology- Head and Neck Surgery. "Many patients seek care from otolaryngologists for TMD-related symptoms. The skilled otolaryngologist must rule out more concerning diagnoses, verify that the TMD diagnosis is correct and educate the patient on both the cause and treatment options for their symptoms."



## Promoting and Advocating for Scientific Research

- For over 30 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.
- Temporomandibular Disorders was one of the topics discussed at the **September 13, 2022 National Institute of Dental and Craniofacial Research Council Meeting**. The TMJ Association highlights three major research topics discussed at that meeting:
  - An up-date on the TMD-IMPACT proposal (see below), presented by Dr. Rena D'Souza, Director of NIDCR
  - Approaches to Complex Diseases, presented by Dr. Robert Carter, Deputy Director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases
  - Multidisciplinary Care, integrating dental and medical research, presented by Dr. R. Bruce Donoff, former Dean of Harvard School of Dental Medicine
- **The TMD IMPACT Concept Proposal**. On January, 25 2022, the National Advisory Dental & Craniofacial Research Council met to review a series of "Concept Clearances", research initiatives deemed to be of high priority to the Institute. A proposal to establish a **TMD Collaborative for Improving Patient-Centered Translational Research (TMD IMPACT)** was presented by Melissa Ghim, PhD, Director of the Institute's Extramural Neuroscience, Orofacial Pain and Temporomandibular Disorders Program. She emphasized the multidisciplinary nature of the Collaborative, as well as the multidisciplinary composition of the teams that would carry out the research, which would include consideration of co-occurring pain and non-pain conditions associated with TMDs. Implicit in that statement is the Institute's recognition that TMDs are complex multifactorial disorders, not dental conditions, mainly treated by dentists.
  - **The Council voted unanimously to approve the Concept** and supports the creation of an NIH inter-institute TMD working group



- 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, 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
- The TMJ Association’s International Scientific Advisory Council (TMJA-ISAC) was established in August 2022. ISAC’s 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

- Notice of Special Interest (NOSI): Research on the Health of Women of Understudied, Underrepresented and Underreported (U3) Populations
- Dr. Hai Yao, a long-time supporter of the efforts of the TMJA, received an NIH grant to study how the TM joint functions.
- Feasibility Studies that Explore Healthy and Diseased Temporomandibular Joints (TMJ) using Single Cell Multi-Omic Analyses
- Trans-NIH Strategic Plan for Women’s Health Research “Advancing Science for the Health of Women”
- The US Department of Defense Chronic Pain Management Research Program invites scientists to submit pain research applications under three targeted areas:



Clinical Exploration Award, Investigator-Initiated Research Award, and Translational Research Award

- In October, 2022, the National Institutes of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), announced its support for a new Consortium whose goal is to be able to restore joint health. The Restoring Joint Health and Function to Reduce Pain (RE-JOIN) Consortium is part of the Helping to End Addiction Long-term Initiative, or NIH HEAL Initiative. The TMJ joint is one of those joints being studied. 2022 RE-JOIN Awardees focused on the TMJ are:
  - **University of Texas Health Science Center** – Project Title: *Comprehensive Functional Phenotyping of Trigeminal Neurons Innervating Temporomandibular Joint (TMJ) Tissues in Male, Female and Aged Mice, Primates, and Humans With and Without TMJ Disorders (TMJD)*
  - **Duke University** - Project Title: *Neural Architecture of the Murine and Human Temporomandibular Joint*
  - **University of Florida** - Project Title: *Innervation of the Knee and TMJ*
- Funding Opportunity Announcement: The Intersection of Sex and Gender Influences on Health and Disease, made available through the Office of Research on Women’s Health and the scientific partnering Institutes and Centers across NIH.
- The TMJA welcomes the announcement by the NIH Office of Research on Women’s Health of the availability of Administrative Supplements to support research on the health of women in understudied, underrepresented, and underreported populations in biomedical research, specifically targeted on sex and gender topics.
- The scientific journal, *Frontiers in Dental Medicine*, accepted manuscripts for review in a special Research Topic focus area, *Temporomandibular Disorder: New Directions in Research and Patient Care.*

## Promoting The TMJ Association

The TMJ Association 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 necessity for more research and funding.

### Representations

- Facial Pain Association, January 29-30 2022. Presentations by Terrie Cowley and Christin Veasley.
- American Academy of Pain Medicine 38<sup>th</sup> annual meeting, March 2022. Presentation by Christin Veasley.
- Participation in University of Minnesota study recruitment project. Lisa Schmidt serving as the TMJA’s patient representative.
- Global Learning Conference – Ehlers Danlos Syndrome, August 6, 2022. Presentation by Lisa Schmidt on living with TMD and EDS.

- Northwestern Medicine, Center for Chronic Pain and Drug Abuse. Terrie Cowley and Christin Veasley patient representatives.
- Practical Pain Management: Chronic Pain Facebook live, September 2021. Christin Veasley presenter.
- International Association for the Study of Pain, Canada, October 2022. Attended by Christin Veasley.
- Partnership with iMD Health, October 2022.
- Kern National Network Meeting in Milwaukee, September 2022. Terrie Cowley, Deanne Clare, and Allen Cowley attended the meeting representing the TMJA

## The TMJA is Grateful for our Many Contributors in 2022

### **\$10,000+**

Alexandra Alger  
Heidi and Kevin Clark  
Terrie and Allen W. Cowley, Jr.  
Stanford University School of Medicine  
Yale University School of Medicine

### **\$1,000-\$5,000**

Carl Altenburg in memory of Joanne E. Altenburg  
Stan Arner & Nancy Arner Charitable Foundation *in honor of Christopher Arner*  
John Benjamin *in memory of Jack and Mary Lemann*  
Karen Berkley *in honor of Terrie Cowley*  
Martha and John Burkhalter  
Facebook (numerous individual donors)  
Independent Charities of America  
Catherine Lemann *in memory of Mary Lemann*  
Stanley and Robin Mendenhall  
Sheila Moore  
Michelle and Patrick Reardon *in honor of Alexandra Reardon*  
John Rideout  
The Schmidt Family Fund  
Meredith Skelton *in honor of Terrie Cowley*  
Louise and Bill Symington  
Carol Tift *in memory of Jennifer Anne Williams*  
Christin and Melvin Veasley

### **\$500-\$999**

Anonymous  
AmazonSmile  
Athanasίου Foundation  
Kay and Fred Austermann *in honor of Terrie Cowley*  
Kathy Barrett *in honor of Barbara Olson and Jerry Woolstrum*  
Susan Cella  
Deanne and Markus Clare  
Etienne and Marianne Clare  
Combined Federal Campaign  
Kumar Family Charitable Fund  
Barbara Laboski  
Felecia McBride  
Greg and Karen McQuestion  
Charles Sturm  
Joseph Thumann *in memory of Frank Deutsch and Family*  
United Way of Greater Milwaukee & Waukesha  
Joan Wilentz

### **\$250-\$499**

Herbert and Noreen Bernet  
William and Gayle Fairchild  
James Farina III  
Richard Hack and Suzan Ben-Poorat *in honor of Terrie Cowley*  
Ipsos Mori Uk Review  
Robert Kerns  
Sean Mackey  
Beverly and Gary Nyhuis *in honor of Marsha Love*  
Stephen Family Foundation  
Cornelia van Ineveld *in honor of Adriana van Ineveld*

### **\$100-\$249**

Janice and Robert Agnew *in memory of Dianne Agnew*  
Laurie and David Brown  
David Brownlee  
Sandra and Jeffrey Canfield  
Norine and Jeffrey Cave  
Kristina Youso Connoy  
Candee Doneiko  
Mark Drangsholt  
Barbara Drexler  
Doris and Ed Heiser *in honor of Terrie Cowley*  
David Hilker and Lisa Walter  
Tricia Kalinowski  
Diana Kennedy  
Ruth Knapp  
Diana Koviack  
Fanny and Jean-Francois Liard  
Dianne Lerner  
Suzi and Scott Lustgarten Family Foundation  
J Mason  
Terrence McCaughey  
Jill McGuire  
Patricia Mineur  
Karen Morin  
Megan Murray  
Glenn Nead *in memory of Catherine E. Loranger-Nead*  
Marie and Connon Odom  
Paypal Giving Fund  
Ritza Reese  
Laura Rodrick  
Bonnie Shultz  
Mr. and Mrs. Steven Sokoloff *in memory of George Hughes*  
Tamara Stevenson  
Gilman Thompson

RY Charitable  
Adriana van Ineveld  
Eleanor and Martin Williams *in memory of Jennifer Williams*  
Hai Yao  
Diana Zuckerman

**\$50-\$99**

Clara Bauer  
Mary Butterfield  
Peggy Dale  
Christina Dawson *in memory of George Hughes*  
Linda Dittamo  
Tracy Downey  
Joanne and Robert Eckert  
Benni Eustace  
Paul Flagg  
Jennifer Green *in memory of Fran Schoen*  
Dana Hawkins-Simmons  
Kristine Hengel  
Shelley Hildebrandt  
IBM Employee Services Center  
IGive  
Susan Logue  
Sister Renee' Mauser  
David McCarthy *in memory of George M Hughes*  
Anaum Naz  
Susan Oelsen  
Adesuwa Porter  
Judi Sanders  
Robert Sloane  
Peter Stasko  
Oscar Suh-Rodriguez  
William Swislow  
Carol and Dennis Weinhoff  
Gina Wetten  
Adele Yessenow

**\$1-\$49**

Anonymous  
America's Charities  
Justin Allen  
Gregory Andreozzi

Nicole Beier  
Jeff Boissoneault  
Gary Brodsky  
Tabitha Brunt  
Edward Burkhard  
Joan Chapp  
Ronald Cwikla  
Ann-Marie DePalma  
Louise Haick  
Joan Hemming  
Leslie Jaspersen  
William Katsereles  
Emania Kingery  
Elaine Kohn  
Mary and Dale Kukla  
Lucille Long  
Lisa Lutz  
Maryland Charity Campaign  
Jennifer McNeese  
Diane Mongiardo  
Vickie Mullins  
Denise Orrico  
Matthew Overlan  
Vasja Petkovska  
Emily Rastl  
Susan Reale  
Maggie Reyes *in honor of Mabel Lewis*  
Paul Ruth  
Jessica Shannon  
Kristin Shepherd  
Joan Siok  
Michael Snegur  
Christine Steele  
Nancy Swinyard  
Jodi Trop  
Karen and Richard Turpin  
Anne Valenti *in honor of Mary Valenti Bloom*  
Ramachandra Yellapragada

**Combined Federal Campaign (Amount not disclosed)**

Garris Green

**Statement of Activities and Changes in Net Assets  
For the Year Ended December 31, 2022**

**Summary of Revenue & Support**

|                                  |                  |
|----------------------------------|------------------|
| Contributions                    | \$121,775        |
| Dividend and interest            | 171              |
| Program earned income            | 19,391           |
| <b>Total revenue and support</b> | <b>\$141,337</b> |

**Summary of Expenses**

|                                |                  |
|--------------------------------|------------------|
| Program                        | \$86,780         |
| Administrative                 | 8,955            |
| Fundraising & Related Expenses | 6,440            |
| <b>Total expenses</b>          | <b>\$102,175</b> |
| Change in net assets           | 39,162           |
| Net assets, beginning of year  | 127,421          |
| <b>Net assets, end of year</b> | <b>\$166,583</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: Krause & Associates, SC, 1214 Bridge Street, Grafton, WI 53024*