

The TMJ Association, Ltd.

2020 Annual Report



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

Message from Our President...

While the solutions needed to bring change to the TMJ field may sound *simple*, they are not *easy* to implement in the current entrenched TMJ health care system. For over 30 years, the TMJ Association has been the major force fighting for change for you! Please know that we're continuing to work tirelessly – presenting your specific needs to all decision makers with the position and ability to enact long-overdue change.

Here are some of the main areas of focus that our dedicated volunteers, staff, and board members worked diligently on in 2020:

- **National Academy of Medicine Report.** The TMJA was the catalyst in obtaining support for this [prestigious organization to conduct its first-ever study](#) on TMJ disorders. The resultant March 2020 report (available on our website) accurately reflects the dismal state of TMJ disorders and provides recommendations on how to “fix this field.” This report cannot sit on the proverbial shelf—we must ensure that the recommendations are carried out, because when they are, the lives of TMJ patients will certainly be improved. To begin this process, we are forming working group of pertinent stakeholders – including patients – to implement the recommendations.
- **TMJ Patient-Led RoundTable.** This first-of-its-kind public-private collaboration began in 2016 and we continue to make steady progress. We are in the beginning phase of developing patient reported outcomes, which will be used in a new TMJ patient registry, ensuring that outcomes identified by patients as important to them will be collected and reported on! Patients continue to play a pivotal role in the RoundTable.
- **New Website.** We are working with a leading advertising and marketing communications firm to develop a new website. The new, updated site will have improved capabilities, such as mobile-friendliness, ease-in-navigation and search-engine-optimization, which will enable us to help us easily reach more people who need help and hope, as well as better organize patient engagement to enact long-overdue change for you.
- **Patient Support.** Our 24/7 online patient support community, *TMJ Café*, continues to grow. It provides patients with a safe environment in which to receive support from 2400 global members.
- **Chronic Pain Research Alliance (CPRA).** TMJ disorders rarely exist alone. People with one pain condition are more apt to develop others. To address this gap, TMJA developed the CPRA initiative to promote research that will result in improved understanding of how these conditions relate and to promote the treatment of the “whole person.” Our advocacy has resulted in action within the National Institutes of Health and other federal health agencies.

Sincerely,

Terrie Cowley
President & Co-Founder

2020 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 continues its critical work.
- 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 (U44I)
 - HEAL Initiative: Clinical Devices to Treat Pain (UH3)
 - HEAL Initiative: Stimulating Peripheral Activity to Relieve Conditions (SPARC)
 - 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
 - The Intersection of Sex and Gender Influences on Health and Disease (R01)
 - Analytical and/or Clinical Validation of a Candidate Biomarker for Pain (R61/R33)
 - 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)
 - Family-Centered Self-Management of Chronic Conditions (R21) (R01)
 - The Biomarkers Consortium
 - Achieving Tissue Robustness Through Harnessing Immune System Plasticity (R21)(R01)
 - Family-Centered Self-Management of Chronic Conditions (R01)(R21)
 - Provider Communication, Adherence to Treatment and Self-Management (R01)(R21)
 - Mechanisms Underlying the Contribution of Sleep Disturbances to Pain (R01)(R21)
- **Patient Clinical Study Opportunities**
 - *All of Us* Research Program
 - On-line Survey Study on Fibromyalgia, Chronic Migraine, Chronic Oral-Facial Pain, and TMD seeks participants
 - University of North Carolina, Duke and University of Los Angeles Study of 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.
- 2020 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.
- Encourages the National Institute of Dental and Cranial Research (NIDCR) to increase funding to expand the science base for the project: Temporomandibular Disorders: From Research Discoveries to Clinical Treatment.
- Supports the creation of an NIH inter-institute TMD working group
- 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 2020 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
 - An Evaluation of the Efficacy and Economic Impact of Oral Splints for Patients with TMD or Bruxism
 - *Treating Temporomandibular Disorders in the 21st Century: Can We Finally Eliminate the ‘Third Pathway?’* – A discussion about why consideration should be given to the removal of treatment of TMD from the dental profession

- A study by researchers at Newcastle University in collaboration with the TMJA: *Persistent Temporomandibular Disorders and Dietary Changes: A Cross-sectional Survey*
- Ehlers-Danlos syndrome (hypermobile joints) is associated with an increased risk of TMJ disorders and other chronic pain conditions (reported in up to 71% of Ehlers-Danlos patients)

- **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 2020:

- The National Academy of Medicine (NAM) Study on Temporomandibular Disorders (TMD) has released its comprehensive study of Temporomandibular Disorders (TMD). The three most important issues are:
 1. Patient Involvement
 2. A Multidisciplinary approach to research and care
 3. A New TMD Treatment Model
- 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.
- Brochure on Overlapping Chronic Pain Conditions
- 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 in 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: Herberto 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
- Have you seen the film *Dark Waters*? If you are a Vitek implant patient, you will find attorney Robert Billott’s real-life 20 year legal battle against DuPont extremely interesting.

- **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 provide forums where the TMJA can share urgent news, as well as invite members to share personal experiences.

The TMJA partnered with *Inspire* and together they are providing TMJ patients with a free, anonymous, online support network/discussion community. Over 2,400 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 TMJ patients and creates opportunities to draw attention to the need for more research and funding.

- **Representation**

- January 27, 2020, TMJ patients, caregivers, and The TMJ Association participated in a group discussion with staff in the FDA's Office of Health Technology at the Center for Devices and Radiological Health in Silver Spring, Maryland.
- March 12, 2020, the TMJA was invited to attend a webinar held by the National Academy of Medicine (NAM). The purpose of the webinar was the presentation of their final report, *Temporomandibular Disorders: Priorities for Research and Care*.

2020 Contributors

\$50,000+

Terrie and Allen Cowley

\$1,000-\$5000

Elizabeth and Donald Birk
Martha and John Burkhalter
Grunenthal
Independent Charities of America
Nancy McGoon
Robin and Stanley Mendenhall
Sheila Moore *in honor of Maureen*
John Rideout
Lisa and Mark Schmidt
Louise and William Symington
Christin and Melvin Veasley

\$500-\$999

Anonymous
AmazonSmile
Kay and Frederick Austermann *in honor of Terrie Cowley*
Susan Cella
Julian Chipkin
Deanne and Markus Clare
Marianne and Etienne Clare
Heidi and Kevin Clark
Kenneth Eiger
Suzi and Scott Lustgarten Family Foundation
Alexandra Reardon
Charles Sturm
Carol Tift *in memory of Jennifer Williams*
TMJ Solutions, Inc.
Joan Wilentz

\$250 - \$499

Cathy and Carl Beard *in memory of Jennifer Williams*
Joel Greenspan
HealthyWomen
Sean Mackey *in memory of William Maixner*
Lutricia Merritt
Morin Family *in honor of Karen Morin*
Beverly and Gary Nyhuis *in honor of Marsha Love*
Lucy and Anthony Shaker

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Virginia Harris
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Doris and Edward Heiser *in honor of Terrie Cowley*
Kristine Hengel *in honor of Terrie Cowley*
Lisa Walter and David Hilker
Munir Azeez
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Nicole Kraft
Barbara Laboski
Todd Lockwood
Felecia McBride
Terrence McCaughey
Karen and Greg McQuestion
Annette Michaluk
Glenn Nead
Catherine Pahuski
Ke Ren
Lia Schmidt
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Richard Traub
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Hai Yao
Adele Yessenow
Anne and Leo Zuckerman Family Fund

\$50 - \$99

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Frank Altomare *in honor of Julie White*
America's Charities
Kathy Barrett *in honor of Jerry Woolstrum and Barbara Olson*
Ed Brinkmeyer
Mary and Len Boczkowski
Mary and John Butterfield
Claudia Bran
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Peter Van der Ven
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\$1-\$49

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Stephanie Hobbins
Carolyn Hudson *in memory of Kelly Rametta*
Mary and Dale Kukla
Mabel Lewis *in honor of Bella Lewis*
Susan Logue
Lisa Lutz
Geoffry Marquardt *in honor of Lindsay*
Maryland Charity Campaign
Jennifer and Thomas McNeese
Linda Morales
Rachel Morales *in honor of Linda Morales*
Patty Muellenberg
Tiffany Myers
Betty and R. Douglas Neal *in memory of Kelly Rametta*
New York City Gives
Kathleen O'Grady *in memory of Kelly Rametta*
Denise Orrico
Joseph Salusti *in memory of Carla Santamaria*
Deena Sanders
Phil Smallwood
Peter Stasko
Nancy Swinyard
Sandra Tapper
Hope Tocci
Karen and Richard Turpin
Nina Van Sant

CFC/United Way - amount not disclosed

David Schroeder

**Statement of Activities and Changes in Net Assets
For the Year Ended December 31, 2020**

Summary of Revenue & Support

Contributions	112,934
Grants	0
Scientific Meeting	0
Dividend and interest	1,093
Other	34
Total revenue and support	\$114,061

Summary of Expenses

Program	\$109,509
Administrative	11,135
Fundraising & Related Expenses	18,123
Total expenses	\$138,767
Change in net assets	(24,706)
Net assets, beginning of year	189,014
Net assets, end of year	\$164,308

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.