

The TMJ Association, Ltd.

2017 Annual Report



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

Message from our Scientific Advisory Council Chair

The mission of The TMJ Association is to improve the quality of health care and lives of everyone affected by Temporomandibular Disorders (TMD). We do this by advocating for the highest quality science to be directed toward these disorders. We educate our federal elected officials about how TMD affects the 36 million Americans with this disease and the need for funding for scientific research. We then work with the pertinent National Institutes of Health agencies to carry out this research in concert with our scientific meetings, which bring together the best researchers in the field and enlist scientists outside the TMJ field to guide research into newly developing areas. Our tenacious advocacy has moved the science of TMD from a trivial problem of teeth and jaws to a complex multisystem illness, with comorbid conditions.



As an academically based biomedical researcher and long-time scientific advisor to The TMJ Association, it has been astonishing to me the difference that an organization with such limited financial resources but an army of volunteers can make in bringing awareness and science to such an overwhelming major health care problem.

With sincere gratitude,

A handwritten signature in black ink, which appears to read 'Allen W. Cowley, Jr.'.

Allen W. Cowley, Jr.
Scientific Advisory Council Chair

2017 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 TMJ Association published and distributed its science journal, *TMJ Science Vol 8, No.1.*, summarizing the meeting proceedings and recommendations from the TMJ Association's 8th scientific meeting.
- *How Can Precision Medicine Be Applied to Temporomandibular Disorders and its Comorbidities?*, meeting summary and abstracts from The TMJA's 8th scientific meeting, published in the journal of *Molecular Pain*, Jan-Dec.13: 2017.
- **NIH Funding Announcements**
 - Family-Centered Self-Management of Chronic Condition (R21 Clinical Trial Optional)
 - mHealth Tools for Individuals with Chronic Conditions to Promote Effective Patient-Provider Communication, Adherence to Treatment and Self-Management (R01 Clinical Trial Optional)mHealth Tools for Individuals with Chronic Conditions to Promote Effective Patient-Provider Communication, Adherence to Treatment and Self-Management (R21 Clinical Trial Optional)
 - Trans-NIH Strategic Plan for Research on Women's Health (NOT-OD-17-108)
 - Blueprint Neurotherapeutics Network: Small Molecule Drug Discovery and Development for Disorders of the Nervous System (UH2/UH3)
Blueprint Neurotherapeutics Network: Small Molecule Drug Discovery and Development for Disorders of the Nervous System (U44)
 - Neuroskeletal Biology of the Dental and Craniofacial Skeletal System (R01)
Neuroskeletal Biology of the Dental and Craniofacial Skeletal System (R21)
 - Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)
Collaborative Research Centers (CRCs) (U54)
 - Data Management and Coordinating Center (DMCC) for the Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Collaborative Research Centers (CRC) (U24)
 - Implementation Science Research to Improve Dental, Oral and Craniofacial Health (U01)
 - Stimulating Peripheral Activity to Relieve Conditions (SPARC): Pre-Clinical Development of Existing Market-Approved Devices to Support New Market Indications (U18)
 - Development of two new research centers as part of the NIDCR's Dental, Oral and Craniofacial Tissue Regeneration Consortium (DOCTRC)
 - School of Dentistry Leads Major New Regenerative Medicine Center Funded by NIH
 - NIH-wide strategic plan for nutrition research

- Development of first public-private partnership (PPP) to develop safe and effective treatments for chronic pain, as well as new treatments for opioid addiction and overdose.
- **Patient Clinical Study Opportunities**
 - Comparative Study of Women Considering or Currently Receiving Botox Injections for TMJ Pain
 - Maternal Chronic Pain Study
 - Understanding Relationships Between Chronic Non-Cancer Pain, Pain-Related Psychosocial Factors, and Exercise Participation
 - Genetics of Facial, Jaw and Headache Pain
 - Biobehavioral Pain Management in TMD
 - Young investigators seeking research funding urged to apply for USBJI Career Development and Grant Mentoring Program

...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.
- On February 29, 2017, TMJA staff and over 70 others participated in the Friends of the National Institute of Dental and Craniofacial Research (NIDCR) American Association of Dental Research Advocacy Day on Capitol Hill.
- 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, plus a discount for those who go to the website to purchase a caddy for themselves or a loved one.
- Christin Veasley, Director of the Chronic Pain Research Alliance, an initiative of TMJA, was invited to participate in a meeting sponsored by NIH to develop a public-private partnership (PPP), which would be a joint effort of the NIH, the U.S. Food and Drug Administration and the pharmaceutical and medical device industry.

...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 2017 included:
 - Are you a TMD patient with tinnitus? There is some support for the theory that patients who experience pain in the chewing muscles may be at a higher risk for developing tinnitus.
 - Suffering from TMD on top of migraine may worsen the migraine attacks in terms of both severity and frequency.
 - New evidence of a genetic connection between migraine and coronary artery disease.
 - Why head and face pain cause more suffering than other kinds of pain: the brain's wiring makes us feel both physical and emotional pain from these areas.

- Thinned and weakened jaw bones are likely side effects of Botox treatment.
 - TMD patients should inform themselves of research on the results of occlusion-changing protocols before embarking on such treatment and seek more appropriate care.
 - Despite the weak scientific evidence supporting its efficacy, acupuncture treatment appears to relieve the signs and symptoms of pain in myofascial TMD.
 - An evidence-practice gap exists for occlusal adjustment for TMD-related pain: the most common treatments for TMD-related pain were reversible treatments; however, over half of dentists performed occlusal adjustment for TMD-related pain.
 - Swearing makes individuals more tolerant of pain! Also, patients found that their grips were stronger following a bout of swearing.
 - For the first time, individual pain processing characteristics have been linked to opioid response in a mixed chronic pain population. This has the potential to personalize treatment of chronic pain and restrict opioid use to patients with high likelihood for response.
 - Having too much sugar, salt, or fat in your diet can raise your risk for certain diseases. Better dietary habits can improve our health quickly, with small changes that can add up over time.
 - Eccentric condylar position, as indicated by imaging, is not an indicator of an abnormal TMJ and should not be used as a reason for treatment. Clinical symptoms of TMJ pain and/or limitation of jaw movement must also be considered. Painless clicking alone is not an indication for treatment.
 - The Delphi Process has established an international consensus regarding the principal components and standardized definition of Self-Management programs. It should allow the evidence base to be expanded in a more homogeneous, comparable manner in order to advance the science behind SM of TMD.
 - Pain drawings are a useful adjunctive tool for screening, assessment and treatment planning for patients with TMD pain.
 - The top co-morbid conditions reported from people with TMJ syndrome, regardless of status are anxiety, depression, insomnia, fatigue and pain.
- **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 2017:
 - 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.
 - An article on the latest in TMD nutrition research by Dr. Justin Durham in Newcastle upon Tyne, England.
 - Lyme disease symptoms often mimic those of TMD. The TMJA encourages patients who think they may have TMD to talk to their medical doctor in order to rule out other conditions which could cause similar symptoms.
 - Educational brochures on chronic overlapping pain conditions (COPCs).
 - Washington Post article on TMD: *If you hear a click in your jaw this is what you need to know*.
- **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. Facebook, Twitter, YouTube, and LinkedIn accounts, where the TMJA can share urgent news, as well as provide for the sharing of personal experiences.



...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**

- Friends of National Institute of Dental and Craniofacial Research and American Association for Dental Research Advocacy Day, February 27-28, 2017, Washington, DC; attended by Deanne Clare.
- Aligning Incentives for Sharing Clinical Trial Data meeting, April 2-4, 2017 in Boston, MA; attended by Terrie Cowley
- MDEpiNet mid-year meeting summary presentation on TMJ RoundTable project, May 16, 2017; presented by Deanne Clare
- MDEpiNet Grand Rounds, May 18, 2017; TMJ RoundTable project presented by Terrie Cowley
- Chronic Pain meeting, New York, NY, June 13, 2017; presentation by Christin Veasley
- Advancing Therapeutic Development for Pain and Opioid Use Disorders through Public-Private Partnerships: A Workshop, National Academies of Science, October 11-12, 2017, Washington D.C.; Christin Veasley presented.
- MDEpiNet Annual Meeting, October 19-20, 2017, Silver Spring, MD; presentation by Terrie Cowley and attended by Deanne Clare
- PCORI Annual Meeting: Delivering Results, Informing Choices, Arlington, VA, October 31-November 2, 2017, presentation by Terrie Cowley.
- National Academies of Science, Science and Entertainment Exchange Writer's Retreat, November 10-12, 2017 Utah, presentation by Christin Veasley

2017 Contributors

\$10,000+

Elizabeth and Donald Birk
Terrie and Allen W. Cowley, Jr.
International Pelvic Pain Society

\$5,000-\$9,999

Sheila and Thomas Moore
National Institutes of Health

\$1,000-\$4,999

Aquinox Pharmaceuticals
John D. Benjamin
Heidi and Kevin Clark
Continuum Clinical
Michael Hack Fund
Independent Charities of America
Catherine Lemann
Suzi and Scott Lustgarten
Robin and Stanley Mendenhall
John Rideout
Louise and William Symington
United Way of Greater Milwaukee & Waukesha

\$500-\$999

Anonymous
Kay and Frederick Austermann
Karen J. Berkley
Susan B. Cella
Deanne and Markus Clare
Carmen and F. William Haberman
Kevin Klas
Karen and Greg McQuestion
TMJ Concepts
Charles M. Sturm
Joan B. Wilentz

\$250-\$499

Joanne and Carl Altenburg
Marianne and Etienne Clare
Color4Fun LLC
Anne Marie Finley
Inderjit Handa
Darin Kellett
Terrence McCaughey

Annette Michaluk
Sylvan Mintz
Beverly and Gary Nyhuis - *in honor of Marsha Love*
Alka Patel
Lucy and Anthony Shaker
Christin and Melvin Veasley

\$100-249

Anonymous
Janice and Robert Agnew - *in memory of Dianne M. Agnew*
AmazonSmile
Lisa Baker
Noreen and Herbert Bernet
BioForward of Wisconsin
Ulrich Broeckel
Laurie and David Brown
Lisa and David Burr
Cathryn Butts
Sandra and Jeffrey Canfield
Barbara L. Drexler
Gayle and William Fairchild
Cheryl and Martin Frank
Joel D. Greenspan
Richard C. Hack
Minnette and Timothy Harrington
Mary Anne Hattemer
Doris and Edward Heiser
Lisa Walter and David Hilker
Barbara Anne Laboski
Todd Lockwood
Ellen and Andrew Lucas
Lutricia Merritt
Dennis Nagy
Glenn A. Nead
Cynthia Peterson
Juan Manuel Prieto Setien
Alice and Edward Riley-King - *in honor of Alexandra Reardon*
Ronald W. Rendell
Tim Sanders
Jana and James Skiba
Jean and Joseph Thumann
Tobi
United Way of Williamson County
Diane and John Watson - *in honor of Terrie and Allen Cowley*

Adele Yessenow
Diana M. Zuckerman - *in honor of Terrie Cowley*

\$50-\$99

Kathy Barrett - *in honor of Barbara and Jerry Woolstrum*
Danny Bullock
Mary and John Butterfield
Dennis J. Charvat
Rosa Colmenares
Sheila and Ronald Cwikla
Ann-Marie DePalma
Candee L. Doneiko
Steven Drager
Irma Fortier
Stephen Gordon
Lisa Harrison-Bernard
Catherine J. Hellner
Sandra and Scott Hoover - *in honor of Linda Hoover*
Barbara and John Horan
IBM Employee Services Center
Diana K. Kennedy
Fanny and Jean-Francois Liard
April Lindquist
Robert Link
Audrey Norman
Marie and Connon Odom
Randy Petty
Mary Kay Ruwette
Lydia Salinas
Judi Sanders
Theresa Sanders
Maria Sifre
Tracy Szpuk - *in honor of Alexandra Reardon*
Gilman R. Thompson
Jennifer Unruh
Lisa Wolff
Hai Yao

\$1-\$49

Anonymous (3)
Gregory P. Andreozzi
Clara Bauer

Toni Becker
Joan C. Chapp
Myrna Cherry
Claire Davidson
Linda A. Dittamo
Ebay
Joanne and Robert Eckert
Judy and Jerry Edelman - *in memory of Esther Yessenow*
Facebook
Ambrose Finnegan
Goodshop
Deborah Hayes
Shelley L. Hildebrandt
Susan and Thomas Joannou
Marian Kasdan
Lisa Lutz
Mary and James Malone
Maryland Charity Campaign
Jean and Paul Mazza - *in memory of Virginia Gisoldi*
Jennifer and Thomas McNeese
Andrew Menzie
Mohamed Mohamed
Raymond H. Morgan
Network For Good
Paypal Giving Fund
Stephanie Perez
Elizabeth Reid
Marguerite and Dennis Skahen
Michael Snegur
Stephanie Spinola
Peter Stasko
Nancy Swinyard
Anne Tennant
Karen and Richard Turpin
Peggy Wilkins
Richard Young

United Way/CFC (Donation amount not disclosed)

Lena Najarian

**Statement of Activities and Changes in Net Assets
For the Year Ended December 31, 2017**

Summary of Revenue & Support

Contributions	\$76,188
Grants	15,000
Scientific Meeting	6,519
Dividend and interest	183
Other	6,901
Total revenue and support	\$104,791

Summary of Expenses

Program	\$103,106
Administrative	8,494
Fundraising & Related Expenses	5,065
Total expenses	\$116,665
Change in net assets	(11,874)
Net assets, beginning of year	281,961
Net assets, end of year	\$270,087

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.