The TMJ Association, Ltd.

2016 Annual Report
Message from the President & Co-Founder

We are grateful for your moral and financial support which has enabled several impressive accomplishments in 2016.

**TMJ Roundtable.** In June, TMJA, in collaboration with the U.S. Food and Drug Administration, led the first-ever Roundtable on TMJ implants. Stakeholder groups representing manufacturers, health care providers, patients and others, engaged in lively discussions, shared challenges, and committed to working collaboratively to rebuild trust and improve the care of TMD patients. Since the June event, several work groups have been formed to implement the goals of this project, which include generating scientific evidence to guide clinicians in determining which treatments are safe and appropriate for different subgroups of TMD patients. They will also develop treatment outcome measures that patients deem meaningful and useful.

**Eighth Scientific Meeting.** In September, TMJA, with components of the National Institutes of Health, held its Eighth Scientific Meeting, *How Can Precision Medicine Be Applied to Temporomandibular Disorders and its Comorbidities?* The goal was to explore how scientific advances in precision medicine can inform TMD treatment so that it aligns with the unique characteristics of each patient in terms of genetic, environmental, behavioral and other factors. The meeting’s recommendations and summary will be included in the Association’s *TMJ Science* journal in early 2017.

**Chronic Pain Research Alliance (CPRA) Initiative.** Because TMD patients frequently suffer from other pain conditions, such as migraines, fibromyalgia or irritable bowel syndrome, TMJA worked collaboratively to establish CPRA, with the intent of advancing scientific, educational and clinical efforts on chronic overlapping pain conditions (COPCs). Toward that end, CPRA launched a new publication, *COPCs Research Advances*, which contains summaries of research articles on COPCs that have appeared in the scientific literature to update the scientific community on the latest findings. CPRA goals for 2017 include securing funding for a continuing medical education program for primary care providers on the diagnosis and treatment of COPCs and establishing startup funding to support future research on COPCs.

In 2017, we will continue our advocacy, information dissemination, patient support and education efforts on TMD and its coexisting conditions.

With deepest gratitude,

Terrie Cowley
President & Co-founder
2016 Achievements

...in Fostering Scientific Research
- The TMJ Association led the first-ever RoundTable, working with the FDA, bringing together all stakeholders concerned with TMJ implants
- The TMJ Association sponsored its 8th scientific meeting focused on how precision medicine can improve the treatment of TMD and the associated comorbid conditions.
- NIH Funding Announcements
  - Tailoring dental treatment for individuals with systemic diseases that compromise oral health (R01) PAR-16-154 and (R21) PAR-16-153, National Institute of Dental and Craniofacial Research
  - Multidisciplinary research in vulvodynia (R21) (PA-16-100) and (R03) (PA-16-101), Eunice Kennedy Shriver National Institute of Child Health and Human Development
  - Development multidisciplinary research in vulvodynia (R01) (PA-16-102), Eunice Kennedy Shriver National Institute of Child Health and Human Development
  - Establishment of resource centers for dental, oral and craniofacial tissue regeneration consortium (U24) RFA-DE-17-001, Administrative Supplements for Research
  - Administrative supplements for research on sleep disturbances and impact on chronic pain (NOT-NS-16-020) PA-16-164
  - Increasing the varieties of marijuana and marijuana products for research (NOT-DA-16-034)
  - Factors underlying differences in female and male presentation for dental, oral and craniofacial diseases and conditions (RO1)(R21)
  - Small research grant for secondary analysis of FaceBase Data (R03), National Institute of Dental and Craniofacial Research
  - 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)

...in Advocating for TMD Patients
- The TMJ Association’s advocacy work has resulted in Senate report language for 2017 for temporomandibular disorders and chronic overlapping pain conditions.
- Participated in Friends of the National Institute of Dental and Craniofacial Research Advocacy Day event on Capitol Hill, February 2016.
- Over the course of the year, The TMJ Association impressed upon federal representatives the need for increased scientific research.
...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 2016 included:
  o Risk factors for chronic facial pains. Investigating the role of increased levels of the pro-inflammatory proteins Calcitonin Gene-Related Peptide (CGRP) and Protein Kinase A (PKA) in a model of TMD.
  o Steroids may ease jaw pain in juvenile idiopathic arthritis, but not totally and not for everyone.
  o CGRP antibodies for migraine? Drug companies think so.
  o Blocking a stress-related gene relieves chronic pain.
  o Unclear results of botulinum toxin therapy for TMD pain.
  o Scientific news: Sleep and TMD.
  o National Pain Study released.
  o Multimodal assessment of body pain in orofacial pain patients.
  o TMD is a complex disease.
  o How accurate are dental websites when it comes to TMD?
  o How does a parent’s chronic pain affect children?
  o Emerging research on orofacial pain.
  o Painful TMD: Decade of Discovery from OPPERA Studies.
  o Should the FDA rush approvals when patients demand it?
  o Genes associated with risk for fibromyalgia found.
  o Estrogen plunge before menstruation linked to migraine.
  o Dopamine in plasma: a biomarker for myofascial TMD pain?
  o Bioengineers grow living bone for facial reconstruction.
  o Smoking marijuana provides more pain relief for men than women.
  o Are TMD patients more pain sensitive? Maybe. But it’s complicated.
  o From functional pains to central sensitivity syndromes.

• 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 2016:
  o The neuroscience of pain, a free webinar on translating science to the patient on BrainFacts.org.
  o 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.
  o 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.
  o *TMJ Science*, which includes the summary and recommendations from our 7th scientific meeting--*Genetic, Epigenetic, and Mechanistic Studies of Temporomandibular Disorders and Overlapping Pain Conditions*. 
- Cutting Edge - Chronic Overlapping Pain Conditions Research Advances, e-newsletter.
- Taking Control: Learn more about accessing your health information by Dr. Francis Collins, NIH Director.
- New FDA safety warnings added to prescription opioid drugs.
- Clinical study opportunity in New York and Los Angeles for TMJ pain.
- TMJ patients needed for research study in Baltimore, MD: Biobehavioral pain management in TMD.
- Clinical study: Genetics of facial, jaw and headache pain.
- Implementation of the National Pain Strategy petition.
- United States Bone and Joint Initiative, Career development & grant mentoring program call for applications.
- Postdoc fellow and junior faculty funding opportunity.
- NSAIDS, acetaminophen potential dangers often go unrecognized.
- Gut check: Know your medicines.
- National prescription drug take-back day.
- IBS awareness.
- Scientists figure out how NSAIDs can harm the heart.
- MedWatch mobile app.
- FDA safety alert: Over-the-Counter antacid products containing aspirin.
- FDA safety alert: Migraine patch risk of burns and scars.
- FDA safety alert: Lopermaide/Imodium.
- Avoid a TMD misdiagnosis: watch out for Lyme disease.
- FDA Safety alert: Opioid pain or cough medicines combined with benzodiazepines.
- Acetaminophen safety awareness.
- Antidepressants: rise in off-label prescriptions.
- Musculoskeletal inflammation and natural products.
- TMJA survey results: here is what you told us.

**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**
  - MDEpiNet TMJ Patient RoundTable at FDA campus, June 16, 2016, Silverspring MD; attended by TMJA staff and several board members.
  - Eighth Scientific Meeting of The TMJ Association, Sept. 11-13, 2016, Bethesda, MD; attended by TMJA staff and several board members.
2016 Contributors

$1-$49
Anonymous (3)
Gregory Andreozzi
Michelle Baratta – in honor of Grace Barotta
Clara Bauer
Mary and Len Boczkowski
Louis Brantmeyer – in honor of Susan Brantmeyer
Joan Chapp
Dennis Charvat
Mary Ann Chirichigno
Jane DeFrancesco
Goodshop
Stephen Gordon
Geraldine Gross
Steven Harris-Scott
Mary Anne Hattemer
Susan Herring
Georgann Higgins
Laura Howard
iGive
Kathleen Kerns
Mary and Dale Kukla
Lisa Lutz
Maryland Charity Campaign
Thomas McNeese
Andrew Menzie
Penny Mindham
Joan and John Norman
Holly Novacich
Matthew Overlan
Jackie Papandrew
Stephanie Perez
Douglas Petroff
JoAnn Pinto
Mary Prewitt – in honor of Richard Riggs
Marguerite Skahen
Barbara Smith
Joy Spalding
Donna Stagg
Peter Stasko
Anne Tennant
Karen and Richard Turpin
Peggy Wilkins
Susan Wilson
Lisa Wolff
Renee Yates

$50-$99
Kathy Barrett – in honor of Barbara Olson & Jerry Woolstrum
Lisa Boyea
Laurie Brustlin – in honor of Alexandra Reardon
Susan Burkard
Mary and John Butterfield
Sandra and Jeffrey Canfield
Mary Coughlin
Ronald Cwikla
Ann-Marie DePalma
Linda Dittamo
Candee Doneiko
Ronald Dubner
Sherry Facteau
Gayle Fairchild
Irene and Ambrose Finnegan
Ima Fortier
Lisa Harrison-Bernard – in honor of Terrie Cowley
Doris and Ed Heiser – in honor of Terrie Cowley
Catherine Hellner
Sandra and Scott Hoover – in honor of Linda Hoover
IBM Employee Charitable Contrib. Campaign
Susan and Thomas Joannou
Diana Kennedy
Fanny and Jean-Francois Liard
Mary Malone
Cory Mitchell
Audrey Norman
Guiovaldo Palva
Paypal Giving Fund
Joan Ponti
Ke Ren
Mary Kay Ruwette
Stanley Salwocki
Juan Manuel Prieto Seitien
Maria Sifre
Robert Sloane
Donna Sponaugle – in memory of Rebecca and Robert Sponaugle
Anne Valenti-Storck
Ruth Veld – in honor of Marsha Love
Carol Weinhoff
David Wood – in honor of Alexandra Reardon
Hai Yao

$100-$249
Anonymous
AmazonSmile
Janice and Robert Agnew – in memory of Dianne Agnew
Lisa Baker
Noreen and Herbert Bernet
Laurie Brown
Cathryn Butts
Robert Cannon
Rose Colmenares
Carol Gillie
Joel Greenspan
Richard Hack
David Harder
Minnette and Timothy Harrington
Kristine Hengel
Lisa Walter and David Hilker
Stephanie Jeffery
Tricia Kalinowski
Ruth Knapp
Doreen Krzyzanowski
John Lucas/Face Caddy
Karen and Greg McQuestion
Annette Michaluk
Sylvan Mintz
Glenn Nead
Ruby Nguyen
Marie Odom
Kiki Papadopoulos
Cynthia Peterson
Donna Pongratz
Ritza Reese
Ronald Rendell
Kathleen Riley
Carolyn and Jack Schaefer
Kathleen and Richard Simon
Meredith Skelton
James Skiba
Barbara Smith
Amy Splane
Patricia Szpuk – in honor of Alexandra Reardon
Gilman Thompson
Jean and Joseph Thumann
Adriana van Ineveld
Diana Zuckerman

$500-$999
Kay and Frederick Austermann – in honor of Terrie Cowley
Karen Berkley – in honor of Terrie Cowley
Ulrich Broeckel
Deanne and Markus Clare – in honor of Terrie Cowley
James Farina III
Heartland Advisors
Tamara Liller
David Samson
Lucy and Anthony Shaker
Louise and William Symington
Charles Sturm
TMJ Solutions, Inc.
Cindy Wilkins
Joan Wilentz

$1,000-$4,999
John Benjamin
Heidi and Kevin Clark
Felicia Furman
Carmen and F. William Haberman
Stanley Hack
Insight Service Group – in honor of Alexandra Reardon
Patrick Kilcoyne
Catherine Lemann
Suzi and Scott Lustgarten Family Foundation
William Maixner
Stanley Mendenhall
Quotient
John Rideout
Nancy McGoon
Christin and Melvin Veasley

$5,000+
Terrie and Allen Cowley, Jr.
Elizabeth and Donald Birk
Independent Charities of America
American Association for Dental Research
Sheila Moore
National Institutes of Health/National Institute of Dental and Craniofacial Research
Purdue Pharma, L.P.

United Way/Combined Federal Campaign
(exact amount donated unknown)
Amber Mann
Lena Najarian
# Statement of Activities and Changes in Net Assets

For the Year Ended December 31, 2016

## Summary of Revenue & Support

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions</td>
<td>$93,986</td>
</tr>
<tr>
<td>Grants</td>
<td>20,000</td>
</tr>
<tr>
<td>Scientific Meeting</td>
<td>45,377</td>
</tr>
<tr>
<td>Dividend and interest</td>
<td>540</td>
</tr>
<tr>
<td>Other</td>
<td>175</td>
</tr>
<tr>
<td><strong>Total revenue and support</strong></td>
<td><strong>$160,078</strong></td>
</tr>
</tbody>
</table>

## Summary of Expenses

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Program</td>
<td>$132,029</td>
</tr>
<tr>
<td>Administrative</td>
<td>9,090</td>
</tr>
<tr>
<td>Fundraising &amp; Related Expenses</td>
<td>5,574</td>
</tr>
<tr>
<td><strong>Total expenses</strong></td>
<td><strong>$146,693</strong></td>
</tr>
</tbody>
</table>

Change in net assets: $13,385

Net assets, beginning of year: $268,576

**Net assets, end of year**: $281,961

*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.*