



*The TMJ Association, Ltd.*

## 2011 ANNUAL REPORT

The TMJ Association (TMJA) is a nonprofit patient advocacy organization, founded on the basis that Temporomandibular Disorders (TMD) are a significant public health issue, that patients have a right to expect treatment options that are scientifically demonstrated to be safe and effective, and that patients can make reasonable treatment decisions only if they have access to credible information.

### MESSAGE FROM THE PRESIDENT

This has been a memorable year in our history and an important one for TMJ patients. This year we've seen new research funded, new research findings and new initiatives announced that respond to our advocacy efforts all these years.



The 2011 Annual report provides a summary of our accomplishments, outlined in the following five sections.

- Promoting Scientific Research
- Advocacy & Raising Awareness
- Providing Information and Support
- Strengthening the Organization
- Financial Status

We're excited by our accomplishments in 2011 and look forward to another productive year in 2012.

A handwritten signature in cursive script that reads "Terrie Cowley".

Terrie Cowley  
President and Co-Founder  
The TMJ Association, Ltd.

## Promoting Scientific Research

In 2011 we witnessed a major paradigm shift in how TMD is researched and viewed. Research has demonstrated that TMD is not just about teeth and jaws, but a complex condition influenced by genes, sex, age, and behavioral and environmental triggers. Additionally TMD appears to be one of a number of other pain conditions that tend to co-occur with TMD such as chronic fatigue syndrome, fibromyalgia, chronic headache, endometriosis, irritable bowel syndrome, and vulvodynia.

One of The TMJ Association's missions is to promote the necessary research which will yield evidence-based treatments for TMD patients. In 2011 the Association did this by:

- Sponsoring the Sixth Scientific Meeting of The TMJ Association, June 5-11 2011 in Bethesda, MD. The meeting, *“Comorbid Chronic Pain Conditions – Mechanisms, Diagnosis, and Treatments”* was a resounding confirmation that research should be directed toward the underlying mechanisms that link the conditions in question, and the answer may lie in the nervous system.



Our 2011 scientific meeting garnered many compliments such as the following: *“It was an honor and a pleasure to attend your meeting. I have rarely met such a fine group of scientists and advocates, passionately committed to making the world a better place for persons with TMJ.”* Dr. Richard Lipton, Albert Einstein College of Medicine, NY

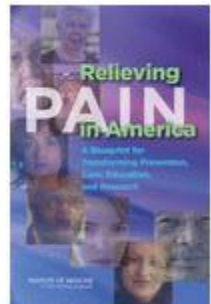
Our 2011 meeting also prompted the NIH to address TMD & comorbid conditions through a workshop to be held in August 2012.

- Participating in the annual Consumers United for Evidence-Based HealthCare meeting.
- Attending the *Pain & Musculoskeletal Disorders: Translating Scientific Advances into Practice* meeting at the NIH campus in Bethesda, Maryland.
- Having a research paper published in the *Clinical Journal of Pain*, Temporomandibular Disorders and Associated Clinical Comorbidities. This publication resulted from a web survey conducted of patients in our database and analysis of the data by scientists at the Medical College of Wisconsin.

## Advocacy & Awareness

An important role for TMJA is raising awareness with the general public, health care providers, the scientific community and regulators, and to advocate on patients' behalf for improved medical care. In 2011 the TMJA:

- Attended the Congressional Hearing on Medical Devices & the FDA Approval Process, advocating for safe and effective TMJ implant devices. The TMJA also submitted a Statement for consideration detailing how the FDA abrogated their responsibility to TMJ patients in the approval and post-market surveillance of TMJ devices.
- Authored a letter (and also joined the Patient, Consumer and Public Health Coalition in a letter) to the Center for Devices and Radiological Health of the Food and Drug Administration urging stricter 510(k) standards. In particular, the Association cited the need for rigorous clinical trials indicating safety and efficacy as well as post-market surveillance.
- TMJA provided testimony at the first public hearing in Washington DC of the Institute of Medicine Committee which drafted the *Report on Pain in America*.
- Accepted an invitation to serve on the Interagency Pain Research Coordinating Committee of the National Institutes of Health.
- Succeeded in sustaining the support of the US Senate through 2012 report language directed toward the Directors of the National Institute of Dental and Craniofacial Research and the National Institute of Arthritis and Musculoskeletal and Skin Diseases.



## Providing Information and Support

Often TMJ sufferers feel alone and abandoned, not knowing where to turn for support. The TMJA provides information and support by continuing to answer patient's questions and provide guidance by phone, via e-mail and through a number of social networking sites like Twitter, and Facebook. We also provide the state of the science on TMJ through our electronic and hard copy publications, *TMJ News Bites*, *TMJ Communiqué*, and our website, <http://www.tmj.org>.

In 2011 the TMJA published an updated educational brochure containing the latest scientific research and findings. The brochure was funded through a restricted educational grant from Purdue Pharma L.P. and additional support provided by the National Institute of Dental and Craniofacial Research (Grant #R13DE019079).

The TMJA also published the sixth edition of *TMJ Science* which summarizes presentations and recommendations from its sixth scientific meeting. Both of these publications were widely distributed to patients, health care professionals, scientists, government officials, and the general public.

Our advocacy, support and educational efforts are greatly needed as evidenced by the comments we continue to receive from TMJ patients such as these:

*"...I am 28 years old and have been consistently suffering from TMD for 4 years with little to no relief. I have been to 3 specialists for treatments, including 2 different mouth appliances, and consistent visits to doctors. I have purchased a TENS machine, special pillows, different suggested vitamins, been on several muscle relaxers, and take NSAIDS on a regular basis. I am super depressed and I spend most of my free time sleeping because I feel exhausted all day long. It even hurts to smile. I have distanced myself from my family and friends because no one knows how to deal with someone who hurts all the time. My doctors have given up on me and my family doesn't know what to do anymore. This is not a normal life. Where do I go from here?" Ashley*

*"...After all the years of suffering and all that I've been through I feel victimized and distrustful of doctors when it comes to TMD. With expensive medication, I deal with it and focus on the "good" things in my life and try not to dwell on the pain and the hand that fate has dealt my life. I am most grateful for your wonderful, informational and support organization. It's soothing to know I am supported by others who totally understand." Carol*

## **Strengthening the Organization**

In 2011 we continue to strengthen The TMJA through our work with the following non-profit partners:

- Chronic Pain Research Alliance
- Consumers United for Evidence-Based Health Care
- Patient, Consumer and Public Health Coalition
- Genetic Alliance
- Alliance for a Stronger FDA
- Partners for Understanding Pain
- Friends of NIDCR
- Bone & Joint Decade

These partnerships continue to help enhance the work of The TMJA by bringing awareness of TMJ disorders and demanding accountability of the health care community.

## **Financial Status**

### **Summary of Revenue & Support (as of December 31, 2011)**

Contributions	\$64,647
Grants	25,000
Scientific Meeting	62,229
Special event	0

Dividend and interest	1,308
Miscellaneous	(12)
Other	207
<b>Total revenue and support</b>	<b>\$153,379</b>

**Summary of Expenses** (as of December 31, 2011)

Program	\$123,497
Administrative	6,200
Fundraising & Related Expenses	4,750
<b>Total expenses</b>	<b>\$134,447</b>
Change in net assets	18,932
Net assets, beginning of year	198,665
<b>Net assets, end of year</b>	<b>\$217,597</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: Mr. David Hilker, CPA, Hilker Associates, 300 W. Walnut Street, Milwaukee, WI 53212.*