



THE TMJ ASSOCIATION, LTD. *Changing The Face of TMJ*

2007 ANNUAL REPORT

The TMJ Association (TMJA) is a nonprofit patient advocacy organization, founded on the basis that temporomandibular joint and muscle disorders (TMJDs) 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.

In 2007, The TMJA continued to fulfill its mission to improve the quality of health care and lives of everyone affected by temporomandibular joint and muscle disorders.

MESSAGE FROM THE PRESIDENT

I am pleased to present the 2007 Annual Report of The TMJ Association. We continue to make progress in our efforts to have quality interdisciplinary research directed toward Temporomandibular Joint and Muscle Disorders and in providing the most comprehensive and credible information on TMJDs to the public. Our 2007 accomplishments are outlined in this report in five sections.

- Raising Awareness
- Promoting Scientific Research
- Advocacy
- Providing Information and Support
- Financial Status

Please note that these successes have been achieved on a very limited budget, with the talents, skills, and commitment of Deanne Clare, our only employee, a number of dedicated volunteers, and the generosity of several hundred supporters. My deepest appreciation goes out to all who make this wonderful organization work!

Terrie Cowley
President & Co-Founder
The TMJ Association

RAISING AWARENESS

In the Media

Terrie Cowley was featured in an article by *Proto – Massachusetts General Hospital Dispatches from Frontiers of Medicine*, published in spring 2007. The article, “The Body in Pain,” presents a comprehensive view of the current state of pain research, including TMJD pain.

The TMJ Association partnered with Stir Marketing in Milwaukee to develop a public service advertisement for participation in the Milwaukee Journal Sentinel’s *Building Partners for Humanity* Campaign. The TMJA worked closely with the agency, which provided pro-bono work in designing an ad that won a \$1,000 award and received a free second run in the newspaper in November.

The TMJA was referenced in the following articles:

- *RDH*, the National Magazine for Dental Hygiene Professionals “The Complexities of TMJD” – October 2007, pg. 60.
- *Tinnitus Today* "Check for Jaw Misalignment" – December 2007, Volume 32, No. 4, pg. 19.
- *Friend of the National Institute of Dental and Craniofacial Research* “NIDCR, patients’ advocates work to solve TMJ puzzle” – Winter 2007, Vol. 3, No.1.
- *Bone & Joint Decade* newsletter “Member News – The TMJ Association”, May/June 2007, Volume 9, Issue 1, pg. 6.

Firstgiving

TMJA launched its online awareness campaign with Firstgiving in March. The campaign, *The TMJ Association - Giving TMJ Patients A Voice*, provided TMJ patients and their loved ones with an opportunity to share their stories with other families, friends, and colleagues and, by doing so, raise much-needed public awareness of TMJDs. The goal of the campaign is to raise funds to support TMJA scientific meetings. This online campaign helped the Association to raise \$1,907.

Golf Outing

TMJA Board member Kevin Clark organized the 2007 TMJA golf outing event which was held September 20 at the Grand Geneva Country Club in Lake Geneva, Wisconsin. The event was attended by 36 golfers and raised over \$20,600 for The TMJA. This golf outing helped us raise awareness about TMJDs among business leaders in the community.

Social Networking

In an effort to inform the general public about often misunderstood and misdiagnosed TMJDs, The TMJ Association has joined the social networking Web site, MySpace. Individuals who have joined the Association's MySpace page are mostly young females—the prime population of TMJD sufferers—allowing us to connect with this segment of the population beyond TMJA's own Web site (www.tmj.org). Participants can contact The TMJ Association, and share and read comments and stories online. By the year's end, Association had over 290 contacts on MySpace.

Women's Leaders Conference

In March, TMJA President Terrie Cowley and TMJA Project Coordinator Deanne Clare attended Milwaukee's Women's Leaders Conference sponsored by Associated Bank and Reinhart Boerner Van Deuren S.C. At this event they had an opportunity to meet and share the TMJA's mission with a number of women leaders in Milwaukee, including guest speakers, Jennifer Buffett, Diane Chamness, Jessie Garcia, and Hannah Rosenthal.

PROMOTING SCIENTIFIC RESEARCH

Fifth Scientific Meeting

The TMJ Association submitted an NIH grant application for co-sponsorship of its Fifth Scientific Meeting, “Can Studies of Comorbidities with TMJDs Reveal Common Mechanisms of Disease?” The Fifth Scientific Meeting of The TMJ Association to be held June 1-3, 2008 in Bethesda, MD was planned to bring together clinical scientists who have made advances in the fields of TMJDs and other poorly understood complex chronic pain conditions that TMJD patients frequently experience.

Government Accountability Office

The TMJA is proud to have initiated a Government Accountability Office (GAO) investigation into the TMJ implant device approval process by the Food and Drug Administration. In January 2005, The TMJA prevailed upon Senator Edward Kennedy (D-MA), member of the Senate Health, Education, Labor and Pensions Committee to submit a request to the GAO to investigate all activities at the Food and Drug Administration involving TMJ devices. The GAO is the investigative arm of Congress. It evaluates federal programs, audits federal expenditures, and issues legal opinions. The study verified what many TMJ implant patients knew: A number of TMJ devices had been approved by the FDA with questionable and inadequate scientific data. The September 2007 GAO report is available on-line at: <http://www.gao.gov/cgi-bin/getrpt?GAO-07-996>.

National Institutes of Health

On September 14 - 15 Terrie Cowley, Dr. Allen Cowley, Jr., Kevin Clark, Joan Wilentz, and Deanne Clare attended the *TMJD Systems Workshop* in Bethesda, MD. This Thought Leaders Workshop brought together world-class multidisciplinary scientists to determine the optimal way to conduct future TMJD research. The recommendations that emerged from the TMJA’s Fourth Scientific Meeting were the catalyst for the *TMJD Systems Workshop*.

Consumers United for Evidence-Based Healthcare (CUE)

On July 16 - 17, Terrie Cowley attended the 2007 Annual CUE meeting sponsored by CUE and the United States Cochrane Center (USCC) in Washington D.C. At this meeting, members discussed current measures being undertaken to require evidence-based medicine by law, free access to the Cochrane Collaboration for evidence-based healthcare, and the potential for further growth in this area.

ADVOCACY

National Institute of Dental and Craniofacial Research

Terrie Cowley attended the National Institute of Dental and Craniofacial Research (NIDCR) Patient Advocates forum in Bethesda MD on April 23rd. The forum is an opportunity for the NIDCR to brief the patient advocates on research activities and other topics of importance to the patient advocates. This also was an opportunity for patient advocates to voice their opinions and suggestions regarding related research and other activities to Institute officials.

On December 10, Terrie Cowley and Joan Wilentz met with Drs. John Kusiak, Ph.D., NIDCR Director of the Molecular and Cellular Neurobiology Program, Division of Basic and Translational Sciences and Nadia Lumelsky, Ph.D., NIDCR Director of Tissue Engineering & Craniofacial & Dental Regenerative Medicine Program. The purpose of the meeting was to discuss the state of NIDCR funded TMJ research, the gaps in present funding, and future directions.

United States Senate

Terrie Cowley met with policy advisors in the offices of Senators Kennedy, Harkin, and Kohl regarding follow-up activities to the General Accountability Office (GAO) report on December 10th.

American Association for Dental Research and Friends of NIDCR

April 24 Ms. Cowley attended the American Association for Dental Research and Friends of NIDCR meeting focused on NIDCR research successes and the importance of increased funding for the NIDCR.

Food and Drug Administration

Terrie Cowley attended an FDA-sponsored Patient Advocates Forum on August 22 as a TMJD patient representative.

FDA Alliance

The TMJ Association has been active in the FDA Alliance, an education and advocacy organization formed to promote increased funding for the Food and Drug Administration. The FDA Alliance advocates for the modernization of the FDA for the 21st century, and for increasing funding to meet the FDA's growing responsibilities.

PROVIDING INFORMATION AND SUPPORT

TMJA Publications

The TMJA provided print correspondence and informational materials to over 23,000 individuals in 2007. Copies of past print and electronic newsletters are also available at The TMJ Association's Web site, www.tmj.org.

- **TMJ Science** - The fourth edition of *TMJ Science* was printed and distributed to government health agency officials, elected federal officials, professional organizations, business professionals, scientists, patient advocacy organizations, and TMJ patients. This publication includes the summary of presentations and resulting recommendations from the Fourth Scientific meeting of The TMJ Association.
- **TMJ Communiqué** - Two issues of the *TMJ Communiqué* were published and distributed. One addressed the key issues identified by TMJ patients in a web-based survey conducted by the TMJA. The priorities were scientific research and public awareness. The other issue highlighted key activities of the TMJA for the year and included the *Proto* magazine article "*The Body Pain.*"
- **TMJ Web Communiqué** - The electronic version of the *TMJ Web Communiqué* was introduced and e-mailed to over 60,000 recipients.

Web site

In 2007 the TMJA's web site, www.tmj.org, received 353,075 visitors from 170 countries/territories. Additionally, 10,346 individuals registered their contact information with The TMJ Association.

Patient Support Network

Patients who contact The TMJ Association (TMJA) and ask to be connected with other patients are referred to a Patient Support Contact. Support Contacts are TMJD patients who understand the physical, financial, emotional and social issues other patients are experiencing. The TMJA holds regular conference calls throughout the year to assess the needs and direction of the Patient Support Network.

FINANCIAL STATUS

Summary of Revenue (as of December 31, 2007)

Contributions	\$123,218
Grants	7,592
Scientific meeting ('06)	-
Special event (golf outing)	25,025
In-kind donations	-
Dividend and interest	5,145
Loss on disposal of assets	(687)
Other	990
Total revenue and support	\$161,283

Summary of Expenses (as of December 31, 2007)

Program	68,503
Administrative	6,396
Fundraising	10,853
Total expenses	\$85,752
Change in net assets	75,531
Net assets, beginning of year	126,957
Net assets, end of year	\$202,488

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.