



2006 ANNUAL REPORT OF ACTIVITIES AND SUCCESSES

Twenty years ago, The TMJ Association (TMJA) was founded on the premise 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 2006, The TMJ Association continued to fulfill its mission to improve the care and treatment of those affected by TMJDs through research and education with the ultimate goal of prevention.

SUMMARY OF THE TMJ ASSOCIATION 2006 ACTIVITIES

- Promoting TMJ Awareness and Research
- Publication Projects
- Economic Status
- Special Events
- Board Meetings

PROMOTING TMJ AWARENESS AND RESEARCH

The Fourth Scientific Meeting

The Fourth Scientific Meeting of The TMJ Association was held September 11th and 12th at the Federation of American Societies for Experimental Biology (FASEB) in Bethesda, MD. The meeting was cosponsored by The National Institute of Dental and Craniofacial Research, the National Institute of Arthritis and Musculoskeletal and Skin Diseases, the National Institute on Deafness and other Communication Disorders, the National Institute on Drug Abuse, the National Institute of Neurological Disorders and Stroke, and the Office of Research on Women's Health. Other individuals and foundations also contributed toward this meeting. The meeting, *A Systems Approach to Understanding TMJ as a Complex Disease*, included medical and dental clinicians, TMJ patients, as well as basic scientists from many disciplines.

The most exciting and encouraging aspect of the meeting was the general feeling that there is now a sufficient critical mass of basic and clinical investigators who understand and appreciate the complex problems TMJDs pose. Based on this recognition, participants recommended a number of strategies and initiatives to facilitate the development of cross-disciplinary and interdisciplinary research programs within the country's academic health centers and across the institutes and centers of the National Institutes of Health. The group concluded that the mechanism of choice to meet these goals would be through the establishment of Regional Centers of Excellence. Such

Centers could be positioned within one or among several academic health centers or institutions, working in collaboration with community caregivers. Meeting participants formally asked the Director of the National Institute of Dental and Craniofacial Research (NIDCR) to convene a special TMJD Thought Leader Conference to develop strategies to achieve integrative and translational research and multidisciplinary educational programs.

This approach signals a paradigm shift in how TMJDs are studied and treated. The conference concluded that TMJDs are complex conditions that are influenced by genes, gender, environmental and behavioral triggers, and may be related to larger health issues. The TMJ Association is pleased that the national policy makers support the concept of TMJDs as exemplars of a complex disease.

Patient Support Contacts

From time to time, TMJ patients who contact The TMJ Association ask to be put in touch with other TMJ patients in order to discuss their common experiences, and a number of individuals have consented to be contacted by other TMJ patients for this purpose. Support Contacts are TMJ patients who understand the physical, financial, emotional, and social issues you may be experiencing. The TMJ Association holds regular conference calls to assess the needs and direction of the Support Contact program throughout the year.

Patient Survey

In April, 10,000 patients from The TMJ Association database were invited to participate in an on-line survey developed in collaboration with scientists at the Medical College of Wisconsin to gain information regarding problems experienced by TMJD patients. Over 1,500 individuals responded to the survey. The majority were women (90%) and of these, over 96% had been diagnosed with a TMJ condition. The information obtained from this survey was presented at the Fourth Scientific Meeting of The TMJ Association and will be submitted to medical professional journals for publication.

TMJ Bioengineering Conference

Terrie Cowley delivered a keynote address at the TMJ Bioengineering Conference in Broomfield, CO, on May 25th-27th, in which she provided directives to the bioengineering community based on the information received from patients over the years. The meeting objective was to provide a unique forum for bioengineers to exchange ideas and perspectives with clinicians and patients in an effort to identify contemporary challenges in treating TMJDs and to devise strategies to address these challenges with bioengineering technology.

Government Accountability Office (GAO)

The TMJA prevailed upon Senator Edward Kennedy (D-MA), ranking minority member of the Senate Health, Education, Labor and Pensions Committee to submit a request to the General Accountability Office (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. When GAO reports its findings to Congress, it recommends actions. Its work

leads to laws and acts that improve government operations. Senators Tom Harkin (D-IA) and Herb Kohl (D-WI) joined Senator Kennedy in the request. The investigation was begun in October with a visit to our office by several GAO investigators. A report is expected in fall 2007.

National Institutes of Health

In April TMJA President Terrie Cowley held meetings with high-level government and agency officials in ongoing advocacy efforts to address TMJ issues and patient needs. In September at the NIH campus, Terrie Cowley met with officials from the National Institute of Dental and Craniofacial Research (NIDCR), the National Institute on Drug Abuse (NIDA), National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). On September 12th, Dr. Allen Cowley and board members Terrie Cowley, Joan Wilentz and Kevin Clark attended a meeting of the TMJ Interagency Working Group at the National Institutes of Health. Members briefed each other on advances in TMJ research within their institutes and centers, and TMJA members relayed information regarding the Association's scientific meeting, which ended that afternoon. Future directives were discussed.

On April 25th, Terrie Cowley and Peter Reinecke attended the National Institute of Dental and Craniofacial Research Patient Advocates Forum and the NIH. These annual meetings give the NIDCR an opportunity to brief patient advocates on their activities, and research advances.

ADA Amalgam Filling Meeting

On September 6th and 7th, TMJA President Terrie Cowley was the patient representative on the Food and Drug Administration Dental Products Panel which convened to assess the state of science on the effects of dental mercury and amalgam alloy.

TMJ Patient Registry

On May 5th, Terrie Cowley, a member of the advisory committee to the National Institute of Dental and Craniofacial Research-TMJ Implant Registry and Repository, participated in a site visit to the University of Minnesota, the repository of the TMJ Patient Implant Registry. Dr. Kyriacos Athanasiou, a member of the TMJA Scientific Advisory board, is chairman of the committee, and also attended the meeting.

FDA Alliance

In November, the TMJA joined 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.

Roadmap Trans-NIH Strategic Initiatives

In November, the TMJA responded to a request from the NIH for suggested research topics, which would fall into the NIH Roadmap Trans-NIH Strategic Initiatives. Dr. Allen Cowley submitted evidence that TMJDs be studied in a systems biology approach.

Consumers United for Evidence-Based Healthcare (CUE)

In 2006, The TMJ Association joined the Consumers United for Evidence-Based Healthcare (CUE), an advocacy group that hopes to provide its members with accurate, evidence-based information and quality research in the healthcare field.

On September 21st, Terrie Cowley attended the 2006 Annual CUE meeting, sponsored by the CUE and the United States Cochrane Center (USCC) in Alexandria, VA. 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.

OPPERA

On December 6-7th, Terrie Cowley visited the University of North Carolina- Chapel Hill, the home of the Orofacial Pain Prospective Evaluation and Risk Assessment Project. This project investigates the genetic and other causes of TMJ pain. Dr. William Maixner, principle investigator, invited the TMJA to share information about the project and solicit suggestions and ideas based on the patient's perspective.

PUBLICATION PROJECTS

- The *TMJ Web Communiqué*, the electronic version of The TMJA's newsletter, was introduced and e-mailed to over 60,000 recipients
- Two volumes of *The TMJ Communiqué* were published and distributed
- The redesign of the Web site, www.tmj.org, began
- TMJA added an informational brochure in French to its website
- Terrie Cowley is listed as a contributing writer in the *Savvy Women Patient Book* by The Society for Women's Health Research

"TMJD --- A Mystery Inside an Enigma"

In the Fall of 2006, Joan Wilentz's article "TMJD --- A Mystery Inside an Enigma" appeared in the American Academy of Pain Management's Publication *The Pain Practitioner*, Volume 16, Number 3. The article explained the prevalence of TMJDs, and the lack of a cohesive body of information on the TMJ, in general. The publication of Ms. Wilentz's article has helped to educate medical professionals about the complexities and need for research on TMJDs.

FINANCIAL STATUS

Internal Revenue Service Status

In July, The TMJ Association was moved from a private to public charity status by the Internal Revenue Service. This new determination will enable the TMJA to be eligible to receive foundation grants from those foundations that exclude private entities. The Association will also be in a more favorable position to receive corporate matching funds.

2006 Financial Statements and Audit

As we have reported in the past, \$75,000 annually is the minimum amount required for the organization to pay salaries for two part-time employees, office rent, utilities, printing, postage, equipment maintenance, insurance, and financial auditing. Programmatic expenses increased in 2006 due to the biennial Fourth Scientific Meeting co-sponsored by The TMJ Association and components of the National Institutes of Health. Fundraising expenses decreased in 2006 due to the decreased marketing consultant services.

Our 2006 expenses were \$142,527, up from \$129,781 in 2005. The rise in expenses is mostly attributed to the Scientific Meeting, which was held in 2006. Revenue totals fell slightly 2006, with \$109,802 in contributions and \$7,403 in grants, as opposed to \$115,224, and \$11,938 respectively. Special event revenue was \$27,893 in 2006, up significantly from \$18,909 in 2005. This increase is attributed to the continuance of corporate sponsorships of the golf outing, an increase in the number of golfers participating and the receipt of a government grant to support the Fourth Scientific Meeting.

2006 was the third year that the TMJA participated in the Combined Federal Campaign (CFC). The CFC allows federal government workers to pledge contributions to The TMJ Association. Final 2006 donation figures will not be in until late 2008; however, the current pledge amount is \$8,712.64. We received over \$6,173.78 in contributions from the 2005 CFC.

Fundraising Appeal

As in the past, fund-raising by direct-mail solicitation of past supporters and new contacts has been our largest source of revenue. In November 2006, the TMJA launched its fall fund-raising appeal. The generosity of more than 173 supporters of the TMJA raised \$63,611.02.

The TMJ Association participated in seven State Employee Contribution Campaigns (SECC): Arizona, Connecticut, Florida, New Jersey, Ohio, Pennsylvania, Rhode Island, and Wisconsin. The TMJA received \$69.05 from the SECC in 2006 and the number is expected to increase in 2007.

SPECIAL EVENTS

National Patient Meeting

The TMJA held a national patient meeting on September 10th, prior to the Scientific Meeting. Patients' concerns and needs were addressed, and they were apprised of the state of The TMJ Association.

TMJA on Ebay

In 2006, the TMJA joined Ebay and Mission Fish to give TMJA members the opportunity to buy and sell items to benefit TMJ research. Sellers can opt to donate a portion of their profits to the TMJA, or buyers are able to purchase items that can benefit our cause. \$262.65 was raised in 2006.

Golf Outing

TMJA Board member Kevin Clark organized The Open Jaw, a golf fund-raising event which was held August 17 at the Grand Geneva Country Club in Geneva, Wisconsin. The event was attended by 50 golfers and raised over \$21,000 for the TMJA. This golf outing was the most successful of any thus far, and this success is attributed to an increase in golfer participation as well as increase in corporate sponsorship.

BOARD MEETINGS

June Board Meeting

On June 7th, the TMJA Board of Directors held its meeting in Milwaukee, WI. During this meeting the board discussed strategies to strengthen the organization, as well as cut costs. The Board of Directors voted to create an Honorary Board of Directors.

October Board Meeting

In October, the TMJA Board of Directors met in Milwaukee, WI to discuss the organization and its goals. Following the completion of the golf outing and the scientific meeting, the board discussed the success of both functions, and their effect on the organization. The board also discussed further ways to increase patient involvement, considering the personnel and financial constraints of the TMJA.

December Board Meeting

The TMJA Board of Directors met again in December to discuss the financial outlook of the organization. The 2007 budget was approved unanimously, and the move from a private to public foundation was discussed.

THE FUTURE

The TMJ Association will continue to participate in United Way, State Employee Contribution Campaigns, and the CFC and hopes to expand the annual golf outing. *TMJ Science*, the journal of The TMJ Associations with proceedings from the scientific meetings, will be published in 2007. Analysis of the 2006 Patient Survey data will continue. Planning for the Fifth Scientific Meeting of The TMJ Association will also begin in 2007.