



2004 ANNUAL REPORT OF ACTIVITIES AND SUCCESSES

Nearly 20 years ago, The TMJ Association was founded on the premise that TMJ diseases and disorders are real, that patients have a right to expect treatment options that are scientifically shown to be safe and effective, and that patients can make reasonable treatment decisions only if they have access to information. In 2004, The TMJ Association continued to fulfill its mission to improve the care of treatment of those affected by TMJ diseases and disorders and ultimately to prevent these problems.

SUMMARY OF THE TMJ ASSOCIATION (TMJA) 2004 ACTIVITIES

- The Third Scientific Meeting
- Promoting TMJ Awareness
- Publication Projects
- Economic Status

THE THIRD SCIENTIFIC MEETING

The TMJ Association's Third Scientific Meeting, *Advancing Diagnostic Approaches for TMJ Diseases and Disorders*, was held May 6 & 7 in Bethesda, Maryland. The scientific goal of the meeting was to assess current methods of diagnosis and explore new ways to define the TMJ vulnerable population through the utilization of new and emerging technologies provided through bioengineering, bioimaging and computational biology.

The meeting, sponsored by the TMJA, and partially supported by a grant from the National Institute of Dental and Craniofacial Research with funding from other National Institutes of Health components (the Office of Rare Diseases, the National Institute of Biomedical Imaging and Bioengineering, the Office of Research on Women's Health and the National Institute of Arthritis and Musculoskeletal and Skin Diseases) brought leading experts in the fields of brain and body imaging together with bioengineers, computer scientists, and specialists who design tools for measuring and modeling jaw joint behavior. The meeting sponsors also included several private individuals and the Whitaker Foundation, which supplied funds for travel to the meeting for young investigators. The first day session began with an overview of TMJ diseases and disorders including a TMJ patient presentation. **Marsha Love**, a multiple surgery patient, provided a clear and dramatic description of her long battle with TMJ.

A dinner for participants in the meeting was held following the first day session on May 6, and included the presentation of a number of awards. **Lisa Brown**, a TMJ patient and former Board

member, was honored for the many contributions she made in the early years of the Association. **John Watson, Ph.D.**, former Director of the Clinical and Molecular Medicine Program at the National Heart, Lung, and Blood Institute and currently Associate Director of The William J. VonLiebig Center for Entrepreneurism and Technology Advancement and Professor of Bioengineering at the University of California, San Diego, was honored for his long-term support and advice to the TMJA. Whitaker Foundation travel award recipients included; **David Soltysik, Ph.D.**, Post Doctoral Fellow., Department of Biophysics, Medical College of Wisconsin, **Michael Detamore, M.S., Ph.D.** Candidate, Department of Bioengineering, Rice University, Houston, TX, **Alejandro Almarza, Ph.D.** Candidate, Department of Bioengineering, Rice University, Houston, TX, **Kyle Allen, Ph.D.** Candidate, Department of Bioengineering, Rice University, Houston, TX, and **Jorge Roldan, BME**, Masters of Science Candidate, Louisiana Tech University, Ruston, LA. The National Institutes of Health Young investigator travel award recipients were: **Bita Arabshahi, M.D.**, Rheumatology Fellow, Children's Hospital of Philadelphia, PA, **Linda Arvidsson, D.D.S.**, Research Fellow in Dept. of Maxillofacial Radiology, Faculty of Dentistry at the University of Oslo, Norway, **Ranjini Ambalavanar, D.V.M., Ph.D.**, Post Doctoral Fellow and Research Assistant Professor in the Department of Biomedical Sciences, University of Maryland Dental School, Baltimore, MD, **Jeremy Horst**, Masters Candidate, University of California San Diego, San Diego, and **Sunil Wadhwa, D.D.S., Ph.D.**, Research Fellow, Craniofacial and Skeletal Diseases Branch of the National Institute of Dental and Craniofacial Research, Bethesda, MD. **Dr. Wadhwa** was awarded the 2004 Young Investigator award by The TMJ Association in recognition of his contributions to research on temporomandibular joint diseases and disorders.

The second day of the Scientific Meeting ended with panel discussions to develop recommendations for basic and clinical research focusing on the new technologies and how they can advance the understanding and resolution of TMJ problems. A report of the meeting, including the research recommendations, was published in Volume III of the *TMJ Science Journal*, with hard copies sent to governmental agencies, professional research organizations, and medical and dental school research deans. As with the earlier TMJA-sponsored scientific meetings, Arthur W. English, Ph.D., editor of the professional journal, *Cells, Tissues, Organs*, will also publish the proceedings of the meeting as a special issue of the journal.

PROMOTING TMJ AWARENESS

TMJA President Terrie Cowley held meetings with high level government and agency officials in the ongoing advocacy to address TMJ points and needs. At the National Institutes of Health in Bethesda, MD she met...

...with **Dr. Story Landis, the new Director of the National Institute of Neurological Disorders and Stroke (NINDS)** to discuss the neurological components of TMJ diseases and disorders. They discussed the fact that pain is the primary reason TMJ patients seek treatment and Terrie cited the recommendations from the 2002 symposium, "Neurobiology and Craniofacial/Deep Tissue Persistent Pain", as a perfect blueprint for research into deep, persistent craniofacial pain. Dr. Landis and the National Institute of Dental and Craniofacial Research's Director, Dr. Lawrence Tabak, co-chairs of the NIH Pain Consortium, a group which includes representatives from the NIH components and was formed to highlight the importance of

research on pain and the need to develop better treatments to manage both acute and chronic pain.

...with **Dr. Belinda Seto, Deputy Director of the National Institute of Biomedical Imaging and Bioengineering** to discuss TMJ imaging research opportunities based on the recommendations from the third scientific meeting of The TMJ Association, *Advancing Diagnostic Approaches for TMJ Diseases and Disorders*, held May 2004.

...with **Dr. Lana Shekim, Health Scientist Administrator of the Speech/Voice Branch of the National Institute on Deafness and Other Communication Disorders (NIDCD)**. Terrie asked that TMJ patients be included in research relating to the special language and speech needs of individuals with TMJ diseases and disorders.

...with **Dr. Lynn Leuthke, Program Director of the National Institute of Deafness and Other Communication Disorders (NIDCD)**, to discuss the hearing and communication conditions that afflict many TMJ patients and to encourage that NIDCD's scientific and intellectual resources be directed toward TMJ diseases and disorders.

...with **Dr. Christopher Platt, Health Scientist Administrator**, also with NIDCD, to ask that the institute investigate the balance and vertigo problems that may result directly from the problems associated with TMJ diseases and disorders and their effects on the vestibular system in the inner ear, which controls balance.

...and with **Dr. David Goldstein, Chief, Clinical Neurocardiology Section**, National Institute of Neurological Disorders and Stroke to discuss investigating TMJ diseases and disorders in a systems biology approach.

Terrie also saw officials at the Food and Drug Administration in Rockville, Maryland. She participated in an FDA-sponsored mentoring workshop for Patient Representatives (PR) and Patient Consultants (PC). Terrie has been a patient representative since 1999. The workshop was designed to train mentors so that they could effectively share their knowledge and experience with newly appointed PRs and PCs.

While in Rockville, Terrie met with FDA's Dr. Daniel Schultz, Director of Devices and Radiological Health, to discuss the many concerns of TMJ implant patients.

Terrie also had several meetings with Washington area-based TMJA Board and Scientific Advisory Board members to discuss future plans for the Association, as well as ways to advance the diagnostic research agenda growing out of The Third Scientific Meeting.

TMJA Communication Statistics

In 2004, our average monthly incoming communication includes:

- Emails: 329
- Phone calls: 184
- Web site visitors: 41,856
- Web site hits: 970,769

PUBLICATION PROJECTS

- Star-News – “The Truth About TMJ” – July 29, 2004
- Good Housekeeping magazine - "Warning! The Medical "Miracles" that May be Hazardous to Your Health" - March 2004
- The Times-Picayune newspaper - "Dental suit could cost state millions" - January 18, 2004
- The TMJ Association was asked by Proctor & Gamble to update the TMJ section of their dental Web site.
- As a member of the National Institutes of Health (NIH) Temporomandibular Interagency Working Group, the TMJA was asked to critique a new NIH brochure on TMJ.
- The TMJA’s new dental hygiene brochures were completed by staff member and dental hygienist Jackie Kaczynski, C.H.E.S: *What TMJ Patients Should Know About Dental Hygiene and Self Care* and *Dental Hygiene Considerations for Patients with Temporomandibular Joint Diseases and Disorders*

ECONOMIC STATUS

2004 Financial Statements and Audit

We limited expenses to the bare minimum required to function in 2004. As we have reported in the past, we require about \$75,000 per year. This is the amount needed to cover salary for our one full-time and one part-time employee and expenses such as office rent, utilities, printing, postage, equipment maintenance, insurance and financial auditing. Expenses increased in 2004 due to the cost of the Scientific Meeting.

Our 2004 expenses were \$157,445, up from \$85,978 in 2003. Scientific Meeting costs of over \$60,000 explain the drastic increase in expenses over the past year. Due largely in part to our end-of-year fund raising appeal and a \$45,000 NIH grant for The Third Scientific Meeting, our revenue increased to \$172,822, up from \$89,308 in 2003.

The additional revenue will enable us to reinstate the quarterly newsletter, which was put on hold to save on printing and postage costs in 2003 and 2004 and replaced with online monthly Office Briefs. In addition, the TMJA received support from the National Institutes of Health grant to fund the Scientific Meeting. 2004 was the second 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 donation figures will not be in until late 2005. However, we received over \$7,000 in contributions from the 2003 CFC, and expect that number to increase once all 2004 CFC contributions are tallied.

Special Events

TMJA Board members Kevin Clark and James Wozniak organized a golf fund raising event which was held August 20 at the Silver Spring Country Club in Menomonee Falls, Wisconsin. The event was attended by 30 golfers and raised over \$5,000 for the TMJA.

Fund Raising 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 September 2004, the TMJA launched it’s fall fund raising appeal and received the largest response to date. The generosity of more than 250 supporters of

the TMJA raised nearly \$90,000. This type of altruism enables the TMJA to continue informing the public and policy makers, to provide empathetic and knowledgeable support to patients and their families, and to strive for multidisciplinary research to effectively treat TMJ diseases and disorders.

THE FUTURE

In 2004, we were able to continue to operate at an effective level, but with reduced direct contact services to patients and other interested individuals. Our successes in 2004 will enable us to reinstate some services to better assist TMJ patients and their families. Looking ahead to 2005, we know that we will have additional expenses with our newsletter, *TMJ Communiqué*, and for a patient support meeting in the fall of 2005. In addition, planning has begun for The Fourth Scientific Meeting to be held in 2006.