

This summary of The TMJ Association (TMJA) activities in 2003 highlights progress in five areas:

- TMJA Impact on National Leaders and Organizations
- Pain Treatment
- Research and Science – Moving TMJ Research into the 21st Century
- Promoting TMJ Awareness
- Organization Structure

For more information, see the *TMJ Communique*, 2003 Summary Edition and the *Monthly Office Briefs* for 2003.

TMJA IMPACT ON NATIONAL LEADERS AND ORGANIZATIONS

National Institutes of Health (NIH) Director

Dr. Elias Zerhouni, Director of the NIH, wrote to the TMJA after he received a copy of our latest TMJ Science journal:

“I am pleased to learn that plans are already underway for the next scientific meeting around the broad theme of imaging the temporomandibular joint and related structures. The broad range of support that the meeting received from various institutes and offices within the NIH is heartening and reflects the multi-faceted nature of research on TMJ disorders.

I understand that the National Institute of Dental and Craniofacial Research (NIDCR) has reviewed the recommendations from the first and second scientific meetings of your association, along with those from several other meetings on TMJ disorders sponsored by other groups, and developed them into an outline of research needs and opportunities. The various institutes, centers, and offices at the NIH, as well as other federal agencies represented on the Temporomandibular Joint and Muscle Disease Interagency Working Group (TMJDIWG), are currently reviewing the outline. Following the review and consolidation, the outline is likely to play a role in developing an NIH-wide research plan in this area. We are pleased to see that your association is one of several represented on the TMJDIWG and, along with the other members, is taking an active role in providing input that can shape the future of research in this area.”

NIH Roadmap

NIH Director Elias A. Zerhouni has unveiled plans to accelerate the movement from basic biomedical discoveries to patient care. The roadmap reflects the thinking of over 300 leaders in academia, industry, government and the public who were consulted by NIH on how best to exploit the rapid gains in knowledge achieved in recent decades (such as the sequencing of the human genome) for the greater benefit of the public's health. Of interest to TMJ patients NIH notes the need to develop new prevention strategies, new diagnostics and treatments including “a pressing need to better quantify clinically important symptoms and outcomes, including pain, fatigue, and quality of life that are now difficult to measure.”

Terrie's trips to Washington D.C. have underscored the importance of interdisciplinary research on TMJ as emphasized in the NIH Road Map and has opened doors to several NIH Institutes whose directors have expressed their interest in expanding/collaborating on TMJ research.

Retiring Heart Institute Director

In response to a letter from Terrie acknowledging Dr. Claude Lenfant's distinguished career as the Director of the National Heart, Lung, and Blood Institute, and in particular, his responsiveness to TMJ issues, the retiring Director replied to Terrie. He thanked her for her “inspirational perseverance in making his institute and NIH as a whole pay attention to diseases which are neglected by the establishment.” Dr. Lenfant said that the effect Terrie and her advocacy had on him made him aware

of the needs of TMJ patients, and also increased his sensitivity to other groups with whom he came in contact. He expressed his wish that the Heart Institute will continue to work with TMJA and, ultimately, that research will bring help to all TMJ patients.

Pain Care Coalition Meeting

The TMJA was one of 44 organizations invited to participate in a meeting held in Chicago in January. The advocates attending this meeting were asked to discuss the strategies and concerns related to each provision in the National Pain Care Policy Act. It was significant that the TMJA was in attendance for several reasons:

- It provided the opportunity for other organizations to hear of the unique concerns of TMJ patients, especially those related to the complex nature of the symptoms and a lack of a clear definition of what TMJ really is.
- It allowed the TMJA to influence the prioritization of research, by pointing out the pitfalls of pursuing some of the other proposed strategies and highlighting the crucial role credible research plays in support of the other issues.

Pain Research: Past, Present, and Future

Dr. Ronald Dubner, a member of The TMJ Association's scientific advisory board, was recently interviewed for the National Institute of Dental and Craniofacial Research's media publication The Inside Scoop. He discussed the promise of new tools and techniques available to pain researchers and care providers. You can view this article on-line at: http://www.nidcr.nih.gov/news/inside_scoop_dubner.asp.

RESEARCH AND SCIENCE – MOVING TMJ RESEARCH INTO THE 21ST CENTURY

TMJ Scientific Meeting

The TMJ Association has developed plans for its third scientific meeting to be held May 6-7, 2004 in Bethesda, MD. We encourage TMJ patients, dentists, physicians, government officials, investigators in musculoskeletal and pain research, medical scientists, and medical imaging specialists to attend this very exciting meeting, which will explore new ways to define TMJ diseases and disorders and will investigate new and emerging technologies provided through bioengineering, bioimaging, and computational biology. Meeting details and registration information are available on our Web site, www.tmj.org or by calling (414) 259-3223.

TMJ Patient Meeting

We are pleased to announce a TMJ patient meeting on May 5th, the day preceding our scientific meeting. This event will be open to all TMJ patients and their loved ones and will be a wonderful opportunity to come together to meet others whose lives have been touched by TMJ diseases/disorders. For meeting details visit our Web site at www.tmj.org or call our office at (414) 259-3223.

Genetic Research Provides New Hope for TMJ Patients

A group of University of Michigan neuroscientists has identified a single gene linked to the level of pain a person can tolerate. The research, reported in the journal *Science*, shows that how much pain you suffer is due, at least in part, to a gene that affects how many endorphins, or natural painkillers, your body produces.

It is extraordinary news for TMJ patients that there is finally a scientifically proven physiological basis to explain the level of pain they experience. Because it is genetically linked, predisposition to heightened pain response can be inherited. Patients who have been told their suffering is psychological now have evidence that their pain is truly physical.

Thanks to the work of these researchers and others committed to discovering the physiological sources of pain, especially for TMJ, there is new hope for research-based therapies. A simple blood test may, in the future, result in predicting which medications would be most effective for an individual sufferer.

The study's authors include Jon-Kar Zubieta, Mary Heitzig, Yolanda Smith, Joshua Bueller, Yanjun Xu, Robert Koeppe, and Christian Stohler of the University of Michigan, and Ke Xu and David Goldman of National Institute of Alcohol Abuse and Alcoholism. Dr. Stohler has credited The TMJ Association with helping him to remain persistent in pursuit of this research: "If it were not for the encouragement and education of The TMJ Association, we would have long given up...because we were told that what we were pursuing could not be done." (Dr. Stohler is now the Dean of the University of Maryland Dental School, Baltimore, Maryland. Dr. Stohler is also a Scientific Advisor to The TMJ Association.)

Three Prominent Scientists Join TMJA Scientific Advisory Board

Kyriacos A. Athanasiou, Ph.D., P.E., is a professor in the Department of Bioengineering at Rice University in Houston, Texas. He also holds adjunct appointments in the Department of Orthopaedics and the Department of Oral and Maxillofacial Surgery at the University of Texas Medical School in Houston. In recent years Dr. Athanasiou has focused on the temporomandibular joint, publishing articles on the structure and function of joint tissue based on animal models. Earlier this year he published a review of the complex biochemical, mechanical, and cellular properties of the joint disc and the challenges these properties pose for tissue engineering approaches to reconstruction.

J. Edward Puzas, Ph.D., is the Donald and Mary Clark Professor of Orthopaedics at the University of Rochester School of Medicine & Dentistry in New York. Dr. Puzas is also president of the Orthopaedic Research Society, a 1,700-member national organization that seeks ways to improve the care of patients with musculoskeletal diseases and injuries. Dr. Puzas commands great respect in the orthopedic community and his research will help enhance the body of knowledge on TMJ. Dr. Puzas was a presenter at both scientific meetings of the TMJA.

David P. White, M.D., is associated with the Division of Sleep Medicine at Boston's Brigham and Women's Hospital and Associate Professor of Medicine at Harvard Medical School. Dr. White conducts research on breathing disturbances in sleep, notably obstructive sleep apnea, in which patients experience multiple episodes of breathing cessation during a night's sleep. Dr. White was a participant in a National Heart, Lung, and Blood Institute workshop on Cardiovascular and Sleep-Related Consequences of Temporomandibular Disorders held at the National Institutes of Health in December 2001. The workshop was designed to create greater awareness among sleep researchers of the variety of sleep problems TMJ patients experience; especially patients with severely altered jaw anatomy and compromised muscle function as well as sleep disorders due to pain. In addition to his patient, teaching, and research responsibilities Dr. White is the editor of the journal, *Sleep*.

PROMOTING TMJ AWARENESS

2000 – 2010 Decade of the Bone & Joint

The Bone and Joint Decade is a worldwide effort to advance the understanding and treatment of musculoskeletal conditions and promote research. Patients, physicians, medical specialty societies, allied health professionals, and health organizations are urging their governments to focus attention on these disorders, which affect millions of people worldwide.

The TMJ Association is a member of the Decade and was asked to participate in a major initiative to improve medical school education in musculoskeletal medicine with the ultimate goal to improve musculoskeletal medical care. The project hopes to have 100% of American medical schools offer a required course in musculoskeletal medicine by the end of the Decade. Currently, only about half of the medical schools require such a course, and the predictable results are seen. Our scientific advisors will represent our contention that the TM joint join the great community of other joints in the body and that the musculoskeletal problems TMJ patients experience be included in medical school curriculum. To learn more about the Bone and Joint Decade go to: <http://www.boneandjointdecade.org/>.

TMJA's Second Scientific Meeting Publication – Cells Tissues Organs

Cells Tissues Organs, an international journal of cell and developmental biology, tissue engineering, and in vitro systems, has published a special topics issue consisting of selected papers presented at the second scientific meeting of The TMJ Association. Dr. Arthur English, editor, has our appreciation for his continuing interest in publishing papers presented at TMJA's scientific meetings.

TMJA Communication Data

In 2003 our average monthly incoming communication includes:

- Web site visitors 35,404
- Web site registrations 871
- Phone calls 81
- Web site hits 638,789
- E-mails 339

Informing Health Care Providers and Researchers

In our continuing effort to disseminate information on TMJ, we have recently sent TMJA brochures and TMJ Science journals to:

- American College of Rheumatology (ACR) conference, held October 23-28 in Orlando, FL
- Interstitial Cystitis Association
- American Dental Association
- American Association of Oral and Maxillofacial Surgeon's (AAOMS) annual meeting, held September 10-13 in Orlando, Florida
- American Academy of Craniofacial Pain, annual international meeting, held July 24-26 in Kansas City, MO
- Sun Valley Hard Tissue Workshop, held August 3-7 in Sun Valley, ID

Information to the Media

The Association linked TMJA patients, via our Web site, to important public awareness initiatives. John Pope and Susan Finch, staff writers at The Times-Picayune in New Orleans, are working on a project about TMJ implants. They want to talk on the record with people who have received implants and had problems with them.

ORGANIZATION STRUCTURE

The TMJ Association greatly strengthened its organization structure in 2003 with the addition of new board members from across the country. The new members are bringing diverse skills and experience, for example, in fundraising, strategic planning, and establishing contacts with media and policymakers, to further the goals of TMJA.

2003 – The Financial Picture

Expenses

The final financial statement for 2003 is not yet available; however, we can present a general overview of our expenses, our fundraising activities and our general financial situation.

We limited expenses to the bare minimum required to function in 2003. As we have reported in the past, we require about \$75,000 per year to exist as an organization. This is the amount needed to cover salary for our one paid employee and expenses such as office rent, utilities, printing, postage, equipment maintenance, insurance and financial auditing. We had no TMJ Association Scientific Meeting in 2003. We have a meeting planned for 2004 which will increase expenses in 2004.

Cost cutting measures included reducing the number of issues of the *TMJ Communique*, our newsletter, to one summary issue published in December. In place of the hardcopy publication of the *TJM Communique*, we added the *Monthly Office Brief* to our web site to keep you informed. We also reduced the amount of one-on-one communication with patients and other interested people. To compensate, we started the *Ask The TMJ Association* feature on our web site to answer the most frequently asked questions that we receive. We know that both of these cost-saving measures have disappointed some of our supporters who valued the more direct communication. We hope that everyone understands that we had no alternative.

Fundraising

As in the past, fundraising by direct-mail solicitation of past supporters and new people who have said they value the information and services we provide, has been our biggest source of revenue. In 2003 we raised \$72,736 by direct mail and other direct contact solicitation of individuals.

We had approximately \$17,000 in other income, mainly from residual grant money associated with our Scientific Meeting in 2002. These funds were used to complete tasks associated with that meeting, including publishing and distributing summaries of the papers presented at the meeting.

In 2003 we participated in the Combined Federal Campaign (CFC) for the first time. The CFC allows federal government workers to pledge contributions to the TMJ Association and have the contributions automatically deducted from their pay and sent to the TMJ Association. The actual contributions will start in 2004 and we do not yet know who or how many people signed up. We expect to get that information in early 2004. Because we are "competing" with hundreds of other organizations for the attention and contributions of federal workers, we expect modest revenue for the first few years of participation.

Bottom Line

In 2003 we were able to continue to operate at an effective level, but with reduced direct contact services to patients and other interested individuals. Continuing the pattern for the past several years, we operated with very little financial reserves. Looking ahead to 2004, we know that we will have additional expenses related to the planned 2004 Scientific Meeting. We hope to offset much of the expense of the meeting with grants from NIH, companies and foundations. As always, that is far from certain, but we continue to work to that goal. We also expect overall expenses for operation to increase in 2004. Our office equipment is getting older and despite low inflation, everything seems to get a little more expensive each year.