



Jaw Joints—TMJ Awareness Month *Getting the Word Out*

Over a decade ago on September 30, 1997, Massachusetts Congressman Barney Frank designated November as Jaw Joints—TMJ Awareness Month. His proclamation acknowledged that TMJDs are “among the more painful, yet least understood disorders affecting people today.”

In May the National Institute of Dental and Craniofacial Research (NIDCR) kicked off an awareness campaign in the Washington, DC area, very smartly suggesting “less is best” as words of advice, cautioning patients against invasive, irreversible procedures.

In November it was our turn to highlight the campaign on our Web site. See page 4 of this *Communiqué* for the NIDCR announcement. When NICDR Director Dr. Lawrence Tabak told us about the campaign at our June scientific meeting, he explained that the theme, “Less is Often Best” was inspired by a major article

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Getting to Know You...Then and Now

Any scrap of paper would suffice. Cocktail napkin. Paper towel. Junk mail. As long as I could write the notes from my conversations with TMJ patients on it, it would do.

The pain never truly let me enter into a deep slumber, but the shriek and whirl of the fax machine or the ringing of the phone would jar me awake. It would be a fax from a desperate patient or a patient leaving a long phone message.

When an article about the TMJ implant disaster came out in the *Ladies Home Journal*, I ran to the grocery store and went for a haircut. When I returned two hours later I had 72 messages on my answering machine. We had an unlisted phone number. Old friends couldn't find us, but the FDA, NIH, and the media gave our number to the TMJ world.

Those were the days when The TMJ Association called my home its headquarters. The house bore witness to the daily chaos as I juggled supporting fellow patients, building patient support networks, advocating for scientific research, demanding answers from the FDA—all the while trying to make sense of what was going on with my own health and doing my darnedest to be a "normal" housewife.

When we moved into the first real

Association office, it took three weeks until the phones were connected. One day two Milwaukee policemen came to the office. They said that a woman in New Hampshire desperately needed information on TMJ and asked for their help in finding me. That was then.

Early on we recognized the importance of the information superhighway and posted all of the latest TMJ information on our Web site. This technology has moved The TMJ Association to the forefront as an international resource center and support group connected in cyberspace. With so much information instantly available, the need for one-on-one phone support has been gradually supplanted by our online patient support network and now through our new TMJA forum (see page 8). The forum gives patients and loved ones the opportunity to share stories, coping mechanisms, book and movie reviews and such things that bring joy to a life in pain. I am excited that this use of the Internet enables us to reach more of you, wherever you are, to create a dynamic TMJ community.

Of course, I am still here reading your e-mails, letters, Web comments, taking notes, and answering your phone calls. This is now. Some things haven't changed. ♦

Terrie Cowley, President

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The TMJ Communiqué

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The *TMJ Communiqué* is intended solely as an information guide and source of support for people with temporomandibular joint and muscle disorders (TMJDs). It does not constitute medical or dental advice, nor is it a substitute for medical or dental advice. Always consult your healthcare professional before starting treatment. The TMJ Association does not provide referrals.

The Association does not endorse any particular healthcare professional, specialty or organization, nor do the opinions of a healthcare professional or organization referred to in the *TMJ Communiqué* reflect the opinions of The TMJ Association.

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Comorbidities Meeting Sparks High Interest – and a Major Research Study

The Fifth Scientific Meeting of the TMJA, *Can Studies of Comorbidities with TMJDs Reveal Common Mechanisms of Disease?* held in Bethesda, MD in June, was probably the best received and most exciting of the scientific meetings that the TMJA has ever held. Four National Institutes of Health (NIH) directors attended the evening opening session and expressed their enthusiasm about the aim of the meeting—to discover common mechanisms to explain overlapping symptoms for a range of poorly understood and painful disorders, including chronic headache, endometriosis, vulvodynia, generalized pain conditions, irritable bowel syndrome, interstitial cystitis, chronic fatigue syndrome, rheumatoid arthritis, fibromyalgia, and TMJDs. Earlier in the day Dr. Story Landis, Director of the National Institute of Neurological Disorders and Stroke, met with the invited advocacy group representatives to discuss what is happening at the NIH with respect to the Pain Consortium, the Neuroscience Blueprint, and other trans-NIH programs and issues relevant to the patient groups' interests. This pre-meeting afforded an opportunity for the representatives to provide information about their organizations, and to discuss how best to work together, given their shared interests and concerns. When groups representing millions of patients can speak with one voice in appealing to government science agencies and members of Congress for increased research, they are more likely to be heard than if each group were to make such appeals on its own.

The patient advocates had a second opportunity to introduce themselves and describe their conditions at a round table during the opening session. Their personal accounts of pain, of frustration in finding healthcare providers who could diagnose their problems and do whatever was possible to help them, were very moving and underscored why the meeting was so important. The NIH Directors listened and were impressed—as were other NIH staff and attendees with whom I spoke. That the TMJA was able to assemble so many representatives of serious illnesses was in itself a coup: “What a brilliant move . . . what a great idea” were some of the comments I heard. There was a feeling that the meeting could generate really exciting research that could move the field ahead and apply across all the diseases and disorders represented. Indeed, the meeting served to cement the interests of this group and legitimize their work in advocating for desperately needed research.

The scientists and clinicians who spoke were chosen for their expertise on each of the comorbid conditions represented. They suggested a number of underlying mechanisms that could give rise to shared symptoms, including genetic factors, a dysfunctional autonomic nervous system, and a malfunctioning immune system. However, there was one feature common to all—chronic pain—which in itself could reflect genetic factors and involve the autonomic nervous system and immune responses. Chronic pain became the focus of the breakout sessions in which attendees considered how best to track which genes are activated that give rise to pain, which may manifest as chronic tension headache in some individuals or as vulvodynia or TMJDs in others. One way to get at the answer is to conduct a genome-wide search for genes that unite the comorbid conditions. It would require a large sample, some 10,000 adults, representing patients with each of the overlapping conditions, as well as symptom-free individuals. Appropriately, such research would entail the cooperation of the patient advocacy groups as a source for volunteers. Additionally, academic health centers and pharmaceutical firms could contribute rosters of patients in order to come up with the numbers needed to create this novel database. Such an ambitious proposal, spanning a collection of diseases and disorders, has never been tried before. The promise of a breakthrough—meaning coming up with a set of genes whose interactions orchestrate the pain and end-organ malfunctions for a set of baffling conditions—is well worth the effort. You can see why people leaving this meeting felt it was the most exciting they had ever attended. ♦

Joan Wilentz, Editor

TMJA Welcomes Donald Birk to the Board

Donald Birk, a principal with Deloitte Consulting in Dallas, Texas, was elected to the Board of Directors in July 2008 and became the Board Chair on August 14, 2008. Mr. Birk brings 24 years of experience advising businesses, government agencies and non-profit organizations on a broad range of topics including information systems design and implementation, strategic planning and process improvement. He and his wife, Elizabeth, a TMJD patient for 26 years, first became aware of the Association when they were searching the Internet for information about the disorder. He said, "My interest in working with The TMJ Association is based on that early exposure. I saw what an impact this organization had on our lives, and I am committed to helping it continue to provide information and hope to the thousands of sufferers who interact with the TMJA every year." ♦

TMJ Awareness Month

Continued from page 1

on TMJDs that appeared in the *Journal of the American Medical Association*. A statement in the article highlighted the fact that tens of thousands of dollars are needlessly spent on TMJ treatments that are unsupported by scientific evidence. Every day is TMJ day for those touched by these conditions. Advocacy and education take place constantly. The designation of this awareness month gives us a specific time in which to educate the public regarding the realities of TMJ disorders. Now is the time for all of us to speak out. Tell us what you have done to publicize TMJDs—we'll include examples of your actions and ideas in our next newsletter. ♦

TMJA Golf Outing

The TMJA held its annual golf outing at the beautiful Grand Geneva Resort & Spa in Lake Geneva, WI on September 4th. Despite the inclement weather due to hurricane Gustav, everyone had a great time. Thanks to all for their support! ♦

Rave Reviews of the Scientific Meeting

"Thanks for the fantastic meeting. I have been going to TMD and pain meetings for over 20 years and this was one of the best that I have ever attended. The idea of bringing together all the experts and patient advocates for all the comorbidities was a great idea. We all need to get together and find those common purposes. The meeting truly reflected what I see as a clinician and what the vast majority of our patients report. Thanks for all of your hard work. It is obvious that you are accomplishing things that could not be done without your efforts! There are a lot of providers and patients who will benefit from what you are doing."

Morris A. Branch, D.D.S., M.S., Bethesda, MD

"Through all the years I have frequently heard [Terrie Cowley] remark 'Where is the science? How can there possibly be answers for these patients without the science?' My participation in the patient roundtable during the TMJA Fifth Scientific Meeting enabled me to appreciate the wisdom in those words. I was able to see first hand the valuable contribution that your efforts were making in bringing the science involved in the complex problems of TMJ into the foreground of scientific research and onto the radar screen at NIH. You have been a true champion of this cause and have certainly spearheaded the progress that has been achieved."

*Claire W. Patterson, Research Committee Member, Board of Directors
American Chronic Pain Association*

"I wanted to congratulate you on a superb conference! Definitely one of the best interdisciplinary gatherings I can remember! I hope that an NIH Road Map Initiative will come out of this."

*Emeran A. Mayer, MD
Director, Center for Neurobiology of Stress - Division of Digestive Diseases
University of California, Los Angeles*

"A goal of The TMJ Association meeting was to discover if there are common roots and physiological pathways among the conditions that often coexist with TMJD. Furthering the understanding of all of them may perhaps provide novel targets for diagnosis and therapy. Bringing together clinicians and investigators knowledgeable about each of the conditions addressed at this meeting may stimulate cross-collaborative studies as a means to accelerate research progress that will ultimately benefit patients. We thank and congratulate Terrie and Allen Cowley as well as the other members of the planning committee for organizing this stimulating and outstanding meeting."

*Nancy J. Norton, Founder and President
International Foundation for Functional Gastrointestinal Disorders*

"Bless you for the fabulous conference. The possibilities of finding underlying mechanisms amongst our comorbidities is so exciting."

*Mary Lou Ballweg, President/Executive Director
Endometriosis Association, Inc.*

"Thank you so much for inviting me to this thrilling meeting. I hope it fulfills its promise - to contribute to and, in fact, to be a leader in the tipping point we are reaching in advancing understanding and treatment of chronic pain conditions, particularly TMJDs."

*Karen Berkley, Ph.D.
Florida State University - Program in Neuroscience* ♦

NIDCR's TMJ Awareness Campaign

Earlier this year the National Institute of Dental and Craniofacial Research (NIDCR) conducted an advertising campaign. The advertisements were posted on Washington, DC transit buses and in Metro stations. Additionally, the ads are part of an outreach effort to over 60 editors at magazines that cater to women and health. The TMJA was very pleased to hear about the NIDCR's campaign and we can't agree more with the message!

Less Is Often Best In Treating TMJ Disorders

Temporomandibular joint and muscle disorders, commonly called "TMJ," are a group of painful conditions that affect the jaw joint and the muscles that control jaw movements. Injury plays a role in some TMJ problems, but for many people, symptoms seem to start without obvious reason. The good news is that for most people, pain in this area is not a signal of a serious problem. Generally, discomfort is occasional and temporary and will go away with little or no treatment. Even if symptoms persist, most patients still do not need aggressive types of treatment.

Scientists sponsored by the National Institute of Dental and Craniofacial Research (NIDCR) are looking for answers to what causes these disorders and how best to treat them. Currently, there is little scientific evidence to show which treatments work and which don't. Until there is science-based evidence to help health care providers make sound treatment decisions, NIDCR suggests the following:

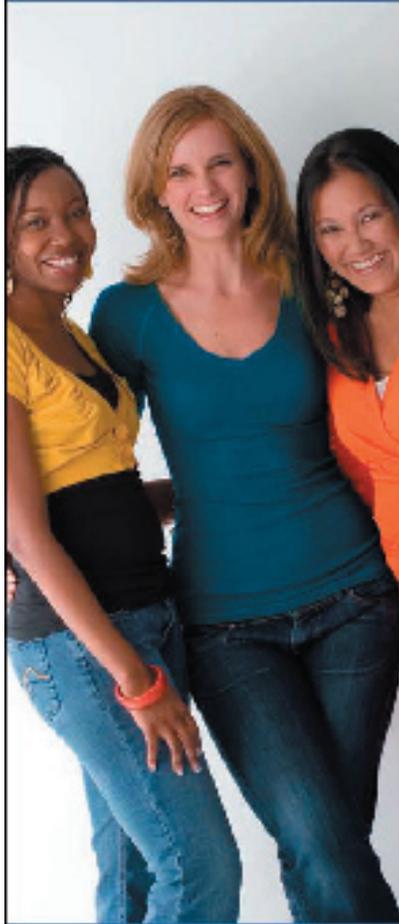
- Try simple self-care practices such as eating soft foods, using ice packs and avoiding extreme jaw movements, like wide yawning and gum chewing. Short-term use of over-the-counter or prescription pain medicines may also provide relief.
- Avoid treatments that cause permanent changes in the bite or jaw. Such treatments include crown and bridge work to balance the bite, orthodontics to change the bite, grinding down teeth to bring the bite into balance (occlusal adjustment), and repositioning splints, which permanently change the bite.
- Avoid, where possible, surgical treatment for TMJ. There have been no long-term studies to test the safety and effectiveness of these procedures. Before considering any surgery on the jaw joint, it's important to get opinions from other doctors and to fully understand the risks.

Finding the Right Care

Because there is no certified specialty for TMJ disorders in either dentistry or medicine, finding the right care can be difficult. Look for a health care provider who understands musculoskeletal disorders (affecting muscle, bone and joints) and who is trained in treating pain conditions. Pain clinics in hospitals and universities are often a good source of advice. ♦



Less is
Often Best



in Treating
TMJ

To view or order a
free booklet about
TMJ disorders, visit
www.nidcr.nih.gov and
click on "Oral Health."

U.S. DEPARTMENT OF HEALTH
AND HUMAN SERVICES
National Institutes of Health
National Institute of Dental and
Craniofacial Research
Office of Research on Women's Health

Medical College of Wisconsin Geneticist Joins TMJA Scientific Advisory Board



The TMJ Association is expanding its Scientific Advisory Board to enrich the range of expertise represented. The newest member is Howard J. Jacob, Ph.D., Director, Human and Molecular Genetics Center and Warren P. Knowles Chair in Genetics at the Medical College of Wisconsin (MCW), and

Professor, Department of Pediatrics, Children's Hospital of Wisconsin. He was appointed to the TMJA Scientific Advisory Board in July 2008.

Dr. Jacob's research career has focused on the genetics of cardiovascular disease, particularly in relation to high blood pressure (hypertension). He has worked extensively in a rat model, studying nervous system mechanisms that control blood pressure and genes predisposing to hypertension. Dr. Jacob's work on rats and the rat genome research program at MCW were featured in an episode of "Modern Marvels" on the History Channel this past spring.

His research dovetails nicely with the discoveries of genes more common to TMJD patients that indicate a heightened sensitivity to pain. As a colleague and friend of Allen W. Cowley, Jr., Professor and Chair of Physiology at the Medical College of Wisconsin, and

Chairman of the Scientific Advisory Board of The TMJ Association, Dr. Jacob has consistently shown interest in the work of the Association.

Dr. Jacob is no newcomer to the TMJ field. He has attended past TMJA Scientific Meetings and in the paper, *Genetics as the Glue for Translational Research*, which he presented at the Fourth Scientific Meeting in 2006, he envisioned that a technique called gene resequencing would enable researchers to identify genes which predispose people to one or another complex disease with a degree of certainty not now possible.

In responding to our invitation to join the board Dr. Jacob stated, "I am delighted to join the Scientific Advisory Board of The TMJ Association. I am truly impressed with the Association's role in advocacy and research. I look forward to working with the Association and the research teams to help bring the power of the human genome project to bear on this significant disease."

A native Midwesterner, Dr. Jacob was born in Topeka, Kansas, earned a B.S. degree in biology at Iowa State and a Ph.D. in pharmacology at the University of Iowa. He has published extensively, received numerous fellowships and awards, and in addition to his academic appointments, is currently the Founder and Interim Chief Executive Officer of PhysioGenix, Inc.

We welcome Dr. Jacob's expertise to the Scientific Advisory Board and the TMJA. ♦

Congress Passes Anti-Discrimination Genetic Act

The TMJ Association was one of hundreds of patient advocacy and healthcare organizations to support the Genetic Information Nondiscrimination Act (GINA) legislation, designed to protect against the misuse of genetic information by health insurance companies and employers. The House voted 420 to 3 in 2007; the Senate unanimously passed the bill in April 2008.

Under GINA, it would be illegal for health insurance companies to raise premiums or deny coverage based on genetic information. Employers would be barred from using genetic information to hire, fire and promote. The law also covers those with a family history of a particular disease. However, a person who already has a disease is not protected under GINA. The passing of this bill gives people the advantage of genetic testing without the fear of the information being used against them.

Recent research indicates that there are numerous genes that could predispose one to getting a TMJ problem. Because science is gradually revealing the role of genetics in determining who might be susceptible to developing TMJDs, the TMJA strongly supported this legislation. ♦

Senate Supports High Tech TMJD Research

This year marks the 14th consecutive year that the U.S. Senate Appropriations Subcommittee on Labor, Health, and Human Services, which funds the National Institutes of Health (NIH), has included language specific to TMJDs in its Appropriations Bill.

Why is Report Language Important?

Report language tells agencies of the NIH that elected officials are concerned about specific issues. This directive has a powerful influence on the decisions made by the government agencies.

What is the NIH?

Why is it Important to TMJ Patients?

The NIH, a part of the U.S. Department of Health and Human Services, is the primary federal agency that conducts and supports medical research. With the support of the American people, the NIH annually invests over \$28 billion in medical research. The NIH is composed of 27 Institutes and Centers. It provides leadership and financial support to researchers in every state and throughout the world. Helping to lead the way toward important medical discoveries that improve people's health and save lives, NIH scientists investigate ways to prevent disease as well as the causes, treatments, and even cures for common and rare diseases. One of those 27 components is the National Institute of Dental and Craniofacial Research (NIDCR), which supports the bulk of research on TMJDs. Because of the complexities of TMJDs, an increasing number of agencies of the NIH are recognizing that they have a significant role in solving the puzzle of TMJDs.

To TMJ Patients:

Our hope for relief from TMJDs lies in the answers only science can provide and that science is based in and funded by the NIH. Please read the report language. In its specificity, you will recognize that the Institutes are directed to use all their expertise to find real solutions to real problems. The significance of this cannot be overstated.

The Report to the National Institute of Dental and Craniofacial Research states:

The Committee encourages the NIDCR¹, along with the NLAMS² and NIBIB³, to put a higher priority on using noninvasive imaging technologies to establish, validate, and standardize clinical diagnostic criteria for TMJDs and to better understand the etiology and mechanisms underlying the symptoms of biomechanical pain and dysfunction. The Committee also calls on the NIDCR to initiate interdisciplinary partnerships within the NIH on chronic pain that is associated not only with TMJDs but other conditions as well. To address these collaborations extramurally, the Committee urges NIDCR to follow the recommendation of

the Fourth Scientific Meeting of The TMJ Association calling for the establishment of regional centers of excellence. Finally, the Committee calls upon the TMJ Interagency Working Group to step up its level of activities and work more effectively to assess the state of science of TMJDs and their co-morbidities, and to develop short- and long-range research plans.

The Report to the National Institute of Arthritis and Musculoskeletal and Skin Diseases states:

Temporomandibular Joint Disorders [TMJDs].—As the temporomandibular joint is a joint in the body, the Committee believes that increased effort by the NLAMS on TMJDs is clearly warranted. Such an effort would greatly accelerate the basic and clinical understanding of this joint, critical to such functions as speaking, breathing, eating, swallowing and making facial expressions. The Committee calls on the NLAMS to work with the NIDCR and NIBIB to develop a research team involving bioengineers, computer scientists, basic and clinical scientists to study the jaw anatomy, physiology and the complex neural, endocrine and immune systems interactions that orchestrate jaw function and trigger pathology of the jaw joint. The Institutes should integrate the findings from interdisciplinary studies of the structure, mechanical function, metabolism, and blood flow of bone, joints, and muscles with studies of central and peripheral neural pathways, and the endocrine, paracrine, and cytokine factors that impact upon these craniofacial structures, as a means to understanding the underlying causes of pain and dysfunction.

The TMJA is grateful to our champions—Senators Harkin, Specter and Kohl—for their continued support. We ask you to please thank them directly.

Senator Herb Kohl of Wisconsin

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Senator Tom Harkin of Iowa

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Senator Arlen Specter of Pennsylvania

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¹ National Institute of Dental and Craniofacial Research,

² National Institute of Arthritis and Musculoskeletal and Skin Diseases

³ National Institute of Biomedical Imaging and BioEngineering

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Your Contribution Will Help the TMJA!

CFC #12102:

The Combined Federal Campaign (CFC) fund drive has begun. If you are a federal employee, your designation of The TMJ Association on your donor form will be invaluable. Simply select #12102 on the donor registration card.

If you're not a federal employee, please share this information with those who are—we all know at least one federal worker, our postal carrier. Also, you may have family members or friends serving in the military who would be willing to support our cause!

SECC:

State employees can contribute through the State Employee Contribution Campaign (SECC). Each state has its own eligibility requirements and the TMJA currently qualifies and participates in the following states:

- Arizona
- California
- Connecticut
- Florida
- Maryland
- Massachusetts
- New Jersey
- New York
- Ohio
- Rhode Island
- Washington
- Wisconsin

United Way:

If your employer participates in the United Way donor program please consider designating The TMJ Association to receive your contribution. Simply write in The TMJ Association on your donor form. ♦

Your contributions, regardless of size, will have a direct, immediate, and positive effect on our efforts to increase our services to those affected by TMJ and to change the face of TMJ!

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TMJ Wristbands Now Available!



You can help promote awareness of TMJDs by wearing an awareness wristband with The TMJ Association's tag line "*Changing the Face of TMJ.*"

For a minimum contribution of \$10 we will send you two wristbands. Please indicate size: medium or large. ♦

TMJA Online Forum

<http://forum.tmj.org>

Two goals of the TMJA, since its founding, have been to disseminate comprehensive and credible information on TMJDs and to provide understanding and support to TMJ patients and their loved ones. The Association has recently introduced an online forum to enhance our capabilities to fulfill these goals. This online community is a part of a larger effort by the organization to reach out to its constituents and TMJD sufferers on the Internet.

TMJA President and Co-Founder Terrie Cowley says, "Patients need to understand that TMJDs remain medical mysteries. We don't understand all the causes and there are no treatments guaranteed to work, so patients need to be wary. We also want patients to realize that they are not alone. There are many other TMJD sufferers and the forum is a way of bringing them together."

The forum, with TMJD patient Stacy Stone as the Association's Online Communications Coordinator to guide operations, adds to our presence on the Internet. The TMJA's Web site, www.tmj.org, has already been recognized as the leading source of reliable information on TMJDs by scientists and health information experts.

The forum is available at <http://forum.tmj.org>. Hope to see you there! ♦

The Word to the Food and Drug Administration: Do More to Track Devices

The Food and Drug Administration (FDA) Modernization Act requires that manufacturers track certain devices when the agency orders them to do so. Tracking is intended to facilitate notification and recall in the event a device presents a serious risk to health that requires prompt attention. Manufacturers have 3 days to provide critical information about devices that have not yet been distributed to a patient and 10 working days for devices that have been distributed to patients. Manufacturers are required to track the TMJ prosthesis, the Glenoid fossa prosthesis and Mandibular condyle prosthesis.

The TMJ Association, a member of the Patient and Consumer Coalition, co-signed a letter to the FDA urging the agency to strengthen its medical device tracking system, to adopt a unique medical device numbering system and to conduct inspections of US manufacturing facilities in a timely manner. The letter emphasized the severity of health problems a patient faces when a medical device does not function properly or fails completely. ♦