



We are deeply saddened by the events that took place on September 11th and our thoughts and prayers are with the victims of this attack and their loved ones.

We'd Like to Do More...

As you may know, The TMJ Association is struggling financially this year. We are extremely thankful to the contributors and dedicated individuals, especially Joan Wilentz, who have made this Communiqué possible.

We regret at this time that we are unable to distribute this issue of the Communiqué to the thousands who have requested hard copies. We will, however, mail a copy to everyone who has recently contributed to the Association. The issue will also be posted on our Web site, www.tmj.org, and we encourage you and all others concerned with TMJ to keep informed through frequent visits to the site.

With your continued help and financial support we hope to follow this edition with another in the not too distant future. We are looking for a sponsor of the Communiqué so that we can return to our regular updates for you. Please let us know if you, your company, or someone you know may be interested in sponsoring an issue or two. It's not a lot of money, but it's important to continue to spread the truth about TMJ and stay connected. ♦

In This Issue...

	page
Pain in the News	1
We'd Like to Do More.....	1
Board Update	2
TMJA Fundraising	2
Editorial	3
TMJ Science.....	4
C&EN	4
TMJA Scientific/Patient Meeting	5
TMJA in the Press.....	5
TMJ Report Language.....	6
Word from Washington.....	7
Awareness Campaign Results.....	8
Your Letters	8
Support Needed	9
In Memorium.....	10

Jaw Pain Study Shows Pain is More Intense for Some; a Clue to Chronic Pain States

A new study proving that some people experience pain and suffering more intensely than others could help TMJ patients find better support for adequate pain management.

A University of Michigan study captured images of the brain in response to sustained pain, demonstrating that some people produce more of the body's natural painkillers, known as endorphins, than others.

People not only differ in their ability to produce these painkillers, but also in the ability of the nervous system to absorb them, the study found. It was funded by the National Institute of Dental and Craniofacial Research.

"We have shown that people vary both in the number of receptors that they have for these anti-pain brain chemicals and in their ability to release the chemicals themselves," said Dr. Jon-Kar Zubieta, the study's lead researcher, speaking to the *Chicago Tribune*. Zubieta is a neurobiologist, psychiatrist and radiologist at the University of Michigan Medical School. TMJA Science Advisory Board member Dr. Christian Stohler was a co-author.

Researchers found that some people may find a certain level of pain agonizing, while others might sense only discomfort. These findings bolster claims that severe pain often goes untreated.

"This may help explain why some people are more sensitive, or less sensitive, than others when it comes to painful sensations," Zubieta said. "Such variability in the pain-response system may help explain why some people react to pain and pain medications differently. It may also be quite relevant to why some people, but not others, develop chronic pain conditions."

In a special twist, the study focused specifically on pain centered in the TMJ. Volunteers were subjected to injections of a highly concentrated salt-water solution in the masseter, one of the jaw muscles, causing rapid, significant pain. The effects lasted about 20 minutes, making this a study of sustained pain, more akin to chronic pain than the acute pain you get with a pinprick. For comparison, the volunteers were injected with a non-painful placebo solution.

When a person experiences pain, the body instantly responds to the sensation and the brain seeks to discover where you hurt, what caused it, and how intense the pain is. At the same time, stress causes the brain to produce natural opiates—endorphins and enkephalins—that inhibit incoming messages from the painful area to lessen your perception and protect you from the full brunt of the experience. As the volunteers underwent positron emission tomography (PET) scans of the brain and the salt water

continued on page 11

The TMJ Communiqué

Joan Wilentz, Editor

Marion Blackburn, Contributing Editor

Terrie Cowley, Contributing Editor

Deanne Clare, Production Manager

Copyright 2001 by:
The TMJ Communiqué

The TMJ Communiqué is intended solely as an information guide and source of support for people with TMJ diseases and disorders. It does not constitute medical advice, nor is it a substitute for medical advice. Always consult your physician before starting treatment. The TMJ Association does not provide physician referrals.

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

Send correspondence to:
Editor, TMJ Communiqué
P.O. Box 26770
Milwaukee, WI 53226-0770
Phone: 414-259-3223
Fax: 414-259-8112
Web site: www.tmj.org
E-mail: info@tmj.org

The TMJ Association, Ltd. is a non-profit 501(c)(3) exempt private foundation.

Photocopying the newsletter without permission is a violation of copyright laws. If you would like to reprint an article appearing in the TMJ Communiqué, please write to The TMJ Association and request permission.

TMJA Board Expands; Emphasizes Fundraising

The TMJA Board of Directors has held three teleconferenced meetings this year on May 23, June 11 and August 8. At the mandatory annual meeting in May, the Directors changed the by-laws to allow for additional Board members and held elections. Terrie Cowley continues as President, Kevin D. Clark as Vice President, Kay Austermann as Treasurer, and new Board member, C. Polly Ellingson, was elected Secretary. Polly is an attorney with a strong background in human resource, health care, and contract law. The two other members added to the Board are James M. Wozniak, a Certified Financial Planner, who is a past president and current Finance Committee member of the Milwaukee Area Technical College Foundation, and Charles Sturm who had served as TMJA's tax accountant for many years. At the June meeting Board member William Layden was elected to the new position of Chairman of the Board and it was agreed to establish Board subcommittees as an efficient management tool to conduct Association business. The how-to's of fundraising and applying for grants were dominant themes at these meetings, with the Association setting a goal of raising \$150,000 by December 31, 2001. Software to enable credit card contributions has now been added to the TMJA Web site. Program initiatives discussed included needs to enhance patient and professional education and ideas for holding a second TMJA scientific meeting to stimulate research. ♦

TMJA Fundraising: How You've Helped — and Can Help

Thanks go to Paul and Coleen Clapper for generating contributions for The TMJ Association. They contacted us and put together 25 packets of information, which they distributed to friends, family members, and business associates. They enclosed a personalized letter, our newsletter, a contribution form with their name noted at the bottom for ease of tracking and self-addressed stamped envelopes with each request. We received many contributions because of the Clappers' efforts.

Linda Hoover suggested TMJA supporters collect their pocket change in a certain place for the remaining part of the year and send in a check for the amount collected at year-end to the Association. She said it would be a great way for individuals to help "change" the face of TMJ.

Marsha Love contacted us about a recent garage sale. She wrote: "Dan and I are happy to send a check to The TMJ Association from our recent garage sale. It was a family affair with our daughter Candice printing the TMJ sign and donating clothing articles, along with a cash donation. My mother came from Indiana with many nice household articles, and my husband Dan and son Matthew took care of the sales. We had NIH brochures available on tables throughout the garage, along with other TMJ information and TMJ Association contact numbers." Several TMJ patients who attended the sale received information provided by Marsha.

Marion Blackburn, the medical writer who joins the Communiqué staff with this issue, is also a runner who suffers occasional bouts of TMJ dysfunction. Marion is planning a benefit run, "Ten Miles for the Jaw Association," next year to raise awareness and money for the TMJ Association. The run will take place in Greenville, N.C. and is open to anyone. Contact her at (252) 931-0728 for information. E-mail mpblackburn@earthlink.net.

Letter from Terrie

The events of September 11th have changed our world forever. We continue to be absorbed with the tragic loss of life, a city disfigured, and new serious concerns. As we empathized with those directly affected, we opened our heavy hearts and perhaps not so heavy wallets in gestures of support. As the President asked us to get our lives back to normal, we returned to the TMJA office knowing that some things had not changed. Your letters, e-mails and telephone calls let us know that TMJ patients are still suffering and that we still must tell you that we lack quality basic and clinical research that will yield answers to your questions.

Though our fifteen years of struggle have yielded many successes, this year we have seen unprecedented action at the National Institutes of Health (NIH), which now appears to be committed to expand the scope and improve the quality of research on TMJ diseases and disorders. As a result of our first scientific meeting of May 2000, and our continuous advocacy for multidisciplinary research, several institutes of the NIH have initiated activities, leading to research specifically focused on TMJ problems.

- **Dr. Lawrence Tabak, Director of the National Institute of Dental and Craniofacial Research (NIDCR)**, has now proposed, and the Institute's Advisory Council has approved, a TMJ implant patient registry. Dr. Tabak assures us that implant patients will be consulted regarding the development of this registry. Since 1992, we have taken every opportunity to impress upon the FDA and NIH the need for a TMJ implant registry and we are encouraged by this action. Dr. Tabak also recognizes the need to augment the TMD Interagency Working Group by conducting scientific discussions with other NIH institutes and offices about gaps in knowledge and future opportunities in TMD research.
- **Dr. Claude Lenfant, Director of the National Heart, Lung, and Blood Institute (NHLBI)**, has formed a committee to determine the aspects of TMJ that lie within the Heart Institute's area of scientific expertise.
- **Dr. Cheryl Kitt, Program Director for Pain Systems and Cognitive Neurosciences at the National Institute of Neurological Diseases and Stroke (NINDS)**, in collaboration with TMJA Science Advisory Board member Dr. Ronald Dubner, has planned a workshop on the Neurobiology of Craniofacial/Deep Tissue Persistent Pain to be held in March, 2002 in connection with the annual meeting of the American Pain Society. TMJ pain will be a critical component of the meeting agenda.
- **Dr. Vivian Pinn, Director of the NIH Office of Research on Women's Health**, has extended her personal support and that of her Office to each of these institutes' projects, as well as taking the initiative to collaborate with other agencies on the development of informational material on TMJ diseases and disorders for health care professionals.
- **The Agency for Healthcare Research and Quality** issued a contract for a study of the per-patient cost and effectiveness of treatments for TMJ problems in response to a request by the Senate Appropriations Committee. The TMJA provided information for this study as well as one conducted by **ECRI**, a nonprofit healthcare review agency which conducted an analysis of clinical studies of TMJ treatments that have been published since the NIH-sponsored Technology Assessment Conference in 1996.
- In May, The TMJA filed a petition with the Food and Drug Administration requesting reconsideration of their approval decision on TMJ Implants, Inc. Fossa Eminence Prosthesis. This decision was contrary to the unanimous non-approvable vote of the Dental Products Panel, which examined the evidence presented by the manufacturer.
- Finally, perhaps our greatest accomplishment is that more TMJ patients are seeking reversible treatments today as a result of our 15-year education campaign. Patients tell us that they are re-evaluating the recommendations of their providers after reading our information. Many take printouts of our Web site information to their providers and report that this information is not being casually dismissed. In fact, since our campaign emphasizing the lack of scientific understanding of TMJ diseases and disorders and any rationale for treatments proposed, similar information is now available from other key sources.

Our successes over the years stand as proof that we're making progress. Yet there are many areas we haven't even begun to address, because of our financial restrictions. The needs of our patients individually and collectively require more of our help than we can give at this time. We are committed to do whatever it takes to keep working for all TMJ patients, but **your contributions are needed to keep this partnership going.**

What has not changed is our determination and commitment to our mission and to the TMJ patients. However, in order to continue this year we must limit our services to the following key priorities.

- We will continue to meet with and maintain regular communication with those officials whose actions affect TMJ policy.
- We will hold our second scientific meeting in May 2002, inviting renowned scientists to address the rheumatological components of TMJ and in this way reinforce the strong impact that our first scientific meeting had on NIH and other key policy makers. *See page 5 for more information.*

Moving Temporomandibular Joint Research into the 21st Century

The TMJA was proud to publish its first science journal, *TMJ Science*, in January 2001. The journal summarized the proceedings at the TMJA's first scientific meeting, titled "Moving Temporomandibular Joint Research into the 21st Century." The journal is available on our Web site at no charge or hard copies may be purchased for \$5.00 each. If you would like to purchase a copy, please send a check payable to The TMJ Association, P.O. Box 26770, Milwaukee, WI 53226.

Cells Tissues Organs, an international journal of modern cell and developmental biology and tissue engineering, has published a special issue containing the papers presented at our conference by experts in arthritis, TMJ pathology, bone, joint, and muscle physiology, neurobiology, pain, genetics, endocrinology, immunology, wound healing and tissue engineering. It is hoped this publication will serve as a starting point for future basic research in this area. The special issue of the *Cells Tissues Organs* journal edited by Drs. Arthur W. English and Christian S. Stohler can be purchased for \$29.00 by calling S. Karger Publishers, Inc. at 1-800-828-5479, or by sending your order to S. Karger Publishers, Inc. 26 West Avon Road, P.O. Box 529, Farmington, CT 06085. (*Cells Tissues Organs*, Vol. 169, No. 1, 2001) ♦

Kudos from an Institute Director

The TMJA sent a copy of *TMJ Science* to each institute director of the NIH. We are extremely pleased to have received the following letter from **Dr. Claude Lenfant, Director of the National Heart, Lung, and Blood Institute**. It is heartening to receive appreciation for our efforts to bring quality science to TMJ diseases and disorders.

Dear Ms. Cowley,

*I am writing this letter to tell you how glad I was to receive a copy of *TMJ Science*. Admittedly, I was surprised at first because I was not aware that the Association to which you are so committed had reached the state where it would have its own publication.*

If I may, I would like to congratulate you and your colleagues for this publication, and also for all that you do to promote work on TMJ. Among the "things" that interest me, I have a great fascination for the power of the public, and I think that what you do is a wonderful example of what is possible.

Again, congratulations and best wishes.

Sincerely yours,

*Claude Lenfant, M.D.
Director - National Heart, Lung, and Blood Institute ♦*

Poorly Understood TMJ Problem Gets Needed Attention

By Maureen Rouhi

Reprinted (Excerpted) with permission by
Chemical & Engineering News

June 26, 2000, 78(26), 41-42

Copyright 2000 American Chemical Society

Last month, researchers met in Bethesda, Md., to help build a scientific basis for research on diseases and disorders of the temporomandibular joint (TMJ). The meeting brought together scientists with expertise in chronic pain; neuromuscular disorders; bone, joint, and muscle physiology; chronic immune and inflammatory diseases; genetics; endocrinology; immunology; bioengineering; and biomaterials. It was organized by The TMJ Association, a patient advocacy group based in Milwaukee, to assess the state of TMJ science, identify research directions, and attract new research to the field.

TMJ diseases and disorders are chronic, painful conditions affecting the area where the lower jaw joins the skull. According to the National Institutes of Health, more than 10 million people, mostly women of childbearing age, are affected in the U.S. More than 50 treatments are in use, a reflection of the poor understanding of these diseases. These treatments range from very conservative, such as palliative measures, to very aggressive and invasive, such as surgery to replace the joint with implants made with various materials.

The Bethesda meeting highlighted the woeful state of the knowledge base for TMJ diseases and disorders and the challenges ahead. For example, even the basic facts of the magnitude and types of loads acting on the joint are not known. And the information will not be easily obtainable, requiring invasive measurements that cannot be done with humans. Observations have to be made with animal models, but "there isn't any model that's good or at least that has been validated," commented Susan W. Herring, a professor of orthodontics at the University of Washington.

Herring's studies with a pig model of the human TMJ show that the joint is subjected to dynamic and variable loads, a situation more complex than previously realized. "The belief that TMJ was only slightly loaded was one factor that led to the disastrous use" of TMJ implants, she noted.

The ill effects suffered by people with TMJ implants (C&EN, June 28, 1999, page 24) was also due to a "cavalier choice of materials without adequate chemistry and chemical engineering input," according to Robert E. Baier, a chemist and executive director of the Industry/University Cooperative Research Center for Biosurfaces at the State University of New York, Buffalo. "The challenge for chemists and chemical engineers is to come up with a rational bases for selection of materials, as well as unique designs of new materials that will adequately serve the needs for function and safety," he told C&EN.

continued on page 11

TMJA in the Press

The TMJA and its board members appeared in the following news articles, which contain quotes or cited references to the Association.

- *Procter & Gamble's* Global Dental Resource Web site, www.dentalcare.com/soap/patient/pe-menu.htm. P&G asked us to write the information that appears on their site concerning Temporomandibular Joint Diseases/Disorders. P&G had the written text translated into 16 different languages and unveiled this piece as part of their presentation at the American Dental Association (ADA) Annual Meeting, October 13-17 2001 in Kansas City, MO.
- *Arthritis Today*, "Why Your Jaw Hurts" September-October 2001 by Mary Anne Dunkin. We are pleased that the Arthritis Foundation addressed the issue of TMJ diseases/disorders in a 2-page article. The TM joint is susceptible to various forms of degenerative disease, including osteo- and rheumatoid arthritis.
- *New York Times*, "When Medical Devices Fail in the Body," pg. A1, August 7, 2001 by Ken Chang. Mr. Chang interviewed Terrie Cowley and a Vitek implant patient we put him in touch with on the TMJ implant issue. It's heartening to know that at last writers of articles on TMJ are seeking and including the patient's perspective. The article reiterated the fact that there are many medical devices being used in people today and no one is tracking them, while many suffer from the failure of the implant.
- *Boulder Colorado Daily Camera*, "Unlocking the Mystery" July 31, 2001 by Kevin Williams. We put Mr. Williams in contact with a TMJ patient in the Boulder CO area to interview for this article. Through various interviews the article demonstrates there is no medical consensus on the diagnosis, treatment and cure of TMJ diseases/disorders.
- *Health Magazine*, "Peace for Troubled Jaws?" pg. 90, March 2001 by Catherine Guthrie. Looks at the current TMJ implant device situation from a patient's perspective. The article goes on to say that TMJ patients need to proceed very cautiously and try the most conservative type treatments first.
- *Washington Post*, "Taking It On the Chin", page HE19 February 27, 2001 by Judy Packer-Turman. Reports "...mainstream practitioners don't have a clear strategy for addressing the painful problem, alternative medicine offers no surefire solutions and there's scant science to back up any treatment approach".
- *The Oregonian*, "Jaw Disorder Keeps Patients in Pain, Keeps Doctors Searching for Cause" December 17, 2000 by Patrick O'Neill. Discusses the lack of clear answers and some possible culprits for the problem.
- *Woman's World*, "What you Should Do About... Jaw Pain" October 31, 2000. Provides self-help tips on controlling jaw pain. ♦

TMJA Fundraising: How You've Helped — and Can Help

continued from page 2

These are great examples of how you can help raise awareness and funds for The TMJ Association. As one familiar with TMJ and The TMJ Association, you know the energy and resources that have been expended simply to achieve our accomplishments to date. More important, you know there is still much more to be done to bring TMJ research and treatment to an acceptable level. With your help, we will be able to continue to carry out our mission, which will lead to improved health care and quality of life for every TMJ patient. **WE NEED YOU!** We are **YOUR** Association and we cannot continue without **YOUR** financial Support.

We would like to take this occasion to acquaint you with other ways you may contribute to the TMJA.

- Consider sharing your tax refund check with the TMJA.
- Check with your employer to see if your company has a matching charitable contribution program.
- Designate the TMJA as a beneficiary in your estate planning.
- Honor or memorialize a loved one or friend by making a contribution in his or her name.
- Expand the number of contributors to the Association by asking your friends and relatives to make a donation. Certainly, they know how TMJ can affect a life and will welcome the opportunity to be part of the solution.
- Fall is the time when many communities around the country kick off their United Way Fund Appeal campaigns. As you know the United Way sponsors a single community approach to raising and distributing charitable gifts. Donors can choose to have their gift help a specific agency. Last year the TMJA received \$15,254 in donations through the United Way's Donor Choice program.
- Our Web site provides for online giving.

These gifts continue to help us promote public awareness and provide information on Temporomandibular Joint Diseases and Disorders (TMJ), provide support to TMJ sufferers and their loved ones, and advocate for basic and applied research that will reveal the causes and appropriate treatments for these complex problems. ♦

TMJA Plans 2nd Scientific Meeting and Patient Meeting

The TMJ Association is proud to sponsor its second scientific meeting *Joint and Muscle Dysfunction of the Temporomandibular Joint* to be held May 6-8, 2002 in Bethesda MD. The fundamental goal of this conference is to enrich the pool of investigators directed to TMJ research by attracting experts from other fields and by stimulating the interest of young investigators in this emerging field of research. The conference will bring together an internationally recognized interdisciplinary group of basic and clinical investigators in rheumatology and musculoskeletal diseases to address the biochemical, molecular, and biomechanical aspects of structure and functions of the TM joint. A patient meeting is planned to follow the scientific meeting. Meeting date(s), location, and other details have not yet been decided, but we'll keep you apprised of this information as it becomes available. Together we are ...*moving TMJ Research into the 21st Century!* ♦

TMJ Report Language

This was the eighth consecutive year that the US Senate has included, as report language, TMJ diseases and disorders in the National Institute of Dental and Craniofacial Research (NIDCR) Budget for fiscal year 2001. What this means is that our elected officials are continuing to respond to the concerns of the TMJ patients of this country. Please send a "Thank You" to each committee member listed below and let them know you appreciate their actions on your behalf. If you are unable to send a note to each committee member, please consider sending a letter to the **Chairman, Senator Tom Harkin, and the Ranking Member, Senator Arlen Specter.**

Over the next few weeks, the committees of the House and Senate will be holding meetings to discuss the budget for fiscal year 2002, which began October 1, 2001. Until we get the research we deserve, we want TMJ to be included in NIH/NIDCR's budget. Please send each of the elected officials listed below a letter or e-mail to let them know how TMJ problems are affecting your life and how desperately we need quality, multidisciplinary research to give us an understanding of TMJ diseases and disorders and ensure that treatments are based on sound science.

On March 26th Senator Harkin's office convened a meeting between The TMJ Association and representatives from the National Institutes of Health (NIH) and the National Institute of Dental and Craniofacial Research (NIDCR). This meeting gave a clear indication to the NIH Director's office and the Director of NIDCR that the Senator is indeed serious about seeing progress on the TMJ research front. We are truly fortunate to have such an advocate for our welfare and ask you to send a special note of thanks to **Senator Harkin** and ask for his continued support and monitoring of NIH research on TMJ.

Members of Senate Committee on Appropriations:

Tom Harkin, Chairman, of Iowa, Ernest Hollings of South Carolina, Daniel Inouye of Hawaii, Harry Reid of Nevada, Herb Kohl of Wisconsin, Patty Murray of Washington, and Mary Landrieu of Louisiana.

Arlen Specter, Ranking Minority Member, of Pennsylvania, Thad Cochran of Mississippi, Judd Gregg of New Hampshire, Larry Craig of Idaho, Kay Bailey Hutchison of Texas, Ted Stevens of Alaska, and Mike DeWine of Ohio.

Address: Committee on Appropriations, Senate Subcommittee on Labor, Health and Human Services, Education, United States Senate, SD-186, The Capitol, Washington, D.C. 20510

It is also important to educate the House Committee on Appropriations. Please send them your TMJ concerns.

Members of the House Committee on Appropriations:

Ralph Regula, Chairman, of Ohio, C.W. Bill Young of Florida, Ernest J. Istook, Jr. of Oklahoma, Dan Miller of Florida, Roger F. Wicker of Mississippi, Anne Northup of Kentucky, Randy "Duke" Cunningham of California, Kay Granger of Texas, John E. Peterson of Pennsylvania, and Don Sherwood of Pennsylvania.

David R. Obey, Ranking Minority Member, of Wisconsin, Steny H. Hoyer of Maryland, Nancy Pelosi of California, Nita M. Lowey of New York, Rosa DeLauro of Connecticut, Jesse L. Jackson, Jr. of Illinois, and Patrick J. Kennedy of Rhode Island.

Address: Committee on Appropriations, House Subcommittee on Labor, Health and Human Services, Education, United States House of Representatives, 2358 Rayburn HOB, Washington, D.C. 20515-6024 ♦

TMJA's Chairman of the Board

The TMJA's newly elected Board Chairman, William Layden, joined The TMJA Board in 1998. Mr. Layden is a Senior Vice President at Porter Novelli, an international public relations and consulting firm. He specializes in food and nutrition policy. Before joining Porter Novelli, he worked in both the executive and legislative branches of the Federal government. He was a professional staff member on the Human Resources and Intergovernmental Relations Subcommittee of the House Committee on Government Operations. Mr. Layden's introduction to TMJ came in 1993 as the legislative aide to Congressman Edolphus Towns (D-NY) who assumed the chairmanship of the subcommittee. Mr. Layden was in charge of the continuing oversight investigation of TMJ, NIH and FDA activities following the NIH congressional hearings titled "Are FDA and NIH Ignoring the Dangers of TMJ (Jaw) Implants?" Initially introduced to TMJ by Terrie Cowley and concerned about the plight of TMJ patients and their families, Mr. Layden has maintained his interest in the issues of TMJ over the years. ♦

The Word from Washington...

- **No Action on a future NIH Director.** The names of two Institute Directors, Anthony Fauci of the National Institute of Allergy and Infectious Disease and Francis Collins of the National Human Genome Research Institute, have emerged as major contenders. Meanwhile, Richard Klausner, Director of the National Cancer Institute, has resigned to become the first president of the Case Institute of Health, Science and Technology. White House decisions for NIH are on hold given the administration's September 11th priorities.
- **Some action in naming an FDA Commissioner.** HHS Secretary Tommy Thompson's choice for the head of FDA appears to be Lester Crawford, Director of Georgetown University's Center for Food & Nutrition Policy and a former Director of FDA's Center for Veterinary Medicine. Action on Thompson's choice may be delayed however, because of the FBI's investigation of the terrorist attacks, which will delay the background check on Crawford. According to Thompson, his choice for commissioner will work to expedite reviews for devices and drugs. "The commissioner [candidate] has already in his interview said that is going to be one of his primary concerns." Thompson acknowledged "we need to do a better job of approving medical devices and getting reimbursement for hospitals and doctors."
- **Compromise on embryonic stem cell research.** On August 9th, President Bush announced his decision on whether or not Federal funds could be spent for research on embryonic stem cells. Embryonic stem cells are derived from the very early stages of development when a fertilized egg undergoes a series of divisions resulting in a microscopic ball of cells. Each of these cells has the potential to develop into mature cell types in the body, such as nerve cells in the brain, or cells of skin, muscle, bone or other organs—with the potential of treating, even curing, many chronic degenerative diseases like Alzheimer's or Parkinson's disease and diabetes. The President's decision is to permit research on already existing stem cell lines derived from embryos discarded in the course of in vitro fertilization treatments of infertile couples. NIH officials have determined that there are over 60 such cell lines. Since the announcement, some scientists have questioned whether there are indeed 60 cell lines, how good they are, whether they come from 60 individuals and are capable of developing into a variety of mature cells. A further complication concerns rights. Private owners of cell lines may impose restrictions on their use as well as rights to the commercial development of promising discoveries. Former NIH head Harold Varmus, now Director of Memorial Sloan-Kettering Cancer Institute in New York, has said that should initial research be successful, "Even 100 good lines will likely be inadequate..."
- **Compromise on patients' bill of rights.** The House has passed a weaker version of a patients' bill of rights bill than that proposed in the Senate (the Kennedy-McCain bill) and by their own member, Georgia congressman and former dentist Charlie Norwood, after Norwood and the President had a one-on-one meeting. The sticking point was the Administration's concern over excessive costs, if patients suing a managed care company filed their cases in state courts, where damages are unlimited, as opposed to Federal courts where damages are strictly limited. The compromise would allow suits to overturn dental or medical care to be filed in state courts, but would impose a limit of \$1.5 million in damages. Other provisions (also in the Senate bill) guarantee access to the nearest hospital emergency room, to gynecologists, and to prescription drugs (even when not on the plan's preferred list) as well as experimental drugs. Senate and House conferees will meet in committee to work out differences before the House bill goes to the Senate for action.
- **Action on the research budget.** Both sides of the aisles of Congress have concurred in the plan to double the NIH budget over a five-year period, so that it would reach \$27.3 billion in FY 2003. The administration reported that its proposed increase for NIH for the coming year (FY 2002) would be \$2.8, bringing the NIH total to \$23.2 billion. However, it appears that \$469,000,000 of that increase would be transferred elsewhere, including some \$300 million to the Agency for Healthcare Research and Quality and \$95 million to international efforts to fight AIDS. Note: All discretionary funding in the budget is subject to change given the terrorist attacks on the U.S.
- **Action on a new bioengineering center.** Overruling NIH administrators who oppose creating new entities on the campus in Bethesda, Congress passed a bill establishing a Center for Biomedical Imaging and Bioengineering. The bioimaging part would spur research to improve existing technologies such as CT scans and magnetic resonance imaging, as well as develop new ones. The Bioengineering part would focus on the newly developing fields of biomimetics and bioengineering in which cells (including stem cells), growth factors and other biological molecules would be combined with biocompatible materials to grow human tissues such as bone, muscles, and cartilage, to replace tissues lost to disease or trauma—research that would be a boon to TMJ patients in need of prostheses. ♦

Awareness Campaign Results

In 1999 Kevin Clark and his wife, Heidi, a TMJ implant patient, contributed \$100,000 to The TMJ Association and earmarked the money for a national campaign to raise Americans' awareness of TMJ diseases and disorders. With the help of a national public relations firm, press packets of TMJ materials were distributed to some 400 health reporters at network television news shows, national newspapers, news weeklies, wire services, radio health shows, and women's and health magazines. Over 370,000 public service announcements were radio broadcast. Materials were also sent to local newspapers and television stations in the top 25 media markets and online sources of health news. These contacts were followed up by phone or e-mail.

By two months into the campaign, 12 million Americans had learned about TMJ through broadcast coverage, such as "Good Morning America" and "Radio Health Journal." Print articles were placed in newspapers and journals across the country and medical editors wrote columns. Visitors to our Web site increased by 10,000 the first month. Our Web site has thousands of pages of information, is the only one of its kind and features information from scientists and top professionals whose work, wholly or in part, is devoted to TMJ research. Regular monthly visitors to our site have since tripled and have stayed at around 30,000 visitors per month, with over a million hits. Since the Awareness Campaign TMJA has replied to over 8,000 e-mails, over 2,000 telephone calls and hundreds of letters. All told, we have had over 538,000 visitors to our Web site and registered over 10,000 people online. From these communications we have learned that the Awareness Campaign has not only educated people, but also directly affected patient's decision-making regarding TMJ treatments. ♦

Online Giving

The TMJA now has online giving available to those who want to contribute using a credit card. The Association has joined GivingCapital, an organization which provides secure online giving opportunities. To contribute online, go to www.tmj.org and click on the "Contribute Online" button. ♦

Your Letters...

I received my TMJ Communiqué today and wanted to congratulate you once again on an informative and "TMJ family feel support" newsletter. I especially want to thank Terrie for the "Moving the Movers and Shakers in Washington" article and written response to ADA News. When I originally read "Maggie and her TMJ" all I could think of, would any other specialist (e.g., an oncologist reacting to a cancer patient while on vacation) responding to another human being react like this dentist? Probably Not. Then the audacity of this so-called professional dentist writing an article about his feelings towards Maggie. Thank you Terrie for standing up for us again. My continued prayers for all of you and thanks again for another outstanding newsletter.

Marsha L.

The last newsletter was so encouraging. When I read your article "Moving the Movers and Shakers in Washington" it truly brought tears to my eyes. To have the multidisciplinary sciences come together is what we have all fought so hard for. I pray this does come to fruition.

Sue Krieger

It was with great interest that I read the latest issue of the TMJ Communiqué from cover to cover. Thanks again for your great work. Your time and efforts are much appreciated. Keep it up!

Christine Steele ♦

The Murphy Story Update:

\$2.76 Million Judgment Stands for Sheriff with TMJ Pain

In Communiqué Volume 2 No. 2, 2000 we featured a patient letter received from Susan and Patrick Murphy. We are happy to report the Washington-state sheriff unjustly charged with felony drug abuse has been awarded \$2.76 million in a civil judgment against the state.

It was the second victory for the sheriff, who suffers from chronic TMJ pain. The initial award came in May when a superior court judge found the state-led investigation of Patrick Murphy for prescription drug abuse was unjust, the *Seattle Times* reported. Murphy, 49, filed the civil suit in 1997, claiming the state pharmacy board was negligent in disclosing his prescription drug information to county officials. The court agreed and the judge denied the state's appeal in June.

During the initial trial, which lasted four weeks, the jury concluded that Murphy was 20 percent at fault for his troubles, but that he committed no felony. It ordered the state to pay \$2.76 million to Murphy and his family.

Murphy has said he suffers from intractable pain and was using the prescription medication for that pain.

Murphy has entered the race for Snohomish City Council — the first run for public office he's made since losing the 1995 sheriff's election amid allegations he had abused prescription drugs.

Murphy's jaw troubles began in 1988, when he was struck in the jaw as he rescued a female bus driver from an attacker. Over the next few years, Murphy sustained more injuries from accidents, including falling 22 feet onto a concrete floor. ♦

SUPPORT NEEDED

Louise Cardillo of New York underwent a root canal procedure and her dentist used a device known as the “rubber dam”. Her jaw became displaced and she suffered very severe injuries as a result. She is now facing a possible open joint procedure, which would entail jaw wiring. She would like to hear from anyone. Please contact Ms. Cardillo by e-mail at cardilloLNC@juno.com.

Joeyln Ciccolella of New Jersey has been in pain for the last seven years and has had three arthroscopies and an open jaw surgery. She says people do not understand how she feels and that is as painful as the TMJ pain itself. Please send Ms. Ciccolella support by e-mail at jppj56@aol.com.

Sally Dahl of Montana contacted us about her 13-year-old son who suffers from TMJ. Anyone who is in a similar situation based on age and gender please feel free to contact her at sallydahl@peoplepc.com. This goes for moms too. Any input would be appreciated. Her son truly feels that he is the only teenage boy who has to go through this and so does his mother. He loves the Internet too!

Marilyn Hegna of Minnesota contacted us and is really in need of support. Ms. Hegna is a TMJ implant patient and would love to hear from others. Please write to: Ms. Marilyn Hegna, 111 2nd St. SE, Apt. 114, Stewartville, MN 55976.

Patricia Mainhart contacted us and told us she desperately needs your prayers and support. Ms. Mainhart has had over 28 jaw surgeries and has been hospitalized due to TMJ problems over 55 times. Please send your support to Ms. Mainhart by e-mail at: lamesa@usachoice.net.

Pam Matthews is a multiple implant patient who could use support at this time. Among the many medical problems Ms. Matthews is dealing with are an unexplained rash from the waist up, sleep disorders and vertigo. If you are having similar symptoms, Ms. Matthews would like to hear from you. Please send cards and letters to: Ms. Pam Matthews, 208 Sparks Lane, Pickens, SC 29671.

Connie Peirson of Texas has been experiencing sharp stabbing pains in the area of a previous skull graft. She currently has the Christensen all-metal implants. If you have had a similar experience, Ms. Peirson would like to speak with you. Please contact The TMJ Association at (414) 259-3223 or by e-mail at info@tmj.org so we can put you in touch with Ms. Peirson.

Joan Policastro of Pennsylvania recently had surgery and could use cards, letters and notes of support at this time. Please send your well wishes to Ms. Policastro by e-mail to: ppjp@mail.uplink.net or by postal mail to: Ms. Joan Policastro, C/O The TMJ Association, P.O. Box 26770, Milwaukee, WI 53226.

Robert Rhoads recently learned he was a Vitek implant recipient. This fact was mentioned in an August 7, 2001 New York Times article on implant failure. Mr. Rhoads underwent TMJ total joint replacement surgery on August 8, 2001. Mr. Rhoads would greatly appreciate hearing from other patients. Please send cards and well wishes by e-mail to rhoadsra@aol.com or by postal mail to 4255 W. Humphrey Street #1511, Tampa, FL 33614.

Mary Ward of Massachusetts recently had TMJ arthroscopic laser surgery. Following the procedure she experienced vision problems. Her ophthalmologist diagnosed the problem as a result of the laser surgery. If this has happened to you or someone you know, Ms. Ward would like to hear from you. Contact her by e-mail at night76782@aol.com and The TMJ Association at info@tmj.org or by mail to: Ms. Mary Ward, C/O The TMJ Association, P.O. Box 26770, Milwaukee, WI 53226.

Candy Van Loo recently had surgery for bilateral TMJ degenerative osteoarthritis. Ms. Van Loo would appreciate your cards and letters of support at this time. Please send them to: Ms. Candy Van Loo, P.O. Box 125, Rockaway Beach, OR 97136.

Mary Ann Verdinelli of New Jersey recently underwent surgery for a total bi-lateral joint replacement. She wrote she really could use any and all support from others. She is not one to ask for help, but seeing others request for support in the newsletter has giving her the courage to reach out to others. Please send cards and letters to Ms. Mary Ann Verdinelli, 812 E. Broad Street, Gibbstown, NJ 08027.

And Some Good News... **Dessie Hightower**, a TMJ Implant patient from Huntsville Texas wants to let everyone know that she has a brand new grandson, Ramond Antonio Collier, III. Congratulations Dessie! ♦

Letter from Terrie

continued from page 3

- We will hold a meeting for TMJ patients following the scientific meeting to relay the information at the scientific meeting, discuss Association activities and projects and provide an opportunity for patients to meet patients.
- We will continue to monitor FDA's actions on TMJ implants and demand accountability regarding their decisions, when warranted.
- We will continue to respond to patient letters, phone calls and e-mails and link patients in need of support with those who can offer it.
- We will work with our scientific advisors, professionals and patients to keep you abreast of scientific updates in TMJ as well as develop specific treatment information, which we will make available on our Web site. We also continue to post information of interest to TMJ patients and invite you to visit www.tmj.org regularly.

We are at a critical threshold and in order to capitalize on momentum we gained in the past year in moving TMJ science and education forward, we need your help. We hope you will give whatever you can, \$5, \$50, \$500 or more to help us help TMJ patients. The other ways you can contribute to the Association are listed on page 5. Remember, any contribution you can make, regardless of size, will have a direct and positive impact. You can take pride in knowing your gift is helping us move closer to our goal of *changing the face of TMJ*. ♦

Terrie Cowley

IN MEMORIUM

Suzanne Schweikert, a multiple-surgical, multiple-implant patient, died on June 23rd at the age of 53. Having known Sue for a number of years, we can tell you that she had a heart of gold and a fantastic sense of humor and she was always glad to help anybody in need. She loved children, the ocean and her dog Reegan. Prior to her TMJ disability Sue served as director of the National Health Laboratories in Linwood, NJ. Sue is survived by three daughters: Danielle, Melissa and Courtney. Messages of sympathy to the family can be sent to Courtney and Edward Huff at 1745 Bay Avenue, Ocean City, New Jersey 08226. Mr. Huff told us that "this is a tragic situation, not just for Sue, but for all TMJ patients suffering as she did." June 23 was doubly tragic for the Huff family, as they also learned of the death of Ed's father.

Theodore "Ted" Wilentz, died May 1 at Sibley Memorial Hospital in Washington D.C. after struggling with heart and lung ailments. He is survived by his wife, **Joan B. Wilentz**, The TMJ Association's newsletter editor, and sons, David and John. Ted was a past president of the American Booksellers Association and he and his wife lived in Chevy Chase, Maryland, where he was a bookstore and literary adviser. From 1947 until 1968, Mr. Wilentz and his brother, Eli, co-owned the Eighth Street Bookshop in New York City, a gathering place for writers, artists, poets and painters. They also founded Corinth Books, which published writings of Beat Generation authors including Jack Kerouac and Allen Ginsberg. Joan, who serves as *Communiqué* editor, also serves on The TMJ Association Board of Directors and is the editor of *TMJ Science*, the journal of The TMJ Association.

Robert (Asa) Gillstrap, a TMJ Implant patient and long time TMJ Association supporter died at home on Saturday, October 28, 2000 at the age of 49. Robert suffered great physical pain due to his severe craniofacial problems and was devastated by the tragic death of his 19-year-old daughter and 2½ year-old grandson in June 1999. Your letters and cards of sympathy can be sent to the Gillstrap family at: PO Box 477, Inverness, FL 34451.

Barbara Melton suffered a fatal heart attack on March 28, 2000 at age 55. Her husband Rodney told us that Mrs. Melton had Vitek, Silastic and other autogenous implants and that she had suffered from TMJ pain for over 20 years. He would like to see research done that would help others avoid the suffering Barbara experienced. Expressions of sympathy can be sent to Mr. Rodney Melton, 108 Bel-Air Avenue, Hamlet, NC, 28345.

Stella Kowick recently notified us of the death of her daughter Christina on September 4, 1999 at the age of 48. Christina was a multiply operated, multiple implant patient. The cause of death was a blood clot. For at least 15 years she fought numerous infections and suffered great pain. Mrs. Kowick, a widow and Christina's caregiver, said that "posting Christina's death on our Web site would be a fitting tribute to my beautiful daughter, so disfigured by the surgeries. It would make Christina happy." Please send notes of sympathy to Mrs. Stella Kowick at 605 Main Street, Toronto, OH 43964-1468. ♦

Poorly Understood TMJ Problem Gets Needed Attention

continued from page 4

However, that challenge cannot be taken on until more is known about the TMJ. To advance TMJ science, participants identified the following needs:

- Thorough testing of any future implants and development of a registry of TMJ implant patients.
- Better methods of characterizing the disease and assessing treatments.
- Studies aimed at reconstructing the TMJ.
- More epidemiological information on TMJ patients.
- Training and engagement of investigators from various disciplines.

The meeting helped to forward NIH's goal of expanding the base of TMJ research, which currently is sparse, beyond dentistry and oral surgery. It was "a wonderful first step in a long journey to unravel the etiology and pathogenesis of this disease or collection of diseases and to start coming up with smart diagnostics and therapeutics," Harold C. Slavkin, director of the National Institute of Dental & Craniofacial Research (NIDCR), told C&EN. "It was very fruitful in that a number of people in the audience who knew nothing about TMJ disorders got excited about the opportunity to pursue this area."

The TMJ problem is complex. Disorders can be traced not only to trauma but also to genetic and physiological factors. Interdisciplinary efforts will be needed to, among others, develop technology for noninvasive study of the joints in humans, drugs to manage symptoms, and biomaterials to be used in repairing and regenerating the joint. In these areas, chemistry and chemical engineering have much to contribute.

Given the limited resources of the organizers, it was inevitable that the meeting could not be fully inclusive. For example, chemists and chemical engineers were underrepresented. But they "absolutely" have contributions to make in this area, Slavkin told C&EN. "We must have engineers and chemists and mathematicians and physicists in the mix," he said. "Because we need combinatorial chemistry, design and synthesis of biologically active motifs, and instrumentation."

In the current fiscal year, only about \$20 million is being spent by NIH on TMJ research according to Slavkin. But it's not for the lack of money. "It's limited by a lack of interest," he told C&EN. In the last funding cycle, for example, NIDCR received no grant proposals for TMJ research, he noted. The climate is favorable for moving the scientific agenda in the field if the scientists would like to pursue it, he said.

The meeting surely has sparked interest. "I know in advance from the hallway talks that a number of new grant proposals will be submitted in this area," Slavkin said. Any new research partnerships likely will emerge just from people discovering potential collaborators at this meeting, Baier noted.

Given what is known about these diseases and disorders, "the hope of the patients is in science," TMJ Association President Terrie Cowley told C&EN. "We are confident that this meeting will expand the intellectual and scientific resources directed toward TMJ diseases and disorders, which in turn can only lead to improved health care and quality of life for the millions of TMJ patients." ♦

Jaw Pain Study Shows Pain is More Intense for Some; a Clue to Chronic Pain States

continued from page 1

was injected, they were asked to rate how much pain they were feeling every 15 seconds. Afterward, the volunteers completed a questionnaire about the emotional qualities of the experience—how unpleasant and disturbing the pain experience was. Zubieta said the results showed that perceived pain decreased as the brain chemicals kicked in, and that the chemical response was strongest in the regions associated with either the sensory or emotional qualities of pain, but that the level of pain relief varied considerably among the 13 men and 7 women studied. The study's results appeared in the July 13 issue of the journal *Science*.

The study also demonstrated a relationship between chronic pain and the psychological distress that accompanies it.

"Many people who suffer from chronic pain have psychiatric symptoms," said Dr. Kenneth Gruber, chief of the chronic diseases branch of the National Institute of Dental and Craniofacial Research. "The question has always been: What came first? This study suggests that the pain causes the mental problems, not vice versa. If your coping system is not reacting appropriately and is being overcome by the pain, the cause of your distress is physical, not psychological." ♦

The *TMJ* Association

Board of Directors

William M. Layden, Chairman
Great Falls, VA

Terrie Cowley, President
Milwaukee, WI

Kevin D. Clark, Vice President
Milwaukee, WI

C. Polly Ellingson, J.D., Secretary
Milwaukee, WI

Kay W. Austermann, Treasurer
Milwaukee, WI

Elizabeth J. Bigge
Fairfield, CT

Lisa G. Brown
Richmond, VA

Charles M. Sturm
Milwaukee, WI

Joan B. Wilentz
Chevy Chase, MD

James M. Wozniak, CPA
Milwaukee, WI

Diana M. Zuckerman, Ph.D.
Washington, DC

Scientific Advisory Board

Robert E. Baier, Ph.D., P.E.
University at Buffalo
State University of New York
Buffalo, NY

Ronald Dubner, D.D.S., Ph.D.
University of Maryland
Baltimore, MD

Julie Glowacki, Ph.D.
Harvard Medical School and
Harvard School of Dental Medicine
Boston, MA

Stephen L. Gordon, Ph.D.
OSIRIS Therapeutics, Inc.
Baltimore, MD

Stephen B. Milam, D.D.S., Ph.D.
University of Texas
Health Science Center
San Antonio, TX

Christian S. Stohler,
D.M.D., Dr. Med. Dent.
University of Michigan
Ann Arbor, MI

Special Advisor

Allen W. Cowley, Jr., Ph.D.
Medical College of Wisconsin
Milwaukee, WI

The *TMJ* Association
P.O. Box 26770
Milwaukee, WI 53226-0770

Return Service Requested

NON PROFIT
ORGANIZATION
U.S. POSTAGE
PAID
MILWAUKEE, WI
PERMIT NO. 1676