

Holiday Greetings

On behalf of all of us at The TMJ Association, we sincerely wish you a wonderful holiday season surrounded by family and friends and a happy and healthy 2022!



In Memory of Daniel Laskin



Dr. Daniel Laskin's [obituary published by the University of Illinois Chicago, College of Dentistry](#) rightly defined Dr. Laskin as a giant in his field. However, few knew how supportive Dr. Laskin was of The TMJ Association and our mission.

The first time I met Dr. Laskin was in 1992 at the Congressional Hearing: *Are FDA and NIH Ignoring the Dangers of TMJ Implants?* and shortly after that Dr. Laskin contacted me for a convenient time to visit me in Milwaukee. He and the Executive Director of the American

Association of Oral Maxillofacial Surgeons (AAMOS) met for an afternoon of discussions on various aspects of TMJ. Most importantly, that meeting began a friendship with Dr. Laskin that continued until the day he died. Over the years, Dan was someone I could turn to anytime we needed help writing articles, editing our website and other informational materials, answering questions, helping patients, and to just have a pleasant conversation. We had many discussions over the years brainstorming on various TMJ issues. When he wrote an article or planned a meeting he would sometimes ask for my opinion and we even co-authored a few articles. He, along with his wife Eve, attended all of our patient meetings at the National Institutes of Health in the 1990s and respectfully answered questions put to him by patients. Dan was the first TMJ professional to build a relationship with us and the day before he died, he answered an email we sent that day needing help for a patient in Virginia. When I discussed developing the TMJ Patient-led RoundTable project

with him he said, "You're doing what everyone else should be doing."

Some of the most memorable conversations took place in the last several years when Deanne and I called him on his birthday and sang happy birthday. He always laughed and said, "You made my day!" This last birthday he told us that he had just completed writing the 100-year history of AAMOS and then moved on to telling us that somebody should write the history of the TMJA because "what you have accomplished is amazing." His very positive attitude, great sense of humor, interest and support of our activities, and especially his kindness have always been uplifting. We already miss him.

Terrie, President & Co-Founder, TMJA

Giving a Voice to the Voiceless - Please Help

The past two years have been especially challenging, however our commitment to *changing the face of TMJ* remains strong. We are writing to ask for your generous financial support in order that the TMJA can continue to serve the needs of the TMJ community.

We serve patients like Jennifer.

"Like many patients who have chased after a cure for many years, I have undergone 18 jaw surgeries. I am so thankful for the work of The TMJ Association to raise awareness on Capitol Hill, at the NIH, FDA, and other government agencies. The community of patients constantly seeking verified information on the subject of TMJ, go to the TMJA for comprehensive and credible research updates. When I can't speak because I am in too much pain or my jaw is literally wired shut, the TMJ Association is my voice. If the TMJ Association wasn't fighting for us, who would?"- Jennifer

We continue to inform and educate health care professionals, policy makers, scientists, and the public about the difficult journey faced by TMJ patients. In November, we partnered with IMD Health Global to provide patients and medical professionals with TMJ resources via the IMD platform.

We are also collaborating with government officials and TMJ stakeholders in developing the first Patient Powered TMJ registry to learn about a patient's journey from initial treatment to their current state. We are working with international scientists on several projects – all with TMJ patient leadership, and with the goal of improving patient care. We will update you regularly in 2022 with more information on each project.

We need to do more! Without an increase in current funding, critical projects, including the development and distribution of TMJ educational material to the dental and medical communities will not be carried out. Your contribution, no matter how small, makes a vital difference in the lives of TMJ patients. **Open your giving heart and send a donation [online](#) or by mail to: The TMJ Association, P.O. Box 26770, Milwaukee, WI 53226 to help us continue to serve TMJ patients and their loved ones.**

On behalf of everyone at The TMJ Association, and those we serve, we wish you a peaceful, pleasant, and healthy holiday season and the best of

Excerpt from the National Academy of Medicine Report on Temporomandibular Disorders

It is so important for patients to share their story of TMJ experiences - about how it impacts your daily life, family's life, social life, and every other way that may be unique to each patient. As you'll see the over 100 patients who provided their story to the National Academies of Sciences, Engineering, Medicine Consensus Study Report on Temporomandibular Disorders - Priorities for Research and Care.

The Report was very comprehensive and covered many aspects of TMJ. Over the upcoming year we will continue to share excerpts with you from the report. The following is from the Report's Summary, pages 2-4. To view the full report, visit: <http://tmj.org/wp-content/uploads/2020/12/NAM-Report-on-TMD.pdf>

Challenges in Care: Patient Experiences

The committee greatly benefited from the input of individuals with a TMD and their family members, many of whom face significant day-to-day challenges in living with a TMD. These challenges include difficulties in eating, in personal and social interactions, and in talking, which are often accompanied by severe ongoing pain. The committee received input from more than 110 individuals through in-person and online opportunities to testify at the committee's public workshop and through written submissions to the study's public access file.¹ Among the many issues raised in these testimonies, several focused on the health care system and the care of individuals with a TMD:

- *Lack of coordinated care and abandonment*—Individuals reported that they were often shuffled back and forth between clinicians in the medical and dental fields with little to no attention paid to a comprehensive approach to coordinated care. Patients also reported being abandoned by their dentists and other clinicians when the treatments did not work, with no referrals or other options provided.
- *Over-treatment/harmful treatment*—Many patients reported on having endured multiple TMD-related surgeries (in some cases more than 20), often with no resolution to their pain or with worsening symptoms. Other individuals reported that they had not had surgery but had had a removable oral appliance, orthodontic correction of the teeth, replacement of teeth, or some combination of these treatments.
- *Impact on quality of life*—Individuals with a TMD described how having a TMD has profound impacts on the quality of their day-to-day lives, from struggling in pain to kiss a loved one to challenges in dining out with friends or simply eating solid foods. Some individuals noted that the disorder affected their ability to work and to care for their families. Many described challenges in dealing with the emotional consequences of their condition and its treatment and with the episodic or ongoing pain that they experience.
- *Expense*—The financial burden of seeking and receiving care for a TMD was noted by individuals and family members. Some people said that they had

received limited insurance coverage, but, for the most part, the coverage was paid out of pocket by the individual at costs of up to tens of thousands of dollars.

- *Identifying qualified health care professionals*—Individuals with a TMD and their families often expressed their frustration at not knowing where to turn for quality care. Primary care and internal medicine clinicians and general dentists often did not know how to help them locate qualified specialists. Patients were highly aware of the TMJ implant failures of the 1970s and 1980s and conveyed their concerns about the lack of quality treatment options for TMDs. Additionally, they noted that misleading advertising practices—in which clinicians claim to be experts but do not have the proper experience or evidence-based practices—further complicate access to quality care.
- *Comorbidities*—Many individuals with a TMD noted challenges with comorbid conditions, including fatigue, widespread pain, fibromyalgia, depression, anxiety, and arthritic conditions.

This brief overview highlights only some of the challenges that continue to be faced by individuals with a TMD and by clinicians in diagnosing TMDs and identifying appropriate care for them. A part of the history of the treatment of TMDs centers on the synthetic implants often used from the late 1960s to early 1990s to replace the condyle, fossa, and articular disc of the TMJ. Many of these implants were either recalled by the Food and Drug Administration or voluntarily withdrawn from the market after they caused a range of adverse health outcomes including severe pain and functional joint impairment.

Patients have played and continue to play a major role in bringing attention to the need to advance the understanding of and ability to treat TMDs.

New NIH Research Grant Opportunities

Notice of Special Interest (NOSI): Research on the Health of Women of Understudied, Underrepresented and Underreported (U3) Populations (Admin Supp Clinical Trial Optional)

The TMJA welcomes the announcement by the NIH Office of Research on Women's Health of the availability of Administrative Supplements to support research on the health of women in understudied, underrepresented, and underreported populations in biomedical research. The prevalence of TMJ is higher in women and yet support for biomedical research specifically targeted to sex and gender topics in TMJ is lacking. Clearly, more research is needed to address molecular, genetic, musculoskeletal, endocrine, neurological, and bio-behavioral aspects of TMJ in women. We hope this announcement will result in many new avenues of research that will clarify the causes of TMJ, elucidate the arc of disease progression, and ultimately, hasten the development of precision treatments for TMJ patients.

<https://grants.nih.gov/grants/guide/notice-files/NOT-OD-22-031.html>

Notice of Intent to Publish a Funding Opportunity Announcement for HEAL Initiative: Advancing Health Equity in Pain and Comorbidities (R61/R33 Clinical Trial Required)

The National Institute of Neurological Disorders and Stroke (NINDS), with other NIH Institutes and Centers (ICs), intends to promote a new initiative by publishing a Funding Opportunity Announcement (FOA) to solicit applications for research that will advance health equity in pain and comorbidities. The FOA will support research to develop, test, and implement novel, culturally-appropriate pain interventions and/or adapt, test and evaluate efficacy and effectiveness of existing pain interventions, in populations that disproportionately experience negative health outcomes. Desired outcomes of these interventions include reduction of pain and pain-related symptoms, and improvement in overall health outcomes, including function and quality of life. Interventions that target populations that experience health disparities with chronic pain in addition to at least one comorbid condition (OUD, mental health disorders and/or chronic health conditions) are of the highest priority.

<https://grants.nih.gov/grants/guide/notice-files/NOT-NS-22-040.html>

Notice of Intent to Publish a Funding Opportunity Announcement for HEAL Initiative: Restoring Joint Health and Function to Reduce Pain Consortium (RE-JOIN)

The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), with the National Institute of Dental and Craniofacial Research (NIDCR), National Center for Complementary and Integrative Health (NCCIH), and National Institute of Neurological Disorders and Stroke (NINDS), intends to promote a new initiative by publishing a Funding Opportunity Announcement (FOA) to solicit applications for research on "Restoring Joint Health and Function to Reduce Pain (RE-JOIN)."

The goal of RE-JOIN will be to define the innervation of the different articular and peri-articular tissues that collectively form the joint (including bone, cartilage, synovium, joint capsule, ligament, tendon, fascia and muscle), by sensory neurons that mediate the sensation of pain. Knowledge about the types and distribution of neurites in joint tissues will facilitate the identification of key receptors and mediators that induce pain by activating specific sensory neurons. These mediators and their receptors will provide novel targets for reducing pain.

Research teams will map the sensory innervation of knee and/or **temporomandibular joint** tissues in animal models and/or human tissues and have the option of including additional joints. Research Teams may also further adapt or develop technologies that would improve the ability to map neurons in joint tissues.

Data harmonization, integration and visualization will require extensive coordination across teams. The goal will be to integrate data from the different teams to produce models of innervation in different joints.

This Notice is being provided to allow potential applicants sufficient time to develop meaningful collaborations and responsive projects.

The FOA is expected to be published in Winter 2022 with an expected application due date in Spring 2022. This FOA will utilize the UC2 Clinical Trial Not Allowed activity code. Details of the planned FOA are provided below.

About The TMJ Association...*Changing the Face of TMJ*

The TMJ Association, Ltd. is a nonprofit, patient advocacy organization whose mission is to improve the quality of health care and lives of everyone affected by Temporomandibular Disorders (TMJ). For over 30 years, we have shared reliable information on TMJ with people like you. We invite you to visit our website, www.tmj.org.



The TMJ Association, Ltd., P.O. Box 26770, Milwaukee, WI 53226

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The TMJ Association, Ltd. is a nonprofit 501(c)(3) tax-exempt organization.

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