

### November is TMJ Awareness Month! Here's What We're Planning...

November marks [TMJ Awareness Month](#), and during this month, the TMJA will be sharing updates on research and content that sheds light on the reality of TMJ conditions.

We are also eager to involve our TMJ community in our social media discussions! Our social platforms will present a "Topic of the Week," such as questions like, "What are your preferred go-to foods?" or "What strategies work best during a TMJ flare?" We encourage you to participate by tagging us in your responses.

Explore our [TMJA Store](#), featuring our TMJ Awareness November 2023 sugar skull design. Your purchase not only allows you to support our cause but also helps raise awareness. We extend our heartfelt thanks to our team of TMJ patient volunteers, Lisa, Michelle, Adriana, Jenny, Alex, and Florin, for their dedicated work on this project!

We encourage you to follow us and share our posts with your friends and family to help raise awareness during the month of November. The TMJA can be found on [Facebook](#), [Instagram](#), [LinkedIn](#), and [X](#).



*November 2023*

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### New Understanding of Our Body's Defense System Could Lead to Better, Safer Implants

An article on the website of the [National Institute of Biomedical Imaging and Bioengineering](#) (an Institute of the National Institutes of Health) sheds new light on medical devices. TMJ implants are medical devices which may benefit from this research.

The introduction of medical devices — commonly made of materials such as titanium, silicone, or collagen — into our bodies can elicit a host of different immune responses. While some responses are harmful, others can help the healing process. Researchers have not fully grasped the reason for the body's

varied reactions, but a new study fills in a critical piece of the puzzle.

By closely examining the immune system's responses to two different materials implanted in mice, researchers at the National Institute of Biomedical Imaging and Bioengineering (NIBIB) have identified key driving factors for implant-induced regeneration vs. damage. The authors suggest that their findings, published in *Nature Materials*, help set the table for the design of new medical devices that influence the immune system to help, rather than harm the body.

The authors observed that some device materials resulted in the recruitment of cells to the implant site that were hostile, leading to inflammation and tissue destruction. Other materials appeared to recruit cells that helped in healing and regeneration.

Medical devices such as pacemakers, breast implants, or knee replacements can trigger hostile immune responses that can damage not only the implants themselves but the surrounding tissue as well. The clinical solution has been to administer drugs that tamp down the body's immune response, known as immunosuppressants, which are not always effective and come with serious risks.

Due to complications including immune-mediated damage, additional surgeries are almost always required, be it months or years later, to remove or replace implants that have been rendered ineffective or dangerous.

However, some implants, such as naturally derived tissue grafts, have shown that they can steer the immune system in a more desirable direction, stimulating reparative processes. While natural biomaterials are not suited to every medical application, they may still hold valuable lessons for other kinds of devices.

"If we could tease out what aspect of these different materials causes certain immune responses, we would have more control in designing materials and devices that encourage the responses we want," said senior author Kaitlyn Sadtler, Ph.D., Earl Stadtman Tenure-Track Investigator and chief of the Section on Immunoengineering at NIBIB. [Read full article here.](#)

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## Remembering Leslie

A long-time friend and supporter of The TMJ Association recently passed away, Leslie Zatezalo of Pennsylvania. Leslie is survived by her husband, Jim.

Leslie had an outstanding affection for squirrels. She often shared how these little creatures with their bushy tails lifted her spirits, and we were fortunate to receive a delightful photo of her beloved squirrel friend, Mr. Peepers. Her



fascination with squirrels began when her husband, who worked as an arborist, brought home a baby squirrel. From that moment, squirrels became more than just animals to Leslie; they became her passion. She actively sought opportunities to engage with groups dedicated to these furry friends.

Leslie was an active participant in our TMJA patient meetings during the 1990s. She was a TMJ Vitek implant patient and faced many health challenges related to this device. Her commitment and willingness to share her experiences left a lasting impact on the TMJA community.

Our hearts go out to Jim and the Zatezalo family during this difficult time. Leslie's love for squirrels and her enduring connection with our organization will be dearly missed. We extend our deepest sympathies to all those who knew and cherished Leslie.

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## Seeking Justice for Joseph



My name is Mara, I am Joseph's mother. My son is Brazilian and American. He underwent TMJ arthroscopy surgery to correct an open bite, something simple and minimally invasive. The surgery was performed by a clinic and hospital in São Paulo Brazil. However, after the surgery, my son was visibly in pain and hours later the hospital performed an angiotomography which revealed a very serious ischemic stroke. Joseph underwent a craniotomy to remove part of his skullcap and on July 22, 2022, he died. He was just 17 years old.

I went into shock and despair, having lost my only son in a simple, uncomplicated surgery. After everything happened, I had access to the medical records and verified several professional and medical errors. They applied off-label medication to the artery and there was also bad professional practice and the anesthetist left. Many mistakes. Today I face legal proceedings against those responsible.

I publicize my son's death in order to save lives. Nobody talks about the risks of this surgery, they only talk about the benefits. There is no reference to death in the literature of a healthy patient undergoing this type of surgery. My son underwent an unnecessary surgery and still died as a result. The doctors and health professionals did not show care towards the patient and life is the only thing we have and it must be preserved. I want to warn people about the risks and save lives. Justice!

At the TMJA, we are continually in touch with individuals from around the globe who are seeking information and support for TMJ disorders. One particularly poignant story that has touched our hearts is Joseph's.

We extend our heartfelt gratitude to Mara, Joseph's mother, for her incredible strength and courage in sharing her son's story with us. By doing so, she has enabled us to shed light on this condition and reinforce our commitment to advocacy for safe and effective treatments.

It is through the bravery of individuals like Mara that we can work towards better understanding, treatment, and support for those affected by TMJ disorders.

If you have a story you would like us to share with the greater TMJ community, please email your story to: [info@tmj.org](mailto:info@tmj.org).

## Thoughts by Terrie

Mara's email about her son's tragedy has prompted me to reflect on my own journey with TMJ. Following my first TMJ surgery in 1982, I awoke to a profoundly altered reality. I experienced neurological challenges including excruciating headaches, vision disturbances, gait instability, and concentration difficulties. I sought answers from my surgeon, only to receive a disheartening response: "Your joints are fine, I don't know what's wrong with you." Four years later the symptoms slowly began to improve.

Years later, I had a conversation with a military oral surgeon who asked me to explain my TMJ journey. After I related my surgical experience, I received an unexpected revelation. He casually asked, "Did anyone tell you that you had a stroke or a traumatic brain injury on the surgical table?" This was the first time someone acknowledged what seemed obvious to me. He went on to explain that changing the head position, which was required during bilateral jaw surgery, could have cut off the blood supply to the brain.

I share this story because issues like these are rarely if ever discussed. There is a significant gap in our understanding of this part of the body, and extensive scientific research is needed. The TMJ Association was established by TMJ patients who experienced harm from TMJ treatments, and we remain committed to demanding the highest standard of scientific inquiry. Our goal is to ensure that future generations do not endure the same challenges we have had and that they have access to safe and effective treatment options.

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## Development of Patient Reported Outcome Measures - A TMJ Patient-led RoundTable Project

### **What are PROs and PROMs and why are they important?**

Patient-reported outcomes (PROs) are patients' reports of their health status in their words, such as stating their symptoms or how well they are functioning. Patient-reported outcome measures (PROMs) are standardized questionnaires and rating scales that can capture PRO information. Valid and reliable PROMs provide a systematic instrument to document and monitor disease, evaluate safety and effectiveness of TMD therapies, and guide healthcare providers in patient care and disease management.

### **Why is this project important?**

Understanding symptoms of TMDs can help healthcare providers and patients document, monitor, and manage the disease and help researchers evaluate interventions. Although a recent review identified more than 120 PROMs that have been used in TMD research, few have robust evidence to support the

reliability and validity of their scores. For example, most did not include patient input in the content generation, and it was unclear whether they addressed the impacts of TMDs from the patients' perspective.

### **Project Results**

We identified 52 distinct concepts across six domains: somatic, physical, social, sexual, affective, and sleep. Focus groups identified the ability to chew and eat; clicking, popping, and other jaw noises; jaw pain and headaches; jaw misalignment or dislocation; grinding, clenching, or chewing, including at night; and ear sensations as most important. Participants with severe TMDs more often reported affective concepts like depression and shame than did participants with mild or moderate TMDs.

Many focus group participants raised issues with their treatments, care delivery, or provider behavior. As these topics are specific to health care delivery and not specific to a description of health outcomes, they are beyond the scope of a PROM, and therefore these comments were not included in the analysis.

### **Conclusions**

Findings support PROM item development for TMDs, including selecting existing PROMs or developing new ones that reflect patients' lived experiences, priorities, and preferred terminology. Such measures are needed to increase understanding of TMDs, promote accurate diagnosis and effective treatment, and help advance research on TMDs.

### **Read the Publication**

Our research project was published in *The Patient - Patient Centered Outcomes Research*. Click here for more details:

<https://pubmed.ncbi.nlm.nih.gov/36840915/>



**Building the Foundation for a Modern Patient-Partnered Infrastructure to Study Temporomandibular Disorders**

**Background:** Conflicting reports from various stakeholders related to prognosis and outcomes following placement of temporomandibular joint (TMJ) implants gave rise to the development of the TMJ Patient-Led RoundTable initiative. Following an assessment of the current availability of data, the RoundTable concluded that a strategically Coordinated Registry Network (CRN) is needed to collect and generate accessible data on temporomandibular disorders (TMDs) and their care. The aim of this study was therefore to advance the clinical understanding, usage, and adoption of a core minimum dataset for TMD patients as the first foundational step toward building the CRN.

**Methods:** Candidate data elements were extracted from existing data sources and included in a Delphi survey administered to 92 participants. Data elements receiving less than 75% consensus were dropped. To reliably collect the identified data elements, the identified core minimum data elements were defined in the context of technical implementation within High-performance Integrated Virtual Environment (HIVE) web-application framework. HIVE was integrated with CHIOS™, an innovative permissioned blockchain platform, to strengthen the provenance of data captured in the registry and drive metadata to record all registry transaction and create a robust consent network.

**Results:** A total of 59 multi-stakeholder participants responded to the Delphi survey. The completion of the Delphi surveys followed by the application of the required group consensus threshold resulted in the selection of 397 data elements (254 for patient-generated data elements and 143 for clinician generated data elements). The infrastructure development and integration of HIVE and CHIOS™ was completed showing the maintenance of all data transaction information in blockchain, flexible recording of patient consent, data cataloging, and consent validation through smart contracts.

**Conclusion:** The identified data elements and development of the technological platform establishes a data infrastructure that facilitates the standardization and harmonization of data as well as the performance of analytics needed to fully leverage the captured patient-generated data, clinical evidence, and other healthcare ecosystem data within the TMJ/TMD-CRN.

[Frontiers | Building the foundation for a modern patient-partnered infrastructure to study temporomandibular disorders \(frontiersin.org\)](https://www.frontiersin.org/articles/10.3389/fmed.2022.881111/full)

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**“Sometimes a TMJ patient needs  
inspiration just to  
get through each day.”**

- The TMJ Association, Ltd.

**Connect with others who understand in the  
new TMJ Cafe Support Community**

**Visit [TMJ.Inspire.com](http://TMJ.Inspire.com)**

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## **Patients Needed**

### **Central and Peripheral Factors in Temporomandibular Disorder (TMD)**

Researchers at Emory University in Atlanta are in need of TMJ patients to participate in their study. They are investigating people who experience chronic pain in the head and/or face in everyday life. They are using unique tests to find out how the brain processes chronic and acute pain messages and will observe patients to see how pain and sensory processing differs in TMD. [Click here to view the informed consent form for this study.](#) Contact Daniel Harper, PhD (Principal Investigator) at 404-727-7789 or [daniel.harper@emory.edu](mailto:daniel.harper@emory.edu) with any questions and to participate.

### **Experiences with Jaw Stretching Devices**

Jonathan Huang, a junior at Washington University in St. Louis Missouri currently in the process of developing a new jaw-stretcher device. Eager to make the device accessible to multiple patient populations, he is hoping to gain some perspective from TMJ patients who currently use jaw-stretchers. If you would like to share your thoughts on current devices with Jonathan, contact him at: [huang.j.j@wustl.edu](mailto:huang.j.j@wustl.edu)

### **Impact of Daily Physical Activity and Chronic Musculoskeletal Pain Survey**

A research team from the Faculty of Rehabilitation Sciences of Hasselt

University in Belgium is investigating the relationship between the intensity of daily physical activity and chronic musculoskeletal pain. They will be looking at fibromyalgia, chronic temporomandibular disorder, osteoarthritis, chronic neck pain, chronic shoulder pain, and chronic low back pain. The study involves an online survey which will take approx. 50 minutes to complete. More details and a link to the study is available at:

[https://uhasselt.qualtrics.com/jfe/form/SV\\_etl78e58y2YeUDQ](https://uhasselt.qualtrics.com/jfe/form/SV_etl78e58y2YeUDQ)

## **TMJ Patients Needed for In-Person Study at the University of Minnesota**

For those of you in the Twin Cities, Duluth, Rochester, or nearby areas, a researcher working with the University of Minnesota is looking for participants to collect data as an early step toward development of a new medical device. There is one brief in-person meeting required, but the researcher can travel around those areas to meet you if you are interested. Please see below for details.

"Have you been diagnosed with TMD/TMJ Pain, Chronic Low Back Pain, and/or Painful Peripheral Neuropathy? Has your pain lasted for more than 3 months with an average daily pain intensity in the past week of  $\geq 3/10$  and at least one instance of pain  $\geq 6/10$  in the past week? If so, please contact [groenke@umn.edu](mailto:groenke@umn.edu) for more information regarding possible participation in an ongoing, at-home research study seeking to learn more about how the body responds to different pain levels. There is a \$20 gratuity payment following successful completion of the study."

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## **The Fall Giving Season is Upon Us**

The TMJ Association (TMJA) is the only nonprofit patient advocacy organization fighting for the best science that will lead to a greater understanding of Temporomandibular and related disorders (TMD), as well as safe and effective treatments. **We cannot change the face of TMJ without YOU!**

**Contribute through your employer programs** by writing The TMJ Association on the donor form. United Way and other nonprofit corporate donor programs are great ways to improve the plight of TMD patients. Simply write The TMJ Association on your donor form. If you don't participate in any of these campaigns, you can still help by [donating directly to The TMJ Association](#).

### **Giving Tuesday is November 28th**

The first Tuesday following Thanksgiving is designated as GivingTuesday. GivingTuesday is a global day of generosity.

**Your contribution will make an impact, whether you donate \$5 or \$500. Every little bit helps. Thank you in advance for your support!**

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## **NIH Grant Opportunity for Researchers**

**HEAL Initiative: Toward Developing Quantitative Imaging and**



## Other Relevant Biomarkers of Myofascial Tissues for Clinical Pain Management (R61/R33, Clinical Trial Required)

The National Institutes of Health (NIH) intends to support the development of innovative quantitative measures involving myofascial tissues for pain management involving research participants using a two-phase grant funding mechanism. This study is part of the NIH's Helping to End Addiction Long-term (HEAL) initiative to speed scientific solutions to the national opioid public health crisis. The NIH HEAL Initiative bolsters research across NIH to (1) improve treatment for opioid misuse and addiction and (2) enhance pain management. More information about the HEAL Initiative is available at: <https://heal.nih.gov/> This notice of a funding opportunity (NOFO) seeks research applications that will develop quantitative measures to facilitate the development of future biomarkers of myofascial tissues and assess their abilities to detect changes in myofascial tissues across a variety of pain management interventions, manipulations, or therapies. Promising quantitative measures may be based on minimally invasive imaging technologies, electrophysiological recordings, integration of multiparametric imaging and electrophysiology approaches, or their integration with other markers (e.g. immune factors, genomic markers, physiological factors) through multiscale modeling or machine learning analysis. The first phase, funded by the R61, will provide funding for up to 3 years to develop quantitative measures that can differentiate abnormal myofascial tissue from healthy tissues, using cross-sectional correlations with clinical signs/symptoms. In addition, the R61 phase should include planning activities for the R33 phase. The second phase, funded under the R33, will support studies to assess the ability of the quantitative measures developed in the R61 phase to detect changes to myofascial tissues across a variety of pain interventions in rigorous, longitudinal clinical studies. The combined R61/R33 cannot exceed 5 years. Transition from the R61 to the R33 phase of the award will be administratively reviewed and will be determined based on successful completion of "Transition Milestones" that need to be clearly specified in the R61 phase application.

More details at: [https://grants.nih.gov/grants/guide/rfa-files/RFA-AT-24-003.html?utm\\_medium=email&utm\\_source=govdelivery](https://grants.nih.gov/grants/guide/rfa-files/RFA-AT-24-003.html?utm_medium=email&utm_source=govdelivery)

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## ***Changing the Face of TMJ***

**We cannot change the face of TMJ without YOU!**

When you donate, you are making the following happen:

- Advancing TMJ Scientific Research
- Advocating for TMJ Patients
- Supporting and Guiding Patients
- Educating Health Care Professionals
- Providing Trusted Information

The TMJ Association is the *ONLY* patient advocacy organization fighting for the best science that will lead to a greater understanding of Temporomandibular and related disorders and treatments that will help and not harm patients.

We cannot change the face of TMJ without YOU. [Make a tax-deductible contribution today!](#) Your contribution is more than a donation. It is how we will ensure that TMJ patients have a voice — through education, patient support and advocacy.

We cannot do this important work without you! Thank you for your generosity.

## 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](http://www.tmj.org).



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

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