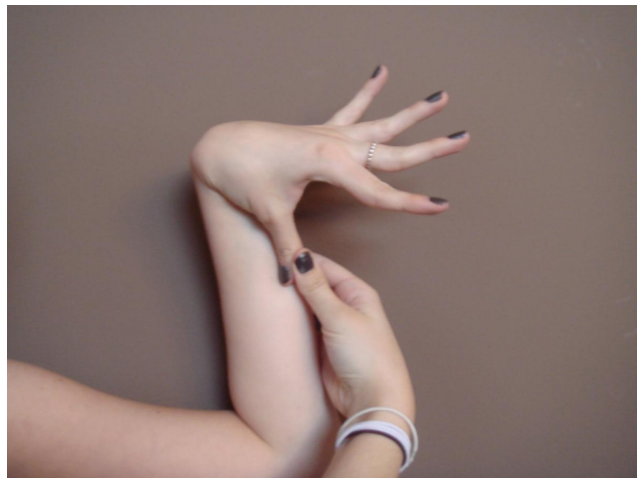


### More News on Disorders Common to TMJ Patients

Research spurred by the TMJ Association (TMJA) over the years has confirmed that a number of disorders often co-occur in TMJ patients, especially in patients in whom Temporomandibular disorders (TMD) are chronic. Many of these disorders, such as irritable bowel syndrome and fibromyalgia, are also painful, leading the Association to establish the **Chronic Pain**



**Research Alliance**, an initiative to stimulate research on *Chronic Overlapping Pain Conditions*.

But there are also disorders, not necessarily painful, that also occur more often in TMJ patients than chance would dictate. Ehlers Danlos Syndromes (EDS), affecting some 7 million in America are a case in point. As the illustration shows, people with EDS have hypermobile joints (sometimes loosely referred to as being “double-jointed”). As a group, EDS are considered inherited connective tissue disorders caused by abnormalities in the structure, production, and/or processing of collagen. Symptoms range from mildly loose joints to serious complications. Features shared by many EDS types, besides joint hypermobility, are soft, velvety skin that is highly stretchy and bruises easily. Genetic variants in a number of genes may lead to EDS, however, the underlying genetic cause in some families is unknown.

Lisa Schmidt, a member of TMJA’s Board of Directors, and a patient advocate, was diagnosed at 47 with EDS. Lisa is currently working on the development of the TMJ registry project of the TMJ Patient-led RoundTable. In that context she became aware of an EDS patient registry and also found that she was qualified for inclusion in the HEDGE study, a research project on hypermobility limited to 1,000 participants. Lisa approached the Ehlers Danlos Society about bringing more awareness to their members of TMJ Disorders and the Society invited her to speak at their annual meeting this past August. We were delighted that Lisa was able to educate meeting participants and would

also like to thank the Ehlers Danlos Society for providing us with the [link to Lisa's presentation](#) to share with our readers.

**Note:** On other occasions, TMJA has been invited to make presentations to nonprofit advocacy groups about TMJ to inform and educate their members about TMJ and any possible connections between TMJ disorders and their conditions. These occasions also serve to lessen any disinformation or misinformation about TMDs that all too often has led to stigmatizing TMJ patients, an issue highlighted in the National Academies/ Report, as noted in the next item in this issue.

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## From the National Academy of Medicine Report on Temporomandibular Disorders

*The National Academies of Sciences, Engineering, and Medicine Consensus Study Report on Temporomandibular Disorders - Priorities for Research and Care was published in March 2020. The excerpt below is from the Summary, pages 13. To view the full report, visit: <http://tmj.org/wp-content/uploads/2020/12/NAM-Report-on-TMD.pdf>.*

“Individuals with a TMD [Temporomandibular Disorders] and their families have contributed significantly to the progress that has been made in TMD research and care. They are among the most persuasive advocates and educators as they have a firsthand picture of the disorder and its impact...

Furthermore, efforts are needed to reduce the stigma that is often associated with TMDs. Although there is a limited amount of research on stigma that is specific to TMDs, research on the impact of stigma from chronic pain, together with patient testimony provided to the committee, eloquently document the stigma suffered by individuals with a TMD and its consequences for patients.

The committee believes that efforts to increase professional education and awareness about TMDs across the dental and medical professions as well as actions to improve the education of patients, families, and the general public are part of the efforts needed to help reduce the stigma of TMDs and improve patient health and well-being.”

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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! Help us to continue our progress towards advancing research, public awareness and safe and effective treatments for this debilitating condition.

[Donate Now!](#)



**THE GIFT OF HOPE!**

Join us in changing the face of TMJ.  
Make a tax-deductible contribution today!

**DONATE NOW!**

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**Coming Soon - "Do's" and "Don'ts" Guide For**

# Providing General Dental Care

As part of ongoing collaborations between Newcastle University, the International Network for Orofacial Pain and Related Disorders Methodology and the TMJA, we are creating a guide for general dentists, dental hygienists and other dental care providers on how best to make dental care for those living with Temporomandibular Disorders (TMD) as safe and comfortable as possible given their symptoms and limitations in jaw function. In its simplest format, it could be considered a “do” and “don’t” list with many helpful pointers, such as:

- the need for extra time in appointments
- deferring elective treatment when there is an active flare-up of TMD

The guide has been developed in partnership between clinicians and patients internationally. Once completed, it will be submitted for publication in a scientific journal and then developed as a leaflet that can be sourced by, or given to dental professionals.

We are hopeful it will receive wide dissemination given the global partnerships involved in its development. It will be a first step towards providing more compassionate care and understanding of TMJ patient issues in the receipt of dental care.

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## Giant Cell Arteritis a Misdiagnosis of TMJ

According to the National Institutes of Health, Giant cell arteritis (GCA) is a form of vasculitis, a group of disorders that cause inflammation of blood vessels. GCA most commonly affects the arteries of the head (especially the temporal arteries, located on each side of the head), but arteries in other areas of the body can also become inflamed. The inflammation narrows the arterial channels, resulting in poor blood flow. Symptoms when arteries in the head are involved may include a throbbing headache on one side or the back of the head, tenderness of the scalp, flu-like symptoms, and/or vision problems.

An article published by MedPageToday, [Giant Cell Arteritis Growing More Lethal](#), states that the data from a study found the average age of patients with GCA was 74 and about two-thirds were women. GCA patients ages 50-64 in the study were more profoundly affected and their mortality rate was nearly triple that of the general population, whereas the mortality rates for GCA patients 85 and older were about 30-40% higher than the overall population.

We bring this article to our readers’ attention because we are aware of several patients whose physicians missed their GCA diagnosis. It is very important not to miss a diagnosis GCA as this condition can increase the risk of stroke and blindness and needs urgent medical attention..

The TMJA encourages patients to share all of their conditions (including TMJ) and symptoms with their primary care physician or internist, even if they don’t think they are relevant or related. Doing so, will help rule out any conditions that mimic TMJ symptoms, such as GCA.

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# Education Bulletin on TMD for Otolaryngology

A recent article on TMD was published by the education committee of the bulletin of The American Academy of Otolaryngology-Head and Neck Surgery. The article states, "Many patients seek care from otolaryngologists [ENTs] for TMD-related symptoms, and our specialty is frequently the first line for assessment of these disorders. The skilled otolaryngologist must rule out more concerning diagnoses, verify that the TMD diagnosis is correct, and educate the patient on both the cause and treatment options for their symptoms."

The TMJA is encouraged by this article as we have been trying for years to bring this issue to the attention of the Otolaryngology community and are pleased with the information provided by the education committee. [Click here to read the article.](#)

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## Mayo Clinic Expert Offers Tips on Headaches

*Headache is yet another overlapping pain condition of TMJ disorders. We found the following article by the Mayo Clinic to be of interest.*

Headache disorders are among the most common health problems worldwide and one of the most underdiagnosed and undertreated, according to the World Health Organization (WHO). In this expert alert, neurologist Amaal Starling, M.D., a headache and migraine expert at Mayo Clinic in Phoenix, offers tips to prevent and manage headache disorders, including migraine and medication-induced rebound headache.

There are more than a dozen different types of headache disorders. The most common disabling headache disorder is migraine. It affects more than 1 billion people around the globe, including 1 in 5 women, 1 in 11 children and 1 in 16 men, and according to WHO, is one of the world's most disabling diseases, Dr. Starling says.

Migraine disease can differ depending on a person's stage in life, she says.

"Infant colic is thought to be the infant variant of migraine. Abdominal migraine and cyclic vomiting syndrome are migraine variants that are common in children," Dr. Starling says. "More classic migraine attacks occur throughout adulthood. In the older adult, the pain associated with migraine lessens; however the associated features such as light sensitivity, sound sensitivity, nausea, vomiting, or aura may be more prominent."

Despite advances in treatment and prevention options, migraine remains underdiagnosed and therefore undertreated, Dr. Starling says. If someone has head pain that makes it difficult to function, odds are that it is migraine; often people think they have sinus headache when it is really migraine, she says. Migraine is a primary headache disorder, meaning it is caused by abnormal function in the brain. Unlike secondary headache disorders, it may not be a symptom of an underlying illness such as an infection or a tumor.

Other common primary headache disorders include cluster headache, which

occurs in bouts of attacks lasting from weeks to months and typically includes intense pain lasting up to three hours in or around one eye; and tension headache, which usually comes with mild to moderate pain and can be chronic. [Click here to read full article](#)

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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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## **TMJ Patient Clinical Study Opportunities**

### **TMD Online Study**

The [Herman Darrow Lab](#) at the University of Minnesota invites those diagnosed with TMD to participate in an online study to understand how TMD affects brain circuitry.

You may be eligible for an online TMJ/TMD study that should take up to 1.5 hours on a computer. You will be paid a \$35.00 Amazon gift card upon completion of the whole study.

If you are interested in participating, please send an email to the Herman-Darrow lab at: [hdlab@umn.edu](mailto:hdlab@umn.edu).

Here's a teaser to see what you might expect if you participate in the study. <https://vimeo.com/689289420>

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## TMD Online Study (Zoom)

We are looking for people with Temporomandibular Disorders (TMD) to help us with our research. We would particularly like to speak to men or people from Black, Asian or other non-Caucasian backgrounds as these characteristics are underrepresented in our interviews to date.

What's involved? Speak to us (online, by Zoom) for up to 1 hour.

The study is organized by Newcastle University

For further information please contact: Dr. Chris Penlington, Chief Investigator at [chris.penlington@ncl.ac.uk](mailto:chris.penlington@ncl.ac.uk)

### Topics include:

- Things you do to help with the pain
  - Do they help?
  - What makes it easy and difficult?
  - How you found about the things that you do to help yourself.
- 

## Action Alert

Your TMJA recently signed on to a [letter to Congress, along with other organizations, regarding the FDA Safety and Landmark Advancements Act](#).

This year, Congress has a big opportunity to make changes to how the U.S. Food and Drug Administration (FDA) protects our food, cosmetics, and health care. A bill moving through Congress re-authorizing funding to the FDA includes much-needed consumer protections. But the food, consumer products, and health care industries are lobbying hard to strip these key protections from the bill. Unless they hear from you, Congress may very well eliminate this opportunity to protect consumers at a critical moment. If you would like to help, go to this [action alert](#) link to contact your members of Congress.

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## Research Grant Opportunities: A Call for Applications

### **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>

## **FY22 Chronic Pain Management Research Program**

The US Department of Defense Chronic Pain Management Research Program invites scientists to submit pain research applications under three targeted areas: Clinical Exploration Award, Investigator-Initiated Research Award and Translational Research Award. Pre-applications are due July 12, 2022.

For additional information, please visit: <https://cdmrp.army.mil/funding/cpmrp>

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## 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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