



TMJ News Bites

Issue 2 2021

The TMJ Association (TMJA) is frequently asked by patients where or how to obtain funding for TMJ treatment. Sometimes TMJ providers ask for payment weeks in advance of a procedure. Patients who do have insurance may also be told that their provider does not accept insurance and be told to file any insurance claim on their own. We've also learned that some TMJ patients and their loved ones have gone online to request funds through crowdfunding sources such as GoFundMe®

That approach turned out to be the basis for several phone calls we had in December 2020 with Dr. Daniel Mullins at the University of Maryland School of Pharmacy and Dhriti Vadlakonda, a high school student in Maryland. The calls led to the development of a research project in which they compared the fundraising results of a GoFundMe® TMJ campaign with four other disease campaigns: breast cancer, chronic Lyme disease, dementia and sickle cell disease. We thank them for the study and for preparing the research article below for us.

Please note that as a patient-based advocacy organization, TMJA has long voiced concern about insurance coverage—or its lack—in paying for TMJ treatments. We have argued the necessity of having evidence of safe and effective treatments for TMJ so that insurers can feel confident that they are paying for quality care and not for procedures that may contribute to increased pain and jaw dysfunction. We remain steadfast in advocating for the research and technological developments that can lead to the quality diagnostics, treatments, and preventive interventions. We welcome your help in this very difficult fight.

Comparing the Success of Temporomandibular Joint Disorder Campaigns with that of Other Diseases on GoFundMe®

by Dhriti Vadlakonda

Abstract

Many patients with Temporomandibular Joint Disorder (TMD) face financial loss and bankruptcy due to costs of healthcare and unpredictable insurance coverage for treatments. Successful crowdfunding campaigns may ease or eliminate the burden of cumulative, expensive medical bills for patients.

The objective of this research was to comprehend how successful TMD patients are at fundraising efforts compared to patients with other diseases. In January 2021, a cross-sectional study of all publicly available crowdfunding pages was conducted, seeking posts on GoFundMe® related to TMD, Breast Cancer, Chronic Lyme Disease, Dementia, and Sickle Cell Disease. For each disease, the average and median [1] donation values across the campaign sample were calculated. The median value for the percent of goal achieved across the campaign sample was also calculated for each disease.

For the donation amounts, the lowest average value of \$2,931 and the lowest median value of \$1,500 across a 157 – campaign sample were associated with TMD. For the percent of goal achieved, the lowest median value of 13.7% across a 157– campaign sample was associated with TMD.

These findings yield important insights for medical professionals and researchers who seek to improve the quality of healthcare and lives of TMD patients. When working with TMD patients, it is essential to take into consideration the out-of-pocket costs associated with each treatment option as they are being discussed in order to prepare patients for possible cumulative expenses. These findings can also be utilized to raise awareness of the inadequate support that TMD patients receive on crowdfunding sites. [Read full article here.](#)

[1] Median refers to the mid-value in the list of donations with half the donations falling below and half above that value

About the Author



Dhriti Vadlakonda, a junior at River Hill High School in Columbia, MD, is passionate about eliminating health inequities faced by patients and improving the well-being of patient communities around the country. This year, Dhriti interned at the University of Maryland (UMD) School of Pharmacy under the mentorship of Dr. C. Daniel Mullins, the executive director of The PATIENTS

Program, and Dr. Joseph Mattingly, the Director of Operations of The PATIENTS Program. After speaking to Mrs. Terrie Cowley about the devastating effects of TMD on patients' everyday lives, including patients' cumulative and burdensome expenses on treatments and surgeries, Dhriti was inspired to learn more about how successful TMD patients are at fundraising efforts compared to patients with other diseases. In January of this year, Dhriti conducted a cross-sectional study of all publicly available crowdfunding pages for posts related to TMD, Breast Cancer, Chronic Lyme Disease, Dementia, and Sickle Cell Disease on GoFundMe®. She found the lack of financial support that TMD patients received on the platform to be concerning. She hopes that her research can be utilized to raise awareness of the inadequate support that TMD patients receive on crowdfunding sites. An aspiring doctor, Dhriti has been delighted to learn so much about patient advocacy, health economics, and medical research throughout her internship and is very grateful for the TMJ Association and The PATIENTS Program for providing her with

the opportunity to delve further into her medical passions.

And her Mentor



C. Daniel Mullins, PhD, is Professor and Chair of the Pharmaceutical Health Services Research (PHSR) Department at the University of Maryland School of Pharmacy. He founded and is the Executive Director of the PATIENTS Program, which is a community-academic partnership which aims to bring the patient voice into research in order to make it more meaningful to patients. As a health economist, Dr. Mullins understands the negative impact that astronomical health care costs can have on a person's wellbeing. Living in downtown Baltimore and spending a lot of time working with communities in low-income

neighborhoods, he has seen the devastating impact of poor health and high costs on vulnerable populations. Having spoken on an FDA panel with Terrie Cowley, Dr. Mullins began to understand the financial impact of TMJ for those individuals who receive expensive surgical interventions that sometimes simply don't solve the problem – or sometimes make the painful aspects of TMJ worse both physically and financially. As a professor, he enjoys mentoring anyone, from high school students such as Dhriti, to junior faculty in order to support the pipeline of future researchers and health care professionals who can solve the physical and financial aspects of medical conditions.

FDA Website Updates

Recently the U.S. Food and Drug Administration (FDA) updated its information for patients and health care providers on Temporomandibular Disorders (TMD) and Temporomandibular Joint Implants.

These updates include:

- Recommendations for patients on how to report a problem with TMD devices
- New information and a video on how the FDA works with people who have TMD and patient organizations, and
- Details about how and why the FDA tracks TMD devices

To find out more, please click on the links below:

[Temporomandibular Disorders \(TMD\) Devices](#)

[Temporomandibular Joint \(TMJ\) Implants](#)

Online Research Survey Opportunity

Cannabinoid use for Chronic Pain: Understanding the Perspectives of Individuals with Chronic Pain

This study is being conducted by Jennifer Gewandter, PhD, MPH, from the University of Rochester and Roy Freeman, MD from Harvard Medical School.

The purpose of this study is to better understand how people who live with chronic pain feel about using cannabinoids (including prescribed medications, CBD, or whole plant cannabis (marijuana)) to treat their pain. We also want to learn how well cannabinoids have worked for those who have tried them. We want to learn about peoples' experiences to inform future research, policy, and patient care with cannabinoids for chronic pain.

If you decide to take part in this study, you will be asked to complete one survey that will take about 10-15 minutes. The survey will ask questions about what types of chronic pain you have and what treatments you use for the pain. It will ask if you currently use or have previously used cannabinoids to treat chronic pain. If you have used or are using cannabinoids to treat chronic pain, the survey will ask how well they are working or worked, what side effects (if any) you experienced, what type of cannabinoids you use or used, how you get (or got) your cannabinoids, and whether you discuss (or discussed) your cannabinoid treatments with your clinician. We will not collect any personal identifiable information from you so your responses cannot be linked to you.

We estimate that approximately 300 participants will take part in this study.

If any of the survey questions are upsetting or make you feel uncomfortable, you can skip any of the questions you do not want to answer. There are no other expected risks. There are also no expected benefits.

You will not be paid for participating in this study.

Funds to support this study are being provided by GW Pharmaceuticals, who will have access to the final data but the data will not have any identifying information.

Your participation in this study is completely voluntary. You are free not to participate or to withdraw at any time, for whatever reason.

For more information or questions about this research you may email Jennifer Gewandter, PhD, MPH (jennifer_gewandter@urmc.rochester.edu) or Roy Freeman, MD (freeman@bidmc.harvard.edu).

[Click this link to go to the survey. By taking the survey, you are agreeing to participate in the survey.](#)

New TMJ Research Articles

We invite you to read the research articles related to temporomandibular disorders on our website at: <https://tmj.org/hope-in-research/research-articles/>. This information will help you stay educated and updated as well as guide you and your loved one in making health care decisions.

The following are some of the new articles we recently posted on our research articles page:

- [Transitioning to Chronic TMD Pain: A Combination of Patient Vulnerabilities and Inflammation](#)
- [Long-term evaluation of temporomandibular disorders in association with cytokine and autoantibody status in young women](#)
- [Parathyroid hormone attenuates osteoarthritis pain by remodeling subchondral bone in mice](#)
- [Do sex hormone imbalances contribute to idiopathic condylar resorption?](#)
- [Transcriptomes in peripheral blood of young females with temporomandibular joint osteoarthritis](#)
- [Proteomic expression profile in human temporomandibular joint dysfunction](#)
- [Temporomandibular Disorders and Dietary Changes: A Cross-sectional Survey](#)
- [Exploring mental health experience in individuals living with temporomandibular](#)

- [disorders](#)
 - [Can Physical Therapies for Chronic Temporomandibular Disorders Cause the Wind-Up of Nociceptive Neurons in the Trigeminal Subnucleus Caudalis?](#)
 - [Experimental Pain Sensitivity in Subjects with Temporomandibular Disorders and Multiple Other Chronic Pain Conditions: The OPPERA Prospective Cohort Study](#)
 - [Self-reported symptoms of temporomandibular pain and jaw dysfunction in adolescents is associated with exposure to violence](#)
 - [Quality of life in young and middle age adult temporomandibular disorders patients and asymptomatic subjects: A systematic review](#)
 - [Frequency of Involvement of Different Head and Neck Sites in Referred Otagia](#)
 - [Animal Models of Temporomandibular Disorder](#)
 - [Clinical, psychological, and sensory characteristics associated with headache attributed to temporomandibular disorder in people with chronic myogenous temporomandibular disorder and primary headaches](#)
 - [Temporomandibular Disorders and Fibromyalgia: A Narrative Review](#)
 - [Treating temporomandibular disorders in the 21st century: Can we finally eliminate the “third pathway”?](#)
 - [Arthrocentesis of the temporomandibular joint: systematic review and clinical implications of research findings](#)
 - [A preliminary analysis of the wear pathways of sliding contacts on temporomandibular joint total joint replacement prostheses](#)
 - [Healthcare burden and associated adverse events from total alloplastic temporomandibular joint replacement: a national United States perspective](#)
 - [Prosthetic temporomandibular joint reconstruction in a cohort of adolescent females with juvenile idiopathic arthritis](#)
 - [Temporomandibular Disorders Slow Down the Regeneration Process of Masticatory Muscles: Transcriptomic Analysis](#)
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U.S. Bone and Joint Decade Initiative

Young Investigator Initiative Grant Mentoring and Career Development Program

DEADLINE FOR APPLICATION SUBMISSIONS: July 15, 2021

Fall Workshop – October 22 - 24, 2021, Chicago, Illinois

The United States Bone and Joint Initiative (USBJI) and Bone and Joint Canada are dedicated to increasing research of musculoskeletal diseases. To keep pace with the high and increasing burden of these diseases, a higher level of research performed by young investigators in the musculoskeletal diseases is required and future levels of research assured. This is particularly important given the current environment for research funding and academic careers. In response, the Young Investigator Initiative is a grant mentoring program providing early-career investigators an opportunity to work with experienced researchers in our field to assist them in securing funding and other survival skills required for pursuing an academic career.

To date, 276 participants (60%) have successfully obtained \$572 million in grants for 1,918 new musculoskeletal research studies. Participants consider this program instrumental to their success. They rate highly the one-on-one mentoring with experienced researchers, the opportunity for inter-disciplinary and peer-to-peer exchange, and collaborations established during workshops.

This grant mentoring program and career development program is open to promising junior faculty, senior fellows or post-doctoral researchers nominated by their department or division chairs seeking to pursue a career in clinical or basic research. It is also open to

senior fellows or residents that are doing research and have a faculty appointment in place or confirmed. Basic and clinical investigators, without or with training awards, are invited to apply. Investigators selected to take part in the program attend two workshops, 12-18 months apart, and work with faculty between workshops to develop their grant applications. The unique aspect of this program is the opportunity for attendees to maintain a relationship with a mentor until their application is funded.

Apply at: <https://www.usbji.org/programs/yii/application-information>

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.



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

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