

TMJ News Bites

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TMJ Device Causing Patient Harm

CBS News and Kaiser Health News recently investigated one of the many temporomandibular disorder (TMD) treatments that are on the market and sold to patients without evidence of safety and efficacy. Professionals and the public routinely get misinformation about TMD treatments, and this investigation portrays the reality of what goes on in this area and the effect of these devices on the lives of TMD patients.

Dental patients complain of harm from an unproven dental device - Patients report irreparable harm by an unregulated dental device. An investigation by CBS News and Kaiser Health News found the device that allegedly left a trail of mangled mouths has not been reviewed by the FDA.

Part 1:





Investigation Update:



You can also read the Kaiser Health News article which is available at: https://khn.org/news/article/dental-device-lawsuits-displaced-teeth-agga-steve-galella/

How to Report a Device Problem

Should you be experiencing ANY type of TMD device problem, including splints, it is important that you <u>report these issues to the FDA through their MedWatch system</u>.

Splints are known by a wide variety of names such as: intraoral appliance, stabilization appliance, occlusal appliance, interocclusal appliance, repositioning splint, bruxism splint, night guard, mouth guard, and others, with names denoting commercial vendors promoting particular designs.

Bringing Dental and Medical Students Together to Learn About TMD

Last year we told you about organizing a TMD educational session with medical and dental students so they could become better informed about the jaw joint and associated muscles and tissues. This was significant because it made clear that TMDs are not strictly a dental problem, but are complex and multi-faceted.



On January 30, 2023, second-year dental students from Marquette University Dental School in Milwaukee joined first-year medical students from the Medical College of Wisconsin (MCW) in the *first* combined TMD educational session that was held at MCW. The session was designed as an interprofessional activity to increase understanding of TMD and the need for collaboration in providing clinical care.

Michelle Reardon, a board member of the TMJA, provided the students with a parent's perspective and a timeline of her daughter's TMD journey. (see video below).



TMJA was represented at this event by Laurie Friedrich, Deanne Clare, Terrie Cowley and Allen Cowley and the following are our observations:

 Both the medical and dental students got along very well and enjoyed their interactions with each other. It was a very collegial and interactive group of students. The post-session student evaluations were very strong which bodes well for future planning and further cross pollination exchanges between the two professions.

- The students greatly appreciated the presence of the TMJA representatives. They interacted with us and showed great interest and asked many questions. They were quite sensitive to the plight of TMD patients. We feel this should be a part of these sessions going forward and a time for these informal interactions should be incorporated into the schedule.
- Organizationally, the session went smoothly although the need for some fine tuning was recognized by the course directors. In general, everything seemed rushed. More time may be required to make this a meaningful interaction and educational experience.
- The anatomical aspects of the curriculum were adequate and first year medical students respected the second-year dental students' knowledge of the anatomy.
- The major weakness was the clinical content of TMJ disorders. For example, information from the <u>OPPERA program</u> and <u>NASEM report</u> was not included in the presentation. Instead, outdated information was mostly presented. Unfortunately, this is the major obstacle that will be faced by interprofessional educational efforts in this field.

After the session, we were contacted by a medical student experiencing TMJ issues who participated in this event. We asked for her perspective on the interprofessional session. <u>Click here to read her summary</u>.

Overall, the meeting was a very important first step! It is our hope that this collaboration will continue to develop into a framework for future interprofessional learning.

Two Champions We've Lost

The TMJ Association (TMJA) mourns the passing of two outstanding leaders in science and in health care advocacy reported earlier this year. **Ronald Dubner, DDS, PhD,** an internationally acclaimed pain scientist, died January 22, 2023. **Mary Kaye Richter,** founder of the National Foundation for Ectodermal Dysplasias, died November 24, 2022. Both dedicated their lives to advancing research to understand and treat complex human disease.

Ronald Dubner

Ronald Dubner's work is directly relevant to the mission of the TMJA and his name may be familiar to readers because he has long been a friend, supporter and contributor to our scientific meetings. Ron trained as a dentist and practiced in the dental clinic when he first came to the National Institutes of Health in the 1960's, but he discovered his true love was basic science. He acquired a PhD in physiology and went on to focus on the workings of the nervous system in



the orofacial region, particularly in relation to the perception of pain.

This was at a time when pain research was in its infancy. However, there was

an innovative "gate theory" gaining ground which said there were both enhancing and inhibiting mechanisms in the nervous system that could worsen (open the gate wide) or moderate (partially or completely close the gate) a person's experience of pain. To a large extent much of Ron's pioneering research was demonstrating the truth of that theory by discovering multiple nerve pathways, cells, neurotransmitters and other molecules responsible for those moderating effects, as well as mechanisms by which the nervous system also interacts with other body systems such as the immune system.

Over the decades as Chief of the Laboratory of Neurobiology and Anesthesiology at the National Institute of Dental Research, (now the National Institute of Dental and Craniofacial Research), Ron mentored dozens of future pain researchers seeding laboratories across the country. As well, he argued for multidisciplinary and collaborative research on pain, recognizing that the experience of pain reflects psychological and social forces as well as biological. He left NIH in 1995 to become Professor and Chair of Oral and Pain sciences at the University of Maryland School of Dentistry, continuing his research and mentoring until he retired in 2017.

We will miss his warmth, his sense of humor, and his support of all of our efforts. Our condolences go out to Ron's family.

Mary Kaye Richter

She was a force of nature. "You didn't say no to Mary Kaye. You didn't step in front of that freight train," said a former chair of the Scientific Advisory Council of the National Foundation for Ectodermal Dysplasias (NFED), the nonprofit health advocacy organization Mary Kaye founded in 1981. That was three years after this farm-raised young woman, married to a farmer, and also running a florist shop in a nearby town, gave birth to her son Charley. At 18 months Charley failed



to produce a single tooth and a dental x-ray showed there were no permanent teeth waiting in his gums. That was a sign that Charley had a type of ectodermal dysplasia, a rare genetic disease (there may be seven cases in the country, she was told), characterized by scant hair, nail and tooth defects, and a lack or malfunctioning of sweat glands. Determined to find out more, Mary Kaye called health agencies and wrote letters, mostly coming up empty. There were no experts, there was no research. But the dental schools she contacted said the condition was not so rare. There were hundreds of cases across the country—enough to start a network for a fledgling foundation. Today NFED serves as a resource and support base for some 9,200 families worldwide, supplying information on its website and holding family conferences on a budget of about a million dollars a year. Most importantly, NFED has promoted research, including studies aimed at correcting the genetic defects of the most common forms of the disease. It was in the context of promoting research that we first encountered Mary Kaye at the dental institute at NIH (NIDCR).

An editorial piece that Mary Kaye wrote for *Special Care in Dentistry* in 1993, entitled, *From Dentistry to Donkey Dung* provides readers with a glimpse of the passion, tenacity, and drive Mary Kaye brought to the oral health arena.

"Why the mouth is routinely segregated from the body in terms of health care

and professional attitudes is something I'll never quite understand. But this mental and physical segregation has served to isolate the practice of medicine from that of dentistry. What a shame! ...Both the body and the professions need to be brought together. ...Now is the time for us to take action. The days of satisfaction with the status quo are over. It is for you to decide whether or not you will be a part of the exciting future or will be left behind in the unsatisfactory past."

Mary Kaye, we couldn't agree with you more!

Our sympathies go out to Mary Fete, Executive Director of the National Foundation for Ectodermal Dysplasias and her staff as well as Mary Kaye's family.

We Need *Your* Financial Support To Continue Our Advocacy Efforts!

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.



Join us in changing the face of TMJ.

Make a tax-deductible contribution today!



patients have a voice — through education, patient support and advocacy.

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





"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

Patients Needed for An Online Research Study

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

Research Grant Opportunities: A Call for Applications

Planning for the TMD Collaborative for IMproving PAtient-Centered Translational Research (TMD IMPACT)

NIDCR invites planning grant applications for its TMD Collaborative for

Improving Patient-Centered Translational Research (TMD IMPACT) to design a national collaborative that will advance research, training, treatments, and

care for temporomandibular disorders (TMDs). NIDCR held a webinar to answer prospective applicants' questions. To access the recording, visit NIDCR's TMD IMPACT webpage. The application deadline is April 14, 2023.

The Intersection of Sex and Gender Influences on Health and Disease

The purpose of this Funding Opportunity Announcement (FOA) is to invite R01 applications on the influence and intersection of sex and gender in health and disease, including: (1) research applications that examine sex and gender factors and their intersection in understanding health and disease; and (2) research that addresses one of the five objectives from Strategic Goal 1 of the 2019-2023 Trans-NIH Strategic Plan for Women's Health Research "Advancing Science for the Health of Women." The awards under this FOA will be administered by NIH ICs using funds that have been made available through the Office of Research on Women's Health (ORWH) and the scientific partnering Institutes and Centers across NIH.

https://grants.nih.gov/grants/guide/rfa-files/RFA-OD-22-028.html

Understanding Chronic Conditions Understudied Among Women

The purpose of this Notice of Funding Opportunity (NOFO) is to invite R01 & R21 applications on chronic conditions understudied among women and/or that disproportionately affect populations of women who are understudied, underrepresented, and underreported in biomedical Research should align with Goal 1 of the 2019-2023 Trans-NIH Strategic Plan for Women's Health Research "Advancing Science for the Health of Women." The awards under this NOFO will be administered by NIH ICs using funds that have been made available through the Office of Research on Women's Health (ORWH) and the scientific partnering Institutes and Centers across NIH.

R21: https://grants.nih.gov/grants/guide/rfa-files/RFA-OD-23-013.html

R01: https://grants.nih.gov/grants/guide/rfa-files/RFA-OD-23-014.html

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. is a nonprofit 501(c)(3) tax-exempt organization.

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