What Allen Told the Committee

Allen Cowley addressed the second open-to-the-public meeting of the National Institute of Medicine’s (NAM) Committee on Temporomandibular Disorders (TMD) held on March 28, 2019 in Washington, DC. No stranger to the world of TMD, Dr. Cowley is the husband of TMJA’s President, Co-founder and TMD patient, Terrie Cowley. Dr. Cowley has had a long and distinguished career as professor and chair of the department of physiology at the Medical College of Wisconsin and as an innovative multi-grant winning researcher in the field of hypertension (high blood pressure). He has also played a principal role as chair of the planning committees for TMJA’s science meetings.

"I was appalled when I started to look at the literature in this field," Dr. Cowley told the committee in a talk which reviewed the history and the state of research and funding on TMD. "In the year 2000 there was no coherent body of knowledge or even a common clinical definition of TMD." That was one of the findings from TMJA’s first scientific meeting held that year, co-sponsored with components of the National Institutes of Health (NIH). Importantly, the meeting resulted in a fundamental change in perspective: TMD was to be recognized "as part of a complex system, rather than a problem of jaw dysfunction and pain in the jaw joints." That view was voiced by Dr. Lawrence Tabak, then Director of the National Institute of Dental and Craniofacial Research. In keeping with that perspective, it was further proposed that there be a multi-disciplinary integrated patient care and research effort.

TMJA, in partnership with NIH, has continued to hold scientific meetings with the eighth meeting in 2016, Dr. Cowley said. All have as their goals an analysis of the state of the science with the intent to bring new ideas and perspectives to the field. All also have asked the scientists attending to formulate recommendations to NIH regarding the gaps and consequent opportunities in TMD basic and clinical sciences.

One of the most important aspects of the meetings has been the participation of patients to provide real-world examples so that the professionals can focus on the priorities only
patients can identify, or, as Dr. Cowley said, "The patients have educated all of us. That's what has driven all of the meetings we've had."

Dr. Cowley went on to describe the formation of the TMJ Patient-led RoundTable in 2016, whose mission is to bring together all stakeholders concerned with TMD and who share the goal of improving the health care of patients. The RoundTable is structured into Working Groups with Working Group 1 concerned with the science. They have identified nine gaps/opportunities in the basic sciences related to TMD. "Gaps" are crucial areas to be addressed, while "opportunities" are directions for research to fill in the gaps, providing needed information for accurate, consistent diagnosis and treatment for TMD and related diseases/disorders:

**Gaps & Opportunities.**

1. Molecular genomics and epigenetics
2. TMD and data science informatics
3. Mechanisms underlying chronic TMD pain and joint-specific pain
4. Sex differences
5. Neuro-endocrine system interactions
6. Immune-inflammatory mechanisms (CNS/Systemic)
7. TM joint tissues and mechanics
8. TM joint tissue engineering and disk displacements
9. Animal models

Each of the nine has been defined in precise terms to guide the development of research in the area. The guiding principle, echoing that first scientific meeting's observation, is that "**TMD must be studied as a complex disorder determined by interacting and redundant systems.**"

Dr. Cowley emphasized that past practices based on only one perspective on the origin/causes of TMD have failed. He stated, "This is where the whole field of research ought to come together." What is needed is information obtained from all related scientific fields.

So where are we now? Where do we stand regarding the funding for the research deemed crucial to answer the needs for diagnosis and effective treatments of TMD?

**Fact #1.** Funding for TMD research at the National Institute of Dental and Craniofacial Research is 3-4% of their budget ($11.2 million vs a total of $371 million). It is important to remember that TMJ affects some 36 million people in the U.S.

**Fact #2.** There is a disconnect between dental and medical schools in basic and translational research: In particular:

- There is little collaboration between medical and dental schools in basic research.
- NIDCR funding for TMD basic research is limited, even in the top 5 research ranked dental schools.
- Aggressive efforts to stimulate an integrated approach to TMD are lacking. The science and funding siloes are a great impediment to progress.
- There is little evidence of efforts to integrate cell/tissue specific functions with those of the whole organism.

In summary, Dr. Cowley reiterated points he had earlier emphasized: TMD basic and translational research must be **extended beyond the narrow province of dentistry to include the basic and clinical disciplines appropriate to this complex**
Basic research in dental schools would greatly benefit from collaborations with medical schools, schools of engineering, pharmacy and a sharing of core facilities.

To coordinate advances in the basic sciences related to TMD Dr. Cowley proposed a **trans-Institute agency research planning group** to set goals based on exciting scientific and clinical missions that will attract basic, clinical, translational scientists and engineers to the field.

And to facilitate these approaches, he again nominated patients **whose expertise should be sought to identify and help focus research areas to encompass areas of greatest relevance to them...**

...adding a final caveat:

Every aspect of basic and clinical TMD research needs a significant increase in funding to attract scientists from those disciplines essential to develop teams of experts to address obvious gaps in the field. As things stand now, “TMD research is so far behind that it has been left in the dust, behind other scientific fields. This is a disorder in trouble in terms of research funding and lacking a critical mass of scientific expertise required to address the underlying mechanisms related to the etiology of this complex disorder.”

**Click here to view Allen’s slides**

**Click here to watch Allen’s presentation**

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**The Committee Heard from Patients, Too**

At the same public meeting NAM committee members had a chance to hear from TMD patients who had submitted testimony for the record. We’ve included a couple of examples (with links to more). Adriana addresses the issue of TMD not having a home in any health specialty while Lutricia’s recounts the brutal history of her treatments and the consequences of a failed implant.

**What Adriana said...**

I’ll get right to the point: we’re here because our current "system" (for lack of a better word) for treating TMD is not only broken but it’s fragmented, and patients are falling through the cracks and left feeling abandoned and alone. These cracks are actually more like one huge gap or a divide between the fields of dentistry and medicine, and it is in this no man's land that TMD patients find themselves. Hip and knee joints belong to medicine, where there are well-established protocols in place, but the TM joint falls under dentistry. This causes all sorts of issues for us in terms of treatment, pain management and insurance.

It’s our dentist that refers us to an oral surgeon, so our family doctor is out of the loop from the get-go; meanwhile, they are the ones that are actually treating our symptoms YET medical doctors have no knowledge of TMD, and round and round we go!

**After my right TM joint was replaced.....**
And I'd like to add here that it was replaced because I was told the joint had fused. I don't recall any alternative options given to me. I was simply told that the joint needed to be replaced and what it needed to be replaced with. He was the surgeon. Who was I to question his diagnosis or treatment plan. I had no reason not to trust him.

After it was replaced, my surgeon deemed the surgery a success because the joint was functioning and my opening was acceptable. I was to come back in a year. When, in tears, I began to list my new, more intense symptoms and the fact that the painkillers I was taking barely touched the pain, he stopped me mid-sentence and said, "you need to deal with those issues with your family doctor." In that moment I felt dismissed, ignored and devastated.

Go to my family doctor? What does she know about any of this? So, according to the surgeon the surgery was a success, but somehow I had to convince my family doctor and the insurance company that I was in MORE pain, and ultimately unable to return to work. But worse than that, was that the one man/doctor "qualified" to acknowledge my pain, to possibly "treat" my pain, had dismissed me and didn't want to hear what I was experiencing!

What do I do now? To whom can I turn? Who will believe me? There was no one else to turn to in dentistry. Oral surgery is the last stop.

So, the patient is left to do the research. They have to fight for and dictate their own treatment. They have to find a way to manage their pain. They have to deal with the fact that every aspect of their life has been affected by "this." And what is it really that we are dealing with? Muscle spasms, nerve pain, headaches, migraines, neck pain, biofilm, sleep apnea, poor diet, depression, job loss, quality of life issues, etc., etc. What what fields do those issues belong to? The pain clinic? Psychiatry? Infectious disease? Sleep disorder clinic?.... And again, what do they know about TMD?

To Whom Do We Turn?

We need a comprehensive approach, a combined effort, a coming together or meeting of the minds to address all aspects of this disorder. The medical and dental communities need to come together on this because TMD is obviously BOTH a dental AND a medical problem!

We have learned, through the collective suffering of TMJ patients, that surgery should be a last resort, and that we should not count on it to help reduce our pain level, BUT when we are in unbearable pain, day after day, and another surgery gives us even a "glimmer" of hope for some relief, we will take it! We will take it if we are facing this alone, if we are facing it without the facts, if we are facing it without an alternative approach, if we have no other supports in place, we will take the risk. This is how desperate we are because our pain is rarely managed well.

At one point I found myself envying cancer patients. That feels even shameful to admit especially since I watched my sister battle cancer for two years. She's okay now. What is really the point is with cancer, one way or another, the suffering ends. But also with
cancer, the world stops for you. Meals are made for you, compassion and support come flooding in. Ribbons and marathons and foundations are everywhere. No one would dare question a cancer patient's symptoms or pain.

Our experience is vastly different. Ours is one of isolation, loneliness, little compassion, and little awareness.

TMD has affected every aspect of my life: physically, emotionally, financially, psychologically, professionally, and it has affected my relationships, my passions, my independence, and at times my dignity. It cut me off at the knees and changed the landscape of my life, and what I imagined my life would be.

I have had to accept that, we've all have no choice but to accept that. It would just be a whole lot easier to do that if what we are experiencing would be taken seriously. If we would stop being dismissed and abandoned.

Click here to read more from Adriana.

And Here is Lutricia's Story

My name is Lutricia. I never had TMJ pain but I did have an overbite which a surgeon attempted to fix with braces and an orthognathic procedure. My teeth were ground down. My right joint became displaced and perforated and the surgeon decided on another procedure and implant.

I am a Vitek Proplast Teflon survivor/victim. It is important for everyone here to know that this implant was put into TMJ patients in the 1980s without evidence of bioengineering, biocompatibility, animal or clinical data - no evidence of safety or efficacy. This implant was sold to patients as a miracle implant. It had a 100% failure rate and in 1991 the FDA issued a class one recall because this created what they called "open communication to the brain." What this means is the implant worked its way through the skull into the brain. The manufacturer shifted his patents off shore, declared bankruptcy and fled the country to Switzerland. The FDA was then put in the position for the first time to handle the recall.

During a Congressional hearing, triggered by The TMJ Association in 1992, we were told things would change and believed a catastrophe like this would never happen again. In 2006, a Government Accountability Office (GAO) report, again requested by The TMJ Association, revealed that TMJ devices currently on the market were approved with minimal to no bioengineering or clinical data. All the studies supporting the PMA applications had many issues including deficient patient follow-up, which made it difficult to determine outcomes over time. The GAO report commented on one device that, "either good engineering data or good clinical data was acceptable to approve a device - not necessarily both" since clinical data was largely missing, bioengineering data was accepted but later admitted to be inadequate. FDA management acknowledged that need for devices outweighed concerns. Another revelation in the GAO report was that FDA management indicated that the clinical data for a device was not expected to be of high quality "because the sponsor was a small manufacturer." In the end these devices were approved because "the patients need something."
Back to myself, the Vitek implant was removed, a total joint prosthesis had to be implanted requiring part of the jaw bone to be removed. Then I had another total joint. Some of the issues I've had following the surgeries/implants until now are constant pain, surgery to tighten loose screws, surgery to remove heterotopic bone and foreign body giant cell reaction - possibly working through the skull to the brain, a compromised immune system, allergies and itchiness all over my body which appears to be like eczema, trigeminal neuralgia, a white mass on my brain, ulcerated esophagus, and facial paralysis.

There has been a disconnect between patients and everybody else. There are few or no answers for patients like me. Patients are left on their own to try and find someone who may listen to them and who may understand something about this TMJ problem. Patients end up being referred from one dental/medical person to another and in the end, little is resolved and some of us keep getting worse. It is common that patients are simply abandoned or their disorder and pain is denied as being real. I for one can no longer trust anybody.

My husband has stood by me all these years, constantly frustrated by this TMJ system. I'm lucky; many patients' marriages have ended up in divorce. Families have disowned patients; friends distanced themselves because they do not understand. Professionals advertise our disorder as a click and a pop easily fixed but do not show the true problems to the public. Homes have been mortgaged and savings exhausted because now, insurance companies will not cover anything relative to TMJ. Patients are forced to give up their jobs and promising careers because of the many medical procedures, pain, disability, expenses and medications they must take just to get through the day.

What I want to see going forward is research on just what Temporomandibular Disorders are – research that validates the safety and effectiveness of every treatment for TMD. I want research on every aspect of a TMJ device and related patient care. I want better practices and protocols for all stages of TMJ surgical procedures and a formal collaboration with the musculoskeletal branches in medicine. There is no reason we should not have the research on the TM joint that exists on every other joint in the body.

Every surgeon who implants a TMJ device must have extensive training. Every device should have a unique identifier so it can be tracked. Manufacturers should come to FDA with all clinical, bioengineering, biocompatibility, animal and clinical data to prove safety and efficacy of their product. We need an independent entity to which all explanted devices can be sent for analysis in which all data submitted, including by patients, can be analyzed and the resulting information credible.

Today I've shared with you an historical perspective of TMJ implants along with my personal experiences in order to show how the lack of science on this condition and the treatments can inform us how to direct future research to ensure a safer scientific evidence based future for TMJ patients. I thank everybody for this extraordinary opportunity for our voices to be heard.

View additional NAM patient presentations:
- Jennifer
- Tricia
And the Committee heard from the American Association of Oral and Maxillofacial Surgeons

At the end of the NAM meeting, Dr. Gregory Ness, representing the American Association of Oral and Maxillofacial Surgeons (AAMOS) gave the following comments:

“AAMOS welcomes the interest and support of the Academies, the NIH, NIDCR, FDA and The TMJ Association in this collaborative effort to improve the care we deliver… I have little time so I am not going to say nearly as much as I'd like on the issues I've been asked to address or to the patients represented here whose contributions have already been deservedly applauded. Most of us have met before and I have heard your stories before, but they are no less difficult [to hear] than the first time and perhaps more powerful because it may have been three to four years now since that first time but that drives home the fact that in the interim you’ve continued to suffer. To someone like me who has spent almost 30 years working very hard to improve people’s TMJ problems and to train others to do the same, this is a difficult emotional issue to be confronted by. So thank you again and to each of you I say, I’m sorry. I'm sorry that you continue to suffer. That we failed in our promise to make you better, not worse. I'm sorry you heard foolish, ignorant, dismissive, carelessly cruel things from those that were supposed to care for you more than when you really needed it the most. I'm sorry you've had far more operations than any one person should ever have, or that you understandably don’t know who to trust. We can point to our many successes, and they are many, but that provides no comfort at all to those of you whom we failed. I think it’s our job now to see how we can shrink your numbers as close to zero as humanly possible so thank you again for pushing us all together. “

View Dr. Ness' presentation here.

Upcoming NAM Public Webinars

The National Academy of Medicine’s (NAM) Committee on Temporomandibular Disorders (TMD): From Research Discoveries to Clinical Treatment is hosting two public web conferences on Wednesday, June 19 and Wednesday, July 31.

Webinar 1: Patient Care – Dental providers will share their experiences caring for people with TMD.
When: June 19, 11:00 AM-1:00 PM ET
Participation: Zoom web conference Register here.

Webinar 2: Professional Education – Panelists will provide insights on the nature and extent of TMD training and opportunities for interprofessional education.
Some Thoughts on Depression

It is hardly surprising that the chronic pain and limitations in function that many long-time TMJ patients experience can be accompanied by a state of depression, a sense of exhaustion and hopelessness. Indeed, any condition that gives rise to chronic pain can result in feelings of depression that contribute to a worsening of the quality of life. We were therefore heartened to read an upbeat account of current research on depression by Joshua A. Gordon, MD, PhD, the current Director of the National Institute of Mental Health, one of the National Institutes of Health. It has been lightly edited for space.

I'm Optimistic about Depression
By Dr. Joshua Gordon

About 7 percent of U.S. adults report experiencing an episode of depression in the past 12 months, according to the 2016 National Survey on Drug Use and Health conducted by the Substance Abuse and Mental Health Services Administration (SAMHSA), a U.S. Government agency. The rate of depression is even higher in women and adolescents. And, while effective treatments exist for depression, many individuals suffer for extended periods or relapse after feeling better. Furthermore, many individuals suffer from comorbid medical and other psychiatric conditions and are at risk for suicidal thoughts and behavior. NIMH-supported research aims to reduce this suffering, through a variety of research programs focused on increasing our understanding of major depressive disorder and on developing and implementing effective therapies.

Click here to read full article.

Young Investigator Initiative Grant Mentoring and Career Developing Program

The TMJ Association is a member of the United States Bone and Joint Initiative and was asked to post the following announcement.

Fall Workshop - October 25-27, 2019, Toronto, ON

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 262 participants (60%) have successfully obtained $486 million in grants for 1,627 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. The Fall 2019 workshop is scheduled to take place on October 25-27, 2019, in Toronto, Canada. The deadline for this workshop is July 15, 2019.

For more about the program and detailed application instructions, please refer to https://www.usbji.org/programs/yii
NIH Funding Opportunities

Basic and Clinical Research

In an effort to promote greater understanding of TMD and to develop safe and effective evidence-based diagnostics and treatments, The TMJ Association promotes and encourages basic and clinical research on Temporomandibular Disorders. Click here to view the latest National Institutes of Health (NIH) funding opportunities for scientists interested in advancing TMJ research. The following NIH research opportunities are currently available:

New Funding Opportunities

- Limited Competition: Dental, Oral and Craniofacial Tissue Regeneration Consortium (U24 Clinical Trial Not Allowed)
- Request for Information (RFI): Identification of Potentially High Value Biomarkers for Predicting Acute to Chronic Pain Transition and Resilience
- Achieving Tissue Robustness Through Harnessing Immune System Plasticity (R21)(R01)
- HEAL Initiative: Translational Development of Devices to Treat Pain (U18)
- HEAL Initiative: Translational Devices to Treat Pain (UG3/UH3)
- HEAL Initiative Translational Devices to Treat Pain (U44I)
- HEAL Initiative: Clinical Devices to Treat Pain (UH3)
- HEAL Initiative: Stimulating Peripheral Activity to Relieve Conditions (SPARC): Anatomical and Functional Mapping of Pain-Related Visceral Organ Neural Circuitry (U01)
- Mechanisms, Models, Measurement, and Management in Pain Research (R01) (R21)
- Global Brain and Nervous System Disorders Research Across the Lifespan (R21)
- NIDCR Small Research Grants for Data Analysis and Statistical Methodology Applied to Genome-wide Data (R03)
- Mechanisms Underlying the Contribution of Sleep Disturbances to Pain (R01)
Research on the Health of Women of Understudied, Underrepresented and Underreported (U3) Populations an ORWH FY19 Administrative Supplement

Additional Funding Opportunities

- Research on Chronic Overlapping Pain Conditions (R01)(R21)
- Analytical and/or Clinical Validation of a Candidate Biomarker for Pain (R61/R33)
- Clinical Validation of Candidate Biomarkers for Neurological Diseases (U01)
- Discover and Validation of Novel Targets for Safe and Effective Pain Treatment (R01)(R21)
- Factors Underlying Differences in Female and Male Presentation for Dental, Oral, and Craniofacial Diseases and Conditions (RO1) (R21)
- NIDCR Small Research Grants for Secondary Analysis of FaceBase Data (RO3)
- Tailoring Dental Treatment for Individuals with Systemic Diseases that Compromise Oral Health (R01) (R21)
- Blueprint Neurotherapeutics Network (BPN): Small Molecule Drug Discovery and Development for Disorders of the Nervous System (UH2/UH3) (U44)
- Population Health Interventions: Integrating Individual and Group Level Evidence (R01)
- Family-Centered Self-Management of Chronic Conditions (R21) (R01)
- mHealth Tools for Individuals with Chronic Conditions to Promote Effective Patient-Provider Communication, Adherence to Treatment and Self-Management (R01) (R21)
- The Biomarkers Consortium
- Blueprint Neurotherapeutic Network Applications Directed at Small Molecule Drug Discovery and Development of Disorders of the Nervous System

Support Our Work

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

Click HERE to make a tax-deductible online contribution today!

Educational Publications

E-Newsletters

*TMJ News Bites*

Read Past issues of TMJ News Bites available on our website.

If you’re not currently receiving TMJ News Bites and would like to be on our mailing list, sign up here.

Chronic Overlapping Pain Conditions Brochure

This brochure addresses Chronic Overlapping Pain Conditions (COPCs), how COPCs are diagnosed, the complexity of the chronic pain experience, and how to
Cutting Edge - COPCs Research Advances

Cutting Edge - COPCs Research Advances, is an electronic newsletter published by the Chronic Pain Research Alliance, an initiative of The TMJ Association. Developed to keep the medical-scientific community abreast of recent research advances, this publication contains abstracts of recently published studies on the epidemiology, pathophysiology, and clinical management of Chronic Overlapping Pain Conditions. These conditions include temporomandibular disorders, chronic low back pain, chronic migraine and tension-type headache, endometriosis, myalgic encephalomyelitis/chronic fatigue syndrome, fibromyalgia, vulvodynia, irritable bowel syndrome, and interstitial cystitis/painful bladder syndrome.

The most current issues are now available for your review at: http://www.cpralliance.org/New_Findings. If you would like to receive future issues of COPCs Research Advances, click here to register.

TMJ Science Journal

Our latest issue of TMJ Science, which includes the summary and recommendations from our 8th scientific meeting-How Can Precision Medicine Be Applied to Temporomandibular Disorders and Its Comorbidities—is now available. We hope you’re impressed with how far the science of Temporomandibular Disorders has come.

We invite you to read this new publication which is available in the publication section of our website as a pdf file.

Your Guide to Temporomandibular Disorders

This brochure, written by The TMJA, is a straightforward, easy-to-read booklet that guides patients in how to make health care decisions. It is available by postal mail or as a PDF on our website, and we encourage you to share it with your friends, health care professionals, and family members.

NIH Brochure on TMJ Disorders

This brochure is produced and distributed by the National Institute of Dental and Craniofacial Research in partnership with the Office of Research on Women's Health, components of the National Institutes of Health (NIH) in Bethesda, Maryland. Part of the U.S. Department of Health and Human Services, NIH is one of the world's foremost medical research centers and the federal focal point for medical research in the United States. This booklet is available in English and Spanish at: https://www.nidcr.nih.gov/OralHealth/Topics/TMJ/TMJDisorders.htm.

Dental Care Guide

Temporomandibular Disorders, Dental Care and You. The TMJ Association developed this guide to provide you with oral hygiene self-care tips that you can do at home, as well as suggestions for future dental appointments. Routine maintenance of your teeth and gums should reduce the risk of dental disease and the need for invasive dental treatments. Click here to view on our website.
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 (TMD). For over 30 years, we have shared reliable information on TMD with people like you. We invite you to visit our website, www.tmj.org.

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