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What Do Patients Want from a Diagnosis?

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For those in the audience not familiar with The TMJ Association I'll start with a bit of background. The TMJ Association is a patient advocacy organization established in 1986 to support those affected by temporomandibular joint and muscle disorders. I am a co-founder and President and also a TMJ implant patient. We began as a support group in Milwaukee and spent our first few years interviewing practitioners treating TMJ patients locally; we read the literature and held support group meetings. It wasn't long before we were convinced that there was poor understanding of TMJ disorders and no scientific validity underlying the wide range of treatments in use.

Following the FDA Class I Recall of the Vitek implant in 1992 we initiated a congressional hearing asking the question: Are FDA and NIH Ignoring the Dangers of TMJ Implants? Our congressional champions encouraged the NIH to convene the 1996 Technology Assessment Conference, a meeting which was pivotal in revealing the sorry state of TMJ research and treatment. Our congressional leaders have continued to work

with us all these years asking the NIH for reports on research activities and advising on how federally funded research dollars should be spent.

In 2000 the Association held the first of what have become biennial international scientific meetings. These meetings, co-sponsored with agencies of the National Institutes of Health, have explored the state of the science of various aspects of the TM joint—its basic anatomy and nervous system innervation, its vascularization, how it differs from other joints in the body, on to the complexity of these disorders and comorbidities as well as advancing diagnostic approaches. The meetings, which have always included patient attendees, were designed to attract experts in other scientific and clinical disciplines and enrich the pool of investigators. The aim was to build a solid scientific basis for TMJ research and define future research directions. The research recommendations developed at our scientific meetings have been translated into NIH initiatives and published in our journal, *TMJ Science*. In addition to our advocacy and promotion of scientific research, we provide comprehensive information on TMJDs through our Web site: www.tmj.org, our newsletter, the *TMJ Communiqué*, as well as a new Internet feature, TMJ News Bites.

The life blood of any advocacy organization is the patients represented. We count on their support and encourage a continuing exchange of information. We truly like to keep our fingers on the patients' pulse, to learn their symptoms, the treatments they've had, what may have helped, what worsened it, what kind of practitioners they saw and how they were treated. We also learn from the patients what other health problems they have, how their condition has affected their lives and the lives of their loved ones, and how

others perceive their disease. We get this information from patients by phone, letter, and e-mails, and from surveys and comments they submit through our Web site. We have recently established a Forum where patients can share their experiences, enabling mutual support and empathy. As a result, I think we have a pretty good idea of what patients are going through, which is a lead-in to why you have asked me here today.

If you want to know what TMJ patients want by way of diagnostics I'll get right to the point by quoting Marianne Genetti, the Executive Director of, In Need of Diagnosis, Inc., She says – *“Patients want prompt and accurate diagnosis of medical disorders.”* I would add they deserve more – the descriptive anatomical and pathology information, such as the meaning of disc displacement, joint degeneration, etc. – not just *“you have TMJ.”* Furthermore, I can't imagine a patient getting a diagnosis and walking out the door without asking the next questions that we are constantly asked; – what doctor should I see, what treatment should I get, is this curable, how will this affect my health, my future? Both diagnosis and treatment options seem inseparable and both should be evidence-based and honest.

Generally if TMJ patients are diagnosed by chiropractors they will treat it, if they see a physician, he or she will immediately say, *“go to your dentist,”* while a dentist will either attempt to treat it or refer the patient to a self-proclaimed specialist. These people subscribe to techniques taught at a number of so called “institutes” or as Dr. Harold Perry dubbed them in the 90's – sporadic, single-concept Hilton University Weekend TMD Education – each zealously espousing their diagnostic and treatment techniques as

successful and able to cure much of everything you suffer. These treatments lack scientific basis and may actually cause harm to the patient. No less an authority than the Cochrane Collaboration finds the science underlying the most frequently prescribed treatment – a splint- inconclusive. This is the milieu which TMJ patients currently find themselves.

The bottom line here is that it is difficult if not impossible for the patient to get an accurate diagnosis when controversy regarding diagnosis still exists within the scientific and treating communities. Furthermore it is virtually impossible for the patient to separate diagnosis from treatment because of the conflicting opinions, the daunting costs, and uncertainty with regard to the outcomes of treatment. And finally, the NIH brochure on TMJ disorders states, “There is no widely accepted, standard test now available to correctly diagnose TMJ disorders.” Before I go on, let me acknowledge that there are dentists who are honest and treat their patients with compassion and patients have told me that they believe their dentist is looking out for their best interests. I also realize that some patients get better after receiving treatment. But without evidence based research to demonstrate safety and efficacy, treatments today are TMJ lotto. The patient may get better because of the treatment, in spite of it, or be worsened by it. The NIH states...that more studies are needed on the safety and effectiveness of most treatments for jaw joints and muscle disorders.

Over the years we have been impressed by the number of patients that tell us about other medical conditions they have. A Kaiser Permanente study of healthcare utilization in

2001 showed TMJ patients had more than twice the health care utilization compared with non-TMJ patients, and the majority of those health care costs were not related to TMJ treatment. When the author discussed the study with me he said, “*When women without TMJ were hospitalized, it was to have babies. Your patients have immune problems and all sorts of other conditions.*” What he was referring to, no doubt, was that for more than 20 years TMJDs have been included in a cluster of conditions including Fibromyalgia, IC, IBS, CFS, Tension Type and Migraine headache, Vulvodynia, and many others. Even though each of these conditions has been researched individually, evidence has increased over the years that there is some relationship linking these conditions so that if you have one of them, there is an increased likelihood that you may develop one or another condition in the cluster. One hypothesis proposed points to structural and neuroendocrine changes in the brain as the root source. We are only now beginning to see research interest in exploring common pathways and mechanisms for the conditions, but I am sure it has not escaped your observation that the conditions in question predominantly or exclusively affect women in their childbearing years and are characterized by chronic pain.

As patient advocates we all share the unique responsibilities of speaking *for* our patients *to* the gatekeepers of research, policy and practice. I, as a representative of TMJD patients must know all the things about the patients that I have been describing to you; identify their needs and priorities, and then advocate for policy measures that will address those needs and priorities. I am aware of current research and communicate the state of science to patients to give them hope.

The TMJ Association relies on scientific advisors within and outside the TMJD area to assess the state of science and develop recommendations for how to move research forward. In planning our fifth scientific meeting, our advisors developed a meeting agenda and invited scientists to address the issue of comorbidities in TMJDs. The meeting was supported by 9 agencies of the NIH, and we welcomed the participation of ten patient advocates as well as leading researchers for these diseases, with the aim of developing research strategies to discover common mechanisms. This was a pivotal decision, one that represents a major paradigm shift in the way the scientific and clinical communities and policymakers should view TMJDs. Consensus now is to view them as more than a problem of pain and jaw joint dysfunction, but rather as a complex family of disorders, mediated by genes, gender, age, behavioral, and environmental triggers.

As such, TMJDs are to be studied using the integrative systems approaches that have emerged in the post-genomic era. In this paradigm the TMJD patient must be seen as a whole individual, one who may express one or more phenotypes including generalized muscle pain, fatigue, sleep disorders, cardiovascular disorders, and many symptoms resembling those described for fibromyalgia, irritable bowel syndrome, interstitial cystitis dysautonomias, vulvodynia, depression, and a variety of chronic pain syndromes.

This demands an integrated and cross-disciplinary systems biology approach to re-examine the etiology, diagnosis and treatment of TMJD patients. Current TMJ researchers MUST broaden their reach to include scientists in many other scientific and clinical disciplines if we are ever to gain understanding of the causes and develop safe

and effective treatments for the patients. Following this approach we should be able to move to a place where categorization and sub-categorization of patients will be possible and guide us to effective treatments and prevention. In the meantime, TMJD patients remain stuck in the quandary of seeing a multitude of physicians and other practitioners who are naïve about TMJDs though they may well be treating these same patients for comorbidities as well as systemic diseases resulting from TMJ implants, multiple surgical procedures, the sequela of living with chronic pain, and treatment caused harm. They must learn that TMJDs are complex conditions with many manifestations that are currently within their turf. It is time for a concerted effort to educate and integrate these *medical* professionals into the TMJ patient's treatment plan. The late Dr. Stephen Milam once told me, *"If we can educate the primary care physician that TMJ pain is real and should be treated, it would keep the patients from seeking treatments that are harmful."*

It is time too to educate *dental* professionals about the state of TMJ science and their limits in treating these conditions. They, too, must learn the complexity of TMJDs, and the lack of science underlying the treatments. They need to understand that there is a time to refer patients to their physicians and in the process educate those physicians about TMJDs. And that understanding and learning should begin in dental school.

You asked me here today to tell you what patients want in terms of diagnosis and I have used it as a platform to say not only what's missing from the state of diagnosis, but why we are still playing TMJ lotto in relation to treatment. I hope I have given you pause to think or re-think your ideas about TMJDs and the new ideas emerging from research.

Once we regard TMJDs as complex diseases that may share common mechanisms with other chronic and painful diseases, I believe it will be the discoveries from this research that will enable us to define and accurately, promptly and honestly diagnose subcategories of TMJDs and provide accurate safe and effective treatments we desperately need.