

ONE OF THE GREATEST OBSTACLES FACING CRPS patients is social isolation, due to logistics and the loss of employment and other essential social systems or because, in any number of areas, issues arise that other people may not “just get.” In this void, many people with CRPS have found online forums as a means of connecting with other similarly situated individuals. Where else could people discuss the extent to which CRPS has had an effect on the most personal aspect of their marriages?

Since being diagnosed with CRPS in 2001, I have been on a number of online



With over 50,000 members — many of whom live abroad— and over 1 million posts to the community annually, NT has moderators around the globe, so all posts are typically reviewed within the hour, or at least that has been my experience whenever something genuinely objectionable has gone online, even in *very* early morning hours. NT takes care to restrict membership to patients or their caregiver. The first line of defense is not allowing very new members (those with fewer than 10 posts) to post links of any kind. Indeed, one of the moderators’ greatest concerns is in weeding out commercial self-promotion.

NeuroTalk’s RSD and CRPS Forum: An Online Community with Valuable Resources

By Franklin Michaels, Jr.

patient groups, where I have met a diverse range of people, well outside what had been my prior experience. And while these forums are “topically” centered on various threads, it soon becomes possible to spot interesting people, often by the syntax they use in an initial post. From these connections, I have built genuine and enduring friendships over the years, and have had the good fortune to spend time with some of them in person, whether while travelling around the country or in the Los Angeles area. Many of these communications were made through private messages over the forum.

Of the groups I’ve experienced, by far the best is NeuroTalk’s Reflex Sympathetic Dystrophy (RSD and CRPS) forum, which can be found at <http://neurotalk.psychcentral.com/forum21.html>. It is well moderated, and each of the moderators has

been trained by and ultimately reports to John Grohol, PsyD, the CEO and Founder of Psych Central, which set up NeuroTalk (NT) in August 2006 after another online community for neurological concerns went offline for nearly a month, and lost all of its accumulated posts. From the start I was aware that the moderators on NT were, by and large, “different” from those I had run into before. First and foremost, they were genuinely conciliatory in handling conflicts as they arose, and secondly, they were knowledgeable in their own right. As such, folks who are in crisis are compassionately counseled, and when an ill-advised treatment is suggested, a moderator will gently appear, often with an impressive array of pertinent links, as though he or she had been waiting on finger-tips, ready to go. And perhaps most impressive, they are fast.

Vibrant Online Community

In NT, members find an online community that is reliably present for their needs. In fact, more often than not, when a newly diagnosed person first posts, it is not the moderators who are first on board to offer sound and comforting responses, but the forum members themselves, who then engage in dialogues that are often as informative as they are substantial.

This leads to what is perhaps the key technical feature of NT: At the top of each page are links to a vast storehouse of public information, specifically, links to:

- PubMed, maintained by the US National Library of Medicine of the National Institute of Health, comprises a readily searchable data-base of links, abstracts, and free full-text articles and

in some cases book chapters, covering (in English) essentially all of the peer-reviewed medical literature in the world;

② MedlinePlus, from the same source, is an authoritative, plain language description of all drugs legally marketed U.S., including statements of known contra-indication; and

③ A medical dictionary to “decode” unfamiliar terms. (This in addition to a compendium of perhaps thousands of primarily CRPS specific links that forum members and moderators have posted though the years, even if a good number of them link back to the RSDSA!).

With these tools, I have seen laypeople create detailed postings on long threads over the years on topics that were then barely in the published medical literature. Two come prominently to mind. One was the role of autoimmunity in CRPS, first subject to detailed postings, including citations to the applicable medical literature, going back to at least December, 2006, which in turn predate any of the four articles listed under that heading in the RSDSA online library of Research and Clinical Articles. At this time neuroimmunologists at most of the major medical centers in the US refused to see people with CRPS because it was then accepted that CRPS was not autoimmune in origin. What set off this spark in the minds of the medical laity? The observation that women tended to go into remission during pregnancy, a hallmark of autoimmune conditions secondary to the need to avoid an immune attack on the “foreign” fetus in utero.

Second was a thread which began in February of this year on the use of Transcranial Direct Current Stimulation (tDCS) in the treatment of CRPS. As of September 29, 2012, there have been 440

posts that have been viewed 41,548 times. Quite a number of people have reported significant progress after initiating long-term tDCS in response to the thread, typically in terms of the sympathetic dysfunctions commonly associated with CRPS (edema, etc). Perhaps more importantly, doctors around the country — motivated by their informed patients — are now beginning to incorporate tDCS into their practices, at considerably less expense to the patient than comparable therapies.

That progress is because of the persistence of the individual — with deep intelligence but no formal training in the sciences — who started the thread. Having participated in a formal trial of tDCS that was deemed a failure because the symptoms returned in three weeks, she had the unique insight to ask why tDCS could not be used as a maintenance therapy when patients were already receiving *far higher* amounts of electrical stimulation as maintenance therapies in Motor Cortical Stimulation and from spinal cord stimulators placed in a high cervical location — albeit as AC rather than DC. In doing so, she has substantially transformed the way many physicians already perceive the possibilities of tDCS.

There is a reason why the RSD/CRPS forum is, according to Psych Central, one of NT’s top five groups, with over 8,000 hits per month, and for which it estimates that the number of individuals who visit the site is “likely in the upper hundreds per month.” (Personal communication to the author.) Of course, many people tire and drop out along the way. I personally have found it necessary to take months off on occasion, simply because of what some may term “compassion fatigue,” but what Joan Halifax, PhD, describes as dysfunction when exposed to prolonged and excessive suffering. But each time I choose to return, I am hopefully better

suiting to be of service to others, as I now perceive that need as perpetually arising.

With that disclosure, I encourage you to check it out. Certainly, you will find calls for help from people who are completely uninformed, and from those who are “lucky” enough to depend on workers’ compensation for their care and are accordingly denied access to treatments that others became accustomed to years ago, or who have no health coverage at all and are destitute. They will find remarkable individuals, as well as new and provocative information and, if need be, critical exchanges. It is not to be overlooked that in repeatedly having to grapple with challenging arguments in writing that our views become more malleable. For example, I would never have made the leap into tDCS therapy but for being repeatedly challenged and encouraged to do so online. I contemplated the changes in my own situation, and would have remained an “informed” skeptic, utterly unaware of the potential of anodal stimulation of the dorsal prefrontal cortex as a means of recovering verbal fluency I had believed forever lost to the ravages of disease. But most important, anyone engaging in the forum on a regular basis will find a large group of people with surprising similarities, and among them a few people with whom they will have mutual recognition of points going well beyond illness, background and lifestyle. Perhaps even someone to meet over lunch. ■

(References available upon request.)

(See, generally, Antal A, Terney D, Kühnl S, Paulus W, Anodal transcranial direct current stimulation of the motor cortex ameliorates chronic pain and reduces short intracortical inhibition, *J. Pain Symptom Manage.* 2010 May; 39(5):890-903. <http://download.journals.elsevierhealth.com/pdfs/journals/0885-3924/PIIS0885392410001582.pdf>)