

Many of you have shared personal stories and specific questions that we do wish to respond to on an individual basis as soon as we can. For the moment we wish to address more broadly many general concerns and questions that are common among many of your messages:

1. At INTiDYN, we are the scientists who do the basic research and the analytical parts of the studies. We are not qualified to answer most of the medical questions related to medications, most effective treatments, etc. As many of you unfortunately know, there is not yet a consensus on these questions. We do hope that the results of our research will provide a foundation to develop such a consensus. The experiences that you have been sharing will also be helpful in this process. We do consult closely with a nationwide network of top rated pain specialists informally referred to as the Neuropathic Pain Research Consortium (NRPC) and have recently submitted a grant proposal to the National Institutes of Health to further this research in collaboration with the Pain Center of Excellence at the University of California San Diego. So please keep your fingers crossed that it will be funded. We are also working together with the Neuropathy Association ([www.neuropathy.org](http://www.neuropathy.org)) and the National Fibromyalgia and Chronic Pain Association ([www.fmcpaware.org](http://www.fmcpaware.org)) who provide a wealth of information on recent developments, ongoing clinical studies and support groups. So please visit their websites for further information.

2. Many of you are seeking specialists in your local area for fibromyalgia and other forms of chronic pain. We will work with the NRPC and others to seek their recommendations for top pain specialists over as many areas of the country as they can cover. We will work with them to develop a way to disseminate this information. To do this, if you haven't already done so, we would appreciate it if you would visit our website and your information and where you live on a form that can be found on our home page.

3. Many of you have shared individual stories of how your fibromyalgia may have started that can be quite different from each other. That is true. Unlike a shingles rash (acute herpes zoster) that can result in chronic pain (postherpetic neuralgia), the source of fibromyalgia is varied and even unknown in many cases. The age of onset can also vary. Likewise, among you are those who can also have other afflictions as well. As, such many of you have felt that your particular case is unique and unlike anyone else. That is not entirely true. We want to assure you, that among all the fibromyalgia patients, there are others who share your story and pain. Regardless of the differences, nearly all of you share the devastating impact that fibromyalgia has or has had on your quality of life, and the frustration of finding a treatment that works. Some have been fortunate to find improvement and others have not. Unfortunately, that is a major problem with almost EVERY type of chronic pain condition. Some things work for some folks and not for others. We don't yet understand why. One of the objectives of pain research being conducted all over the world is to try and find the right match between the right patient and the right therapeutic approach. The objective is referred to as "personalized medicine". This is why it is important for you to share your stories especially with pain specialists who are aware of the latest research. See #1 and #2 above. What we do know is that those who refuse to surrender to their pain and engage in activities despite the pain, those individuals generally fare better in managing their pain.

4. In order to focus on fibromyalgia alone, our study had to look only at patients who did not have other afflictions, but our study patients did vary with their age of onset and potential reasons why their fibromyalgia may have started. Among them, the pathology involving the nerve fibers on the blood vessels was very similar, so that is at least a start. Many of you have inquired about participating in research. It will be important for our nationwide team and other researchers, to make sure our results are consistent among a larger number of fibromyalgia patients which will include men as well as women. So we appreciate your offer to participate as we plan to broaden the extent of the research. This will not happen soon enough for those who are suffering. It will happen but we need your help. It is important for you to get the word out to others that patients are needed who would be willing to volunteer for research, which will help in preparing for this effort. For these types of studies, it is equally important to get friends who don't have fibromyalgia

to be willing to participate as "control" subjects like those who volunteered for our study. Sometimes it is harder for researchers to recruit control subjects because they are not hurting and don't realize how important it is for them to participate as well.

5. Was our study a hoax? We were asked this question by some inquiries. We can assure you that Dr. Albrecht and I are well recognized internationally for our years of quality research in the peripheral nervous system under normal conditions, during development, and under disease conditions. We developed our technology with collaborators at the Karolinska Institute in Sweden, and our international network of collaborators has included 5 Howard Hughes Investigators and numerous researchers from major universities including Johns Hopkins, Harvard, Yale, Caltech, University of California San Francisco and San Diego, Cambridge, Oxford, Heidelberg and Uppsala, as well as institutes such as the National Institutes of Health, the Karolinska Institute, Israel Institute of Technology, and the Max Planck Institutes. Although this was our first study of fibromyalgia, our collaborations have extensive published and ongoing research on other chronic pain afflictions such as postherpetic neuropathy, complex regional pain syndrome, diabetic neuropathy, and post-traumatic stress. We have brought this background to bear on the fibromyalgia study in collaboration with a pain specialist team at Albany Medical College led by Charles Argoff MD who is rated among the top pain specialists by the U.S. News and World Report. By some standards, our study was small, but the results were so profound that they achieved an especially high level of significance. The standard for significance in scientific studies is what is referred to as a "p value of 0.05" which means that there is only a 5% possibility that the results could be explained by chance. Our results were a p value of 0.0001 which means a 0.01% likelihood of occurring by chance. Of course, there is an outside chance that our results will be an exception to the rule in a larger study.

6. Can the biopsies be used for diagnosing fibromyalgia? That is a good possibility but policies and validation are not yet in place. First, any attempt to do that needs to involve a physician who has the right kind of experience in doing a thorough job with the clinical part of the diagnosis. Second, we could then do our biopsy analysis to confirm whether or not there are excessive nerve fibers associated with shunts like that which we found in our study. However, our findings are too new and would need to be shown in many more patients before insurance companies would pay for the cost. So someone, wishing to have this tested would have to pay for the cost themselves. We are sorry about that. As noted above, we are in the process of finding financial support from grants, contracts or donations which would cover the cost for those who would qualify for enrollment in a funded research study. I apologize for the length of this message, but I hope it addresses most of your questions. In closing, we have been overwhelmed by messages of gratitude for the research to date and the sense of relief that something definitive was discovered. This propels us and other scientists forward to tackle the challenges of this difficult research. We get a sense that many of you can feel more confident about openly discussing fibromyalgia with others. A major problem with fibromyalgia as well as other chronic pain conditions is a lack of a visible champion and spokesperson such as a Michael J. Fox for Parkinson's Disease or the late President Reagan for Alzheimer's Disease. Consequently, except for arthritis, the general public is not aware of the extent and difficulties in diagnosing and treating chronic pain.

Best wishes,

Dr. Rice