

LEADERSHIP

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QUESTION: "I read with enthusiasm that PHI awarded \$25,000 to the University of Arkansas for Medical Sciences to do a pilot study to determine if there is a unique biomarker (Tregs) in the immune system of individuals with post-polio syndrome. One member was less-enthusiastic because it was feared that if he/she did not have the biomarker the physicians would not treat them for PPS. This fear was fueled by the fact that it was so difficult to get the diagnosis of post-polio syndrome in the first place. Can you help resolve this fear?"

ANSWER: We've come a long way, baby! And what a switch! Isn't it refreshing to hear concerns from people who are worried that having a PPS diagnosis available will get in the way of appropriate medical treatment—when for years some of us were certain that NOT having a PPS diagnosis would end our chances to be properly cared for!

Indeed, there was a time when some of us seemed more concerned with having the initials "PPS" tacked onto our condition than we were with having an accurate diagnosis. Years ago some fought for those initials even when such a designation made it difficult to get disability, and perhaps impossible to get treatment. Were we truly looking for a solution?

Remember how it was in the beginning? For a while we didn't even have a name for the condition that needed a diagnosis. Should it be "Post - Polio Sequelae"? Or "Late Onset Polio Sequelae"? Or "Late Effects of Polio"? Or, well, any number of others that indicated that something was happening beyond polio that needed attention. In the end, the powers that be settled on post-polio syndrome, and for all these years we've received various degrees of help for PPS, even without a definitive method of diagnosis. We still rely pretty much on a diagnosis of exclusion.

In case anyone thinks we're at the end of the line here, and there's no longer a need to develop easy diagnosis, take a look at these estimated figures: Of 640,000 * polio survivors in the United States, 300,000 of them may already have PPS. Population-based studies show that anywhere from 20-78% of polio survivors complain of new neuromuscular symptoms often attributed to PPS. Worldwide, as many as twenty million polio survivors live with, or are at risk for acquiring, PPS. And acute poliomyelitis continues to this day in certain parts of the world. It's going to be a long time before there won't be any more polio survivors seeking a diagnosis for PPS.

Small preliminary studies already indicate that excessive numbers of regulatory T cells (Tregs) show up in people with PPS, but not in healthy individuals who were vaccinated with oral (live) polio vaccine, and that Tregs from some of those with PPS do not function normally. If this situation occurs in a larger study (this time including those with PPS, those with polio but no PPS, and those who are healthy), then this could mean these Tregs are a biomarker pointing to PPS. That could be cause for a PPS diagnosis.

Would this mean that polio survivors without those extra Tregs will not receive treatment for PPS? Possibly. This is all speculative, of course, but I can't imagine why people without PPS would be treated for PPS—or why they would want to be. At the same time, I'm not exactly sure what that

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means. We all had polio, and surely we would be treated for our polio problems, commensurate with their severity. Certainly no doctor would insist on seeing further deterioration through PPS before treating an imminent difficulty.

Leaders of polio groups can find a wonderful opportunity for discussion in this topic. What do your members have to say about some of these questions?

- Can certain polio survivors who may never develop PPS still have significant physical difficulties? What if these problems require careful attention or even necessitate procedures such as major surgery, for example? Would any doctor refuse to address these situations adequately?
- Isn't "the late effects of polio" a term that defines all of us, while "post-polio syndrome" indicates that some of us have late effects that go further than our initial polio? Do we all fall at a slightly different place in this continuum? What does this have to do with diagnosing PPS?
- How do we explain the importance of this research? If this hypothesis regarding regulatory T cells in PPS immune systems proves significant, is it possible that this could lead to even greater discoveries, perhaps in the area of PPS treatment?

Years ago we had a quadriplegic member on our board of directors at Nebraska Polio Survivors Association who used to joke he wasn't worried about getting PPS since he had nothing more to lose. Whether he was right or wrong was irrelevant. It didn't matter where he landed on the "late effects" progression. We were glad he was there, lending his considerable expertise, helping our organization bring valid information to as many as possible in the polio and medical communities, and demonstrating the importance of reaching out. It was a good mission.

* Joan L. Headley tells me that PHI is investigating this number as well as the age distribution of polio survivors. We await the analysis and the numbers.

Nancy Baldwin Carter and Joan L. Headley are co-authors of the chapter "Support Groups: Keeping Them Active and Useful" in Lauro Halstead, MD's new book *Managing Post-Polio: A Guide to Living and Aging Well With Post-Polio Syndrome*. The book is now available online at www.nrhrehab.org.
