

Spinal tap for PPS? NO !!!

by Tom Walter

Tom Walter is a Polio Survivor. Up until a few years ago, 30 years or so on from recovering from Polio, he walked unaided with only a slight limp, working and living a normal life. He didn't even know any other people with Polio. He now has difficulty swallowing and breathing and spends most of his days in a wheelchair or propped up in bed. With his laptop computer he collects and dispenses advice and information on post-polio syndrome. Tom, or TominCal as he is known by his email name, is highly regarded and respected as a source of reliable information by the online post-polio community worldwide. In 1997 he was interviewed by Susan Kelleher of the Orange County Register for an article "Polio strikes back". The article is no longer freely available at the <u>Orange County Register</u> site. It can be located via their archive section (using search keywords "polio" and "strikes") but access to the complete text requires a small payment.

LincsPPN Web Administration.

Over the past couple of years some interesting and exciting discoveries have been made about the polio virus that were unknown before. Researchers at the National Institutes of Health in Bethesda, Maryland (USA) and at the Pasteur Institute in France have been able to identify fragments of mutated polio virus RNA genetic material from the spinal fluid of people who had "wild" polio (like most of us) and from the spinal fluid of those who had the polio vaccines.

It was previously not known that polio virus RNA had any capability whatsoever to survive and/or reproduce in any form. And it is likely that advances in the fields of biotechnology and immunochemistry derived directly or indirectly from work on AIDS gave the tools to make these surprising findings. (By the way, it does not appear that these fragments are a "reactivation" of the polio virus itself or that it is "communicable" in any way in this form.)

A study from France reports that of 10 people with Post-Polio Syndrome, five of them also had antibodies present for these mutated virus fragments and five of them did not. However, at this time, there has been absolutely no cause and effect relationship established from this data that could assist in establishing the cause of PPS or in diagnosing PPS or in treating PPS. That may be in the future.

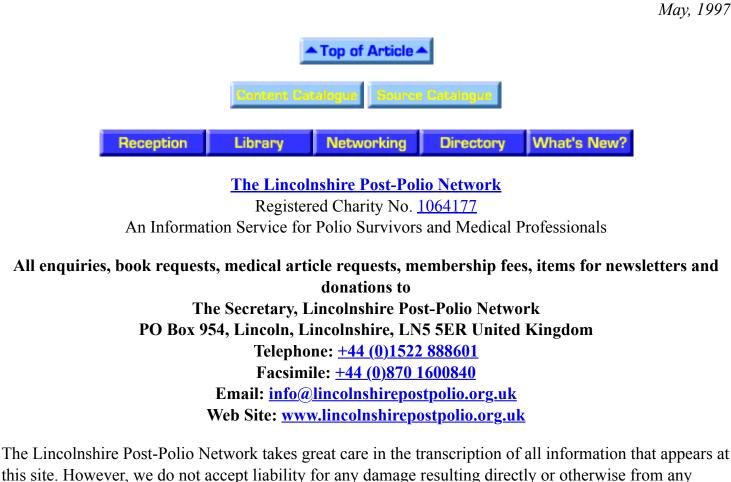
Unfortunately, some researchers and some doctors purporting to diagnose and treat PPS have jumped to the unwarranted conclusion that PPS can be diagnosed or "ruled out" by analyzing fluid taken during a spinal tap. Many of us had this procedure done at the time of onset of the polio virus to help in diagnosing it. Spinal taps can be very painful and lead to serious complications. Based on our knowledge at this time, there is absolutely no value to having a spinal tap done now for the diagnosis or treatment of PPS.

This was my "common sense" conclusion after reading the literature and discussing it on the Internet with

those more knowledgable in the sciences. I double-checked with Dr. Lauro Halstead, a prominent PPS researcher, writer, and Supervisor of the Post-Polio Clinic at the National Rehabilitation Hospital in Washington DC, and he agrees emphatically.

A spinal tap may be appropriate to diagnose or rule out some other serious disease; or it may be undergone for purposes of legitimate research. But, at this time, it has no value in the diagnosis and treatment of PPS. Before undergoing one, I would certainly want to know more about what information was being sought, how the fluid would be analyzed and what the results would mean.

Tom Walter



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