

# PPASS Times

Newsletter of Post Polio Awareness & Support Society of MN

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On the Web at [Http://www.ppassmn.org](http://www.ppassmn.org)

## From Where I Sit

By Nancy Gosz, Chair

**F**rom where I sit today is the living room of the Gosz family cabin on Woman Lake in Longville, MN. This is the annual family weekend at the cabin where our family of 17 people and four dogs inhabit an approximately 800 square foot cabin. We do incorporate a tent and a camper, mainly to add sleeping space. Our one bathroom is complemented by an outhouse (generally only used when the bathroom line-up is long!) This is the only time we are all here, usually we are smaller groups up for weekends, or full week vacations. I joined the Gosz gang 20 years ago as a walker; passing, as we like to say, for normal. Gradually my new family learned the truth and has witnessed my diagnosis of PPS and my progression to the use of walking aids and wheels. Somehow scooters were an easy add on for me, maybe because they've been fun, freeing me to walk dogs, go shopping independently, garden, play outside, pop wheelies (oh yeah, I can clear 12 inches of air, and did in the halls of Methodist hospital the night my grandson was born, to the horror of my observant brother). Scooters

also generally indicate the user can walk. Wheelchairs were different and I dreaded and avoided them for too long. They meant failure, disability, inability.....the very thought had one word bouncing all around my skull: never, never, never, never, never, never!

In the early years at this cabin, on a beautiful wooded lake lot, I helped paint the cabin and shed which was built, in part, by my husband Mike and his now deceased father. I have planted gardens and baby pines on the lot, raked leaves in the fall and spring, spent hours with the other adults making feasts for the evenings, huge breakfasts for the mornings, cleaning up the aftermath. I've stood on the dock fishing, have bounced around on a fast ride in an old boat to tour this lovely chain of lakes and to walk from the town harbor up to the ice cream shop for ice cream cones. I've hiked the woods collecting garden rocks, walked dogs, played games with all of our nieces and nephews in the yard and more... ah, the good old days! The days where I was busily and unknowingly, encouraging my own future disability. "Use it or lose it" my head kept telling me, along with

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## Special Issue

By Larry Kohout

**Y**ou will notice that almost this entire issue is devoted to the "Mayo Clinic News Release." I'm sure most of you have heard about this issue by now and if you haven't you can read the news release on page 3. I am much indebted to Dr. Mary Westbrook and Gillian Thomas of the Post-Polio Network (NSW) Inc. Network News for allowing me to reprint much of the material here. Additionally, I do have the independent permission of both Dr. Marsha Falconer and Professor Edward Bollenbach to reprint their analysis of the Mayo News release. In addition to the material in the *NSW Network News*, I have gotten a news release from Post-Polio Health International (PHI) with the responses of three members of the 17 member Medical Advisory Committee. However, it should be noted that Mary Westbrook, Ph.D, AM, is also a member of this committee, and has her views expressed separately in the newsletter.

Please remember that Australian spelling is more like the British conventions than the American

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## From Where I Sit

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the next message, “don't let them know you aren't just like them - hide it! Just keep doing it all!” Of course it's not all bad; I never do any mealtime clean up anymore! Can't complain about that. Jody, my wonderful mother-in-law and my 3 sweet sisters-in-law make sure I'm only in the kitchen long enough to peer into the refrigerator for snacks, even then Carol asks suspiciously, “what are you doing?”

On the home front my in-laws were seeing other changes - like the warm Thanksgiving in 2001 when I brought a scooter to join the *walking off dinner* group. Canes had already made an appearance—first in the form of fun and unique walking sticks, my diamond willow stick with the antique brass handle (handmade and sold by a sweet old gentleman in Longville) became the kids favorite—the boys finding it a great dueling sword until the adults noticed and retrieved it. “Nobody plays with Nancy's sticks” became the decree given to the kids by their parents. And bless their hearts, they obeyed without question.

Although I got my first wheelchair in 2003, a donated used chair, and had my own chair specifically built for me in 2004, it was not until my foot surgery in late 2005, that I used a chair at a Gosz family function. I actually had been hiding my wheelchair when I had company - into the closet it went, literally. (This is a factual ‘out of the closet’ story!) That Thanksgiving I had no choice as my chair's leg extender was up in place,

properly pillowed, to support my non-weight bearing, casted leg and foot.

Gradually I began bringing my chair: to my brother-in-law Pete's new and large home, too big for my legs to walk; to my nephew's confirmation, another new and large house. While my trips to the cabin had included a scooter for outdoor use since 2001, the summer of 2005 was my first family weekend at the cabin with an assortment of canes, my outside 4 wheel scooter, and at last the BIG ONE: my wheelchair. Even the small cabin by then was too much legwork. As I write this article, I am sitting in my chair which, with its cushioned seat and inflatable lumbar roll, has been given the dubious distinction of being the most comfortable chair in the cabin. When I'm not using it, someone else, with my *carte-blanche* approval, is usually sitting in it. I sleep late up here; no thoughts of household chores drive me out of bed. The younger kids are up and playing their games when I stumble out of our bedroom on my cane. Whoever is comfortably seated in my chair immediately jumps up, brings it to me, and asks me where I want to go. My sweet 10 year old Maria and 12 year old Patrick make certain I don't have to push myself through the carpeted cabin if they are around.

Here at the cabin, Mike and I have our own bedroom near the back door; the primary depository for shoes. Jody and Mike have asked the kids repeatedly over the years to keep their shoes to the side “so Aunt Nancy won't fall,” with Mike adding; “You'd feel really bad if Aunt Nancy fell!” These

kids, being young and impulsive would hang their heads in brief and questionable shame, and later run back in the door kicking off their shoes all across that hallway. Maturing into wonderfully helpful young people, ages 10-22, with the addition of adorable niece Zoë 18 months ago, they now faithfully keep their shoes out of the way with very few reminders. And of course I always look where I'm walking or wheeling. The dogs, 3 of them quite large, seem to be frequently sprawled across my path. One accidental run over a tail taught them to hustle when they see the wheels approaching.

It seems my family has progressed along with my own progression. They have followed along with the progression of my PPS symptoms and my slower progression out of denial and alleged normalcy. They openly encourage me to tell them about PPS, asking good questions. Two nights ago, my brother-in-law, Kelly, asked me if all people with PPS progress at a similar pace. I have not witnessed a PPSer with a short answer, and I'm among the worst - I answered for about 30 minutes. From my peripheral vision, I saw Patrick turn away from the game he was playing and sit very still listening to everything his dad and I talked about. Recognizing his need to process, I waited until the next day to ask him what he learned from our conversation. “I know now why you use a wheelchair even though you can walk. And I know why it's important we help push you, because I didn't know your arms were getting weaker.” Wow. I think we need to recruit him to PPASS. He is advancing quickly in the Awareness

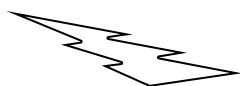
part of our name. Steve, another brother-in-law even added my scooter to the annual Christmas joke gift. Having drawn my name, he presented me with a bright blue bicycle horn, a perfect match for my blue scooter. And darn it, I forget to bring it! Zoë sat on my lap for scooter rides, pressing the little white “toot toot” button. I’d loved to have had her squeezing the black bulb on the real horn and producing a decent honk!

I don’t think I can complete this story without a little disability boasting. During one of many dog walks this weekend, along the hard packed dirt road leading to many cabins, with Mike as my witness; I approached a man with 2 children on a real 4 wheeler, the kind normal people use in the woods. I asked him if he wanted to race, he grinned at that challenge, took the wheel from his little boy, hit the throttle and we took off. I left him in the dust, my 4 wheeler won! There is no denying scooters are fun.

Oh, one other thing. We have a smooth riding pontoon now, so boat rides are back on my activity list, though I send someone else to the ice cream shop. I hope they aren’t licking my ice cream cone on the way back to me.



Two cannibals are eating a clown. One says to the other, "Does this taste funny to you?"



## Special Issue

*(Continued from page 1)*

conventions. I have made no attempt to change any of this. The material is as I received it with the exception of the page layout.

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Stories based on the following Mayo Clinic News Release have been quick to appear in the media around the world. Many of the stories have regrettably sensationalised and/or misreported the research findings. Such journalism may be distressing to Australian polio survivors who are experiencing polio’s late effects and already having difficulty getting their problems acknowledged, assessed and treated. In order to make more sense for the non-technical reader of the research being reported, the original Mayo Clinic News Release is reproduced here, together with informative analyses by Dr Marcia Falconer PhD and Professor Edward Bollenbach, and by Dr Mary Westbrook PhD AM.

### Survivors of Childhood Polio Do Well Decades Later As They Age

News Release Issued by the Mayo Clinic, Rochester, Minnesota, USA  
Dateline: Monday, August 21, 2006

**M**ayo Clinic researchers have found that years after experiencing childhood polio, most survivors do not experience declines greater than expected in their elderly counterparts, but rather experience only

modest increased weakness which may be commensurate with normal aging.

“Other researchers have suggested that polio is a more aggressive condition later in life, but we’ve actually found it to be relatively benign”, says Eric Sorenson, MD, Mayo Clinic neurologist and lead study researcher. “Our results suggest that polio survivors may not age any differently than those in the normal population – they’re not doing too badly compared to their peers. This tells us that the cause for the decline in muscle strength in polio survivors may be aging alone.”

Polio is a contagious, viral illness that peaked in the United States in 1952, when 3,000 people died of the disease. Mass immunizations in the mid-1950s began to slow the spread of the disease, and the last case of polio not caused by a vaccine occurred in the United States in 1979. The three major types of polio include spinal polio, a paralytic polio that attacks nerve cells in the spinal cord; bulbar polio, in which the virus attacks motor neurons in the brainstem; and bulbospinal polio, a combination of spinal and bulbar polios. The effects of polio run the gamut from a complete return to normal function to paralysis of limbs to acute death. Following the illness, most patients are worried about their long-term prognoses, according to Dr. Sorenson.

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## Survivors of Childhood Polio Do Well Decades Later

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To conduct this study, the researchers randomly selected a group of 50 polio survivors from the general population of Olmsted County, home of Mayo Clinic, and followed them for 15 years. The average age of participants at the study's start was 53, and the patients were an average of 40 years past their childhood experience with polio. The researchers measured strength and loss of neurons at the beginning of this period, and then again five and 15 years later with electrophysiological testing, strength testing and timed tests of performing basic functions. They found modest declines. Each patient also completed questionnaires about symptoms of progressive weakness at the beginning and end of the study period. Though the majority complained of progressive weakness during the time they were studied, these symptoms did not correspond with their actual magnitudes of decline over time. Rather, the researchers found patients' symptoms experienced were associated with the degree of residual weakness immediately following their polio infections.

"Overall, we found that strength changed very little in these polio survivors as they grew older, and we discov-

ered the neurons dropped off at a rate comparable to other non-polio survivors as they aged", says Dr Sorenson.

"We concluded this was normal aging on top of their old deficits. Very few had to change their homes or add adaptive equipment. Those who had weakness problems during our study had a larger deficit at the end of their childhood disease, making them more likely to develop symptoms. So, as deficits at the end of the disease increase, the probability of experiencing post-polio symptoms increases."

The discrepancy between what some of the patients experienced with growing weakness and their actual measurements of strength and neuronal loss likely is due to increased sensitivity due to their disease experiences, according to Dr Sorenson.

"Patients feel their weakness progressing, but when you measure it, it's very modest", he says. "Likely, they lost so much strength at the time of their illness that any change is very noticeable to them. Though the likelihood is high that patients who have had childhood polio will complain of weakness later in life, they can expect years of stability without the need for major lifestyle modifications."

Other Mayo Clinic researchers involved in this study include Anthony Windebank, MD, and Jasper Daube, MD.

## Examining a Controversial PPS Publication

Dr Marcia Falconer, PhD  
Professor Edward Bollenbach

Marcia Falconer has a PhD in neuronal cell biology from University of Ottawa, Ottawa, Canada, and undertook post-doctoral study in molecular biology at Massachusetts Institute of Technology, Cambridge, Massachusetts, USA. Marcia led a virology laboratory with biotechnology applications at the Centre for Food and Animal Research, Agriculture Canada, Ottawa. She also holds an MSc in cell biology from Carleton University, Ottawa, Canada and a BSc from Simmons College, Boston, Massachusetts. Marcia is a speaker at many PPS conferences and meetings in Canada, Australia and Britain. Now retired, she researches and writes about Post-Polio Syndrome. She has numerous publications in peer-reviewed journals and on the Web, and is currently writing a book about inflammation and PPS.

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Edward Bollenbach is an Emeritus Professor of Biology. He has been a full Professor of Biology since the age of 39; he won the first Educational Excellence and Distinguished Service Award in the Connecticut Community College System, and has specialized in the Teaching of Microbiology and Chemistry at Northwestern Connecticut Community College for 32 years. Edward holds a Master of Arts in Biology from the State University of New York and New Paltz, New York, and graduate certificates in Cryptogamic Botany, Origins of Life, and Holistic Health. He currently writes about and researches Post-Polio Syndrome and has several articles in print and on the Web.

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**R**ecently a controversial article,

“Electrophysiological findings in a cohort of old polio survivors” by Sorenson, Daube and Windebank was published in the *Journal of the Peripheral Nervous System*, volume 11, pages 241-246, September 2006. The findings in this article are the subject of heated discussion in the PPS world. Below we examine this article.

A scientific article usually is divided into parts: an abstract, which gives a brief overview of the article; the introduction, where related findings are discussed; the methods, which tell how the work was done; the results, which tell what was found in the study; and the discussion in which the results are put into context with previous findings. In this final section the authors can speculate on wider implications of their findings.

The discussion section is often the source of intellectual debate. On occasion this debate can be vigorous, particularly when data from different studies point toward very different conclusions. Science would not be science if it was not exciting and controversial. We can expect scientists to have honest disagreements about methods, results and especially the discussion section of a paper. Unfortunately the debate is sometimes removed from the scientific arena to the public one when the popular press, or the internet, seizes upon an idea or a statement in the article.

This appears to be the case in

the article by Sorenson et al. In particular, one statement in the discussion section has been sensationalized. The statement is: “This suggests that the most likely cause for the decline in our polio survivors is aging alone.” It is easy to understand why this sentence was highlighted. Taken out of context, this statement can infer that Post-Polio Syndrome (PPS) does not exist. It can even be interpreted, incorrectly, to mean that people with PPS are no worse off than their similarly aged peers with all this implies. Taken within the context of the reported data, the statement does not mean any of this.

This study is based upon two electrophysiological studies with the results explained using statistical methods and models. It is complex for the layperson to read and understand but it was not designed for the general reader. It is designed to pass specific data to people working in the field who are conversant with the methods and the interpretations of this data. We present here a less technical, but still scientifically accurate, summary of the main points in this paper.

In this study, the muscle strength and symptoms of 38 people with a history of prior paralytic polio were studied at 5 year intervals for 15 years. Innervation to two muscle groups, the thenar muscle at the base of the thumb and the digitorum brevis muscle on the sole of the foot, was examined using two electrophysiological measurements. One technique,

CMAP (compound muscle action potential), examines the maximum amount of muscle contraction that can be achieved. The second technique, MUNE (motor unit number estimate), provides information about the number of motor units in that muscle. A motor unit is a group of muscle fibers for which the message to contract is carried by a single neuron coming from the anterior horn of the spinal column. Both techniques indicate the functionality of the nerve that is tested.

The underlying cause of Post-Polio Syndrome remains unknown. Current theories include chronic inflammation of the spinal cord and die-back of recovered neurons from overuse. The “die-back hypothesis” suggests that fragile neuronal sprouts (which reinnervate muscles after the loss of neurons during acute polio) die because of metabolic stress caused by overuse. These two suggested origins for PPS are not necessarily contradictory but rather examples of different levels of observation; one at the tissue level, the other at the cellular level.

Thirty-one of the 38 people in the Sorenson study indicated they have PPS and experienced progressive muscle weakness during the 15 year period. Seven did not have PPS symptoms and did not experience this. It was found that the amount a muscle could contract (CMAP measurements) declined equally in people with PPS symptoms and people

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## Examining a Controversial PPS Publication

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without symptoms. The number of motor units that could be activated (MUNE measurements) declined in both groups, but, oddly, there was a greater decline in people who did not report new muscle weakness! Since increasing weakness is associated with increasing loss of nerve connections to motor units, clarification or discussion of this unexpected result would be good.

A significant flaw in this article is the use of results derived from another study with different methods. It is acceptable to discuss and compare results from different studies. It is not acceptable to use the results of others to replace missing elements of your own study. This is particularly true when different methods were used to obtain the results. The authors did exactly this in the most provocative part of the publication. Because this study does not have a 'normal control group', the authors took the results from another, undefined, study with different methodology, to get data about people who did not have polio. They then compared the results from their electrophysiology study on polio survivors with the results from this undocumented study. By doing this, their comparison of the effects of aging in polio survivors and normal people is meaningless.

It is clear that the statements

causing most concern to people with PPS are the ones least supported by the evidence. Unfortunately, these statements also are the ones most likely to be picked up and sensationalized. They are, in the authors' own words, "... the similarity of our results suggests that our polio cohort did not age any differently than a normal population. This suggests that the most likely cause for the decline in our polio survivors is aging alone." To make a statement with such import, the data that supports it must be impeccable. It is not. Without appropriate data the conclusion is unfounded and inflammatory.

Saying that "the most likely cause for the decline in our polio survivors is aging alone" invites many questions. For example, all polio survivors age, but not all polio survivors report an accelerated decline. What about them? What about young people, from the less developed world where polio is still endemic? They are reporting symptoms of PPS and they are not at the point where age causes loss of neurons. To ascribe aging as the main cause of PPS new muscle weakness ignores the other severe problem of PPS—central fatigue—which has no obvious connection to aging.

Indeed, to say that the decline is due to aging alone also suggests that the aging process is the root cause of PPS. This is a gigantic leap and ignores documented differences between similar aged polio survivors who have PPS and those who do not. Specifically, the profile

of proinflammatory cytokines is significantly different in the two groups (Gonzalez et al J. Neurol. Sci. [2002] 205: 9-13), as is the presence or absence of poliovirus fragments in cerebrospinal fluid (Leparc-Goffart et al J. Clin. Microbiol. [1996] 34: 2023-2026). Neither of these is typical of an aging population.

In addition, the Sorenson et al citation of work by McComas et al is perplexing. McComas disagrees about aging being the most likely cause of new weak-

**To ascribe aging as the main cause of PPS new muscle weakness ignores the other severe problem of PPS—central fatigue—**

ness. Indeed, he actually says the opposite. To quote from McComas et al "... denervation progresses in patients with prior poliomyelitis ... and ... this progression is more rapid than that occurring in normal aging." (McComas et. al. Brain [1977] 120, 1415-1421).

The data in the current study shows that people with prior polio lost motor units at 3% per year. In the McComas article people with prior polio lost motor units at the rate of 6.7% per year and people without prior polio lost motor units at half this rate. Sorenson et al then say that, "The rate of decline in our polio cohort was approximately the same as the normal population in the McComas study but about half that in

their polio patients.” It is not clear why this statement is included. It appears the authors are saying that the decline in the polio group in their study is the same as the decline in the normal population of the McComas study and this supports their contention that PPS weakness is due to normal aging. However they are comparing apples and oranges – results from two different studies. Moreover, the two studies came to diametrically opposed conclusions about PPS weakness and aging.

Another controversial part of the article is the suggestion by Sorenson et al that there are two models to explain new muscle weakness in PPS. One is “linear loss” where the loss of neurons (and hence of strength) is a constant rate of decline for everyone as happens in normal aging. The other model is “proportional decline” where the loss is related to the amount of damage from acute polio. In the discussion, the authors say that the proportional model best explains their findings. However the authors also say that neither model closely fits their data! This strongly suggests that neither model is correct. Therefore, the pattern for new muscle weakness is not related to a slow general loss (as is found in everybody with aging) and it is not (solely) related to the amount of original paralysis. There are other rate laws which could describe the way new muscle weakness is appearing. It might have been illustrative if these had been explored. It appears that the model preferred by the authors does not support their hypothesis that muscle weakness (loss) is related to normal aging (the first model).

Sorenson et al tell us that “The large degree of variation seen in both models may be a reflection of the underlying variation known to occur with most MUNE techniques available currently.” This means that the method used to obtain this data may not be adequate for the job asked of it. In other words, be a bit skeptical about the results.

On a different topic, the authors say that “There was no association between the magnitude of decline in either the summated CMAP amplitude or the summated MUNE and the presence of symptomatic progression.” One interpretation of this data is that a decline in the

function of the two muscles they tested does not correlate with symptoms of new muscle weakness elsewhere in the body. If there is a significant relationship between the muscles tested and those generally reported as becoming weaker, this should be demonstrated or referenced.

This article is controversial not because of its actual findings, but because of the interpretation of its findings. The authors were poorly served by reviewers whose job was to point out all of the inconsistencies described above. This article has many statements that are not supported by the evidence. Unfortunately the popular press found a critical one and sensationalized it.

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# Inaccurate Mayo Clinic News Release Threatens Polio Survivors' Wellbeing and Healthcare

Dr Mary Westbrook PhD AM

Mary Westbrook was Associate Professor in Psychology in the Faculty of Health Sciences at the University of Sydney before her retirement from fulltime work. She is now Conjoint Associate Professor in the Centre for Clinical Governance Research in Health in the Faculty of Medicine, University of NSW. Mary has published over a hundred research articles in peer reviewed scientific journals. She has published much about the late effects of polio and is currently part of a team evaluating the state-wide patient safety programs put in place by NSW Health over the last few years.

**T**he Mayo Clinic has issued a News Release on Sorenson et al's research which does not accurately reflect the research findings and limitations. The research failed to distinguish which, and how many, of the 38 polio survivors in the research sample had, or did not have, post-polio syndrome (PPS). The research also failed to include measures of major aspects of PPS, namely fatigue and pain. Although his research team found a significant decline over 15 years in around half of the measures of muscle strength made on their subjects, Sorenson said in the News Release that the late effects of polio are "relatively benign" and due to ageing. This oversimplification of what the results mean has been picked up by other media and further simplified so that by the time it was reported by the BBC news there were said to

be "no polio effects in later life." There is a very large body of rigorous research showing the significant negative impact on functioning and quality of life that PPS causes for those polio survivors who develop it. It is disturbing to consider the impact of this News Release on the families and health professionals of polio survivors with PPS. They may well dismiss the reality of PPS thereby discrediting the reality of the symptoms that polio survivors with PPS experience. The reality of the problems polio support groups and post-polio clinics have struggled to bring to community attention may now also be dismissed.

I have read a copy of the Sorenson et al article "Electrophysiological findings in a cohort of old polio survivors," published in the Journal of Peripheral Nervous System [Volume 11, pages 241-246, 2006], on which the Mayo Clinic News Release is based. These authors have also published a recent article in the journal Neurology titled, "A 15 year follow-up of neuromuscular function in patients with prior poliomyelitis" [Volume 64, pages 1070-1072, 2005]. The same sample of polio survivors was the focus of the two papers. In the Mayo Clinic News Release Sorenson refers to findings from both these articles.

The aim of the article in the Neurology article was to examine "1) the stability of strength in this cohort, 2) whether symptoms of progressive weakness are associated with the magnitude of the decline, and 3) whether symptoms of progressive weakness are associated with the magnitude of baseline residual deficits." The article briefly describes 27 measures

taken on each participant. These include the 2 electrophysiological assessments described in the 2006 paper. The aim of the most recent (2006) paper (discussed by Falconer and Bollenbach) was to describe in more detail the results obtained from the 2 electrophysiological measures.

The article published in 2005 Neurology gives a clearer overview of the whole research project undertaken and is easier for a non-neurologist to follow than the 2006 article. As the Neurology article is presented in the journal as a "brief communication" there is not great detail concerning the tests used and how they were scored so I may possibly have misinterpreted some of the authors' research procedure. The 27 measures taken on each subject included pulmonary vital capacity, tests of strength of 18 muscle groups, and a set of timed functional tasks such as time to walk 100 yards, and screw manipulation and pegboard tests requiring placement and displacement of objects. Depending on the statistical method you use to decide whether a real change in function had occurred over the 15 years (as opposed to a change so small it could only be attributed to chance), there was a significant change over time on 16 (59%), or 13 (48%), of the 27 measurements collected for survivors. For all of these measures a significant decline in function had occurred over the 15 years with the exception of one measure that showed an improvement in function over time. Ten of the measures that did not change over time were tests of muscle groups' strength. Decreased endurance often presents a

greater problem for polio survivors than does decreased strength [1, 2]. In some instances survivors can perform an action once, or a few times, but their lower endurance prevents them from continuing to repeat the task the number of times their able-bodied counterparts can achieve. When examining survivors, health professionals may ask the person to perform a movement and assume they can perform it all the time whereas they may only be able to do so again after a long rest period. Sorenson et al also calculated what they called a Neurological Disability Score by combining each subject's strength scores (from manual muscle testing) for some 27 muscles. Manual muscle testing is often unreliable and it frequently overestimates polio muscle strength [3] which may help explain why on this measure the subjects scored as having significantly less disability at the 15 year follow-up than they had when the research commenced. To help make more sense of the research findings we need to consider the actual sample used and its composition.

A major problem of the research is the sample of survivors used. The size of sample was small (making statistical inferences drawn from it, and particularly comparisons of the small sub-samples, questionable). Sorenson et al admit in their 2006 article that: the fact that only seven subjects remained asymptomatic does limit our power to correlate progression with time to the development of symptoms. The sample consisted of both polio survivors who did and did not report experiencing increasing weakness. The original study sample had consisted of 50 polio sur-

vivors tested 15 years previously. They had been randomly selected from the documented records of polio cases in Olmsted County, Minnesota. At the 15 year follow-up the number of subjects had decreased. Three had died and 9 refused to participate. Thus the sample size had dropped to 38 (though media reports keep talking about a sample of 50). In the Neurology paper the authors say that 25 (66%) of these 38 subjects had reported progressive weakness at the beginning of the study in 1987 and only 7 (18%) remained asymptomatic (reporting no increase in muscle weakness) at the 15 year follow-up. Clearly there seems to have been a mixture of survivors who did not have PPS with some (how many is impossible to say) who would be diagnosed with PPS at a post-polio clinic.

The major finding reported in the Neurology paper was: "The greatest risk factor for the presence of progressive symptoms was the magnitude of neurologic deficit at baseline. In nearly all our measures, there was an association between symptomatic progression and magnitude of deficit at baseline." In other words, survivors who had more polio related problems at the beginning of the study were more likely to experience progression of symptoms over the 15 year period. However, rate of progression of weakness was not related to the person's baseline symptoms.

Falconer and Bollenbach have described various other inadequacies in the research. However by far the most disturbing aspect of this research is not the research methods used but the chirpy media-catching spin put on them in the

Mayo Clinic News Release. The release is being reported in many newspapers around the world. The BBC News (26/8/2006) had as a headline "No polio effects in later life," followed by "People who survive polio in childhood will not suffer further effects later in life, say US researchers." As a result of such inaccurate publicity many health professionals and family members and colleagues of polio survivors with PPS may dismiss their problems as 'all in the mind.' The hard work that polio survivors have done, and are doing, to try and obtain healthcare resources may be in some jeopardy. How do we convince governments of our requirements if research findings 'proving' there are no effects from polio in later life, are in circulation?

What the News Release from Mayo failed to explain was that:

- 1) There is a difference between the problems experienced by polio survivors with post-polio syndrome and other polio survivors. The latter may well experience late effects from living with a body compromised by polio (for example, carpal tunnel syndrome from using crutches) but do not report the combined symptoms of profound fatigue, increasing muscle weakness and pain reported by those diagnosed with PPS. Of course survivors with PPS may also have such other late effects such as degenerative arthritis in overused joints.
- 2) Sorenson et al's sample contained both types of polio survivor, that is, those with PPS

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## Inaccurate Mayo Clinic News Release

(Continued from page 9)

- whom we would predict would be more likely to decline in muscle strength and those who did not have PPS who would be relatively stable. (We can't assume that people who said they had experienced new weakness in the initial study would have been diagnosed as having PPS in a post-polio clinic.)
- 3) The results of a relatively small loss of muscle strength in a polio survivor can result in loss of ability to perform important, even major, functions. So a relatively slight loss on some of the type of measures used in Sorenson at al's research can have a dramatic impact ... in my case losing the ability to walk and needing to use a wheelchair. Sorenson's comments in the News Release that "the discrepancy between what some of the patients experienced with growing weakness and their actual measurements of strength and neuronal loss likely is due to increased sensitivity to their disease experiences." This reads to me like another 'all in your mind' judgment. It implies that survivors' early experiences as polio patients have turned them into fussy, over-reactive hypochondriacs.
  - 4) Some experts on PPS see fatigue as both the most frequent and the defining characteristic of PPS. Polio survivors with PPS frequently say that the fatigue and pain of the syn-

drome interfere with their quality of life far more than does the loss of muscle strength. Dr Lauro Halstead, post-polio researcher and polio survivor with PPS, wrote: "Of all the symptoms of PPS, new weakness is the easiest to study, and, thus has stimulated the most research. The results from this research have provided a better understanding of this symptom than any other aspect of PPS. Ironically, the symptom of fatigue is more common than new weakness in most studies, but, because it is more difficult to investigate, much less is known about the cause ... In addition to peripheral fatigue, another type is known as central fatigue. For many individuals, this type is the most disabling symptom of PPS" [4, page 17]. Sorenson et al failed to include measures of PPS symptoms other than increased muscle weakness in their research.

Thus it is clear that this recent research suffers from several significant limitations. The sample was small in size and did not identify those with PPS and those without PPS. The measures failed to include important symptoms of PPS and these often have the most negative influence on survivors' quality of life. The spin placed on the results by the Mayo Clinic News Release is inconsistent with the study's results. The release ignores, and is contrary to, findings from a very large body of rigorous research into the late effects of polio; many examples of such research can be found in Silver and Gawne's recent book [5]. The greatest concern for polio survivors is the potential damage that

this media release may cause by undermining their family and social support and increasing the risk that health professionals may dismiss their symptoms or prescribe inappropriate treatments. Post-polio support groups frequently witness how such happenings can have very detrimental effects on polio survivors' wellbeing.

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## Responses from Medical Advisory Committee Members

Post-Polio Health International  
Press Release

"The Mayo Clinic researchers are to be congratulated for having carried out a well-designed, rigorous prospective study over the past 15 years. The results represent an important contribution to the literature. It is also interesting, historically, that they provide confirmation for one of the earliest hypothesis regard-

ing late-onset symptoms - namely aging, and it was discussed at the two Warm Springs conferences in 1984 and 1986. I only wish that a similar study could have been accomplished at my clinic and many others around the country.

“The central question it raises for many of us is, ‘How representative is this study group of the larger population of polio survivors in this country?’ Based on my experience-and that of many others-it probably represents a majority of individuals who visit post-polio clinics. However, it clearly doesn't represent an important minority-perhaps 5-15%-who are experiencing significant functional deterioration, especially in recent years.

“Many of these people are similar to the group of patients described by Mulder et al. in 1972 in the Mayo Clinic Proceedings in the article entitled 'Late progression of poliomyelitis or forme fruste amyotrophic lateral sclerosis.' Although details are lacking, they might also be similar to the control

subjects in the 2006 Swedish paper describing the results of IVIG therapy. Thus, it's important to keep in mind that the Mayo Clinic study represents only one part, all be it a large one, of the post-polio spectrum.”

Lauro S. Halstead, MD, Director, Post-Polio Program, National Rehabilitation Hospital, Washington, DC

“The Mayo Clinic findings are similar to my own clinical experience: that is, post-polio people with the greatest initial losses and proportionally the greatest recovery are the most vulnerable to later-life functional declines.

“I believe the confusion/controversy about this issue comes from the poor correlation between the severity (percentage) of motor neuron (MN) loss and the severity of clinical weakness or functional disability.

“Thus, some polio survivors had severe losses but made significant functional recovery (by very hard work at rehabilitation) to apparently become normal (not disabled).

“After age-related proportional losses of MU's, as suggested by Sorenson's study, they experience very significant and distressing increased weakness and functional losses (i.e., post-polio syndrome).

“Nevertheless, the study suggests that it is age-related cell losses, not unexplained or immunologic accelerated MU losses that lead to increased weakness, functional declines and pain in many polio survivors.

“Certainly, the study does not invalidate the distressing increased weakness and functional declines experienced by many polio survivors. Rather, it offers data to support a different explanation for these symptoms.”

Fred Maynard, MD, UP Rehab Medicine Assoc PC, Marquette, Michigan

“I think this is interesting and positive, but impossible to extrapolate to a worldwide population of 20 million polio survivors.”

Julie K. Silver, MD, International Rehabilitation Center for Polio at Spaulding-Framingham, Massachusetts



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Our support group feels an exchange of information between groups is important, and it is our hope for the future that all groups will join those of us who take the time and effort to research, contribute, and educate responsibly



Newsletter of the Post Polio Awareness & Support Society of Minnesota

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