

## **Polio Survivors throw doubt on Study.**

Hilary Boone, Lincolnshire Post-Polio Network.

***'Survivors of childhood polio do well decades later as they age' [a],  
'Polio Survivors faring well' [b], "No polio effects' in later life' [c]***

For Revision History see end of document.

*The above three press statements* were made in sequence during the last ten days of August 2006. The initial statement, on the 21<sup>st</sup> August 2006, was the announcement by the Newsbureau of the Mayo Clinic in Rochester, Minnesota, [a] of the research findings reported in an article in the Journal of the Peripheral Nervous System, 'Electrophysiological findings in a cohort of old polio survivors' by Eric J. Sorenson, Jasper R. Daube, and Anthony J. Windebank. Their research used a cohort of patients that they had been studying over the last 15 years. [1,2,3,3a,4,5] A cohort of 50, reduced over the 15 years to 38 'old polio survivors'. Within days the findings had been reported by other media and by the time it was on the BBC News - Health there were 'No polio effects in later life'. [c]

**Polio Survivors** who are NOT doing well decades after recovery; who do have polio effects in later life; who have been presenting with well documented new symptoms – including considerable functional decline in actions of daily living - to recognised Post-Polio Clinics and Specialists during the last 25 years are once again disappointed that this cohort continues to be used as representative of the polio population. In the authors' own words in the 1996 article '...we believe that our findings can be extrapolated to the whole population of polio survivors in the United States.' [4]

McCarthy reviewed the 1996 article [4] in the Lancet in February 1996 [8] with the heading

### ***Study throws doubt on post-polio syndrome***

Helena Edwards of the Leicestershire Post-Polio Network in her rebuttal stated, 'We, in the UK, heard from people whose doctors were assuring them that PPS did not exist, and in some cases the doctors mentioned that their information came from an article they had read recently.' [9]

We present the following issues that we believe need to be taken into account before conclusive statements can be made regarding findings from Sorenson et al's research report. Authors who raise other issues with this research, and the way findings have been presented, are included in References at the end of this paper [d,e,f,g].

1. We believe the people in Sorenson et al's study cannot be extrapolated to the 'polio population', because 90% of their cohort is towards one end of the scale, towards more severe deficits.
2. There are important facts from 10% [5 of 50 subjects] of their study group that appear to have been dismissed when in fact they appear to show what is happening at the other end of the scale, those of us presenting to PPS specialists and PPS Clinics; polio survivors who recovered well and now have new symptoms and considerable functional decline in activities of daily living.
3. Their use of numbers and phrases can easily be misinterpreted without the full facts from previous articles.
4. Sorenson et al make several statements of caution, regarding comparing studies with the normal population, then appear to proceed to 'overcome' or 'ignore' them in this article. Yet just eighteen months earlier they stated 'the effects of normal aging in this cohort cannot be commented on.' [5]
5. We question the validity and reliability of Manual Muscle Testing to grade muscles.
6. We question the reliability of a YES/NO questionnaire. Ask 50 Polio Survivors "Can you do x?" and the vast majority will say "Yes". Ask the same number "How do you do x?" and you are likely to get a huge variety of answers.
7. The extent of recovery from paralytic polio experienced by many polio survivors is often not realised.

### Issue 1.

**Quite simply, in the authors own words, from two of the articles, the cohort used is weighted towards people whose polio residuals were more visible.**

- 'we selected those survivors from the original cohort [223] who currently reside in Rochester and the surrounding area' [2]
- 'we also randomly selected an equal number from those who were complaining of deterioration and those who were not.' This intentionally biases the study toward those with difficulty... At this time, 31 patients have completed the study.' [2]
- 'From the **247 survivors**, we selected 50 subjects.' [3 - Abstract]
- 'Fifty survivors who lived closest to Rochester were selected for the study. This group was likely to stay in the area and be available for follow-up study.'" [3]
- '58 subjects were called in order to recruit fifty' [3]
- 'Those evaluated showed a trend towards more severe deficits' [3]
- 'There may be a tendency for more handicapped residents to remain geographically closer to our clinic.' [3]
- 'These subjects were not seeking medical attention; they were invited to participate on the basis of their having had polio.' [3]

### Issue 2.

Important facts in their study actually relate to the other end of the scale, of polio survivors who are experiencing new symptoms and functional decline, do not seem to have been given equal attention. Again using the authors own words. [3]

- '*that 5 subjects who had made the greatest recovery were all experiencing new difficulties*'
- '*One of the two nearing retirement who had made an occupation change because of leg weakness was a surgeon. He had significant progressive leg weakness so that ambulation had deteriorated from requiring no aids to needing a cane and then a walker and finally a wheelchair for distances*'
- '*that nine limbs that were newly symptomatic that had not been paralyzed during the acute illness were in 4 subjects.*  
*Three of the four had purely bulbar polio but now complained of limb symptoms.*  
*The fourth had paralysis involving the legs and now complained of arm pain*'
- '*That in no case did they find new complaints in a limb that showed no electrophysical evidence of having been affected by the original disease.*'

### Issue 3.

The use of numbers and phrases in their articles can easily be misinterpreted without reading all previous articles relating to the study. For instance the article that triggered the recent press releases, 'Electrophysiological findings in a cohort of old polio survivors', stated:-

- **Fifty representative subjects were randomly chosen from 298 patients** with a documented history of paralytic poliomyelitis residing in Olmsted County at the time of the infection. [6]

Compare that statement with the following quotes from the progression of articles from 1984 to 2005, referenced [1,2,3,4,5], relating to this study group. We accept that these quotes are taken in isolation and not the full context, but they do not appear to be consistent.

1984 'Patients were required to have had established residence in Rochester prior to diagnosis for inclusion in this study.'

'Of the 316, 201 had paralytic polio and 115 had nonparalytic polio.'

'23 died in the acute phase of the illness.... 7 deaths in subsequent years.'

... 'a questionnaire was circulated in April 1984 to all traceable patients who had had paralytic poliomyelitis.'

'Of 171 potential respondents... 23 people remain untraced at the time of presentation of this data'

'Replies have been received from 128.., three persons were unwilling to participate.'

'Of the 125 remaining, 97 patients indicated stability and 28 indicated deterioration since their maximal recovery from polio.'

'This questionnaire was supplemented by a detailed telephone interview for those who indicated deterioration since their maximal functional recovery from polio.' [1]

1987 'This group has subsequently been expanded to include all residents of Olmstead County, who had paralytic polio between 1935 and 1959. Two hundred eighty six subjects were identified, and 276 have been located for follow-up.

'Thirty people (10.5%) died in the acute phase of the illness, and 23 died in later years.'

'The remaining 233 formed the cohort for the follow-up. Two hundred twenty-three have been located'.

'At this time, 31 patients have completed the study. Ten individuals reported no difficulties of any kind... Seventeen reported new, perceived, specific limb weakness.' [2]

1991 'We identified a cohort of 300 individuals who had paralytic polio between 1935 and 1955. All lived in Olmstead County, Minnesota.'

'Two hundred ninety-three of the 300 cases were traced. Of the 300 subjects, 53 were known to have died'.

'Fifty survivors who lived closest to Rochester were selected for the study. This group was likely to stay in the area and be available for follow-up study.'

'58 subjects were called in order to recruit 50.'

In response to the questionnaire, 32 individuals complained of some new difficulty (Table 4)

Table 4 – No new symptoms 18. \*Types of complaints reported by 32 of the subjects with paralytic polio.

More subjects (21 of 33) complained of lower limb difficulty than upper limb problems (nine of thirty)

The cause of the symptoms is unclear but they are not attributable to age alone because the population is still relatively young (median age 49 years) [3]

1995 'Of the 300 cases, 298 identified for follow-up. 53 had died;'

'From the population of 300, 50 survivors were chosen on the basis of proximity of residence to Rochester. This group was chosen because they were likely to stay in the area and be available for detailed repeated measurements.'

'Detailed comparisons between 50 and the other 197 survivors to ensure that the cohort was representative.'

'This group of subjects was then reconstructed after five years. All gave information about their present status, and 46 underwent again the complete battery of tests described above.'

'The number of subjects reporting new symptoms of weakness, pain, or fatigue remained constant over the five year interval. Of 30 individuals who had symptoms at the first study point, 23 continued to have symptoms and 7 did not. Six individuals who did not have symptoms at the first time point did have symptoms after five years.'

'..(Table 1), the distribution remained similar except that more patients were likely to be complaining of all three symptoms at the second evaluation.' [3a]

- 1996 'Three hundred individuals met the criteria for paralytic poliomyelitis. 298 of whom were available for follow-up; (n.b. 53 had died) we chose a representative cohort of 50 individuals for prospective, sequential evaluations. They were chosen because they represented the whole cohort...'  
'Of the 50 patients, 46 completed the detailed 5 year study. Four patients declined to complete the tests but were contacted by telephone; all four reported that they were asymptomatic and did not want to participate in further detailed physiologic testing.' [4]
- 2005 'In 1987, we began a population-based cohort study of 50 subjects with a remote history of paralytic poliomyelitis.'  
'Fifty representative subjects were chosen from 298 patients who previously had well-documented paralytic poliomyelitis, living in Olmstead County at the time of the infection.' (n.b. 53 had died)  
Of the original 50 subjects of the cohort, three subjects died during the 15 year follow-up period. Nine of the remaining 47 refused further participation.'  
'Thirty-one of the 38 subjects whom we followed for 15 years reported symptoms of progressive weakness during the study period. Only seven subjects remained asymptomatic.' [5]

#### **Issue 4.**

Sorenson et al make several statements of caution when comparing their study to others then appear to proceed to 'overcome' or 'ignore' them. E.g. Regarding the McComas study Sorenson states 'Without such a control group, one cannot reliably compare the changes in the polio group with those in a normal aging population.' [6]

The first paragraph of their Press Release on 21<sup>st</sup> August 2006 states:-

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

ROCHESTER, Minn. Mayo 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.' [a]

Compare that to the statement in their 15 year follow-up article published in March 2005, just eighteen months earlier.

'How the changes identified in our polio cohort compare with those of a normal aging population remains unknown. We did not include a normal control group at the inception of the cohort. In the absence of a normal control population, the effects of normal aging in this cohort cannot be commented on.' [5]

#### **Issue 5.**

Manual Muscle Testing – How valid and reliable is this as a form of grading muscles?

Professor W.J.W. Sharrard – a world renowned Polio Professor from the 1950's, who wrote 'Muscle recovery in Poliomyelitis' [10], studied polio patients at autopsy and found that 'muscle grades of 3 were given to individuals with 85% denervation of the muscles. In other words, profound muscle weakness must be evident before abnormal grades are given.'

The Mayo Clinic states that Manual Muscle Testing and Isometric testing across different joints were used to grade muscles. They have not used the normal MRC grading scale but used the following scale, which they state 'has the advantage that numbers can be handled additively for additional analysis' [2]

0	Normal Strength
1	25% loss of strength
2	50% loss of strength
3	75% loss of strength
4	100% loss of strength.

The issue with Manual Muscle Testing – most often performed as a single action – is that it will not tell the health professional how long the patient can sustain that action, repeat that action, or how they use that action in a pattern of movement. According to Westbrook in her rebuttal of the 5 year study [9] Windebank et al derived their “Neurological Disability Score” from the results of manual muscle testing, a method that is notorious for overestimating polio muscle strength.[11] Polio survivors developed many trick movements; use other muscles instead of or to assist weakened ones. Important evidence of reported new weakness and compensatory strategies can be missed unless people are observed performing actions of daily living over a period of time.

Polio Survivors, who have often taken months or even years before presenting new weakness to a health professional, report again and again that ‘They say I am strong, that I have nothing wrong with me. Then why can I no longer do the things I used to a few years ago?’ To ensure this is not misinterpreted as age loss; such comments are coming from individuals in their 40’s and 50’s. The following are two responses to the Lincolnshire Post-Polio Network in May 2002:

"Regarding the MMT you are correct. **If done only a single time, it can give an erroneous idea of the true muscle strength and endurance.** In a way, the key word here is "endurance" which reflects muscle strength on multiple contractions. Many polios will have good strength on a single contraction only to get weaker on repeated contractions."  
Lauro S. Halstead M.D. Director of Post-Polio Program, National Rehabilitation Hospital, Washington DC, USA.

"You have done a brilliant job of describing a real problem for polio survivors and professionals that is, **the limitations of the Manual Muscle Testing (MMT)** scheme (a British invention, circa 1950, by the way). I quite agree with your comments and observations".  
Fred Maynard, M.D. Marquette, Michigan, USA - President Board of Directors, Post-Polio Health International.

#### **Issue 6.**

Each participant completed a questionnaire of 337 items enquiring about limb and bulbar weakness, pain, fatigue and activities of daily living, in a YES/NO format.

There is an issue here that is well recognised and reported on in medical articles, [12] that polio survivors are strong willed, determined, highly capable people, who, regardless of level of disability/ability, do not need any help thank you. They are reluctant to admit that they are having new symptoms, new functional decline, and even when admitted and/or confirmed by testing, it can still be some time before they take the advice to pace and rest and use aids and equipment. Using a yes/no questionnaire does not necessarily allow polio survivors to convey to the health professional HOW they actually perform the action in question. ‘*Independently and with ease*’ for ‘*I could/can manage a small flight of stairs (about 10 steps)*’ might turn out to be going up backwards sitting on their bottom.

Sorenson et al recognised ‘*that it had been difficult to ascertain whether limbs, apparently uninvolved by the original disease process, might become affected by progressive symptoms years later. This is because of the reliance of the memories of an illness that occurred 30 to 50 years earlier.*’

The mean age at polio onset was variously reported as 9, 12 or 13 with the youngest age at one year or less. Not only is it difficult for affected individuals and family members to remember, it must also be taken into account that the youngest patients had limited language levels at the time of their polio.

#### **Issue 7.**

The high levels of recovery from Paralytic Polio of some polio survivors, including some who were in iron lungs, is often not realised. Many have competed in professional or high level amateur sports, some have joined the police and armed forces, or had other highly physical jobs. The damage from their polio was not easily visible externally.

Following a presentation at St. Thomas Hospital in London by Dr. Windebank on the results of the first five years study [4], Hilary Boone asked “How many of the 50 did sport?” Dr. Windebank replied that “one man could manage three holes of golf.” When asked, ‘No

swimmers, athletes, rugby referees, people in the police or armed forces?’ he emphatically replied, ‘these people had paralytic polio’. Hilary Boone replied, ‘so did the people I am talking about, including myself. They all had paralytic polio and some were even in iron lungs’. The seminar restarted and Dr. Windebank did not answer a follow-up letter.

### **Conclusion.**

We believe the above throws doubt on the methods used in this study and the conclusions the authors made and continue to make from this research. The cohort steered towards those

- who had more severe deficits following recovery, [Method and Results 1991 - 3]
- who geographically still lived near to the clinic, [Method and Results 1991 - 3]
- ‘These subjects were not seeking medical attention; they were invited to participate on the basis of their having had polio’ [Discussion 1991 - 3]

It is highly possible that this cohort is not representative of the 608 residents of Olmstead County who had acute polio between 1935 and 1960. The results of the 50, now 38, people in this study cannot be extrapolated to the polio population of the United States. Sorenson et al’s conclusions, based on a study of patients who have been chosen/selected, without a control group, believed by them to be representative of the ‘polio population’, can in fact be misleading.

Sorenson et al state, ‘There are no confirmatory tests to reliably distinguish between the effects of the old disease from new progressive difficulties. It is a clinical diagnosis following history taking, physical examination, and test results.’ [3] Therefore we believe it is essential that any study group mentioned in a polio/post polio medical article is more clearly defined to allow readers to make comparisons with their patients.

More and more polio survivors who recovered to the greatest degree from paralytic polio are now presenting to health professionals with new symptoms of weakness, pain, fatigue and considerable functional decline in actions of daily living. These are people who have often led active lives, have competed at amateur and professional sports, and who have had highly physically demanding jobs. They now find they have to:-

- Change their occupation and often medically retire early
- Return to using/start using aids and orthotics
- Go back to/start using canes, crutches, walkers, electric scooters and wheelchairs.
- Modify their homes and/or move to single story homes
- Be prescribed or purchase electrically operated chairs and beds
- Recommence using/start using respiratory aids
- Go from being very fit and active to being less able than their parents

In fact the results of this study can and should only be compared to those polio survivors who match the level of ability, disability, symptoms and lifestyle of the 50 participants, now 38.

This cohort has also been used in another article in Neurology in 2005. [7]

### **Where do we go from here?**

Terminology: Are reported symptoms related to the late effects of polio, post polio syndrome, post polio sequelae, unstable polio, post-polio muscular atrophy, another medical condition; or a combination?

To be perfectly frank Polio Survivors already experiencing new and unexpected symptoms and functional decline do not care what label they are given so long as:-

- All our reported symptoms are accurately assessed and recorded.
- Other conditions are checked for as there are no diagnostic tests.
- We are given the medical and financial support to manage our lives.

The Mayo Clinic have been aware for ten years since publishing the results of the 5 year level of their study that other health professionals and post polio support groups do not entirely agree with all the statements made regarding their Olmstead County Polio research. It is regrettable that following such critique, they did not extend their study to include more polio survivors who had recovered like the surgeon and were now experiencing considerable new difficulties.

It is a sorry state of affairs when polio survivors around the world must give up hours of their time to research their medical condition. To have to continually question and research the results of testing that do not corroborate your reported symptoms because of the way it has been carried out or recorded is unjust. Struggling on year after year, often deteriorating through incorrect advice and treatment or lack of it, has to come to an end.

Polio Survivors – a strong willed, determined, highly motivated, hard working group of people – want to live for as long as possible, doing as much as possible. We need a full and accurate base line assessment that takes into account the endurance of our weakening muscles. We need advice, and the understanding that it takes time to accept that we have to change our lifestyle. We need treatment where it is available, appropriate aids and equipment, and benefits so that we can financially cope in this world where anything ‘disabled’ has a high price label.

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October 8<sup>th</sup>, 2006.

Page 1 – Para 1 Article reference [3a] added.

Page 1 – Item 2 10% - added [5 of 50] for clarification.

Page 2 – Issue 1, First sentence reworded for clarification.

Page 3 – 1991 – Information added.

Page 3 – 1995 – Further article information added.

Page 7 – Reference 2 – Corrected article reference.

Page 7 – Reference 3a – Further article added in date sequence.

Page 8 – Reference 10 – Page number corrected and link added.

**October 16<sup>th</sup> 2017**

**Lincolnshire Post-Polio Network references changed to Polio Survivors Network.**

**N.B. References d, f, and g, and the full revision copy of this article are no longer accessible on the url link provided.**

**They will be added to our Website Polio Survivors Network as soon as we can arrange this.**