The LincPIN

The Lincolnshire Post-Polio Information Newsletter
Volume 5 - Issue 4 — June 2005

WebSite - http://www.lincolnshirepostpolio.org.uk

Lincolnshire Post-Polio Network's Website is referenced in new article followed by another article by Member Ruth Bridgens in the BRITISH MEDICAL JOURNAL

BMJ 2005;330:1314-1318 (4 June), doi:10.1136/bmj.330.7503.1314

Poliomyelitis and the postpolio syndrome

Robin S Howard, *consultant neurologist*[1]

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Excerpt from full article—Management

The effective management of postpolio functional deterioration requires a multidisciplinary approach involving both specific management of increasing impairment and a process of enabling patients to cope with new disabilities. Polio survivors are often extremely motivated and driven; they have conquered their disability, often by ignoring it completely, and have the most remarkable stories of achievement.[24] However, many continue to deal with increasing disability by intensive exercise regimens to regain muscle mass, strength, and function. Although some exercise is necessary to prevent wasting and stiffness from immobility, it is essential to strike a balance so that exercise regimens alleviate symptoms without causing increasing weakness and fatigue in damaged muscles.

Excerpt from Resources—Useful websites for patients

Lincolnshire Post-Polio Network (www.ott.zynet.co.uk/polio/lincolnshire/)—extremely helpful resource centre established by a UK regional group with valuable and accurate links to relevant articles and clinical and research sites

http://bmj.bmjjournals.com/cgi/content/full/330/7503/1314?etoc

BMJ 2005;330:1318-1319 (4 June), doi:10.1136/bmj.330.7503.1318

Postpolio syndrome—"We aren't dead yet"

Ruth Bridgens, *PhD candidate, medical sociology*[1]

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http://bmj.bmjjournals.com/cgi/content/extract/330/7503/1318

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WE WOULD LIKE TO THANK THE FOLLOWING
FOR DONATIONS RECEIVED TOWARDS OUR WORK.

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Donations large and small towards our work are always welcome.

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Please make cheques payable to 'Lincolnshire Post-Polio Network'
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Next LincPIN Newsletter - August 2005
Articles for publication 15th July by post or - newsletter@lincolnshirepostpolio.org.uk

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Editorial

Mary, Denise and I attended the 3 day Post-Polio Health International Conference in St. Louis Missouri last week. Three very full days of conference meetings, networking, and renewing and making new friends. We had a great, though exhausting, time and the next three newsletters will include reports from this Conference. This issue I will focus on our own presentation. The next two issues Mary and Denise will be reporting on the remainder of the conference.

EDUCATE YOUR HEALTH PROFESSIONALS

IF THEY KNOW LITTLE ABOUT PPS THEN FIND SOMEONE WHO DOES OR WHO IS WILLING TO WORK WITH YOU

So many times this was said by the Polio and PPS knowledgeable health professionals presenting to us.

It must be very difficult and embarrassing to be a health professional and have a patient come in for an appointment who has more knowledge about their condition than you do.

I believe that this imbalance has led to some patients being told that ‘pps does not exist’, ‘you do not have pps’, when in fact some years later after further rounds of hospital departments they get that diagnosis. What happens in the intervening years, the patient is likely to suffer from a variety of issues:-

- Overgraded muscles leading to:
    1. Weakness reported not being corroborated
    2. Exercise program set too high
    3. and in some cases operations where muscles are not strong enough to complete recovery,
- Turned down for benefits,
- Turned down for medical retirement,
- Not allowed aids and equipment that would allow you to manage your life more effectively,
- Untold stress that your reported symptoms are not believed leading in many cases to family, friends, and work colleagues believing you are just being lazy, making it all up, and if only you would just make that little more effort you would be fine again. Some are being divorced or worse!

In the UK we have free health care but we pay for this in our taxes. We can pay to see health professionals in private practice to speed up the waiting time for the appointment and/or treatment. In the USA patients are paying for Health Insurance or if on Medicare paying 20% towards the cost of the appointment and have to find health professionals who will take the often considerably reduced amount Medicare dictates for each procedure.

We are paying something towards the cost of the appointments but expected to provide information on our condition. With tongue in cheek, maybe we can work out a sliding scale of payments to us for the amount of information we provide. What bugs me more than anything is the enormous waste of money spent on all the unproductive appointments whilst we search for help that could be used to improve the quality of our initial assessment.

I urge all Polio and PPS Organizations and knowledgeable Health Professionals to work together and ask Colleges of Medicine to address this situation. Provide all students and graduates with more information now.

Message from the Chair

Welcome to the newsletter. We had a good response to our questionnaire issued in April, and are still assessing the responses coming in. Please continue to send your responses to recent questions, if you haven't already, but have been meaning to!

As chairperson, it behoves me to put readers' minds at rest concerning matters to do with the charity, as well as to provide transparency on the work we do as an elected committee. We need to remind readers that our constitution binds us to strict rules of adherence when it comes to spending money. Our treasurer has just completed the Charity Commission's audit, and we also have rigorous financial audits on an annual basis, to which all members are entitled to have access. As the chair of this organisation, I am re-assuring our readers that NO funds will come out of the charity's budget for the up-coming trip to Post-Polio Health International 9th Annual Conference in St Louis. Hilary Hallam is raising her own funds and is putting long hours into the preparation.

Two volunteers, namely Mary Kinane (the writer) and Dr Denise Carlyle are also raising funds privately to attend what we see as an important networking event about matters to do with managing PPS and delivering information back to polio survivors. We see this as a valuable opportunity, not only to meet others working in this field, but also to bring back useful and current thinking on various topics around PPS – we think that our members deserve to have this feedback, which will be delivered in a number of stages via the newsletter on our return. We also feel that attending and presenting on Self-Assessment will help to enhance our conference and presentation skills, especially in light of our current project with NHS Trusts in England, to disseminate information and raise awareness about PPS as widely as possible.

In May two volunteers were hosted by our Dublin friends to make a presentation on Polio Partners, at the PPSG's AGM. We look forward to the feedback from Robin & Pauline, as well hearing news from old friends.

In recent times, many volunteers have stopped claiming ordinary expenses incurred during the course of their valuable work – e.g. printing and postage costs for writing to new members, phone calls made at home, petrol expenses, etc. They do this because, as members will know, we have been operating on small grants for some time, 'though we still manage to pull through - thanks to regular donations from some members and periodic donations from others. We do not expect everyone to donate – we are only too aware of the financial constraints on some who find it difficult even to claim the benefits in the UK to which they are entitled. We welcome all contributions, whether financial or in kind – we couldn't continue to run things as they are without these voluntary contributions of time and energy as well as money.

We wish all our members good health and a happy summer.

Best wishes

Mary Kinane. Chair
mary.kinane@lincolnshirepostpolio.org.uk

Treasurer's Thoughts June 2005

Firstly I would like to thank all of our members who took the time to send me back the questionnaire in the April newsletter by post or email. Preliminary findings indicate that these members feel that reducing the number of newsletters per year, cutting the number of pages per issue, and increasing the annual membership fee would be acceptable ways of reducing costs. If you have not sent your questionnaire back and wish your voice to be heard, I urge you to send it to me as soon a possible before the findings are finalised at the end of June.

Many members generously sent donations of £5 or £10, and I wish to thank you for helping us to continue to support polio survivors. There were also many useful suggestions as to the way forward for LPPN, which the committee is looking into.

I would welcome any suggestions/comments you might like to make. You can contact me via email: denise.carlyle@lincolnshirepostpolio.org.uk

Cholesterol Drugs May Increase Risk of Nerve Damage

From Neurology May 14th 2002,
58: 1321-1322, 133-1337

Cholesterol-lowering drugs called statins may increase the risk of nerve damage called neuropathy. But the well known benefits of statins far outweigh the risk of neuropathy, which remains very low. Peripheral neuropathy occurs when nerves in the peripheral nervous system – those outside of the brain and spinal cord – become damaged. Symptoms may include tingling, numbness and burning pain as well as decreased sensitivity to temperature or pain.

Diabetes, kidney disease, thyroid disease and alcohol abuse can all lead to neuropathy, but the nerve damage, known as polyneuropathy when it affects more than one nerve, may develop independently of these conditions.

As more and more people have started taking statins on a long-term basis, a small number of patients have developed cases of nerve damage with no apparent or obvious cause. Investigators report the results of a larger study that seems to confirm the link between statins and neuropathy. In the population-based study in a Danish county, the researchers identified 166 first-time cases of neuropathy that did not have an obvious cause.

The cases were divided into definite, probable and possible cases, depending on how certain the researchers were that the nerve damage could not have been caused by some other condition. Nine of the patients had taken statins, with the average length of treatment being nearly 3 years.

Compared to a control group of people who did not have neuropathy, people who had taken statins were 4 to 14 times more likely to develop polyneuropathy that did not have a known cause. Several of the statins taken by patients in the study list peripheral neuropathy as a possible side-effect.

See special note at the end of article on Creatine Kinase by Gladys Swensrud pages 18to 22].

EYE EXERCISES

From a recent phone enquiry to PPS WA (Post Polio Syndrome Western Australia)

Shireen: Since all my muscles got weaker some years ago, when the doctor had me on those cholesterol-reducing drugs, now I have problems with my eyes too. They don't seem to focus very well. I have tried taking Vitamin A and B2 but still have problems. What else can I do?

Tessa Jupp: This is an eye muscle problem, not a vision problem. Eyes need exercising to keep them going just like other muscles. Here are 2 simple ones to start off with that will help your eye muscle focus. Do them 2-3 times a day when you are not tired.

1. Hold a pen tip (or even a fingernail) at arms length and slowly bring up to your nose, keeping your eyes focused on one point – then move out again. Repeat this several times.

2. Draw a line on stiff 9" by 4" piece of cardboard and draw a cross every inch apart. Hold one end up to your nose and shift your focus on each cross getting closer up to your nose, then go back out again. As you get better at it, count to 5 then 10 etc at each cross, maintaining the focus at that point for the count. You should see the lines cross like railway tracks at the point you are focusing on. Repeat 5 times, several times a day.

[Editors Note—on eye problems.]

Going back about 7 years a discussion took place on the St. Johns Polio List about eye problems. Four people took their problems to a small email list and compared notes. My eye problems where visual disturbance for a short time and difficulty when going from a lit room to the dark, I had hawked this round the Eye Departments of two hospitals over 4 years. I had had numerous tests, and you guessed it… could be peripheral neuropathy but the test results don't match. 'Can you imagine what they would have said if I had said, has my waist down paralytic polio got anything to do with this?'

I was asked a few questions by the polio survivor in Australia and was told that their problems matched mine and he gave me the information from his optician to take to mine. I made an appointment and asked 'would you be prepared to examine me, then read some information I have and examine me again.' My optician said, 'Oh I love mysteries and its about time someone found out what is causing your problems.' He examined me for the second time and said.. 'Yes, the muscles that move your eyes on the left side of your face are weaker than the right—and weaken further with repetition. When you move your eyes left to right, right to left, there is a time lag on the left side. Easy to sort that out, just move your head and not your eyes. Also when I shine a bright light into your eyes the pupil goes small but takes much much longer to return to normal which is why you can't see properly for a short time when you go from the light to the dark, till your pupils sort themselves out.' He wrote me a comprehensive report for my GP.

I gave my GP the report - who months earlier doubted it was polio related - who said that she was impressed by my tenacity in searching for answers, and added, 'I don't think there would be much to gain from your returning to the Eye Department for further appointments unless things change'. [4 years of appointments and I find the answer on the Internet]

Remember not everything is Post Polio, but the fact that you had scattered nerve damage from the Polio virus means that it may impact on symptoms in areas not thought to have been previously affected.

How self assessment can help you in obtaining better care from heatlh professionals.

Ninth International Conference on Post-Polio Health
and Ventilator-Assisted Living
STRATEGIES FOR LIVING WELL
St. Louis, Missouri, USA.

Reactor – Carol Vandenakker MD
Physical Medicine & Rehabilitation, University of California Davis Medical Center.

Speakers:
Mary Kinane, BA, PGCE - Chair
Hilary Hallam, FIST - Founder and Secretary
Denise Carlyle, BA, MA, PhD, LRAM - Treasurer

Lincolnshire Post-Polio Network – U.K.
www.lincolnshirepostpolio.org.uk

A Summary of our Presentation.
'Make sure the picture in your mind matches the picture in the Health Professionals'

Compiling the many and varied comments made to the Lincolnshire Post Polio Network—not just in the U.K. but from around the world—has highlighted the following problems.

1 . When the polio vaccine became 'safe and effective' 50 years ago this year the numbers of polio cases reduced and subsequently so did the number of facts taught in Medical Schools. Some Colleges do not even mention polio, others give just a few basic facts, leaving many health professionals in a very awkward position when a Polio Survivor turns up for an appointment not only knowing more about polio but having found out via the Internet or the media that there are late effects following recovery and many years of stable functioning. There are still hundreds and thousands of health professionals in the world that are unaware that PPS exists, or have heard the term but have had little experience with the condition. How many of the 20 million polio survivors in the world still do not know it exists?

2. Manual Muscle Testing. This, as our readers know, is one of the biggest stumbling blocks in obtaining a full and accurate assessment. Manual Muscle Testing was developed in Britain over 50 years ago but there is a massive problem with validity and reliability. Firstly there could be up to 70% weakness in a muscle before it is detected by this method, secondly most testing is done a single time not picking up weakness that occurs at a later repetition or longer sustained time, and thirdly it does not test pattern of movement. [My medical for the Police in 1969 passed me fit, it did not pick up the fact that I could not run or rise from a squatting position.]

Health professionals will tell you that they use this method, e.g. grip my hand, pull against me, push against my, looking for weakness. If no weakness is found on a single action test then often the tester moves on. If you are reporting weakness in a muscle and like so many of us nothing is found we end up doing the rounds of hospital departments, being tested the same way again and again and our symptoms go uncorroborated. The money being wasted and the frustration, stress and often unnecessary further deterioration that occurs is unacceptable. [See chart bottom of page 22]

3. Another problem is being caused when a few facts or a few lines are taken from a medical article that leaves out a critical piece of information. For example:-

> ∗ The results of this study of x number of polio survivors revealed y… important studies but do the polio survivors you are seeing match the people who were examined for this study?
>
> ∗ Muscles graded 5 can be exercised vigorously … but only after full and thorough history taking and physical examination of a polio survivor by a Polio and PPS knowledgeable health professional.

4. The diagnostic name given to you at the time of your polio related to the worst affected area of your body. No name was given to the rest of your body. After test results that showed you had been in contact with one of the three polio viruses a physical examination would take place and reported as follows:-

> ∗ Paralysis in any part of your body then you had Paralytic Polio,
>
> ∗ Clinically evident weakness but no paralysis then Non Paralytic Polio.
>
> ∗ No clinical weakness evident and your diagnosis was Abortive Polio.

BUT you could have had

> ∗ up to 44% nerve damage with NO clinically evident weakness
>
> ∗ up to 59% nerve damage before paralysis was evident. [Two charts on back page]

What many health professionals are failing to consider is how much damage was caused to the rest of your body. How much damage occurred in the ‘good’ leg, or ‘good’ arm or even ‘good’ part of a limb? Did you have sub clinical damage in the bulbar area? Should all Polio Survivors who are reporting new symptoms, problems with functional decline be given a full physical assessment including Respiratory Testing? In my opinion YES, to pick up problems before they cause too much unnecessary deterioration.

5. The level of recovery is often not realised. Attend conferences and PPS meetings and see how many Polio Survivors do NOT show easily visible external signs of atrophy, short limbs, different size feet, even operations that fixed joints in various parts of the body. If polio is taught then the pictures shown are likely to include an iron lung, a person with obvious atrophy. However, many of us, maybe even 80% , until our bodies start showing the signs of our new symptoms have been asked ’Are you sure you had Polio, do you have any records to corroborate this?’ [See the two photos of the same person on the back page]

6. There are no tests that can say you have PPS? Diagnosis comes by exclusion of all other conditions, and a full and through history taking, physical examination and tests deemed necessary. We also strongly advocate that observation takes place of the changes in

daily function that we can demonstrate. If we were able to do an action five years ago one way and now have had to alter that way considerably there has to be a reason why. Self Assessment—which we will go into next will help you give this information to the health professional so you can ask, why has this happened?

7. **The way we are asked and answer questions**.. Polio Survivors are notorious for not admitting that we cannot do something. If we are asked 'Can you walk? And we will say 'Yes' when it could be swinging legs through using arm crutches. We ask health Professionals to rephrase their questions to How do you do x?, and Polio Survivors try and answer this way even if you have been asked Can you. Be honest and tell it like it really is, get the help and advice you need as early as possible.

8. **Lastly how you present your information**. You need to consider the length of the appointment and why are you seeing this health professional, and start with the most obvious problem that you now have, then move to the next most obvious. Make other appointments for the rest, don't try and rush through all your problems.

So where do you start……..

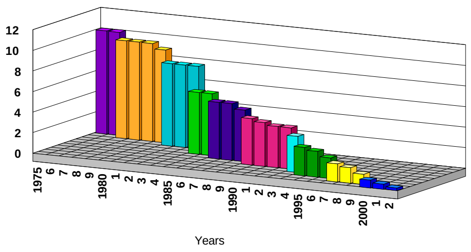
You have been having problems of new pain, weakness, fatigue and functional decline for some time and at last have plucked up courage to go see a doctor. You do not know how he/ she are going to conduct this appointment although you know they are going to want your medical history and symptoms. It is difficult to keep all these facts in your head so you need to write them down. The health professional will most likely have a time plan and pattern for this type of appointment. So much for history taking, so much for examination, tests, recording their comments and giving you some information.

So how much information do you need to record? For your own use, you can record as much information as you like. Make up a ring bound file and include anything you think might be relevant to attending a medical appointment in the future. You can include your life history, family medical history, your medical history, work history, sporting or other achievements, test results, a few photographs, newspaper articles and medical articles. It is not a good idea to go to an appointment armed with huge files and bags of medical articles. Always take someone with you to your appointments to help record what is said, and if you really think it could help put the file in a bag and give it to the person with you in case you need to refer to a date, or test result.

Now put yourself in the position of the health professional you are going to see. What do you think he/she is going to ask you, and write down on your records. You need to look at the type of appointment and time allotted and pick the facts from your file that are relevant and can be discussed during the time allowed. You have your blank file open in front of you, what do you think are the facts that they are going to consider relevant and record? At some time in the future they may need to write a report on your condition, letter of referral, fill out a benefits form, etc. They will only need what is relevant to their specialism. Write/ type this out on a separate sheet double spaced and politely offer them and say 'I have made a few notes so that I don't forget things and have a copy for you if you would like it.'.

What other types of information can you give to them that will quickly show important points. Just a couple of items, again not a bag full. If you have not seen this health professional before he/she will be seeing you as you are now and will have no idea of how you were five/ten/twenty years ago. Maybe you have a couple of photographs showing ability in the past you do not have now, or can make up a chart showing decline in distance walked over the last few years, etc. Chart shows the number of city blocks that Dr. Halstead has been able to walk over the last 27 years.

How a Chart quickly shows decline in walking ability



Progression of Symptoms – City blocks walked 1975 - 2002
Dr. Lauro S. Halstead – November 2002

Decline in functional ability. In most cases decline in functional ability is a slow process and often we do not ‘see’ it, or want to ‘see’ it. We just adapt the way we do the action and that becomes normal for us. However, this might not be ‘normal’ in the mind of the health professional you are seeing and it is important to ensure that the picture in their mind of how you do an action is the same as yours. When asked, ‘Can you get up a flight of stairs?’ It is so easy to say ‘Yes’, and smile and be proud of the fact that you can still do this, albeit on your bottom, backwards and one step at a time. The pertinent facts are, has there been a change in the way you do this action and if so when did this start and what are the changes? You might have always done it that way since polio, or you may have new weakness in an area that is causing you to do the action in a different way. From the list of actions overleaf write out on a separate sheet how you do the action now, and how you used to do it in the past. Then make short notes for the sheets and number them from 1 starting with the action that shows the most change. The action that shows the most change is your starting point. Walking a few steps across a doctor’s office can look fine, but if you can walk 20 paces that look ‘normal’ before your gait changes, your speed declines, and you have to stop and rest, then that is what you need to say and demonstrate if possible.

Try writing a report, letter back to your General Practitioner, letter of referral, to help you keep to important and relevant facts and give you some idea of what you hope the outcome of your appointment will be. It all helps to get the facts clear in your mind. Try and put out of your mind the problems with past appointments. Smile, be polite and ensure the health professional knows that you really do want to see an improvement in your condition and are ready to work with them on a plan to achieve this.

On pages 13 to 15 are 3 Objective Assessment Forms - Neck and Trunk, Shoulder to Wrist and Hip to Ankle - that I have worked on with a Senior Physiotherapist that could be used to assess you. The reasoning behind this is that the physical assessment should take into account the changes in function that you are reporting, that your actions are observed. If is also important that the position you were tested in is recorded so that another person can test you later to see if there is any further decline or even improvement following treatment.

Remember, you need to find out how long the appointment is, you need to be clear in your mind why you are going, what you want out of this appointment, and what are the most important points that you will have time to discuss. Set the scene and say ‘Good morning, Dr. X, thank you for seeing me about my ………..

.

FUNCTIONS TO CONSIDER

Two columns are given. Now and pre present problems. Add extra columns for all or some items if this shows progression of deterioration, e.g. stairs, two at a time, normal, one step at a time, + stop halfway

	Before	**How do you do this action NOW?**
Posture		
Gait		
Walking without aids		
Walking with aids		
Walking carrying items		
Standing without aids		
Standing with aids		
Going up and down stairs		
Using stairs carrying items		
Getting in/out of dining chair		
Getting in/out of arm chair		
Getting in/out of bed		
Turning over in bed		
Getting in/out of car		
Getting up/down from floor		
Working whilst sitting on floor		
Using bath		
Using shower		
Washing hair		
Shopping for food		
Shopping for other items		
Housework - dusting		
Housework - vacuuming		

Changing duvet cover/bed		
Kitchen - stand/sit		
Kitchen - use hands at sink		
Kitchen - hands peeling veg		
Kitchen - beating/cutting		
Using desktop computer		
Using laptop computer		
Clapping action		
General work in workshop		
Sawing, sanding etc.		
Gardening - heavy work		
Gardening - planting/weeding		
Decorating - wallpapering		
Decorating - painting		
Craft -		
Sport -		
Sport -		
Driving in town		
Driving long distances		
Driving - change to auto?		
Other		

OBJECTIVE ASSESSMENT - Date of Assessment …………………………………..
Name …………………………….. D.o.B. ……………… Age ……. Page 1 of 3

Please notate exact starting position for measurements of joints to ensure repeatability, i.e. patient sitting, shoulder in 90 deg. abduction

NECK						**Norm**	**Comment**
	Flexion					c to c	
	Extension					130	
	Left side flexion	**L**				45	
	Right side flexion				**R**		
	Left neck rotation	**L**				80	
	Right neck rotation				**R**		

N.B. C to C - Chin to Chest.

THORACIC SPINE				
	Kyphosis			
	Scoliosis			
	Flexion		70	
	Extension		+25	
	Chest expansion		varies	
	Equal			
	Cough			
	Sneeze			
	Use of abdominals			

LUMBAR SPINE				
	Standing Time			
	Lordosis			
	Flexion		7cm off floor	
	Extension		35 deg	
	Left side flexion		30	
	Right side flexion			
	Left rotation sit/stand		45	
	Right rotation sit/stand			
	Any spasm			
	Imbalance of movement			

Notes.

N.B. REF - rubber end feel BEF - boney end feel.

OBJECTIVE ASSESSMENT - Date of Assessment …………………………………..
Name …………………………….. D.o.B. ………………. Age ……. Page 2 of 3

						Norm	Comment
SHOULDER							
	Long Lever	L				0 - 165	
					R		
	Symmetry						
	Abduction	L				0 - 170	
					R		
	Extension	L				60	
					R		
	Horizontal flexion	L				0 - 140	
					R		
	Horizontal extension	L				0 - 50	
					R		
	Medial rotation	L				70	
					R		
	Lateral rotation	L				100	
					R		
ELBOW							
	Flexion	L				0 - 145	
					R		
	Extension	L				full	
					R		
	Any blocking of movement		none				
	Supination	L				80	
					R		
	Pronation	L				75	
					R		
WRIST							
	Flexion	L				75	
					R		
	Extension	L				75	
					R		
	Ulnar Deviation	L				35	
					R		
	Radial Deviation	L				20	
					R		
	Finger Flexion	L				full	
					R		
	Opposition	L				full	
					R		
	Power Grip	L					
					R		
	Any deformities	L					
					R		
	Any functional problems						

OBJECTIVE ASSESSMENT - Date of Assessment …………………………...
Name ……………………………………….. D.o.B. ………….. Age …….. Page 3 of 3

HIP						**Norm**	**Comment**
	Flexion standing	**L**				120	
	lying	**L**					
	standing				**R**	120	
	lying				**R**		
	Extension	**L**				5 to 20	
					R		
	Any flexion deformity						
	Abduction	**L**				40	
					R		
	Adduction	**L**				25	
					R		
	Medial rotation	**L**				45	
					R		
	Lateral rotation	**L**				45	
					R		
KNEE							
	Flexion	**L**				135	
					R		
	Extension - active and passive	**L**					
					R		
	Any flexion deformity?						
	Any extensor lag?						
ANKLE							
	Dorsi flexion	**L**				15	
					R		
	Plantar flexion	**L**				55	
					R		
	Pronation	**L**				45	
					R		
	Supination	**L**				45	
					R		
	Heel raises - can maintain or repeat	**L**					
					R		
	Ability to push off	**L**					
					R		

Notes.

The following is condensed from a full report to give you some idea of the facts that have now been revealed. NB most of these facts, especially with the upper body, have not been picked up by standard single action Manual Muscle Testing. NB upper body continually recorded as ‘power and tone normal.’

OBJECTIVE ASSESSMENT - Date of assessment—mid 2004.

Name D.o.B. Age

1. Brief Outline of Patients Medical History.

2. Brief Outline of Patients Work History.

3. Patients Physical Ability before current problems

4. Brief outline of the problems patient has had trying to find out what is wrong with them, diagnosis, treatment, employment and benefit issues

5. POSTURE - (Whilst not wearing left leg KAFO and right leg AFO)

6. GAIT .

7. SUMMARY.

    1. Neck movements all limited and need stretching.
    2. Right shoulder medial rotation is limited along with forward flexion.
    3. Supinators and shoulder abductors are very weak and lack sustainability. See if any other ways to modify activities.
    4. Chest expansion is very poor at 2.5cm.
    5. Thoracic/lumbar spine extension severely limited. Needs stretching and possibly mobilising.
    6. Very tight calf muscles especially on the left which affects her balance. Tight hamstrings, left in particular. Bilateral hip flexion contractures/ left, knee contracture possible due to shortened calf muscles.
    7. Ankle movements are restricted due to bilateral tendon transplants as a child, involving tendon transposition to allow some active dorsi flexion. Investigate lower limb braces further.

FUNCTIONAL OBSERVATIONS.

Clapping – hands on knees to clap on knee. After 10 reps shoulder abduction no longer sustainable, elbow flexion sustainability on the left is affected.

Supination activities - i.e. scrambling an egg. Unable to sustain supination beyond 4 – 5 repeats, right worse than left. Elbow rotation reps about 12 – 15. Right worse than left.

Standing at a work surface - Leans propped against work surface, fixates thru her elbows due to reduced sustainability of shoulder abductors. In order to peel a carrot peels away from herself - using wobbly peeler - and pronators due to sustainability problems in supinator, interossei and lumbricals.

Using both hands - has to lean against something to give trunkal stability, and allow short arm lever work due to poor sustainability of shoulder abductors. Arms angled down at 45 degrees – not possible sitting and arms at 90 degrees. Whole free arm movement are not possible. Muscle pain can be a problem if needs to repeat or sustain actions past her normal levels for each action. [e.g. this can be as little as 5 repeats or stand for more than 2 mins.]

Typing – now uses a hand and arm rest at main computer – but much more energy efficient to use laptop on lap on reclined chair with arms resting on chair arms. Left hand rests on front of laptop allowing fingers to be rested in optimum functional position to allow maximal use of finger extensor power available. Left arm is weaker, fixates thru elbows and shoulders.

Reaching forwards – can manage 3 reps before fatigue or muscle pain.

Hip and pelvic stability – has noted reduced significantly since diagnosis in Dec 1997.

Driving - Used to be advanced police driver using manual transmission. Unable to lift leg into car uses hand to lift. Unable to lift left leg onto clutch now has to drive automatic. Left leg was left the weakest following polio.

Getting out of a chair – Has to get to the very edge of the chair, moves weight fully forwards. Uses her hands to walk herself up to 90 degrees plus ad then uses her back extensors.

Getting out of a low car – lifts her legs out of the car, puts arms against the side of the car and 'jumps' arms up. Legs need to be at 90 degrees flexion before she is efficiently able to sit to stand.

Getting up from the floor – V shaped closing action. This is a method used since first contracting polio, but is now becoming harder to perform. Uses hamstrings and back extensors to achieve this manoeuvre rather than quadriceps.

Housekeeping – Vacuuming, dusting, ironing, washing up, hand washing, soon fatigues as involve shoulder abduction and forearm supination. Soon fatigues, for her is e.g. ironing only two items, vacuuming quarter of average sized lounge.

Patient also reports the following symptoms [headings only]

- Fasciculations and peripheral neuropathy—**improved by getting legs up in recliner chair at every opportunity.**
- Weakness of eye movement muscles—turns head instead of moving eyes.
- Swallowing difficulties on occasion—needs further testing.
- Voice get hoarse after speaking for some time, has lowered in depth.
- Breathing – shallow and upper chest, needs investigation
- Sleep – snores badly, has to wake to higher level of consciousness to turn over causing disturbed sleep.

Questions about Creatine Kinase

By Gladys Swensrud, Polio Survivor, San Diego

Polio survivors were often left with visible, physical deficits to which they adjusted. And in spite of inconveniences created along the way by these physical shortcomings, they continue to live long, full, productive lives. It is the late effects of polio, the often-invisible deficits created by old polio, which is a conundrum today for both the medical community and those experiencing Post Polio Syndrome.

As I read and learn more and more about the difficulties associated with Post Polio Syndrome, I often wish there was easily attainable, in-depth information available on some topics I find of interest. It is more likely I will stumble upon information by chance, kind of like a treasure hunt that has serious implications if I don't find the hidden treasure. And often, when I figure out the *right* questions to ask, a few *kind* doctors will fill in some of the blanks (thanks docs!) to form a more complete picture in my mind's eye. And so it was with my interest in Creatine Kinase (CK) levels and how those levels affect my particular case of PPS.

Although I had probably seen the term dozens of times in the last few years, I first became truly aware of the usage of "CK level" while reading Postpolio Syndrome, by Dr. Julie K. Silver and Dr. Anne Gawne, in 2004. Of the eight references to Creatine Kinase in their book, confusion still abounded in my mind about how exactly it could be applied to Post Polio Syndrome. References ran the gamut from - the connection should be further studied - to the significance of some findings was unknown. But the twists and turns of CK kept swirling in my mind as I came across more and more information relating to Creatine Kinase levels in connection with Post Polio Syndrome and other neuro-muscular disorders and diseases.

I began this particular quest by first searching for a clear and concise definition of *Creatine Kinase*. I found the web an extremely valuable source of information, and in an article within the Dr. Joseph F. Smith Medical Library on the topic of "Creatine Kinase Testing," I found the basis from which to begin my exploration of this subject. In my reading, I (at the very basic level) learned that, "Creatine Kinase (CK or CPK) is an enzyme (a type of protein), which is found in muscle and brain. Normally, very little CK is found circulating in the blood. Elevated levels indicate damage to either muscle or brain – possibly from a heart attack, **muscle disease** or stroke. *There are three types, or isoforms, of CK:*

- CK-I, or BB, is produced primarily by brain and smooth muscle.
- CK-II, or MB, is produced primarily by heart muscle.
- CK-III, or MM, is produced primarily by skeletal muscle."

A logical next step to understanding this mystery was to determine what is considered a "normal" CK level. And it was at this point I began to realize exactly why there aren't more definitive answers about CK and its use as a diagnostic tool! Analysis of CK levels is based on several factors; it is very individual to each person, so to make generalizations is difficult. In my research on problems associated with old polio in particular and reading CK levels to understand them, I found conflicting information such as: …*findings suggest that muscle overuse is either not important or inadequately measured by CK,* **or** *these findings support the hypothesis that chronic muscle overuse may be a contributing factor…in* *neuromuscular compromise*.

Another challenge is the fact that analyzing how CK levels are read is also dependent upon how the lab, analyzing the results, reads the test. From what I was able to discern, gender, age, race, and activity level all play a part in determining normal CK levels. Needless to say, there are no "norms", but taking the above into consideration, the following information is what I found to be a general rule of thumb: *In females, total CK should be 10-70 units per liter (U/L) with the midrange around 59 units per liter, and in males, total CK should be 17-148 U/L, with mid-range around 79 units per liter.*

With my curiosity piqued, in August 2004, I first approached my family practice doctor about testing my Creatine Kinase level. My plan was to test my level at various stages of activities of daily living and then see how adding a low impact exercise regimen to that would affect my personal, muscle situation. My objective was two-fold: 1) I wanted to know if my Creatine Kinase level rises when I get the flu-like symptoms I seem to experience with fatigue, late in the day, or sometimes with seemingly simple physical exertion, like shopping or standing too long in line at the store, and 2) If my CK level doesn't rise any further than **my** "normal," would it be possible for me to engage in a modified exercise program without doing further muscle irritation or damage? I felt I could stand the additional muscle pain that accompanied more exercise if it wasn't causing further harm to my muscles. Dr. Lamantia, my wonderful family practice physician, agreed this project had merit in my case, so we set a plan in motion that would, as it turned out, cover the better part of 6 months.

My first test was completed in September 2004, following right-hand, carpal tunnel surgery. Since my right hand is my dominant hand, I thought testing at a time when I was doing absolutely nothing might be a good baseline against which to compare future tests. However, as my doctor later explained, doing *nothing*, when your degree of activity usually includes doing *something*, can influence the test findings as well. She said a rise in CK might not be unusual at this particular time since being sedentary often leads to a mildly elevated CK level. Keeping that in mind, when my first test results were returned, my CK level was **162 U/L**. It was definitely higher than the female norm of 59 U/L, but as I soon also learned, a mildly elevated CK (in the grand scope of things 162 U/L is considered *mildly elevated*) is also consistent with post-polio. So, another twist presented itself!

As a natural part of the learning process, several questions followed my first CK test results, which were reported as a *CK total*. Since there are three types of CK, I was puzzled about how the test is read as a *total*. My questions were as follows:

- Wouldn't it have been more effective to know the breakdown between CK-1, CK-II and CK-III instead of just reporting the *total* back to me?
- Since an elevation of CK-III indicates skeletal muscle damage, wouldn't this be the information I am really seeking?
- As I learned, CK-III normally makes up the vast majority (~95%) of CK in the blood; so, unless one has reason to suspect that he/she has recently had a heart attack or stroke, it's reasonably safe to assume that an elevated CK consists mainly of CK-III.

Based on that information, knowing that my brain and heart were not of concern, I realized an understanding of CK III level was the only one still needing clarification to bring straightforward answers to my confusion and focus to my investigation.

The next CK was rechecked just as I returned to a normal, *quiet* routine in November 2004, and my level was recorded at **153 U/L**. I had been approved to return to normal activities, but my hand was tender, so I was still babying it, and my always rather quiet activities were still modified. Since this was lower than my first test, I could see that my doctor was probably right on target about your CK being elevated with inactivity, but it appeared as though this range might be "normal CK" in my case since the two totals were fairly similar.

Based on these findings, I speculated: 1) My normal CK level is possibly around 150 U/L. 2) Might it be possible to add some type of low impact exercise without raising my CK level? and 3) Could I figure out a correlation between my CK levels and my degree of discomfort as I pursued some type of exercise plan? So I set out to devise a program that might answer some of these questions with test #3.

I have felt, based on my change in pain level, there must be a measurable way of gauging the discomfort that mounts during my day. When I get to the end of my day, usually from just "normal" activities, like stopping by school to turn in a project I worked on at home, a trip to Costco to drop off film or a stop at Wal-Mart to buy material, by late afternoon I often feel ill; you can't pinpoint the source. It is like my body is at the muscle-ache stage of having the flu - in my case my muscles feel tight, which from 4 years of experience I know is pain registering in an odd way. When I get to that degree of discomfort, I know I am at the stopping point and past the mid-line of what daily activities are acceptable for me.

Under the watchful eye of Dr. Lamantia, at the beginning of the year I added a Parkinson's disease exercise class that is given at the YMCA under the direction of specially trained Parkinson's instructors. I wanted to know: If I worked my muscles doing minimal exercise, how would 1 hour of very low impact exercises, meant for another group of neuro-muscular patients, 2 days a week (on Monday and Friday), affect my CK level? How could I, as a PPS patient, fit into that group?

I knew from the start, each day I attended the class, I was probably in muscle trouble. I felt muscle pain and flu-like symptoms by late afternoon, and I pinned down the fact that it was uncomfortable sleeping each night I exercised with this group, so the effects of pain continued to climb 18 or more hours after the class. Anytime I have a particularly difficult day, I often awaken a few times during the night with painfully tight muscles in spite of my regular dose of Neurontin at bedtime. To explain it further, it is like I just can’t get comfortable, no matter how hard I try to relax. I, sadly, realized nights were always painful on the days I took my exercise class.

The results of working my muscles on the minor exercise days were sobering. My doctor ran a CK test again in March 2005, and my results showed that on the day the blood sample was drawn, my CK level had risen from **153U/L** to nearly double that, **299U/L**. I timed the scheduling of the blood test to reflect how I felt physically that day; I waited until the flu-like feeling began, so at that moment, I could actually feel the muscle changes. And based on the change in my CK level from the 150 U/L range to the 300 U/L range, I knew my latest formal exercise plan wasn't going to work. It was painfully evident continuing with this program was counter productive to what I had hoped to accomplish, and it could, in fact, be detrimental to my overall, muscle health. But the results were important to know because I *think* I now have bounds to proceed with activities which might be acceptable for me, and to understand a little better those which are not.

The biggest advantage from this self-study is: I believe I can now tell when my CK rises, and I now have an idea of when I am within the 300 range just doing everyday tasks. Obviously the objective for me, since I am experiencing the symptoms of PPS, might be to keep my CK level as low as possible. Since I feel ill when my CK level is high, I believe I now have a guide with which to track myself. Whether or not I will be able to follow my own instructions is another issue all together. As I have learned from my research, you don't feel the ill effects for hours and possibly days after you have overdone. That is a stumbling block for certain...at least for me! And since I don't like to fill my day just sitting and crocheting, it can potentially be a problem for me from this point forward, just as it has been in the past.

Do I pay for overdoing? **Yes!** Is it like the average polio survivor pays for overdoing? Maybe. Some people with PPS experience pain, and others do not. Is the pain related to a rise in CK level? In my case, I believe it is. When I hurt is actual muscle damage being done? I can only surmise the answer to that question is yes.

As a wise doctor recently told me, "even healthy people show an increase in blood CK levels after exercise.......can easily rise to 300 or more.” However, he added, “ ...even if their CK goes up as high as yours.......maybe you (and I) can 'afford' it less.......” I would venture a guess that since normal exercise doesn't make the average person feel physically ill, as it does me, the damage (or perhaps the degree of inflammation being caused) is greater for me than it would be for her/him.

In the process of looking for answers, I really just created an entire new realm of unanswerable questions. Does the feeling of pain or flu-like symptoms mean I am just feeling the effects of inflammation or, in time, will it translate to real muscle loss? On a normal day at a CK of 150(+)U/L, am I taxing my muscles at 2½ times that of the normal woman with a CK of around 59U/L? Would it be useful to do a study of CK levels from a PPS group experiencing symptoms - side by side with those who had polio but are *not* experiencing PPS symptoms - and that of a control group within the same age category who did *not have polio*? **Would all PPS patients benefit from having their CK tested?** Like everyone else with PPS, I am caught in the crosshairs of that discussion, but judging by my recent experience, I would have to say, “Yes!”

To take this idea a step further, should I then logically ask the questions:

- For polio survivors <u>not</u> experiencing pain, could they be unknowingly doing muscle damage each and every day?
- **And**, could testing CK levels on a regular basis, perhaps every 6 months, reveal whether or not damage was occurring?
- If routine CK levels could be used to trace muscle damage, then is it possible that the presence or absence of pain could be referenced as a reliable means of setting our activity levels?

I am, as my family practice doctor will attest, always on the lookout for a “plan” that works for me! Although this experience has taught me I can't join an organized exercise program, I intend to keep searching until I find an exercise *plan* that complements my situation. There is a balance between doing too much and doing too little; striking that balance is important for overall fitness and improved quality of life.

I realize that results from a one-person study can't be generalized for the entire PPS population, but I am convinced knowing one's CK level could be important for polio survivors whether or not they are experiencing PPS symptoms. If a person with PPS knows their CK level, they may have tangible proof of how to measure what they can do...and what they can't do. It is one thing for someone to *tell you*, "If you use it, you'll lose it!" But if you can visibly see the implications of overuse and muscle abuse in solid numbers, it is another level of understanding altogether.

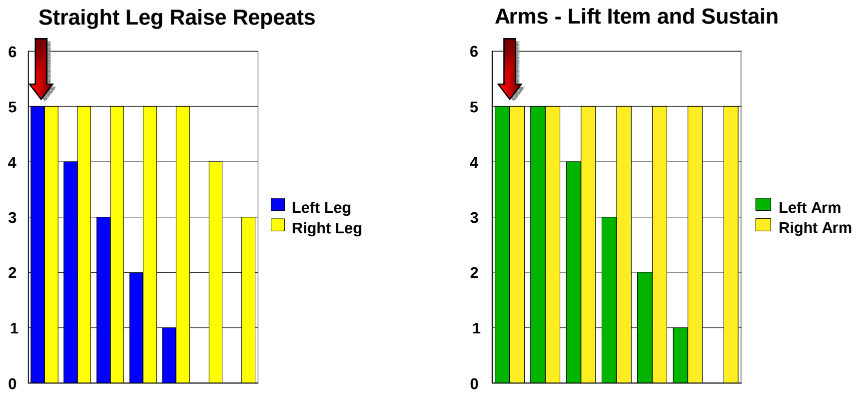
*****SPECIAL NOTE*****

One final comment to the Creatine Kinase puzzle came at the suggestion of a wise doctor from whom I sought advice about my interest in CK related issues. He pointed out that it should be noted "…people with (or at risk for) PPS should be especially careful when taking drugs which are known to have the side-effect of damaging skeletal muscle -- for example, the 'statin' drugs." He felt strongly that anyone with PPS who is on a statin should have their CK monitored on a regular basis.

Please contact me with any comments or observations. We learn so much more by sharing information. If you are not on the Internet then please send me a letter via the Lincolnshire Post Polio Network main address.

Gladys Swensrud, email… swensrud@pacbell.net

Slide from PHI Conference—See page 7, item 2. When Manual Muscle Testing is done a single time or less repeats or length of sustaining action than where you are reporting weakness then it will NOT corroborate what you are saying. For instance if you are told that your right arm is strong [Chart on right] and you are able to lift a jug of iced water for four seconds but not sustain that or pour the water out without bringing your elbow into your side and using your other arm to support the left, then you need to ask to demonstrate this.



N.B. My reported functional decline was not corroborated by single action Manual Muscle Testing.

☺

Waiting for an elevator at our hospital, I stood next to a maintenance man holding a bicycle pump. Noticing my curious stares, he looked at me and remarked with a grin, "It's the new Medicare oxygen program.".

A woman was taking her time browsing through everything at a neighbor's large yard sale, and said to her, "My husband is going to be very angry I stopped at a yard sale."

"I'm sure Charley will understand when you tell him about all the bargains you found," her friend replied.

"Normally, yes," she said. "But he just broke his leg brace, and he's waiting for me to take it to the brace shop to have it fixed.

"Wong Mee and his wife, Virginia, were married for 50 years, but finally health problems got the best of them,
Wong Mee in particular. He suffered from Alzheimer's and the polio he'd had in his youth that left his legs in a crippled condition seemed to be making him even weaker.

One day he wandered from home, and his wife was very worried. When the police found him, he was only three blocks from home, but lost, confused, and unable to walk.

They had to 'carry Mee back to old Virginny.'

If there's a competition for Worst Waiter of the Year I've got a good candidate. He was working at my aunt's favorite restaurant when we took her there for her 60th birthday.

It started right away. We asked him to seat us where my nephew's electric wheelchair would easily fit. The waiter then marched off to a booth in the rear. Even he had to turn sideways to get between some of the already seated patrons at the over-packed tables.

Finally we got seated and then this guy messed up every order! She asked for pork. He brought beef. We requested beans. We got corn. And so on.

At the end of our meal, he asked, "Would anyone like dessert?"

We had a good laugh when my aunt answers, "What do I have to order to get a piece of cheesecake?"

"I must be getting old. I'm starting to talk to myself."
"We all do, Ralph."
"Well, I find it annoying."
"Why?"
"Because I'm also losing my hearing and I have to repeat everything."

What is the laziest part of a powerchair?
The wheels - they're always tired.

When the guy who bowled from a wheelchair was filmed for an ad,
he became a roll model.

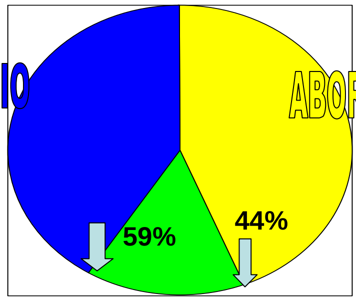
There aren't nearly enough crutches in the world for all the lame excuses why your homework's not done!

The spinal column is a long bunch of bones. The head sits on the top, and you sit on the bottom.

Crip Humor
By and For the Severely Euphemized
Please submit jokes about and for
PWDs [People with Disabilities]
eMail marsha1945@sbcglobal.net

3 - A diagnosis was made after virus test +polio and clinical observation of the weakest part of the body

Bodian D and Sharrard WJW found levels of nerve damage on autopsy
and compared them with the results of the physical examinations before death



Paralysis was clinically evident from 60% nerve damage

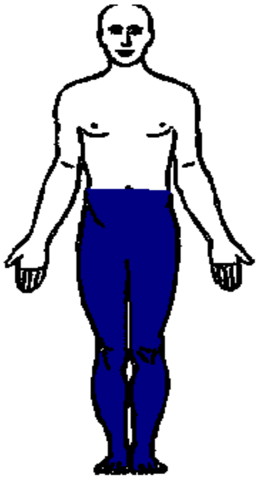
Found no clinical weakness evident below 44% nerve damage

Weakness became clinically evident at 45% nerve damage

KEY OMMISIONS

How much nerve damage occurred in the Upper Body?

Was the bulbar area affected to any degree?



95% of the body was affected.

A diagnosis might be given as follows:

Upper body
No medically recorded weakness
Diagnosis not given

Lower body
Waist down paralysis
60% plus nerve damage.
Diagnosis: Paralytic Polio

4 - Extent of recovery from Polio is often not recognised

This patient presents herself at your office In 2003

Would you expect her to produce this photograph of herself taken in 1995?