



The LincPIN

The **L**incolnshire **P**ost-Polio **I**nformation **N**ewsletter
Volume 5 - Issue 2 — February 2005

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Issue Number 50

February 14th

8th Anniversary of our Website

April 12th 2005

50th Anniversary of the announcement 'the Salk Polio Vaccine is safe and effective'

June 2nd to 4th, 2005 - St. Louis, Missouri Ninth International Conference on Post-Polio Health and Ventilator-Assisted Living: Strategies for Living Well

See Back Page



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Lincolnshire Post-Polio Network - UK Registered Charity No. 1064177

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

Ewan Peddie	Jenny Rayner	Sylvia Fortune	M Guild
M Horton	J Shaw	R Candy	S Dunnett
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Please make cheques payable to 'Lincolnshire Post-Polio Network'

Post to Membership Sec, 78 Heron Road, Larkfield, Aylesford, Kent ME20 6JZ, UK

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Next LincPIN Newsletter - April 2005

Articles for publication 15th March by post or - newsletter@lincolnshirepostpolio.org.uk

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Editorial

This is Issue Number 50 and I have to thank our member the 'One Arm Bandit' in Texas, Ellen Riddle for her hard work in helping put this issue together. In essence, she did all the research and provided me with the information and I have just set it up. Delay in your receiving this is due to the Printer being on holiday till mid February.

Polio Survivors around the world share information and personal experiences. Time and again it is these experiences that trigger another to take extra information to their health professionals and get answers for themselves. This is one of those times for us. Richard has just had some unexpected and unwelcome reactions to recent drug changes. With all the work I have done, all the advice searched for and offered in our newsletters and 'we' did not ask enough questions or ensure that information provided earlier had been remembered. Coping with all this has been exhausting.

There are times when we have to take drugs to manage our health. It is imperative that we discuss the drugs with our health professionals.

- * What is this new drug called?
- * Which symptom are you giving me this drug for and what response are you hoping for?
- * Are there any side effects I should be aware of?
- * How long will I have to take this drug?
- * Will it interact with the other drugs I am taking?
- * Have you remembered that I am allergic/intolerant to x?
- * Have you given this drug to other polio survivors?
- * Are you aware that polio survivors often tolerate much lower doses?
- * How much is the drug?

Richard was given a new drug from sample packs—take one now. When the side effects

started and we took out the drug package, and this really surprised us, is that the information normally contained with your prescription was not printed on/or included in the sample pack. Thank goodness for the Internet where we could read up the full report from the Drug Company regarding the drug and possible side effects etc.

Remember if there is information that you need to give a doctor/pharmacist regarding your allergies/intolerances etc., carry copies with you when you leave your house. Keep a few copies of a card showing the prescriptions you are currently taking, the dosages, timings and what for—in your wallet/purse, in your car, in a bottle marked with large Red Cross in your fridge. Use a magnet and make a card for the fridge door.

As we have members in different countries a little bit of information on cost only.... Basically, in the UK the charge for each item is £6.40 (about \$11 US.) In the USA I have seen prescription charges from \$11 for 90 tablets to \$650 for 60 tablets.

Ninth International Conference on Post Polio Health and Ventilator Assisted Living:

Mary, Denise and myself had our presentation **How Self Assessment can help you provide better information for Health Professionals** accepted and we will be doing this on Friday 3rd June at 3.15 p.m. More info on the back page, in the next LincPIN or at

www.post-polio.org/conf9th/prog.html

If you are not on the Net and would like information on attending the Conference now then send us a s.a.e.

I am now going to hand you over to Ellen to tell you all about how and why this Issue was put together.

(Continued on page 8)

Message from the Chair

Hello Readers,

Welcome to Edition no 50, which coincides with the 50th anniversary of the announcement of the Salk Polio Vaccine being 'safe and effective'. Ellen Riddle has donated her time and energy this month in assisting us with the newsletter and you can read her contributions from page 8. We extend our thanks for her time and energy. We also acknowledge that it has been a particularly difficult month for Hilary and her partner Richard, and thank Hilary for setting up this edition.

We also wish to extend our condolences to the family and friends of member Eileen Bunclark, of Rotherham, Yorkshire, who passed on recently.

Later this year, the Manchester Polio Group (a branch of the British Polio Fellowship) are hosting a conference on August 22nd for which we are happy to provide contact information. Although already there is pressure on capacity as the venue is not huge, registration will be accepted on a "first come first serve" registration basis: If you are interested in attending, or would like more information to help you to decide whether to attend, please write to:

Eric Cook,
107 Ashton Road East, Failsworth, Manchester M35 9PP, U.K.
(enclosing an S.A.E)
or call Eric Cook on: 0161 682 5847 or
Guido D'Isidoro on: 0161 881 1248

The conference is titled "North West Post-Polio Syndrome Conference", Monday 22nd August 2005, to be hosted at Tameside College, Ashton under Lyne, Manchester. This venue is small and non-residential but it is accessible and has its own car park, with parking for wheelchair users. There will be a charge of £15 a head, which will include lunch and all refreshments.

The Manchester Polio Group is a friendly and organised group who meet at an accessible venue every month in Manchester. They have invited two consultants to attend as speakers – Consultant Dr Carolyn Young, MD, FRCP, Neurologist at the Walton Centre for Neurology and Neurosurgery, Liverpool; and Consultant Dr Peter Mohr, Neurologist, Hope Hospital, Salford, Manchester.

That's all the news for this edition – We wish all our members and friends good health and continue to encourage you to write, phone or e-mail us with your views. All contact information on inside front cover.

Best wishes, Mary Kinane, Chair.

Freedom of Information Act - Your right to know

By Di Newman, Committee Member

The right under the Freedom of Information (FOI) Act and the Environmental Information Regulations (EIR) to request information held by public authorities, known as the 'right to know' came into effect on 1 January 2005, where you can ask for access to information held by all public authorities e.g. * central government and government departments e.g. * House of Commons and House of Lords * local authorities * hospitals, doctors' surgeries, dentists, pharmacists and opticians * state schools, colleges, and universities * police forces and prison services.

The Act and the EIR allows access to recorded information (such as emails, meeting minutes, research or reports) held by public authorities in England, Northern Ireland and Wales. This Act will give us all greater access to information e.g. about how decisions are taken in government and how public services are developed and delivered. **The FOI Act** operates alongside the Data Protection Act; which allows people to access information about themselves (e.g. personnel records, or information held by credit reference agencies) and ERI, which give people access to information about the environment.

Requests for information must be made in writing (e.g. letter, fax, e-mail), stating the information you are requesting and supply your full name and address. You do not need to state why you want the information. You can ask to have any recorded information. This could be in the form of e-mails, notebooks, videos or tapes. A response, in any event, must be received within 20 days, or an explanation as to why it cannot, and inform you when you can receive a reply. Should your request be declined - you must be provided with a reason. You can ask for it to be reconsidered and if necessary ask the Information Commissioner's Office (ICO), which is an independent body that enforces the FOI Act, and Data Protection Act, and the EIR, for a review. The ICO ensures the information is disclosed promptly and exemptions from enclosed applied lawfully, and in cases where excessive delays, refusals and disputes apply. There are 23 exemptions in the Act, some of which are 'absolute' and some 'qualified' (information relating to national security). A lot of information may be supplied free of charge. However, where any fee applies, you will be notified in advanced.

National Archives: The provisions under the Public Records Act - under which public records are closed until they are 30 years old - these are now available, as the so-called '30 yr. rule' has now disappeared. To mark full implementation of the Freedom of Information Act, over 50,000 files that are less than 30 years old have been released at the National Archives. This batch of releases, cover a range of topics - from The Ministry of Defence, Metropolitan Police and topics from - "research at Porton Down to arranged marriages." Many, medical research, health and medical related matters including DSS benefits etc will be now available. Even thirty files on UFOs!

For further information and links:

Guidance on Freedom of Information: www.foi.gov.uk

Complaints, Resolution, Information Commissioner's Helpline 01625 545 545

www.informationcommissioner.gov.uk

The National Archives: www.nationalarchives.gov.uk

List of public authorities covered by FOI Act:

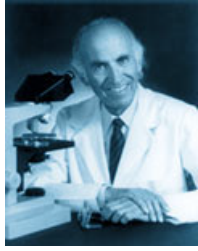
Department for Constitutional Affairs - (Justice, rights and democracy):

Information Rights Division, Selbourne House, 54 Victoria Street, London SW1E 6QW

www.dca.gov.uk/foi/coverage.htm

For list of government A-Z of local councils and central government:

www.direct.gov.uk



April 12th 1955—Announcement,

‘The Salk Polio Vaccine is Safe and Effective.’

**I feel that the greatest reward for success is the opportunity to do more.
Jonas Salk.**

When Dr. Jonas Salk envisioned the idea of the Salk Institute for Biological Studies, it was with the idea of creating a vibrant, intellectual community, dedicated to pursuing the kinds of scientific achievements that had made him an international figure only five years before.

Salk came to La Jolla following a career in clinical medicine and virology research. After obtaining his M.D. degree at the New York University School of Medicine in 1939, he was a staff physician at Mount Sinai Hospital in New York City.

He then joined his mentor, Dr. Thomas Francis, as a research fellow at the University of Michigan. There, he worked to develop an influenza vaccine at the behest of the U.S. Army. In 1947, he was appointed director of the Virus Research Laboratory at the University of Pittsburgh School of Medicine.

It was in Pittsburgh that Salk began to put together the techniques that would lead to his polio vaccine. He was already struck by the principle of vaccination: that if the body is artificially exposed to a harmless form of a disease virus, the body will produce antibodies that resist or kill the dangerous form of the virus if later exposed. In contrast to the Pasteurian dogma of the times, Salk believed that protective immunity could be induced without infection by a living virus such as those used in the vaccines against smallpox and rabies. In developing the influenza vaccine, he had observed that protection could be established using non-infectious, inactivated (killed) viruses.

Salk's research caught the attention of Basil O'Connor, president of the National Foundation for Infantile Paralysis (now known as the March of Dimes Birth Defects Foundation). The organization decided to fund Salk's efforts to develop a killed virus vaccine against the most frightening scourge of the time: paralytic poliomyelitis.

Using formaldehyde, Salk killed the poliovirus, but kept it intact enough to trigger the necessary immune response. His work was enabled by a key achievement made by Harvard researcher John Enders. Enders and his team had figured out how to grow poliovirus in test tubes. This step was necessary to obtain the quantities of pure virus needed to develop and manufacture a vaccine.

The resulting injectable vaccine was tested first in monkeys and then in patients at the D.T. Watson Home for Crippled Children (now The Watson Institute), who already had polio.

Next, vaccine was given to volunteers who had not had polio, including Salk, his laboratory staff, his wife and their children. The volunteers developed anti-polio antibodies and none had bad reactions to the vaccine. Finally, in 1954, national testing began on one million children, ages six to nine, who became known as the Polio Pioneers: half received the vaccine, and half received a placebo. One-third of the children, who lived in areas where vaccine was not available, were observed to evaluate the background level of polio in this

age group. **On April 12, 1955**, the results were announced: the vaccine was safe and effective. In the two years before vaccine was widely available, the average number of polio cases in the U.S. was more than 45,000. By 1962, that number had dropped to 910. Salk never patented the vaccine, nor did he earn any money from his discovery, preferring to see it distributed as widely as possible.

Given the fear and anxiety that polio caused during the first half of the century, the vaccine's success in 1955 made Salk an international hero, and he spent the late 1950s refining the vaccine and establishing the scientific principles behind it. By 1960, however, Salk was ready to move on. Salk's dream was to create an independent research center where a community of scholars interested in different aspects of biology—the study of life—could come together to follow their curiosity.

For more than a year, Salk toured the country in search of the right location for his research center. Finally, wooed by San Diego Mayor Charles Dail, who had had polio, he was drawn to 27 acres on a mesa in La Jolla, just west of the proposed site for the new University of California campus then planned for San Diego. With a gift of the land from the citizens of San Diego and with initial financial support from the National Foundation/March of Dimes, Salk was able to proceed. To bring his concept of free-flowing labs and quiet studies to life, Salk recruited architect Louis Kahn. The resulting collaboration is a series of elegant concrete structures that overlook the Pacific Ocean.

Under Salk's direction, the Institute began research activities in 1963 and gradually expanded its faculty and the areas of their research interests. Salk's personal research activities included multiple sclerosis and autoimmune diseases, cancer immunology, improved manufacture and standardization of killed poliovirus vaccine, and the development of an AIDS vaccine. He published several philosophical books and advocated cooperative rather than confrontational approaches to addressing human needs.

Completed in 1967, the original Institute buildings were declared an historic landmark in 1991. During Salk's tenure as Founding Director, a major building addition consistent with his and Louis Kahn's original architectural vision was designed and constructed. The Institute now has 56 faculty members and a scientific staff of more than 850, with labs that house research on everything from cancer, diabetes and birth defects to Alzheimer's disease, Parkinson's disease, AIDS and plant biology.

The Salk Institute truly reflects the broad, humanistic interests of its namesake.

Salk died at age 80 on June 23, 1995. A memorial at the Institute with a statement from Salk captures his vision: "Hope lies in dreams, in imagination and in the courage of those who dare to make dreams into reality."

Learn more....

<http://www.salk.edu/jonassalk/>

Jonas Salk's Legacy: The History of Jonas Salk, the Polio Vaccine and the Salk Institute.

This program is available online courtesy of UCSD-TV and is viewable in Streaming RealPlayer

© The Salk Institute.

(Continued from page 3)

*“Be good to yourself. If you don’t take care of your body, where will you live?”
Kobi Yamada*

A couple years ago I received this quote on a post card in the mail from a friend of mine. She is one of those people who have not only seen me go from very active to less active, from walking and hiking to wheeling around but has also taken the time to learn about PPS and has been walking beside me on this journey. On the flip side of the post card she wrote that she had picked the card up some years before just on a whim and had it in her stationary drawer. On this particular day she saw it, thought of me and sent it off.

It now hangs on the inside of my medicine cabinet where I see it throughout the day. Not that I always look. But I believe its being there is a helpful reminder. I simply must continue learning how to take care of my body. Something that until PPS came along I not only never thought about but I didn’t really do despite my exercising, dieting, jogging and push-ups because until PPS garnered my attention I never listened to my body’s complaints about my over zealous beating up on my body in the name of ‘good health’.

When Hilary called me to brainstorm about ideas for this month’s newsletter I had been looking at the post card at least once a day and asking myself if I was honestly taking care of my body or was I sort of hedging the corners, making exceptions and falling back into turning a deaf ear to its cries for proper attention? Hence we found the theme for this month’s newsletter.

It just happens that this corresponds with the 50th issue of the newsletter, and the 50th anniversary of the announcement on the Salk Polio vaccine. What better way to celebrate both of these 50’s than by going back to past issues of the LincPIN and pulling up “bits and tips” from some of the many articles published since the first newsletter printed in September of 1996? What follows are ‘bits and tips’ from articles that I thought would be of interest to read — reread if you have been a member that long. The complete articles can be found on our Website or if you would like to order back copies of newsletters please contact Robin Butler. [See Page 2]. Volume 2 bits in next newsletter.

Let’s kick off 2005 with a renewed determination to continue learning about PPS, how it affects us and those we love, and what we can do to once again go beyond just ‘surviving’ but enjoying life to the full within our limits. After all, it’s your body, take care of it, if you don’t, where will you live?

I’ve just finished the 50 “bits and tips” from Volumes 1 and 2 of the newsletter. I sit back with a few feelings that I wish to share with you. One is amazement that so much of what was printed between the fall of 1996 to the fall of 2000 is still very relevant today. Yes, there are some articles that when I scanned I realized that with more study and information the ideas have been improved, tweaked and maybe even changed, but over all there is a lot of really good stuff lurking in these past issues.

Another, is that I was struck by how many PPS-ers who are members of Lincolnshire Post-Polio Network from around world were making contributions back then. Sadly, I read a few from those who have ended this part of their life journey and felt the sharp pangs of realizing just how missed they are. But, there are many still here and many new folks who weren't members back then. I would like to encourage everyone to take a few moments as you go through the riches found in this newsletter and note that while some are from the professionals doing much to help us along, many items are from every day survivors; other PPS-ers just like you and me. I encourage you to sit back and think of what you might be able to contribute. Be it experiences, your polio/pps story, things that you've found that make your day to day living easier and more 'body friendly'. Maybe it's a good or a not so good experience with a doctor or clinic and how you handled it.

Yes, it takes time and energy to contribute. Actually doing it can be as simple as forwarding a copy of an email you sent to one of the pps groups you are active with to Hilary to include. Not to worry about writing the 'perfect piece' any more than you do when you help others by sharing via email/letter/phone. Share your successes and your problems; your questions and fears along with your answers and hopes.

If more of us jump in and share then when we reach the point of celebrating 100 issues there will once again be so much to choose from that whom ever is doing the 'bits and tips' will find themselves sitting back in amazement at the wealth of information as I have done this time.

Finally, I have a confession to make. I caught myself up short as I went through the newsletters. It was difficult to remain really objective and select "tips and bits" that I felt would be of interest to everyone. I think over all I succeeded until I reached an issue that mainly dealt with calipers and bracing. I didn't at first include any of these articles. Then as I was falling asleep that night I sat up and asked myself 'why?' The reason is simple. I'm an upside down polio. I have never had braces of any kind. But more than that, in the pit of my being it is something I deeply fear. That even though I've gone to using a power chair more and more in hopes of conserving and keeping my legs at the strength they now are I don't really have any guarantees that I won't find myself needing a brace. This is something I have really avoided even pondering by simply skipping over such discussions on the lists as well as articles about them in newsletters since they 'don't pertain to me and I have nothing to contribute anyway'.

The next morning I got up, went to the computer and pulled up those issues. You will find a couple "bits and tips" on braces in the next issue. I wish I could say that doing this, really reading these articles, calmed my inner fears. It didn't, but that is ok. At least I have admitted to the fear and will continue to hope that it doesn't happen to me as I say the words we all say when faced with a PPS related fear, "we are all different." At the same time I will be listening even more to my legs and taking the best care of them as I can, even if some day this means looking into the possibility of a brace. Now, all of you right side up polios, my hope is that you do the same with your arms. Just as I can lose ability in my legs you can lose ability in your arms if you don't hear their whisper cries for care.

Member Ellen Riddle, the One Armed Texan Bandit.
moonshadow@lonellen.com
With an upside down view...

Basic PPS - Vol 1, Issue 1, September 1996

POST POLIO SEQUELAE - True Answers for Friends and Family. R. L. Bruno PhD What are the treatments for PPS?

Polio Survivors basically need to conserve energy to stop blowing their bodies 'fuses'. Polio survivors must walk less, use needed assistive devices (a brace, crutches, a scooter), stop working before symptoms come on, and plan rest periods throughout the day.

Are treatments for PPS effective?

Yes. The worst case is that patients who stop the overuse abuse will have their PPS symptoms plateau. However, when survivors start taking care of themselves, the overwhelming majority have noticeable decreases in fatigue, weakness and pain.

Isn't exercise the only way to strengthen weakened muscles?

No. Since PPS symptoms result from too many 'appliances' being plugged into an overloaded nervous system, muscle strengthening exercise would be like plugging in a dozen additional toasters. While stretching exercise can be helpful, pumping iron and 'feeling the burn' means that polio damaged neurons are burning out. Also, polio survivors typically can't exercise the way others do to condition their hearts and try to prevent osteoporosis.

Energy Conservation - Vol 1, Issue 2, November 1996

BOUNCING BACK WITHOUT GUILT - Wendy Clyne PsyD.

When you were recovering from polio no one said to you, 'You're doing a great job but down the road, twenty, thirty, forty years from now you might have some problems'. To have to deal with the unpredictability of having symptoms returning or other symptoms coming back is extremely unsettling. Whenever someone feels like they've gotten sideswiped in life like this, feelings of being helpless, feelings of being out of control, feelings of vulnerability are very normal. Feelings of denial, anger, and frustration are also normal in these situations.

.....your reactions are coloured not only by the physical limitations that you have, they're also coloured by your memories from the past. They're coloured by how much interference those physical limitations caused in your lifestyle, in your sense of self, and in your coping strategies.

.....you might start having trouble breathing and start to panic; you're not reacting just to the current situation of breathing trouble, you're reacting to that situation plus being flooded with memories of having trouble breathing and wondering if you were going to survive when you were a child. You may not be aware of it, it may be happening unconsciously.

.....You've worked very hard to get where you are. Now suddenly, people are telling you to slow down, don't push so hard, don't work so hard. This goes against everything you've learned to do to overcome your disability.

.....A piece of grieving and loss is trying to redefine your sense of self, regaining your sense of self-esteem. If you were praised and recognized for overcoming your obstacles and for your productivity and suddenly you're no longer able to produce, many people start to devalue themselves. You need to value yourself outside your accomplishments.

One Doctors View - Vol 1, Issue 3, January 1997

Dr. Henry writes...

I find that the central fatigue when it is debilitating causes sleep disturbance, a feeling of being constantly tired even when one wakes up and tends to become more severe in the late afternoon. Everyone with PPS has tried to find what works best for them, and there is much variety.

I remind myself that the polio virus was very specific in where it did its damage, but no two cases of acute polio were exactly alike. Consequently, although there are many similarities in the symptoms of PPS (that is why it is called a 'syndrome'), the manifestations of PPS are never EXACTLY the same in any two of us. As a result, the medical profession is puzzled as to what to do even when medical people are knowledgeable about PPS.

Do you exercise or not? Do you prescribe pain meds and contribute to someone attempting to resume activity and further weaken motor function?

Do you prescribe antidepressants since some surveys indicate one quarter to one third of PPS'ers meet the diagnostic criteria for Major Depression? But what dose do you prescribe since most PPS'ers respond to lower doses if they respond, and it seem most PPS'ers are more sensitive to side effects than just depressed patients.

Henry Holland, MD. [Henry4FDR@aol.com]

PPS general - Vol 1, Issue 3, January 1997

KISSING FROGS BY TANIA IN USA - (Sound familiar?)

Thanks to this Newsgroup and other Internet resources I finally self-diagnosed myself as PPS.

Been to see my General Practitioner, and she agreed and sent me to a Neurologist. Neurologist, very nice, wanting to learn but less knowledgeable than I am, From there to a Physical Therapist, also nice, but not knowledgeable either, Requested a Physician, got another darling doctor who didn't know much either.

So after kissing all these well meaning frogs..... I have decided on my own course of action, the least intrusive possible. Absolutely no pharmaceuticals at this point. Physical therapy in a WARM pool (we're fortunate to have one in town) Acupuncture and Chinese herbs, good vitamins and supplements.

Physical Therapy and PPS - Vol 1, Issue 3, January 1997

POST-POLIO AND PHYSICAL THERAPY—Susan L Fish MAPT Do's and Don'ts to keep in mind when going for physical therapy.

- * **Do** trust yourself and the knowledge you have gained over the years about your body.
- * **Do** be willing to alter your lifestyle.
- * **Do** avoid fatigue.
- * **Do** get enough rest.
- * **Do** pace your activities rather than discontinuing them.
- * **Do** conserve energy. It may make more sense to spread your activities out, allowing for rest periods, rather than eliminating interests and activities.
- * **Do** recognise that your body is aging and some physical changes will occur which are not related to post-polio. There IS a normal aging process even though post-polio may be a part of it.
- * **Do** respect your feelings. This may be a difficult adjustment time for you; seeking emotional as well as physical guidance may be a wise thing to consider.

- * **Don't** follow advice regarding physical exercise if you become fatigued while doing it.
- * **Don't** become short of breath with exercise.
- * **Don't** do more than your body feels comfortable doing.
- * **Don't** cause pain with activity or exercise.
- * **Don't** gain weight.
- * **Don't** reject using aids and assisting devices without giving them serious thought. (They are meant to conserve energy and preserve anatomical structures, i.e. joints, muscles, tendons, cartilage and ligaments.) Most are delighted and surprised by the increased endurance and energy they have with the use of canes, wheelchairs, motorised scooters or the many other easily found assisting devices

PPS and Exercise - Vol 1, Issue 3, January 1997

EXERCISE - WHAT IS RIGHT FOR YOU. Mavis J. Matheson. MD. April 1995.

Determining how much we should do isn't easy. We must learn to recognize fatigue. We must learn which pains mean overworked muscle and which are part of normal aging. We need to pay attention to our bodies and use pain and fatigue as signals. We have to let go of the 'no pain, no gain' philosophy we learned while we were recovering from polio.

.....For each limb, ask yourself "What is the most severely involved muscle in this limb?" "is that muscle weak?" and "Am I noticing signs of increasing weakness in that muscle?" Increased pain in the muscle, twitching, decrease in quality of movement, being able to walk shorter distances, having more trouble with stairs, more difficulty standing, muscle wasting, difficulty holding your arm up, driving, dressing and tiring with fewer and fewer repetitions during your regular

exercise routine are common signs of increased weakness in a muscle or limb.
.....Whatever your exercise program, continue to make changes to help you conserve energy. Pay attention to fatigue and rest when you are tired (before you are exhausted). If you are overweight you need to lose weight.

PPS general - Vol 1, Issue 4, March 1997

PPS QUESTIONS AND ANSWERS, MARCH, 1995 by Drs Richard Bruno and Nancy Frick

Every Polio Survivor [PS] is different. But, the rules that apply to every mortal apply to PS. Anyone who has too few overworked, damaged nerves compensating for muscle weakness for over 40 years is bound to have some problems. And, when you add PS super Type A lifestyles and the fact that they work more hours of overtime than non-disabled people, something's got to give.

....the good news is that the study cited below and our new follow-up study of all the patients we have treated show that if you listen to your body and stop doing the things that cause weakness, fatigue and pain, PPS often plateau and can even decrease

....Listen to your body! If you are doing things that cause fatigue, weakness or pain STOP DOING THEM!!!

....Pacing and resting doesn't mean sitting or sleeping all day and not moving. You should be doing what you need to do for yourself, and at your job, but in a paced, energy conserving, Type B fashion.

...In our follow-up of all the patients we have treated, the three factors that were related to a significant decrease in fatigue were

1. completing the PPS therapy program;
2. doing absolutely nothing for 15 minutes twice a day;
3. using a wheelchair or scooter for distances

....Cold is the Number 2 cause of muscle weakness in PS but is the easiest to treat.

....even if drugs are found that help, PS must still listen to their bodies and live their lives in a paced, energy conserving, Type B fashion. There is no magic pill.

....sleep disorders, such as sleep apnea, are not uncommon in PS. If you snore, wake not rested, with a headache or are depressed, you should talk to your doctor about a sleep study.

Many PS report another kind of muscle movement during the day: fasciculation's. These are muscle twitches you can see or feel. Fasciculation's are found in many non-disabled people. Usually, they are a sign, as is muscle pain, of muscle overuse. Again, talk to your doctor about any twitching.

Humour/Humor- Vol 1, Issue 4, March 1997

Politically Correct from Dan Miller in Washington State

In the 1950's they called me crippled.
In the 1960's I was handicapped.
In the 70's the term was disabled.
Then in the 80's I was physically challenged.
Now in the 90's I am mobility impaired.
I wonder what I will be next?

Doctor, Wheel Thyself - By Richard Louis Bruno, PhD.
[Evening conversation in hospital lift/elevator between
R.L.Bruno in wheelchair and lady visitor.....and its raining 'cats and dogs' outside]

"You're not leaving the hospital," she asked.
"Yes ma'am, " I muttered, desperate not to have a conversation.
"Who in their right mind would give you a pass on a night like this,"
she said, her voice rising an octave.
"I'm going home," I answered,
beginning to understand where she was coming from.
She smiled immediately: "That's just wonderful. How long
have you been hospitalized?"
"I'm not a patient," I said, "I work here."
"Oh! " she beamed, "isn't it wonderful
that the hospital gives its former patients jobs!"

Energy conservation - Vol 1, Issue 4, March 1997

Excerpts from Changing Your Life By Conserving Energy
by Mavis J. Matheson MD.— A fellow Polio Survivor—Revised May 1995

The main principles of Conserving Energy include:

- doing what you most want to do
- planning activities for times when you have the most energy
- learning what your maximum work is and respecting the signs of fatigue
you experience
- stopping before you become exhausted.

PPS diagnosis problem Vol 1, Issue 5, May 1997

I think I have PPS. Why? Judge for yourselves.

Why will all the medical profession not listen. I may be getting older - aren't we all -
but I know my own body. My life style has been turned upside down and I know I
had infantile paralysis in 1938. Why do I have to battle so hard for an answer?

'Mystified' '
Still mystified'
'Its all in your mind'
Fibromyalgia, No.
Then Polymyositis, No.
Then Arthritis and Rheumatism, No.
We can't get below the Polio Barrier, but PPS does not exist.
'X-rays show definite Polio spine, you should not be walking upright'
'Did you really have Polio, maybe it was something else?'

The fact that I cannot cross my right leg over the left is immaterial. The fact that my left leg has collapsed under me three times in the last eighteen months is due to the fact that I have been overdoing it but I have only been out socially three times in the last four years because of the pain and exhaustion. The fact that I now have no control over my thighs and drop into a chair like a sack of coal is ignored. I am so frustrated. Why will the medical profession not believe me?

.....Why will they not listen to me and take all my symptoms into account? Why were the old medical records destroyed? Why does the diagnosis keep changing? Why can't they give me a firm diagnosis for all my problems? When they do make a decision to give me some treatment how long do I have to wait before they tell my GP of their decision? Why is so much time, energy and money being wasted? Why do I have these symptoms, I have not been physically ill, this wasn't gradual like just getting old, it happened overnight, I know its not just age, I have had this body a long time and I know how it feels.

[Ellen comments. This is still happening today 7 years later. The whole article is a good read for anyone still struggling to get a diagnosis for their symptoms.]

Muscle atrophy is not necessary for PPS diagnosis

Vol 1, Issue 5, May 1997

The following is part of a depersonalised letter which may be of interest - done at the suggestion and with the permission of Professor Richard L. Bruno PhD

You have been told that one had to have significant damage from the polio and muscle atrophy to have PPS.

Neither the severity of the original polio infection nor muscle atrophy, either due to the original polio or late-onset atrophy - are required for the diagnosis nor are predictors of PPS. The postmortem studies of Professor David Bodian of Johns Hopkins University in the 1940's showed that anyone who had paralytic polio lost on average 50% of their anterior horn cells but required the death more than 60% to demonstrate any paralysis (Bodian D. Histopathological basis of clinical findings in poliomyelitis. *American Journal of Medicine*, 1949; 6: 563-578.)

Medications and PPS - Vol 1, Issue 5, May 1997

What you should know about your Medications. A guide for Polio Survivors. [Part of full article]

Ask your doctor about potential side effects, particularly those that may increase or cause

- * fatigue
- * respiratory weakness
- * muscle weakness
- * dizziness and/or drowsiness which may impede your balance and cause falls
- * increase depression thus changing your perception of pain, making it seem worse
- * insomnia, sleeplessness, will increase fatigue
- * vaso-constriction, may increase cold intolerance.

PPS and Respiratory Problems - Vol 1, Issue 7, November 1997

RESPIRATORY QUESTIONS

Ask Wayne - Registered Respiratory Therapist.

Pulmonary Function tests

1. Will rule out or in, the reactive airways disease with tests specific to your flow rates
2. This next one is superb for PPS'ers, the test normally done sitting in chair, should be done while laying on one side, and repeated on the other. This is because PPS'ers often have a paralysis of one dome of diaphragm, which can be picked up with this type test (right side down testing, then same study repeated on left side). If the results are markedly different, problems relating to diaphragmatic excursion can then be pinpointed.
3. Arterial Blood Gases....Both at rest, and after exertion.....This will be the key in factoring out the fatigue thing... Arterial Blood Gases gives information about one's ability to ventilate normally, at rest, and then under exertion. This test is momentarily painful, because it requires sampling of arterial blood, usually but not always from the radial artery... In other words it hurts like hell. This test is done to check the adequacy of ventilation. In other words, oxygenation is not the important thing here.....
4. In order to rule out oxygen deficiency, simpler oxygen saturation measurements can be recorded. But again they should be done at rest...and then after exertion.

Finally, I would recommend a sleep study, but at a bona fide sleep center with holistic knowledge of PPS. In conclusion:

- * Peak Flow Tests sitting, and repeated lying on both sides.
- * Oxygen saturation at rest and following exertion.
- * Arterial Blood Gases, both at rest and after exertion.
- * And finally, a full blown sleep study connected to an EEG machine to check frequency of REM sleep, or lack thereof.

Should pin point any and/or all of these components which could be your problem.

PPS diagnosis - Vol 1, Issue 9, January 1998

Question asked on the [St. Johns Post-Polio-Med List](#)

Is it possible to have PPS with an EMG that doesn't show the patterns of polio on the unaffected side?

As far as diagnosing post polio syndrome with no definitive historical data to support an attack of paralytic polio, there are several alternative approaches.

- * Exclude any known causes for your new symptoms other than post-polio.
- * Do a careful exam of your affected and unaffected sides both clinically and if necessary with an EMG including single fiber EMG to look for changes suggestive of post polio.
- * Observe you periodically for any signs of progression of symptoms

Energy conservation - Vol 1, Issue 9, January 1998

Energy Presents

I discovered that if I count my energy presents like people who are dieting count their calories and fat grams I have much less problem with fatigue. During this busy holiday I am sure all of us can use the reminder that we need to use our energy wisely.

Imagine yourself with a basket of presents everyday. In the basket are 5—10 presents. Each present is a Unit of Energy. As you go through your day you will use a present for every task you perform. When you take a shower and dress for the day you will need an energy present. If you run errands, for each place you stop may require a whole energy present just getting to and from the buildings. I have discovered for every 45 min I sit at the computer I use a present. If you prepare a meal that will take a present. Others may use more or less depending on your abilities and fatigue levels. Obviously it does not take long to use up that basket of presents in a normal day. So make sure that each of you use your gifts wisely. It requires rest (sleep) to refill the basket. Once the basket is empty there are no reserves and you must sleep to recharge and wait for the basket to refill.

PPS muscles/fatigue/more - Vol 1, Issue 9, January 1998

Grace R. Young, MA, OTR, and Polio Survivor writes....

about muscles...

Even though you were told that you had "non-paralytic" polio, this doesn't mean that you didn't lose some motor units during the acute attack. It means that there was no clinical weakness. A muscle can lose as much as 50% of its motor units and still not show clinical weakness. However, the remaining motor units are working harder and longer. After many years of overworking, some of the remaining motor units start to give out.

about fatigue...

I think most of us can relate to delayed fatigue. We overdo on good days and then are sidelined for several. It helps if you can identify right when the fatigue starts and

stop for a rest before you reach the "point of no return" (easier said than done).

Here are a few ideas:

1. Stop when you feel a little tired.
2. Decreased quality of movement. Stop if motions that are usually done smoothly develop a tremor or become shaky.
3. Decreased quantity of movement. Stop if your range of motion declines while you are working.
4. Stop if you start using compensatory motions

Helpful Tips - Vol 1, Issue 10, March 1998

USING YOUR BODY EFFICIENTLY—*Grace R. Young, MA, OTR*

The basic principles of good body mechanics apply to disabled as well as non-disabled individuals. However, polio survivors have individual patterns of muscle weakness and unique ways of compensating, so there are no 'cookbook' rules that apply to everyone. Here are some general principles that apply to most of us.

.....SIT INSTEAD OF STAND WHEREVER POSSIBLE

- It takes approximately 25% more energy to perform an activity standing than sitting.

.....USE MECHANICAL HELP FOR CARRYING

- Carrying objects changes your centre of gravity and can stress your arms and overuse your leg muscles.

Pain and PPS - Vol 1, Issue 10, March 1998

PAIN IN POST-POLIO SYNDROME - By C. Vandenakker, MD

CAUSES OF PAIN IN THE POLIO SURVIVOR

**Post-Polio Muscle Pain
Overuse Pain
Biochemical Pain
Bone Pain**

EVALUATION OF PAIN—Thorough medical assessment.

MANAGEMENT OF PAIN - Therapies utilized

**...medications... behavioral modifications (pacing)..
bracing.... weight loss
avoiding the 'pain cycle'**

A lot more helpful information in this article.

Resting and Pacing - Vol 1, Issue 11, May 1998

REST, PACING AND TIMING - Grace R. Young, MA, OTR

Fatigue and pain must be respected. Overuse to muscles is not always apparent while it is occurring. Muscle pain is a warning signal that the muscles have been overused. The damage accumulates over a period of time and may not become obvious until you lose the ability to do an activity which was previously possible.

REST - Try to rest at least one hour during the day.... Lie down to rest so your back doesn't have to support your body weight. Sitting takes 1/3 more energy than reclining...

PACING -Prolonged activities such as cleaning house or gardening, can leave you exhausted for the rest of the day unless you break them up into short segments with rest breaks in between. Before starting an extended activity, decide how long you will work at it and allow a 15-minute rest break every 30 minutes. Use a kitchen timer to let you know when to stop working and when to start up again. Alternate light and heavy tasks throughout the week

HOW CAN YOU JUDGE IF AN ACTIVITY IS TOO STRESSFUL? - The easiest sign is a feeling of fatigue while you are in the midst of the activity.....

Dieting and PPS - Vol 1, Issue 11, June 1998

HINTS AND TIPS THAT MIGHT HELP YOU TO DIET

collected by Carole Lee

Dieting and not being able to exercise like we used to is difficult.

Here are some day-to-day tricks and tips for dieting ...

Set a reasonable goal.... Say "NO" to sugar, salt, and excess fat!....

Weigh yourself only once a week. ... Fiber is important in your program..

Good sources: whole grain cereals, bran, wheat germ, fresh fruits and vegetables...

Diet doctors insist on us having a good breakfast... Keep fresh fruit ready-to-eat in your fridge

Enjoy carrot sticks, celery sticks & other raw veggies

with low-fat cottage cheese or salt-free peanut butter....

Using Assistive Devices - Vol 1, Issue 12, August 1998

ROLLING ALONG - Grace R. Young, MA, OTR

Many of us who had polio were pushed to exercise vigorously and discard canes, braces, and wheelchairs as quickly as possible. The primary goal was to become "normal" and this meant casting off equipment and doing everything other people did. To us and our families, continuing to use equipment meant that we had not been "cured". Therefore, it is not surprising that we feel a sense of failure if we have to start using wheelchairs or scooters or return to the equipment we left behind many years ago.

.... Canes or crutches may suit your needs when you're at home or need to ambulate very short distances. However, using a wheelchair or electric scooter for longer distances or in challenging situations may actually prolong your ability to walk by preventing overuse of your legs. And there are other advantages to using wheelchairs or electric scooters instead of canes and crutches. [see full article]

Acceptance of PPS - Vol 1, Issue 12, August 1998

Permission Giving: Emotional Adjustments and the Late Effects of Polio
Karen Kennedy, MSW CSW, [West Park Hospital](#), Toronto

All of us have encountered situations in life where we have had to seek permission from another person or group in order to complete the task at hand. If that permission is not forthcoming, our efforts may be thwarted and the task halted. In consulting my Collins Gem dictionary, I discover that the word *permission* means authorization, which in turn means to empower, permit or sanction. The word *giving* means elasticity and yielding. The word *give* means to bestow or confer ownership. The task at hand is the ongoing adjustment to life with new fatigue, pain, weakness and general changes in physical and emotional tolerance caused by the late effects of polio.

The ideas of permission giving and adjustments are inseparable. I would like to suggest that the idea of personal emotional permission giving is central to the discussion of adjustment to living with the late effects of polio. The emotional permission giver controls the answer. There will be times when the permission giver may not see the need or may refuse to see the need to give permission - permission to acknowledge reality and initiate purposeful change in order to manage the late effects, instead of being managed by them.

...Permission To Do What?

Make Changes: Give yourself permission to make changes. Acknowledge your new limitations and adjust your expectations of self. Consider how altering your lifestyle can help you maintain your independence.....

Set Limits: Dr. Margaret Backman, a psychologist in New York.... suggests that learning to set limits is key. Learn how and when to ask for help and how and when not to give help.....

Ask for Help: Remind people if they need prompting. Don't expect others to always remember or anticipate your needs.....

Express And Be Heard: Openly express your needs, preferences and feelings.....

...Outcome Of Withholding Permission.

- Increased frustration, anger and irritability
- Increased pain and fatigue
- Stressed relationships
- Frustrated family members who are standing by willing to assist
- Increased difficulty accepting suggestions or new ideas for coping
- Energy wasted on fighting the symptoms instead of channelling energy to adapt and take back control
- Fighting against the symptoms tends to increase their impact instead of

lessening them

- A survival mentality where there is no reserve energy left at the end of the day for leisure or life
- Decreased social involvement due to fatigue levels and a private approach to the polio issues.

...Support for Change.

- Family and Friends**
- Support Groups and Newsletters**

Aging with PPS - Vol 1, Issue 12, August 1998

AGING WITH POST-POLIO - Dr. Mavis Matheson [Polio Survivor]

.....In order to feel young, we must adapt to the changes in our lives. Today, I'd like to talk to you about making life changes in general and to suggest some options for change in the five areas that are the most effective with the least risk. These areas are, relaxation, nutrition, values and goals, communication and appropriate exercise.

...Making life changes. Don't base major life changes on the latest self-improvement trend, magazine article, or TV advert. Do your research. Keeping an open mind is a virtue - but as the space engineer James Oberg once said - "not so open that your brains fall out." Has it been tried with people like you? (If your nerves are burning out, a vigorous exercise program is not for you, no matter how much good it did those university age students.) Let someone else take the risk and find out what doesn't work. Check your "downside risk" before making a change. What are the costs in terms of side effects, money, time and energy? What is the least stressful way to make the improvement you have chosen? The greater the risk to you, the more evidence you need that an intervention is likely to work.

...Set goals for change based on what you want out of your life. Your goals should be specific, measurable, realistic, and truthful. Make very specific changes one at a time. Once you have made a change evaluate it regularly. Feel good about what you are doing.

....What I did find was that the safest and most effective anti-aging interventions will also help with PPS symptoms. They are relaxation, good nutrition, working from your own basic values toward your own goals, improving communication skills and appropriate exercise.

1. Effective relaxation

I have considered marketing a pill to treat PPS. You would take it after lunch. Then you would have to lie down for 1 hour and relax completely. I am sure it would be a very effective treatment. It wouldn't be better than placebo though. Polio researcher, Dr. Paul Peach pointed out that "Weakness and fatigue are the body's way of telling polio survivors to rest." Drs. Bruno and Frick of the Kessler Institute found that polio survivors who comply with treatment-pace activities, conserve energy, take two 15

minute rest breaks a day, and use assistive devices (a brace, cane, crutches, wheelchair or scooter) have up to 22 percent less pain, weakness and fatigue 18 months after therapy ends.

To treat your fatigue, you need to take time to rest. Nap (if possible) during the day, work fewer hours, and take longer vacations. Rest is the best known treatment for joint and muscle pain. Relaxation is the classic treatment for stress. The risks of relaxation are very small. There are no known side effects. It is free or at most the cost of a relaxation tape.

2. Nutrition and Vitamin-mineral supplement

Last October, Dr. Susan Creange, a research fellow at the Post-Polio Institute at Englewood (New Jersey) presented a study of diet in polio survivors. Dr. Creange found that, "Polio survivors often have a 'Type A diet': drinking three cups of coffee for breakfast, not having lunch and eating cold pizza for dinner. When they put polio survivors on a hypoglycemia diet, that requires eating protein at breakfast and small, non-carbohydrate snacks throughout the day, they had a remarkable reduction in nearly all symptoms of post-polio fatigue."

The basic principles are:

- Eat a variety of unprocessed (and little processed) foods
- with high nutrient density
- in moderate amounts
- during at **least** three regular meals a day, including breakfast,
- with protein at each meal
- combined with smart snacking patterns (including beverages)
- while drinking at least six glasses of fluid daily, two of them water,
- and taking a broad-based vitamin- mineral supplement.
- I don't recommend megadoses of anything!

There are a few other things I would like to suggest under nutrition. I recommend you decrease your caffeine intake so you can monitor your fatigue more accurately. I also suggest you use alcohol in moderation. Alcohol inhibits swallowing, interferes with nutrition, and causes falls and accidents. Alcohol at bedtime interferes with the quality of your sleep. If you smoke, QUIT. If you are a smoker, quitting smoking is the most effective anti-aging intervention you can make. If you don't smoke, great.

3. Values & Goals Clarification

Once you clarify your own values, you can set goals within your strength or endurance limits, and avoid going repeatedly to that limit. By doing so, you can reduce the fatigue, joint and muscle pain, muscle weakness, and psychological stresses of Post-polio Syndrome. When you decide to clarify your values, begin by identifying 5 core values. A core value is an aspect of life that is particularly important to you. It may be something like being confident, learning, being creative, time with family, time with friends, exploring the world, success, helping others, laughing and enjoying, being in attractive surroundings, being independent, getting recognition or being challenged. Be honest with yourself about what matters to you.

Don't get trapped into living someone else's values.

4. Self affirming Communication

A satisfying long term relationship is one of the main determinants of a long and happy life. Good communication skills will help you to develop and maintain satisfying long term relationships. Self affirming communication means having the courage to reveal to others who you are and what you want, expressing yourself assertively and listening actively, and replacing self-defeating communication behaviors and styles with self-affirming communication skills. Self-assertive language is used when you say "I" when you mean "I".

Another very important communication skill is giving and receiving feedback. When you give feedback, avoid value judgements by describing a situation. Be specific with your concerns. Report the impact of a behavior without judging the behavior. The best feedback is solicited, focused on things that can be changed, and immediate. When you are getting feedback, get more than one person's feedback. Active listening is much easier if you frame the conversation. Try to set limits and impose structure on the information you are receiving. Recognize that disturbance takes precedence if you are not comfortable standing, stop the conversation by explaining you need to sit down, sit down, and then continue the conversation. Try to listen to both verbal and non-verbal messages. Recreate what you are hearing and play it back to the speaker.

5. Appropriate Exercise

Get enough exercise to prevent disuse atrophy, but not enough to produce overuse damage. Many survivors are prescribed or actually ask for the kind of physical therapy they had right after polio: exercising to the point of exhaustion. Several studies show that pumping iron will not increase the strength of muscles that are becoming weaker, and can actually cause an irreversible loss of strength.

'Bit' to make you smile

After a long and productive lifetime of hunching over her bubbling cauldron muttering incantations and concocting various enchanted brews, the wretched crone finally came to the realization that she was no longer in her prime. In addition to the pronounced dowager's hump she had developed, her arthritic feet were an almost constant source of pain and torment for her. She could barely stuff her wrinkled toes into those pointed boots any longer.

sack onto her enormous chopping block and began the tedious task of mincing up a fresh batch of bat tongues and newt eyes, an idea suddenly dawned upon her. If she had a smaller, more portable cutting board, she might just as easily process these ingredients in her lap as she was comfortably seated beside her boiling cauldron.

"Ah, yes," She muttered to herself. "It would be nice to be able to sit for a spell."

~by Gary Hallock

One evening as she emptied her tote

<http://www.topica.com/lists/CripHumor>

Ninth International Conference on Post-Polio Health and Ventilator-Assisted Living: Strategies for Living Well

**Thursday 2nd June 2005
to Saturday 4th June 2005
Marriott Saint Louis Downtown,
St. Louis, Missouri, U.S.A.**

To learn personal STRATEGIES FOR LIVING WELL

**To provide information and support
to families and friends of polio survivors and ventilator users**

To exchange ideas with polio survivors and ventilator users

To exchange ideas with health professionals

**To contribute to the worldwide activities supporting the improved health
and independence of polio survivors and ventilator users**

To renew old acquaintances and make new friends

Friday June 3rd 2005—3.15 to 4.30 p.m.

**HOW SELF ASSESSMENT CAN HELP YOU
IN OBTAINING BETTER CARE FROM HEALTH PROFESSIONALS**

Hilary Hallam

Denise Carlyle, BA, MA, PhD, LRAM

Mary Kinane, BA, PGCE

Lincolnshire Post-Polio Network, Lincolnshire, United Kingdom

Reactor: Carol Vandenakker, MD

Physical Medicine & Rehabilitation, University of California Davis Medical Center

<http://www.post-polio.org/conf9th/prog.html>