



The LincPIN

The **L**incolnshire **P**ost-Polio **I**nformation **N**ewsletter
Volume 4 - Issue 7 - December 2003

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



Best Wishes
for Christmas and the New Year
from

Gillian Merron
Member of Parliament
For Lincoln

Big Ben surrounded by Fireworks at night—Composite Michael McQueen—Simon Elvin Limited

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ALWAYS consult your doctor before trying anything recommended in this or any other publication.

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

CONTENTS.

- Page 3—Editorial
Page 4—Treasurers Thoughts
Pages 5 to 7—Muscle Spasms from Member Len Van Zyl
Page 7—Rotator Cuff Surgery Question from Member Barbara Taverner
Page 8—Learning the Truth from Member Malc Gray
Pages 9 to 10—More from the day of the AGM from Members Robin Butler and Anne Wood
Pages 11 to 17—Second half of the report of the San Francisco Conference
Page 18 to 20—New PPS Book—Review by Member Dr. Mary Westbrook
Page 20—Our advert in the Chartered Society of Physiotherapists Magazine—Frontline
Page 21—Upside Down View Number Two from the Texas One Arm Bandit
Page 21 to 23— Radio Days and Old Time Radio from Member Patricia Bamford
Page 23—Information Page
Page 24—Advert from Member Ann Stevens for the Lantern Hotel

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

Gift Aid—Anne Stone, Mary Guild, Irene Meade, Richard Watts, Ewan Peddie,
Donations—Monthly, Sylvia Fortune and J Raynor

Donations—Jean Simm, Barbara Stevens, S. Upton, Jenni Paulger, Vic Oliver,
Robin & Pauline Butler, Anne Stone, Mary Guild, Irene Meade, Eunice Stone, Alan Standan,
Carol Collins, Richard Watts, Hilary Hallam, Peggy Hibbard, and Yash Airth's brother in law
Ashok Bansal owner of Language.Source.com for a keyboard to replace my coffee filled one.
N.B. New and Renewed Members names will be included from Jan 1st 2004

Lincolnshire Post-Polio Network - UK Registered Charity 1064177
Donations large and small towards our work are always welcome.

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Membership Information

Renewal dates are the first of the Months of Feb, Apr, Jun, Aug, Oct, Dec.

Please make cheques payable to 'Lincolnshire Post-Polio Network'

(UK £ post to Membership Sec, 78 Heron Road, Larkfield, Aylesford, Kent ME20 6JZ, UK
(US\$ checks post to Lincs PPN. c/o 4212 Blanding Blvd, Jacksonville FL 32210, USA)

UK Membership - Life Member (LM) £150 or £5 x 30 months S.O. - Member £10 a year.
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USA - LM US\$375, Member US\$25 a year - **Canada** - LM C\$550, Member C\$40 a year
Other Countries please contact membership@lincolnshirepostpolio.org.uk for details.

Next LincPIN Newsletter - February 2004

Articles for publication mid Jan. 2004 by post or - newsletter@lincolnshirepostpolio.org.uk

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EDITORIAL—As I start this editorial, just three days before Christmas, the sun is shining through the window, long shadows, its cold, although above freezing and the weather forecast for today—snow coming down from the north. Will it reach Lincoln? As we have members in other countries I wonder how many will see snow this winter? If it snows where you live how does this impact on using canes, crutches, wheelchairs and scooters?

On the front cover of the Newsletter I have reproduced the card that the LincsPPN have received from our MP Gillian Merron—and I would also like to take the opportunity on behalf of the committee of wishing you all a healthy and happy 2004. Richard and I will be back in the States by the time you receive this and I am going to be taking the month of January off from LincsPPN work. As mentioned on our Members Email Discussion list [info on page 23] I too am finding that the more fatigued I am — both mentally and physically — the more I forget words, forget what I was saying and sometimes think I have had conversations that I am later told can only have taken place in my mind. Some weeks to save energy I only get dressed on the days I am going out... this is not good for my health. We will always be grateful to anyone who can spare us a few hours a month to help share the workload.

On another issue, I took a phone call from a member who said he does not wish to rejoin because there is too much American information and this is not what he wants to read. Unfortunately he ended the call before I could ask what he does want to read. Can I please remind all members that the articles/titbits etc. that appear in the newsletter are what I am sent directly, what I find on discussion lists from other ppsers and pps newsletters around the world, and attending meetings and conferences. It is constructive criticism,

and welcome, if you tell us what you think is missing from our newsletters. Your comments, hints and tips, questions, stories, précis of books, etc., are always more than welcome.

This issue contains an email—with permission— from Len Van Zyl that has kicked off an excellent discussion on our email list. Please write/email/phone us with your comments. You might be surprised how snippets of information in pps newsletters trigger response from around the world of similar problems, medical articles or of information others are unaware. Again and again I am told by health professionals how useful they find the search engine on our Website when they are looking for information to help their patients/research. Our Online Library contains over 100 medical articles on pps and that is only part of the website. [see page 23]

As an example my four years of medically noted yet unexplained eye problems were explained once my optician had read information from a PPSer in Australia. The muscles that move my left eye are now weaker than the right and I get a visual disturbance that increases as the day goes on when looking left/right/left, [tracking]

Gaby Martin kindly donated half the cost of our advert in the September issue of Frontline—the newsletter of the Chartered Society of Physiotherapy and I thought it would be nice to reproduce it here. [page 20] Firstly, to say a big thank you for the donation and secondly so that if you are seeing a physiotherapist you can refer them to our half page advert. It appeared on the inside back page underneath the advert for The Arachnoiditis Trust.

The load of tomorrow, added to that of yesterday, carried today will break the back of the strongest person.

A way to live..on this journey is a habit to be acquired gradually with long and steady repetition. It is the practice of living for this day only. Our worries

Treasurer's Thoughts

Our previous treasurer Jenni is off in sunnier climes. I feel somewhat envious. It's a dark December morning as I write this, raining heavily, and with the need for artificial light at 11 am. I am not an accountant, so, while I am happy to carry out the day-to-day duties of the treasurer, Jenni will continue in her role as financial adviser. I am following her instructions!

Your support.

Your generosity continues. Last year, our total income was £5,578, of which £2,877 (52%) came from members' donations. 55 of our members have now completed Gift Aid Declarations. The amount of tax reclaimed through the Inland Revenue last year came to £586 - a substantial percentage of our total income (10.5%).

Gift Aid provides a great opportunity for all our members to increase the value of their membership fees and donations to LPPN. All we need is a single Gift Aid Declaration from each supporter who pays UK tax. The only people who should not return a form are those who pay no tax, or always give through a scheme, such as CAF, where tax has already been reclaimed.

The Gift Aid scheme applies to any donation, large or small, regular or one-off. That single declaration form will cover any number of donations, of any size, at any time in the future - we just need to have the form on our file when we receive money from you, and we can immediately reclaim the tax. Completing a form is not a promise to give to LincsPPN, but it allows us to increase the value of anything you do give us in the future. A gift of £10, covered by a declaration, is worth an extra 22 pence in the pound to us. If you have not already done so, please fill in a form.

Fundraising.

We have been unsuccessful in finding a volunteer to take on fundraising responsibilities. We have also been unsuccessful in our efforts in applying for funds this year. Sheila Dunnett, one of our new committee members, is again looking into local and national options. If you have any suggestions, or could offer a few hours a month, she would welcome your help.

The newsletter is one of our major outgoings, last year costing over £400 per issue. This is the main way we keep in touch with our members. One of our members gave me cause for thought at the AGM. He informed the forum that although he had life membership, he felt he had a moral obligation to continue to pay the costs of his newsletters. This may surprise you, but I must say that this had not occurred to me. Now, we don't all necessarily feel this way.

I joined LincsPPN as a life member, and with escalating costs over the years, I realise I will shortly be receiving the newsletter virtually 'free'. I decided that I would give a regular sum. Although like many PPSers, I have had to retire early from work, and am dependent on the UK benefits system. This means I do not pay tax and therefore LincsPPN could not benefit directly through gift aid from me. I was discussing this with my younger son when he offered to pay a regular sum in my name, sign a gift aid declaration as he pays income tax, thereby increasing the value of the donation.

I would welcome any suggestions/comments you might like to make. Write to me c/o the LincsPPN address on page 2 or email:
denise.carlyle@lincolnshirepostpolio.org.uk

Muscle Spasms

The following is taken from our Members email List. Len Van Zyl added a PS to his response to a post about the pricing of drugs in the USA..

P.S. Anyone interested to know how we managed to get control over life-hanging neuropathic pain and muscle spasms, please let me know and I will be happy to share that with you.

Four Members responded with information and request to read Len's personal experience.

We have not got the space to discuss pain and spasms as I have experienced it and almost made it my speciality in the last near 5 years :-)

What I have learnt is that there can be such a chicken and egg situation between neuropathic pain (did not know the term at the time) and spasms. I have always tried to work out which triggered which and there was no obvious pattern.

What you describe almost sounds like a bolt of spasm (you call it "sharp") ?? How long does the actual spasm last? and if a bunch of them in succession.....how long might that last? The only time I experienced SPASM in such a surge that I could only describe it as a bolt (zap) was the few times that my diaphragm went into spasm. This left me almost unable to breathe because it hurt so much. This could have lasted in the severe form anything from about 5 minutes to over an hour at its worst. Even after it relaxed it would leave me feel bruised or perhaps best to describe that the whole area on left side of ribs and deep tissue feeling very irate, even to light touch.

What you could possibly also think about is that for whatever reason you

might have neuropathic pain. That becomes complex because it can, I suspect be either a trapped nerve or as in my case they simply never worked out why.

In the end they have prescribed medication that somehow blocks the signal from reaching the intended point. I got my own back on my brain. For years it sent out these rogue pain messages and now it is still doing it and likely does not even know it never reaches its destination :-). This type of bolt could and would most often leave the area irate and tender.

Something else to bear in mind is that when you have spasms that continue for any period of time, these spasms pinch the nerve sheathes and then you end up with inflammation of the nerve sheathes. At the lower end of the scale you can end up feeling like a good bout of flu coming or in worst cases (and I can only relate to my experiences) bolts of pain from hell. At times I felt as if I am having severe electrical shocks and at other times it was distinctly more like a blade being thrust into my body. (Never been stabbed before but it is the only language I have to describe it). Both electrical shocks and stabs at its worst would physically send me jumping or reeling and to be honest in the dark of night it at times made me feel I needed to run away from it.

The other thing I have learnt the hard way is that we all describe things in different ways. A spasm to one individual might indicate a fleeting event and in other it might actually last for hours in which case the initial spasm has a knock-on effect on surrounding areas after some time and more muscles go into spasm in "sympathy". Has anybody worked out the difference between a spasms and a cramp? !!

Robin, another few questions: (and this is simply to induce some discussion and

hopefully to make you think of circumstances)

1.. Does this only occur when you sit? or stand? or 100% variable?

2.. If it happens when you are sitting, can you define for the period in before, what your posture was? (Reason I ask is that I slump forward and to the left. This was the side I was more inclined to get zaps and tender ribs after sitting up for too long without getting on with mixing in other activities)

3.. If lying down, can you pin-point a specific position you are most likely to have been in, in the time running up to the incident?

4.. How long does the actual spasm last?

5.. AND if a bunch of them in succession.....how long might that last?

A few comments from me:

1.. If these symptoms persist, I would really advise you (but then you know that) to refer it to your GP

2.. With deep muscle spasms it can sometimes be difficult to pin-point as to exactly where it originates. I have had spasms in my back so severe that it also felt it affected my entire upper torso where it might not have (earlier I did explain that with spasms of longer duration it can actually have a domino-effect on surrounding muscles)

3.. When you experience a combination of these neuropathic pain sessions but also spasms, you can clearly see when the Neurologists' eyes cloud over. They have a tendency to only really cope with one issue at a time in my experience.

Medication that has worked in limited fashion until I got where I am now:

1.. In the beginning I was on 150mg

(3x50mg) of Amitryptaline per day to help control neuropathic pain. I believe it works better for some than for others. I also know that some might not tolerate ANYWHERE near that dosage per day. I have heard some say that as little as 5mg knocks them out. This helped more in the beginning and then my body seemed to adjust to it and it lost its effects over about 12-14months)

2.. Some Neurologists believe that Carbamazepine <spelling?> does the trick. In the end I was on a combination of both and that extended the period of relative pain control

3.. Since I was referred to a pain clinic relatively recently, I was put onto 3,600mg per day of Gabapentin and then I slowly managed to withdraw the use of Amitryptiline (Carbamazepine having been stopped near 2 years ago)

4.. Spasms—I guess it really depends on the pattern of spasms. If you have a spasm once in a blue moon as little as 5mg of Diazepam can help release it. In my case it took 20mg per instance. This, I do not think, is a constant-use solution and most certainly not easily to be considered for anybody with respiratory risks without explicit medical opinion. I had my then GP prescribe that to me until a neurologist confirmed that, but when the neurologist referred me for respiratory function tests, this practice was stopped immediately after the respirologist advised me to come off Diazepam.

5.. Baclofen works wonders for spasms but things to watch out for is for those with respiratory risks, to either NOT take it or to take it under direct medical supervision and by that I mean in Hospital. Initially after I was prescribed Baclofen, it almost worked within 8 hrs but after, I am not sure whether 2 or 3 days, I got home and felt tired thinking it was the busy day and went up for a rest. Almost immediately after I got to lie down I had respiratory

depression. A nasty thing as I had a high speed chase to the local A&E and a stay in high care. It was almost immediately ascribed to my use of Baclofen and I stopped using it and had a reasonably quick recovery.

6.. ZANAFLEX is the modern equivalent of Baclofen but somehow works differently. Zanaflex (Tizanidine) comes in 4mg tablets and again it depends on the individual as to what dosage works. The short of it is to start LOW and then slowly titrate upwards by increments of 4mg. Be sure to give it a good time before increasing dosage as I have gathered that Zanaflex can take its time to get control. If I recall correctly 32mg per day is highest dosage and I had to go up to 28mg per day to get 95% control. I was in 7th heaven to find this solution as life was pretty much hell before then. My bubble was burst however when I got to a Rehab Specialist Neurologist, Dr Christine Collin and she made it clear that she considered that as total over-prescription and she instructed me to come off Zanaflex entirely. I refused as I was entirely happy with not having anything up to 14 hour spasms sessions and I was prepared to have monthly liver function tests as in a low % of users, Zanaflex can cause liver problems. To date it has done my liver no harm (28 months later). Instead I insisted to be referred to a Pain Management Centre as I was tired of being the ping-pong ball between medical professionals at loggerheads with one another. I was referred to a Pain Management Clinic at the Royal Berkshire Hospital and can only sing the praises of Dr Allen (Anaesthetist). He is the person who prescribed the Gabapentin, I have managed to get Zanaflex down to 20mg per day and I am now entirely off Amitriptyline. Sounds like a result to me !!

Tomorrow I see Mr Theologis at the Nuffield Hospital as the final part of the

pain.spasm jig-saw needs to be resolved. That is the structural issue of my spine curving and that playing havoc with my thoracic spinal region, neck and shoulders.

I am sorry this e-mail is so long but it is and remains a complex subject I am afraid.

Regards

Len Ivz@TESCO.NET

Can you please ask in the next LincPIN newsletter, does anyone know anyone who has had to have rotator cuff surgery done over 60. What was the success rate for them, how did they manage afterwards/ aftercare, living solo, and what did they have to do to help themselves. Without my arms I can't pull the rest of my body around nor dress/underwear properly. I couldn't get out of bed, so now have a hoist 3 weeks ago. I can't use crutches, in less than half an hour my arms collapsed and pain ++. I was given crutches 1998 after stair fall and back damage. I couldn't manage them. I still have them. It had to be wheelchair only – I couldn't stand up for sciatica.

Rotator Cuff Surgery Question

Barbara Taverner

barbara.taverner@btinternet.com

Learning the Truth

**by Member Malc Gray,
Personal Trainer &
Lifestyle Consultant**

The Janis Ian song says "I learned the truth at seventeen". For most of us, I think we learnt it a lot earlier than that. Having had polio in 1958 when I was 18 months old I find my day full of past thoughts of my childhood.

As a personal trainer and lifestyle consultant my day is full of giving advice on exercise and health. Exercise has always been a big part of my life and now I earn a living from it.

I knew something was not quite right 5 to 6 years ago, when it was taking me longer to recover from my TaeKwonDo lessons. I put it down to my age at the time. Little did I know then about PPS. I was a cash-in-transit security guard with a very physical day, 5 long shifts per week, plus 5 to 6 training sessions as well, either TaeKwonDo or in the gym. I could not understand how it was taking my body longer and longer to recover. I was spiralling down and down until I found out about PPS and the Lincolnshire website.

When I started reading the articles and the great wealth of information I then started to put together a picture about my state of health and mind. It was like a jigsaw coming together at last.

Since those early days of PPS there has been a great question for me to answer, How much is too much? I found it very hard to accept that after a night at TaeKwonDo (that I loved) I could hardly get out of bed the next day, or if I could then walking was difficult and as for energy levels, I had none.

More and more often as a security guard I felt vulnerable to the point I had to leave the job. However that has been

a great move since now I have retrained successfully to be able to do the job I have always wanted to do, be a personal trainer. This has helped me answer my question of how much is too much. Maybe some of these ideas may help you too.

We are told to monitor just about everything in our lives and this is no exception. Most of the exercises I do are functional. This means I try to strengthen or maintain the muscles that help me move in day to day life. Think about how you move, i.e. not just walking around, but also lifting objects, cups even. Because we are individuals and all different in our limitations and abilities I cannot write a "one size fits all" program in a short article but the way I write programmes for people is to look at their risks to benefits. This means I weigh up the risks of potential injury against the benefits of that person performing a particular movement – will it improve the quality of their life?

I have a club foot, shorter left leg, twisted hip and twisted lower spine. Consequently I never do squatting exercises, but I need to maintain some strength in my legs, so I do something else instead. I believe that any problem areas can be worked around most of the time. Some body movement will help maintain circulation in your pulmonary system which pumps blood and oxygen around our bodies. I find a moderate amount of body movement every other day works best, giving my body time to recover. Recovery time is so important so the body can regenerate.

Yesterday I tried to paint a bedroom ceiling wobbling on a chair. I have not done this for about 5 years or more. Today my whole body aches, especially my legs and I am very tired. So I will be not be doing a great deal, adjusting my calorie intake accordingly and later I will ask my wife to assist me in some stretching exercises to alleviate the pain

and discomfort. Tomorrow is another day.

I hope you have found this little insight into my world interesting. I firmly believe that whatever someone's status of movement is, there is always a way to improve their lifestyle, even if it is only by exercising their mind in a positive light.

Malc Gray <malc2@mg-gray.fsnet.co.uk>
I was privileged to be one of those that Aaron worked with over the weekend of our AGM. I knew the moment I saw Aaron and he shook my hand that he was someone very special. Later I was to find out that the Mattes method of Active Isolated Stretching was indeed

Aaron Mattes and the Mattes Method

very special, he started working on my legs and to be honest I did not think it possible to put them in such places but we did and then Aaron worked on my arms and neck. I had polio in 1948 and there are muscles in my arms that have not worked since then, but after Aaron working on them we could identify some muscle movement. This has to be worked on but the possibilities are that in time I could regain some upper arm movement as up to now I have only been experiencing muscle depreciation. To me this definite reversal of what up to now has been an inevitable downward trend has given me new hope and I can expect my mobility to, at least, not depreciate as quickly as I had expected.

The treatment is not exactly painful but very nearly is, by that I mean you are about to yell out (each stretch is only held for 1.5 seconds) and the pressure is taken off and all is well again. Then the same movement is repeated, but just a little further. Each stretch is repeated about 10 times and at the end of each exercise, the limb is so much

more flexible and free of any stiffness.

I had several sessions with Aaron and each time I was pleasantly surprised with the increased mobility I had. After the treatment I drove off in my car only to realise that the mirrors needed to be adjusted as I was sitting a couple of inches higher. I also find walking much easier now I am more upright and my neck is in a better position. I did not realise how badly I was walking before I had the treatment but friends have noticed the difference and that is very satisfying. I suppose they should have said something before about how badly I was walking, but that's not what we do is it?

Pauline my wife helps me with the daily exercises that are necessary to maintain the regained mobility but there are several little stretches that I am able to do while sitting in my car at traffic lights or in the inevitable jams we all have to put up with. I expect other drivers think I am a bit mad but that's nothing new to me.

Robin Butler [Membership Secretary]
In my youth I was a keen boy scout and our motto was and still is be prepared.

Well our recent visit to the AGM and our stay at the Ibis hotel brought it all back. Two years ago we were in the same hotel for the AGM and at 1.30 am the fire alarm went off. I had to put on my trousers and my boots to enable me to walk. All this took several minutes. This time Pauline and I thought let's be

Be Prepared

prepared so we went equipped for the alarm to go off, with jogger bottoms and a pair of slippers. We did this a little tongue in cheek as we did not really expect it to happen again, but at about 2.30 am. it did. We assumed it to be a false alarm but what the heck, we were

ready for it and in a matter of seconds we were on our way out to the car park.

There was no panic and everyone, despite being so rudely awoken, was in a fairly jovial mood, now standing out in the car park. Hamish, our youngest member, carried by his dad, was getting a bit chilly as the wind was quite keen, so we sat him in my car out of the cold. In a few minutes the Fire Brigade arrived, this brought a comment from Hamish, who on seeing the blue lights wanted to be lifted out of the car. He said, "How cool is that". I thought, well it was a worth while exercise just to let Hamish see the fire engines in action, fortunately just blue lights and not the full fire and rescue bit.

Any ideas what we should do if we stay at the Ibis Hotel again? Well I think we shall go prepared again in case third time is not lucky.

Robin Butler [Membership Secretary]

I'd like to thank Hilary, her lovely daughter, Alison, the committee, Aaron Mattes and everyone else who helped organise and run this year's AGM. It was a long haul up from the south coast but I found the meetings and discussions, and the neck stretching by Aaron, interesting and worthwhile. I aim to try out the stretching exercises on all parts of my body, probably with my husband's help, and will give my physiotherapist a call this week.

I have been concerned at the shortening of my tendons and muscles for some time and this has given me a kick-start.

It was good to meet other members and to put faces to names - always interesting! Young Hamish is a poppet, 6 years old now, and by all accounts going great guns under the hands of Aaron this weekend.

Those of us staying over had a shock

Saturday night when the fire alarm sounded in the hotel at 2.10am. Some wit thought it would be fun to smash the glass and set off the alarm, then leg it. Although I am a wheelchair user and stairs are a no-no except in cases of fire, I didn't think to ask for a ground floor room when booking. We all had to vacate our rooms and gather outside, until the fire brigade declared all was safe. On this occasion my husband went down on his own to assess the situation while I waited on the landing. A young lad on night duty rushed up to say I was safe where I was, luckily, but I was very touched at the many offers of help getting me down the stairs.

This was my first fire alarm and it was scary for a while. I have learned a lesson.....ground floor only in future even if offered a room opposite the lift.

Anne
anne87@BTINTERNET.COM

FOR SALE

**Book—Active Isolated Stretching:
The Mattes Method [1]**

176 pages with photos—£22.50 P&P

**Book—Specific Stretching for Everyone
By Aaron Mattes [1]**

60 pages with photographs—£10 P&P

Ropes [2] - £7.00 each P&P.

**OAKLAND KAISER CONFERENCE
POST POLIO SYNDROME
AGING WITH A DISABILITY**

September 19, 2003

**Notes by Gladys Swensrud,
San Diego**

Afternoon Session.

[Morning session in last newsletter]

The conference on September 19, 2003, was held at the City Center Marriott in Oakland, California. The purpose was to bring health professionals together with Polio survivors for a day of information sharing and learning about the disorder of Post Polio Syndrome.

Report continues.

The afternoon session was jam packed with information, and it closely followed the syllabus that each attendee received. Because there was so much Post Polio territory to cover and discuss, time, throughout the conference, was an issue. Because of that some of the syllabus items were quickly brushed over. Because of the completeness of the syllabus information, I have chosen to include some of it directly into this report. Drugs that might work, or at least held some hope of doing so, fell into that category. I have chosen to include this first because the afternoon session continued with a quick review of this subject. Please bear with me on this lengthy info because it is important information for us to know!

The following drug review is a direct quote from the syllabus:

Therapeutic Trials in PPS

Selegiline (Deprenyl), a neuroprotective agent primarily used for the treatment of Parkinson's disease, may warrant further study on the basis of initial results from case reports. Two cases showed that selegiline produced an improvement in PPS symptoms; this

improvement ended after the drug was discontinued.

Bromocriptine mesylate (Parlodel), a dopamine receptor agonist used to treat conditions such as Parkinson's disease, was evaluated in 5 patients with PPS and produced improvements in fatigue symptoms in 3 of the participants.

(Dr. Sandel said to the group that she is interested in Dopamine agents, and she sees some promise here for fatigue. The greater issue here is that fatigue must be defined.)

The anticholinesterase pyridostigmine (Mestinon), which is already approved for treatment of myasthenia gravis, has demonstrated some promise in relieving the symptoms of weakness and fatigue in patients with PPS. In an open trial of 17 patients taking a daily dose of 180 mg pyridostigmine, a significant relationship was found between subjective fatigue response to pyridostigmine and improvement in neuromuscular junction transmission after administration of edrophonium (a short-acting anticholinesterase similar to pyridostigmine.) In another open trial with 27 patients, 59% who received pyridostigmine reported an improvement in fatigue with the medication and requested continuation of treatment. In addition, a double-blind placebo-controlled, crossover trial demonstrated improvements in some objective measures of strength and subjective measures of fatigue when pyridostigmine, 180 mg/day, was given to 27 patients. Adverse events, including loose stool and intestinal cramps, blurred vision, increased urinary frequency, muscle cramps and fasciculations or muscle twitches, were seen in approximately 50% of patients participating in these three trials.

The ongoing North American Postpoliomyelitis Pyridostigmine Study (NAPPS) is a multicenter, randomized,

double-blind placebo-controlled phase II trial involving 126 patients with PPS. The study is designed to determine the efficacy of pyridostigmine, 180 mg/day, in relieving PPS symptoms using measures of fatigue, muscle strength, and health-related quality of life. NAPPS was also designed to determine the incidence and severity of any side effects associated with pyridostigmine. The study showed no difference between patients who received pyridostigmine and those who received placebo with regard to health-related quality of life, fatigue, and most measures of isometric strength. However, a trend to increase strength in very weak muscles was seen at 6 months with pyridostigmine. The result of no significant difference in outcome measures between patient groups did not correlate with the investigators' clinical impression that the medication appeared to be beneficial in a proportion of patients with PPS.

[Editors note:- I asked Dr. Trojan from the Montreal Neurological Institute at the Jena Conference in Germany in 1998 about this. From LincPIN v2 issue 2—*There have been some drug trials and as many of us are concerned about the immediate suggestion that we take drugs. I asked when should drugs be considered. Dr. Trojan answered and it was confirmed by other doctors on the panel that drugs are only used once all other methods have been tried. A change of lifestyle, the use of aids and assistive devices to conserve energy, and pacing and resting **must be tried first.***— I respectfully suggest that if you find a treatment/aid/assistive device increases your energy levels increase what you do slowly and record this—do not overdo and lose it.]

SPEAKER – Dr. Edward Oppenheimer

Of great interest to me were the presentations on respiratory problems and PPS discussed by Dr. Edward Oppenheimer, a past chief of the

Division of Pulmonary and Critical Care Medicine at the LA Kaiser Permanente Medical Center, and his discussant, Dr. George Grossman, Pulmonologist, Kaiser Medical Center, Vallejo. Dr. Oppenheimer followed the syllabus very closely, assisted by a power point presentation to the same. He first discussed some of the typical patterns of respiratory disorders in polio survivors

- A. Persisting need for assisted ventilation after acute paralytic polio, often for 50+ years
- B. Respiratory and/or bulbar impairments appear 15+ years later and require MV
- C. Sleep disordered breathing appears 15+ years later, with or without hypoventilation**

He then asked the question, "Who is at risk?"

And responded that, "**All polio survivors are at risk.**"

He added that the risk is higher if there was paralytic polio with respiratory or bulbar problems (weakness) during the acute polio illness. New breathing problems were reported by 42% of patients with post polio syndrome; and 88% of those who needed assistance during the acute phase needed assistance again in 3 to 59 years. Breathing problems are especially likely to occur in patients with residual respiratory muscle weakness.

[**Editors note**—if at the time of your polio no bulbar damage was seen/ documented/remembered that does not mean that you did not have some weakness in this area. You could have had up to 44% nerve damage without any clinical weakness being observed— UK Prof. WJW Sharrard 1954 and articles by David Bodian.]

In the discussion of the physiology of the respiratory disorders in PPS, among

the many facts that Dr. Oppenheimer presented, I found particularly interesting the fact that

“Deep stages of sleep worsens respiratory muscle weakness and results in a cascade of event that increase progression of respiratory failure and daytime disability.”

Also of particular interest to my situation was that,

“Sleep disordered breathing (e.g.: OSA, CSA, hypopneas, etc.) are due to bulbar impairment and/or central) brain changes.”

Then came the question, “Is there hypoventilation vs. SDB (Sleep Disorder Breathing) without respiratory muscle weakness?”

He also went through the litany of symptom related to PPS respiratory difficulty, and he noted that these symptoms are often misinterpreted. He also noted that,

“...the very slow progression of motor neuron impairment in PPS may result in early symptoms being overlooked both by the individual and the physician.”

He then added a quote by Laghi and Tobin (2003),

“Respiratory muscle weakness frequently goes undetected in patients with neuromuscular disease until ventilatory failure is precipitated by aspiration pneumonia or cor pulmonale. Diagnosis is delayed because limb muscle weakness prevents patients from exceeding their limited ventilatory capacity. A few patients develop severe respiratory muscle weakness despite little or no peripheral

muscle weakness.”

Dr. Oppenheimer added to the respiratory symptoms list that,

“Central (brain) changes may contribute: such as central dysregulation of breathing and decreased respiratory drive.”

Tests that may be helpful for baseline evaluation and for follow-up:

- § Spirometry to include slow VC – upright and supine; and MVV
- § MIF and MEF (Pimax and Pemax)
- § Peak cough flow (PCF)
- § Pulse oximetry and (occasionally) ABG
- § Echocardiogram
- § Overnight home oximetry monitoring – if needed
- § Sleep study if no hypoventilation but question of sleep apnea or other SDB

And that,

“Patients with diaphragmatic weakness are at particular risk of developing hypoventilation during rapid eye movement (REM) sleep.”

Dr. Oppenheimer cautioned that sleep disorders occur frequently in patients with PPS and it is important to determine if these are due to respiratory insufficiency/chronic alveolar hypoventilation (CAH) or sleep apnea and other sleep disordered breathing (SDB) with CAH. Sleep apnea may be central, obstructive, or mixed – it is treated similarly to sleep apnea seen in patients without PPS. He also noted that if breathing problems are not recognized, diagnosed and treated, the PPS patient might be susceptible to serious complications and death (as also noted by Frisca Yan-go in 1999).

He told the audience that a survivor who is having breathing problems has four

choices:

1. Decline assisted ventilation and use only palliative care
2. Use only Noninvasive Positive Pressure Ventilation (NPPV), such as BiPAP or VPAP
3. Use assisted ventilation only for acute episodes, such as pneumonia – or
4. Use whatever ventilation support is needed for long-term survival, including trach positive pressure ventilation if needed.

The goals of noninvasive ventilation include to relieve symptoms, normalize sleep, improve QOL, improve survival, improve cognitive function, survive acute respiratory infections without crisis, avoid hospitalizations, maintain SaO₂ greater or equal to 95% without added oxygen.

Because of Respiratory Muscle Fatigue, it is valuable to start ventilation early in the condition of PPS. Some advantages of starting MV (Mechanical Ventilation) “earlier” if related symptoms are present are

- 1) Using a night breathing machine is never detrimental,
- 2) it provides experience with noninvasive ventilatory equipment (such as BiPAP or VPAP) before a crisis occurs,
- 3) the patient will then have the ability to survive an acute respiratory infection if it does develop. And,
- 4) this also provides a “hands on” trial of the equipment to help decision making (like a test drive).

As a side note, Dr. Oppenheimer added that all patients receiving breathing assistance should have all three breathing options with their machine. They need a mask, nose device and a mouthpiece for when patients have a cold or times when they have nose-breathing difficulties.

He also said that a CPAP should not be used for sleep disorders with hypoventilation.

[Editors note– Dr. Oppenheimer offered to answer any questions our members might have, so write or email us with these]

Discussant – Dr. George Grossman

Dr. Grossman had an opportunity to answer a couple of questions, but the one most important to me was one in which someone in the audience asked about asthma and it's relationship to PPS.

Dr. Grossman was emphatic that Asthma and night breathing problems *could*, indeed, be both related to PPS.

[Another top PPS Respiratory Doctor
John R Bach, MD.

UMDNJ—New Jersey, USA
www.DoctorBach.com - The Centre for
Non-invasive Mechanical Ventilation
Alternatives and Pulmonary Rehabilitation]

SPEAKER – Dr. Selma Calmes [Polio survivor and Professor of Anaesthesiology]

Dr. Selma Calmes did an EXCELLENT presentation on Anesthetic Agents and other Medication Considerations and Contra-Indications. She went into great detail explaining what kind of anesthesia is best, describing the three types which are general anesthesia (being completely asleep), regional anesthesia (only the part of the body being operated is on anesthesia) or Monitored Anesthesia Care (MAC – the surgeon injects a local anesthesia at the site of surgery and the anesthesiologist sedates and monitors the patient).

One highlight of her talk was that there is fear of regional anesthesia among

post-polio patients. Since it might be spinal (administered in the fluid around the spinal cord) or epidural (given in a potential space before the spinal cord to anesthetize the lower part of the body), there is fear that it will further compromise neurons in an already compromised post-polio spinal cord. Whether the spinal cord is normal or already compromised, she had specific recommendations about the drugs patients could use with the input of their doctor and anesthesiologist if a patient chooses a spinal anesthesia. Dr. Calmes did not, however, go as far as to recommend regional anesthesia for Post Polio patients.

Her surgery suggestions were many, but the ones that applied to breathing were of particular interest to me. In her information, she noted a that, "If a post-polio patient needs assisted ventilation for daily living, obviously this will have to continue postop, and ventilatory requirements may get worse immediately postop. These patients usually use negative pressure or non-invasive methods of ventilation, unfamiliar techniques for modern intensivists, who usually manage postoperative ventilation only in hospitalized patients.

Planning for these patients needs to involve whoever is managing the patient's ventilatory needs." ALSO, "Polio patients who were not in an iron lung can also have laryngeal and swallowing problems and may need preop ENT evaluation also. Evaluating preoperatively can eliminate some unplanned problems postop.

[**Editors note:-** remember Prof. Calmes is a Polio Survivor herself and has considerable knowledge of polio and PPS and takes this into consideration. Many health professionals do not have this knowledge, or level of knowledge and understanding.

We strongly recommend that when discussing anaesthesia with health professionals you are polite but firm in ensuring that your concerns are listened to. If you take medical articles with you try highlighting a few paragraphs that you would like them to read in case they do not have time to read it all. Tell your assigned nurse if you are still not happy and why.

Members are reporting that this is helping and one member that all the staff on the ward had read all the articles provided and asked many questions to increase their knowledge.]

The remainder of the afternoon session was devoted to Rehabilitation. Involved in the team discussions were physical therapists (which discussed such things as gait, balance, and bracing), a Speech Therapist who talked about Dysphagia, Cognition and Speech related issues, and an exceptionally good occupational therapist, Grace Young, who herself is a polio survivor, that addressed issues of daily function and living.

A brief outline of Grace Young's information was as follows:

A. Use your body efficiently

1. Use good posture
2. Correct seating is critical
3. Sit whenever possible
4. Use correct methods for lifting
5. Use mechanical help for carrying (i.e. in carts)

B. Protecting your joints

1. Use the largest joints available for any activity.
2. The joints closest to the body are the largest and strongest
3. Maintaining joints in one position causes muscles to fatigue.
4. **Prevent pressure on the thumb**

side of your fingers, which pushes the fingers into a deforming position.

C. Rest, Pacing and Timing

1. Rest at least one hour a day.
2. Break up stressful activities such as vacuuming into work 30 minutes/rest 15 minutes/work 30 minutes/rest 15 minutes...
3. Use a timer to be sure that you aren't over estimating the time that you are working.
4. Pace yourself – It is tempting to overdo on your good days, but you'll be more productive over-all if you plan ahead.
5. Alternate light and heavy activities throughout the day. Don't do a heavy activity if you are going out in the evening.
6. Timing can make a difference in how you feel. You have different levels of pain and fatigue at various times of the day. Plan activities accordingly.

D. Home Modifications

1. Correct work heights preserve energy
2. Organize your kitchen
3. Throughout the house:
4. Store everyday dishes in stacks of their own kind.
5. Vinyl coated wire racks preserve space and energy by limiting lifting.
6. Use lever handles on interior doors and for bathroom faucets.
7. Eliminate stairs.
8. Remove thresholds or install a gentle sloping beveled ramp.
9. Enlarge doorways with Swing-Clear hinges.
10. Automate your home.
11. X-10 technology works through the existing AC wire in your house, gives automatic or remote control lights, heating/cooling, audio, videos, drapes, door locks, alarm system, pet feeder, and hundreds of other devices.

E. Simplify your work

1. Don't put away the most frequently used dishes, pans or skillets
2. Store towels, sheets, and pillowcases in each room where they are used instead of a central linen closet.
3. Put duplicate supplies in each area where used.
4. Prepare double recipes and freeze half for use at another time.
5. Do chores the same way each time. Repetition increases efficiency.
6. When shopping, have groceries bagged according to category to simplify putting items away.

F. Use energy-efficient equipment

1. Reachers with a locking device
2. Electric knife for hard cheese, vegetables, fruits, etc.
3. Cordless, lightweight can opener by Black and Decker
4. Correlle [Pyrex] dishes instead of stoneware
5. Lightweight non-stick skillets

As you can tell, this was an enlightened presenter since she was writing from the perspective of a handicapped person who lives these limitations herself.

The remaining time was devoted to Rehabilitation Interventions in the Vocational Setting. The two presenters in this area were Ana Verran and Jeff Symons of Project Threshold. Project Threshold helps individuals with physical disabilities solve task performance problems through the use of assistive technology or environmental modifications. Individuals who are having difficulties at work, at school, or at home with independent living skills are candidates for the services of Project Threshold.

In their presentations, they covered the issues of on the job modifications for

disabled workers who choose to continue working in spite of their handicaps and what equipment modifications are available to make their jobs easier.

I would rate this conference as an A+! It had all the components to make such an event successful. The speakers were highly rated professionals, outstanding in their respective fields. There was information available from which everyone could learn. Whether the attendee was there as a learning professional, an informed Post Polio Survivor or a newly diagnosed Post Polio survivor, the information was current and well delivered.

[Editors note: Kaiser Permanente Physiotherapist Anne von Reiche made a very important statement at the start of her presentation,

**'when I greet my patients
I tell them what my expectation
of the appointment
is going to be'.**

I would recommend all Polio survivors to take note of this and try greeting their next health professional as follows:-

'Good morning Dr. Y, thank you for seeing me to..... About..... For the results of my etc.

[Editors note—again my thanks to Gladys Swensrud from San Diego for allowing us to use her comprehensive

report. As I was speaking myself I did not have the time or energy to take notes of this quantity and quality].

It is with sadness that I have to report the death of member Lynn Singleton—a very gutsy lady—who I met because she was sitting next to someone, at a meeting in the south of England, who had my email address. We emailed for a few months and then Lynn agreed to come with me to the States for the PPS Conference in Toronto. We met for the first time at Heathrow Airport and travelled over 3,000 miles by hire car from New York to Toronto and back again visiting with PPSers on the way. My most favourite memory is when staying with Dr. Henry Holland. On the morning of the 4th July he asked us 'Are you sure you gals want to go to the celebrations tonight?' 'Of course, we do, why do you ask?' 'Well we did beat you', said Dr. Henry with a huge smile on his face. Lynn immediately came back with a twinkle in her eye 'Welllll we have had a couple of altercations with the Germans since then'. We went and the final frame of the firework display saw the whole sky above us one mass of red white and blue starbursts.

NEW PPS BOOK

**Another Informative Guide
to Coping with Post-Polio Symptoms
Review by Australian Member
Dr. Mary Westbrook,**

Post-Polio Syndrome: A Guide for Polio Survivors and their Families by **Julie Silver MD**, director of the International Center for Polio in Framingham, Massachusetts was recently published by Yale University Press. Dr Silver's mother, brother and grandfather all contracted polio so the disease has always been part of her life.

Her book comes three years after Lauro Halstead's *Managing Post-Polio: A Guide to Living Well with Post-Polio Syndrome*, which has been available to Network members for several years at a special rate. Inevitably the books will be compared. Silver's book of 280 pages is 40 pages longer than Halstead's and has 26 chapters compared to Halstead's 13. In Silver's book you can find specific chapters on virtually any post-polio relevant topic e.g. swallowing issues, nutrition and weight, respiratory problems, prevailing over pain, sex and intimacy, preventing falls, controlling cold intolerance, EMGs and bracing, shoes and assistive devices. It's harder to find relevant material in Halstead's book which lacks the excellent cross-referencing between chapters that Silver employs.

If you want a practical, clear instructional guide you may prefer Silver. She gives *definite* doctor's orders on dealing with post-polio symptoms but also regularly instructs readers to seek their doctors' advice. If only there were Dr Silver clones around Australia that polio survivors could easily consult! If you prefer a more in depth discursive style which gives greater emphasis to the physiological causes and

psychosocial aspects of post-polio then Halstead is your book.

Silver highlights many important practical issues that rarely receive attention. In the chapter *Preserving and Protecting Your Arms* Silver argues that *your arms are your key to independence. Think about it. If you cannot use your legs at all, you can still remain totally independent—living alone, bathing yourself, feeding yourself, driving a car. But if you cannot use your arms at all, you immediately cease to be independent and must rely on others to help you with the most routine (and intimate) activities of daily living.* She outlines three major causes of arm problems.

Firstly, there is post-polio muscle pain, an aching, cramping, burning or tired feeling in the muscles rather than the joints. It often occurs at night or after activity. It indicates overuse and arms should be rested as much as possible.

Secondly, there are soft tissue injuries such as muscle and ligament strains, tendonitis and bursitis. *Often these injuries occur in the arms from repetitive activities such as using a computer, chopping vegetables, knitting...In polio survivors these types of soft-tissue injury occur frequently and often without an obvious reason. This is because many polio survivors have some upper body weakness (which may be subtle) that makes their arms more susceptible to injury. Also, polio survivors who have decreased lower-body strength tend to rely on their arms to assist them with mobility (as in getting up from a chair).* She urges medical, not self, diagnosis and treatment to avoid further and permanent weakness. Treatment may include avoidance of activities that exacerbate symptoms, ice, heat, splints, physiotherapy, occupational therapy, injections, medication and very occasionally surgery.

Thirdly, there is biomechanical pain that usually presents as joint or neck pain. Silver says that such biomechanical pain is often attributed to arthritis and thought to be untreatable. Though arthritis may be present it may not be the major source of the pain. She has found that polio survivors frequently develop neck pain and headaches at the back of their heads due partly to poor posture and muscular strain. *Initial treatment may include improving one's sitting posture and avoiding neck strain, physical therapy, massage, heat oral medications, and topical creams. If these treatments fail, injections may be useful.*

The chapter *Keeping Bones Healthy and Strong* differentiates generalised and localised osteoporosis in polio survivors. The latter often occurs in limbs that are paralysed or very weak. Such limbs are particularly vulnerable to fractures. Some survivors, like the able-bodied population, may develop generalised osteoporosis, which affects bones throughout the skeleton. Silver has little advice on localised osteoporosis (probably because it is not well understood) but she discusses what can be done about generalised osteoporosis. She emphasises the importance of early diagnosis. In Australia this is often done by bone density scans of the spine and one hip. **However a polio survivor needs to explain to the doctor about polio related localised osteoporosis or an inaccurate assessment may result.** In my case I insisted that both hips be scanned. The hip of my weaker leg is very osteoporotic but the hip of the other leg and spine have better than average bone density.

Silver presents a practical 10-step plan for energy conservation and pacing. She quotes polio survivor Hugh Gallagher: *Growing old with polio is a matter of economics: cost/benefit analysis. How much expenditure of*

limited energy for how much satisfaction. Minimize the exertion; maximize the pleasure. Silver suggests you start by keeping a log of activities for three days. Also document episodes of pain and fatigue, the time they occur and your activities around this time. Highlight low, moderate and high energy activities in different colours. Consider how high energy activities can be modified to become lower energy tasks. Lots of examples are given. Silver cites Josephine, a polio survivor, who is known to her family and friends as the *One-a-Day Girl* because she will only schedule one major outing each day. When friends contact her they ask, *Is your One-a-Day booked on such-and-such a day?*

In the chapter on exercise considerable emphasis is given to flexibility exercises. These are a critical *but often neglected part of any exercise program*. They can dramatically increase range of motion, and reduce pain and degree of disability. Again diagrammatic examples are given. Silver talks about reserve strength, which is something we count on to *sustain us as we age. In polio survivors, it is often markedly diminished and contributes to increasing disability that may present without much warning.* An example of reserve strength is given. *A certain threshold of strength is needed to do any activity. Imagine that it takes 30 percent of your total arm strength to lift a gallon of milk. This means that 30 percent is the threshold of strength your arm needs to lift the milk: if your strength falls below that mark you are unable to lift the milk. If you had polio and lost 50 percent of your strength, this is still an easy task to accomplish. ...you have 20 percent in reserve. But suppose through normal aging, disuse, overuse, and perhaps some other factors, you lose 1 to 2 percent of your arm strength each year...when the amount of strength you have lost starts to get close to 30 percent, you are likely to notice that*

lifting a gallon of milk is becoming more difficult...and if the next year you drop to 29 percent, you will go from being able to lift the milk to not being able to lift it. Silver calls this the all-of-a-sudden phenomenon because polio patients often report such losses. The original bout with polio reduced our reserve strength and this contributes to the accelerated (compared to our able-bodied counterparts) loss of strength we experience as we age.

Some noteworthy comments from the book include: *“A syndrome is a collection of symptoms that characteristically occur together... Because syndromes do not have specific tests that can unquestionably identify them, they are subject to interpretation. Often their validity is challenged within the medical community. PPS is no exception... Generally it is inexperienced health-care providers, unfamiliar with treating polio survivors, who dismiss the syndrome.*

Those of us who routinely participate in the care of polio survivors have no doubt that PPS is real”. “Polio truly is a chronic illness that lasts a lifetime”. “It is important to recognize that some people may not have a classic history of polio but may indeed have had the disease. Moreover some of these individuals may be experiencing PPS”.

The book is available from Internet bookshops barnesandnoble.com and amazon.com for \$US22 plus handling.

Any of your clients have a history of Polio?

Before you answer...

During the initial acute stage of poliomyelitis infection, a considerable proportion of motor cells may be damaged or destroyed without clinical paralysis presenting. The nerve supply to some muscles, especially those supplied by short cell columns, may have been diminished by up to 60 per cent.

Cases of 'non-paralytic' polio (and even cases with mild paralysis) may never have been diagnosed as having polio and may not even know they had polio. Nevertheless, a degree of permanent damage may have been sustained.

The surviving motor neurons develop additional axon sprouts to 'orphaned' muscle fibers (reinnervation). This process can lead to apparent full recovery, even in cases of clinical paralysis. However, the increased workload results in a continuous cycle of denervation and reinnervation. Ultimately, after 15 years or more, the cycle begins to break down and may present as new muscle weakness or fatigue - the late effects of polio.

Physiotherapy protocols for other medical conditions presenting may initiate or worsen new muscle weakness in cases also having a history of polio.

Further reading material specifically selected for this CSP journal supplement can be found at <http://www.lincolnshirepostpolio.org.uk/csp/>



The Lincolnshire Post-Polio Network
A Post-Polio Information Service for Polio Survivors and Medical Professionals
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Upside Down View Number 2

**From the Texas One Armed Bandit
Ellen.riddle@sbcglobal.net**

Like many PPSers I have acquired my power chair. It's a deep maroon color (quickie's idea of red) has all sorts of bells and whistles that really do make my life better. That is when I use it.

Like many of us it is amazing how I can find reasons not to use it.

My favorite reason is that I'm just running into the store for a few minutes. It will take longer to get it out of the van. Even though invariably I end up going up and down more aisles than I planned on and/or standing in a long checkout line wondering why I didn't get my chair. I really do know better.

Then there is the next reason. I feel good today; it won't hurt me to walk a bit. You know, get a bit of exercise. I can see y'all shaking your heads and in fact, inside deep somewhere I am right there with you. I know better, but... before I think again I'm off and walking.

I've asked regular polio's about this. I've asked why it is so difficult to just use it. Why is it so hard to accept when I know its benefits? Most just smile at me and say it's simply because I can still walk and stand.

So here are the reasons I've typed up and carry with me to remind me why it's a better idea to use my wheels.

1. Almost totally pain free. Literally. When I use my wheels my legs ache a lot less, my side hurts less as I'm not trying to hold it up; and even my shoulders don't hurt or go numb.
2. An absence of the sudden fatigue wall. If anything when I use my chair those with me get tired long before I do. This means no un-reasonable crabbiness, frustration or anger at finding I have to stop sooner than I want to.
3. I will have the energy to read, write, yes, to think.
4. I am able to do the things I had given up. Take long walks, enjoying them. I can even hike trails in my wheels.
5. I can carry more. I have a bag in back I can fill up, plus put bags on the handles and am amazed at how many things I can carry on my chair. Being an upside down polio this is a big advantage as I never could carry much using only one arm.

Hopefully this list will help me be kinder and gentler to myself in 2004. After all I want to have the choice of walking/standing when it is really worth it. And, I definitely don't want to lose the use of my good arm. It is amazing how using my wheels also helps my arm.

Think about it. When I am using my wheels I carry things on my lap. Plus, others offer to help me when I need it. When I walk with my cane the perception is that I don't need any help so I struggle to carry things I really shouldn't.

**From Member Patricia Bamford.
Patricia.Bamford@phonecoop.coop**

During the past year, non related illness has been exacerbated by PPS which has brought new challenges to health challenges. One of the biggest

Radio Days and Old Time Radio

felt losses was when text/print reading became too tiring on the eye muscles for anything but shortish periods of time.

The big turnaround in coping for me, was discovering the world of audio listening. I would certainly say that my recent improving state, after a year's really poor health, was largely down to discovering the world of audio. And laughter certainly is the best medicine. Pain and worry depletes - laughter energises.

"Listening in" on several mediums has become a new and lively interest, a grand source of mental stimulus; feeds the creative thought processes with great narrative and drama, gives many laughter opportunities which works very neatly in helping switch the mind off pain and the problems that go with it. And in expanding and discovering the diversity of our world.

If one lives alone, then audio is a great partner; and new and old comedy radio shows are wonderful for relieving tension in tired muscles and generating new perspective when things feel particularly low. It's a great journey and encompasses being able to access library C.D.'s and spoken word cassettes, Radio, Digital Radio and internet radio.

As well as local BBC and commercial AM stations, there are of course BBC radios 1, 2, 3, 4, and 5. Radio 2 and 4 being especially good for comedy shows, discussion, news and drama.

"The Radio Times, a weekly TV and radio programmes listings magazine, covers local, national and some commercial radio stations as well as internet and digital. Through its occasional articles on internet and digital stations, it literally opened up the world of radio to me. A growing number of commercial stations are going digital but it was the BBC who pioneered digital broadcasting, and they have so far produced 7 new stations. On DAB (Digital Audio Broadcasting) radio sets, the sound is very clear; no static. Digital sets are being manufactured by many brands and offer several different features. The newest sets offer radio on demand; where you get to choose when you listen to a listed programme. Prices start from about £90 and

are reducing the more popular DAB becomes. Choice of stations is growing and opening up all the time. Some digital radio stations can be listened to through channels on TV set-top boxes, like BBC Freeview and Sky. Of the 7 new BBC digital stations, 2 are speech based..." There are many music station and Saga Radio has 1 or 2 while more and more stations are coming on stream.

Five of the BBC DAB stations offer music and two are spoken word stations. BBC7 is the laughter station; offering old classics like the Goon Show, Hancock, Round the Horn, Clithero Kid, and a whole range of new and old comedy shows. Caught Paul Temple and Journey Into Space the other day and their theme tunes took me back to catching them first time round, as a child. Twice a day they have two hours for children's listening. Lots of fun and a good energy station for a blue, slow day.

DAB's other speech station is BBC "oneword". They offer a lot of drama, reading instalments of bestseller books, discussion with authors, and some evenings, have slots for Vintage radio - airing some of the old American favourites, like Gunsmoke and Jack Benny. At the back of the Radio Times, they cram all the Digital programme listings onto one page; very difficult to read the small print, but they run the same format everyday until a series or story is finished. Every week they suggest a new internet station to give a try to, one of which was www.702talk.com, Johannesburg, and is a good listen.

If you have a computer, sound card, speakers and are connected to the internet, then the planet's radio stations are literally a world in your ear. To access the radio stations you need to install either, BBC Player, Microsoft Media Player, or Real One Player UK. These are all free and can be downloaded when you find them on your search engine install them. To do this you have to go through the step-by-step procedure to log on by getting an "account" with them, which is just a registering process and no fees are involved. You cannot activate radio sites sound until you complete log-in with one of the above (or other) Players.

Radio Times very best tip was logging on to www.live365.com. It tells you that it's the worlds largest internet radio network. Some of its stations are premium stations where you pay a small monthly fee to access, but many are free and from around the world. Most are in America and offer so many genres, e.g. all sorts of music, spoken word, news, talk, religious, new age, alternative, and one of my favourites, old American radio shows and comedy. (Again like on the BBC media player, on 365 you have to go through and complete the registration process (free) and only after logging-in with them with your password confirmed, will you be able to tune in).

There are a staggering amount of American net stations streaming out, on tape, through-out the day,

all the well known (and little known) comedy shows and serials of America's golden radio years, the 1940's and '50's.

Anything which can switch us over from pain and exhaustion zones into intrigued interest, laugh-out-loud and pure feel good zones has to be a great and good thing.

One of my favourite stations for lightening the pain and fatigue bouts is www.otrnow.com which is the site for Old Time Radio Now station. At the top of their Homepage there's a red "click here" spot for getting large print. It's not only useful for this, but tells you (or someone who can help you) how to sign-in to install the free live365 player). OTR is also free and is streamed from the US. The site owner is a genuine lover and collector of old time American radio. His site says he has a collection of over 40,000 shows (some of which you can download). You can be transported into a world of Burns & Allen, Hope & Crosby, Milton Berle, Groucho, Martin & Lewis etc etc. And listen to radio drama featuring Cary Grant, Gregory Peck, Marlene Dietrich, Boris Karloff, Barbara Stanwyck, Kirk Douglas/Vincent Price. "The Great Detectives -Dagnet/Philip Marlow/Ellery Queen". Great Westerns -Gunsmoke/Paladin/Mat Dillon/ Hopalong Cassidy/the Cisco Kid/Lone Ranger". And of course the great serials like Sherlock Holmes/ The Flacon and Orson Welles in The Shadow, etc., Fibber McGee and Mystery Playhouse etc.

Another site to bookmark on your favourites list is www.UKradiostations.com which gives over 200 national and local UK stations on the internet.

Non computer audio sources outside of radio are the libraries of course, who are adding more and more audiobooks titles on C.D. and cassette, to their stock. And two charities supply audio books on cassette by post:- Listening Books are at 0207- 407 - 9417. They charge an initial fee on joining and then an annual fee. But they sometimes wave this if finances are a difficulty.

Calibre (Cassette Library) are on 01296 - 432 - 339. Don't think they charge a fee. (If you know someone with a computer, and get Listening Books and the Calibre site on the search engine, you will find their cassette book titles catalogues).

If you're not already enjoying the world of audio, hope you'll give it a try and receive some of the pleasures and sheer fun that can be had from some of the above sources.

Hope some of you will share your favourite radio stations, internet radio sites or audio sources, good listening...

PS. Web links for digital radio=
www.Digitalradionow.com
www.ukdigitalradio.com
www.bbc.co.uk/digitalradio

Web audio and radio links =
www.live365.com
www.brsmedia.com
<http://windowsmedia.com/radiotuner>
And for downloading Real One Player, UK
www.real.co.uk/guide

Members Email List.—If you are a member and have an email address then you can subscribe to our Members Email Discussion List. You need to tell us your email address and that you wish to subscribe. Note we do not do this automatically when we receive your membership form with your email address on it as not everyone wishes to join. Once we have subscribed you we will send you an email with all the information on how this works. If any member has something they want to say to others then they email the list address with this and all others subscribed can read it. There is no obligation to reply but if you want to you can and all will read your reply. The discussion on muscle spasms has been very interesting. See page 5.

Our Website Online Medical Article Library contains over 100 medical articles in full text that you can read and/or print if you wish. We provide a search engine on the Website so that you can enter a word or phrase and see if that appears in the content on our site. E.g. if you wanted to see if there was anything relating to knees this produced 65 results with the word knee or knees. As an example the first one is:-

1. Lincolnshire Post-Polio Library [Findings in Post-Poliomyelitis Syndrome] •••
Lincolnshire Post-Polio Library [Findings in Post-Poliomyelitis Syndrome] The purpose of this study was to identify overuse of muscles and other alterations...
...of the foot with the floor, temporal-spatial parameters, and motion of the **knee** and ankle were recorded. The principal mechanisms of substitution for a...
...(twelve patients); and avoidance of loading-response flexion of the **knee** (five patients). Most patients used more than one method of substitution. These...
...It is well known that the quadriceps stabilizes the **knee** as the limb is loaded: less recognized is the action of the muscles of the calf particularly...
73% Fri, 17 Mar 2000 01:15:20 GMT 54312 bytes <http://www.ott.zynet.co.uk/polio/lincolnshire/library/perry/findingsinpps.html>

Other Polio/Post Polio Organisations - UK and Eire.

The Scottish Post Polio Network, sppn@sppn.org
www.musselburgh.demon.co.uk/sppn

Post Polio Support Group of Ireland
Carmichael Centre, North Brunswick Street, Dublin 7
+353—873 0338 info@ppsg.ie

The British Polio Fellowship, Ground Floor, Unit A, Eagle Office Centre. The Runway
South Ruislip, Middlesex. HA4 6SE, UK
Tel (FreePhone): 0800 0180586 Fax: +44 (0)20 8842 0555 Email: info@britishpolio.org
www.britishpolio.org/

Post-PolioUK (formerly Leicestershire Post Polio Network)
Phone No. (0116) 220-9188 Fax (0116) 224-8810 E-mail: polio.uk@poliouk.org
www.post-poliouk.org
Please reply to 34 Tyler Court, Jaffray Rd., Erdington, Birmingham B24 8AY

Post Polio Health International

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<i>April</i>	200	250
<i>May</i>	255	325
<i>June ~ August</i>	300	340
<i>September</i>	265	325
<i>October</i>	200	250
<i>Nov & Dec</i>	175	210

For more information contact the Duty Manager at:

The Lantern Hotel
54 Shelley Road
Worthing
West Sussex BN11 4BX
Tel: 0845 450 0227
Fax :0845 450 0228
(Local call rates)

LincsPPN and British Polio Fellowship Member Ann Stevens— Annstevensnco@aol.com produced the above advert and requested its inclusion in the LincPIN.