The Lincolnshire Post-Polio Network
POST-POLIO INFORMATION SERVICE
NETWORKING

The LincPIN

The Lincolnshire Post-Polio Information Newsletter

Volume 2 - Issue No. 8 - December 1999

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The Lincolnshire Post Polio Network

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All our Members and their Families
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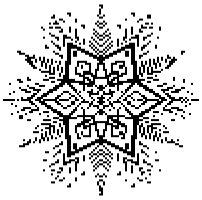
A Happy New Millenium



CHRISTMAS CARD SCRAPBOOK

Today
a light snow fell
dusting
everything white
from
my living room window
the neighbor's small house
comes into sight
cunningly framed
by fir boughs
and snow-frosted hedges
tiny, twinkling
Christmas tree lights
fill one window
their chimney puffs smoke
welcoming father
who trudges into sight
with a peddler's pack
bulging over one shoulder
pulling a child-laden sled
while their spotted dog
sporting a red bow
dances alongside
as they reach the
front walk
the whole house lights up
red! yellow! blue!
green! orange! white!
along the snow-laden rooftop
I think this is a living Christmas card
to be pasted into my
scrapbook of memories.

Vonnejo@AOL.COM
LaVonne Schoneman, HOW TO COPE books

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Online Reading Navigation Tip - Selecting Cathedral logo will return you to the above contents.

Remember the opinions expressed are those of the individual writer(s) and do not necessarily constitute an endorsement or approval by the Lincolnshire Post-Polio Network. ***ALWAYS*** *consult your doctor before trying anything recommended in this or any other publication.*

Editorial by Hilary Hallam

Much has happened in the last two months, although it only seems like a few weeks. To bring you up to date. We have added new articles to our WebSite (pages 21-22). We have attended the first full meeting of the reformed Neuroscience's Group for Lincolnshire. With Councillor Barry Fippard from the Central Lincoln Community Health Council in the Chair, Deborah Jaines from the LHA as organiser and secretary, more neurological support groups represented (others to be invited), other CHC's, and with representatives to join for the next meeting from the PCG's, the Neurological Services and Social Services, we are happy that a positive step has been taken and that future meetings (every three months) will cover all aspects of healthcare and see better services in the future for those with neurological conditions. We would like to express our thanks to David and Anne Proctor of the Scoliosis Association UK who worked very hard to see this failing group reformed in a better format, and to the ME Self Help Group in Lincoln who also stood with us.

Joan Headley the Executive Director of GINI (Gazette International Networking Institute) has written to tell me that the organising committee have accepted my presentation to speak at GINI's Eighth International Post-Polio and Independent Living Conference in St. Louis, Missouri, June 8th - 10th 2000. I look forward to what is going to be an exciting and rewarding experience. Meeting Joan Headley and others at GINI, PPS Specialists, Dorothea Nudelman who wrote Healing the Blues (see page 9), other speakers and most of all Polio Survivors, many of whom I have corresponded with on the Internet, some of whom I have already met.

To take the most advantage of the flight across to the States I am looking to hire a vehicle and visit some more PPS Clinics, PPS Specialists and Groups. I have already been asked if I will give my presentation after the conference at two other venues. If anyone has any spare air miles, or would like to help me raise the necessary sponsorship/funds for this trip then please get in touch.

Marsh Gelbart wrote an article in the Nursing Times (8 - 14th September) on Post-Polio. Part of the article featured one of our members Len Van Zyl. Ken Spooner from Ambroise UK Limited saw the Nursing Times on a coffee table in a hospital and got in touch with Len who now has a new Utx KAFO. Read Len's PPS story page 11 and Maggie's page 10.

Lots of discussion is taking place on polio lists about family relationships and how difficult it is to decide how much to tell your family and friends about how you really are and feel. They also have similar problems in knowing what to ask and what to say. Counselling can help - see articles pages 4 - 7.

Can I please remind members who joined us last November/December that their memberships are due for renewal. Thank you to those who have already sent their fees.

‘No treatment for PPS so no need for Assessment'
If you have been told this it is not true.

Phone calls are coming in from many counties - my GP tells me there is no treatment for PPS so no need to send me for any assessments. So far we have been unable to find out where this advice is coming from.

Firstly there is need for correct assessment by a mutli-disciplinary team to ensure that our muscles are being correctly graded with repetitive and sustaining testing included. We need to be seen doing actions, not just examined lying on a couch.

Secondly, just because we had polio and/or now have a diagnosis of PPS, it does not mean we cannot have or get other conditions as well.

Thirdly, there are many articles on the treatments and aids that should be considered in managing our energy levels e.g. canes, crutches, electric scooter and wheelchairs, Braces, Callipers, Body Supports, Ventilators, Physiotherapy, Hydrotherapy etc.

Read the abstract of the article (Page 21) presented by Mary Westbrook PhD at the International Federation of Physical Medicine and Rehabilitation in Sydney March 1995 entitled Changes in Post-Polio Survivors Over Five Years: Symptoms and Reactions to Treatments.

Also Dr. Ali Arshad has just had the results of his PPS survey in Leeds mostly from British Polio Fellowship Members of the Leeds Branch published in Yorkshire Medicine. He concludes with the statement:

> Rehabilitation Specialists can provide a suitable treatment package and can co-ordinate referrals for physiotherapy, orthotic devices and other interventions. There are also support groups where additional help may be sought.

And read the email from John in Sweden page 7.

If you have not already written to us with detaits of how you have fared in getting assessed, advised and treated and would like to do so, then we would like to hear it, good and bad. We have to prove the need to get Polio Survivors the PPS Clinics and trained PPS personal that are needed. We are told there is no need, there are not enough of us to warrant it. However, in Lincolnshire, and possibly other counties, the Health Authorities do not record which condition you have on their outpatient clinic statistics. Your information could help us and the British Polio Fellowship prove the need.

If you think a request to us has not produced the desired response then we would prefer you to ring and remind us than continue to wait.

May I take this opportunity of wishing you all Seasons Greetings and A Happy New Year / Decade / Century / Millenium.

PSYCHOLOGICAL ISSUES AND FAMILY RELATIONS IN POSTPOLIO SURVIVORS

by Drs. Susan and David O'Grady, Ph.D.

PART 1.

How does post polio syndrome affect survivors and their families emotionally and interpersonally? It was our hope that by talking about these things, you will be better able to understand yourself, what you want and need, why you feel what you feel, and how you can better understand your partners feelings.

Our focus was on communication. How polio survivors can better communicate to their partners and family what the polio experience is like for them, and so partners and family can communicate to the polio survivor what their own experience is like. We all know very well that in human interaction misunderstandings are common. We misread each other, assume things erroneously, fail to listen, and fail to put our thoughts into words.

Many things stand in the way of communication, but when we are successful and do communicate, we naturally feel a great sense of relief at being understood, and this feels good. But more than just making us feel good, we now know, from the results of years of medical research, that expressing feelings and tending to your close personal relationships is good for your health. It helps those with cancer live longer, it diminishes the effects of heart disease, controls hypertension and strengthens the immune system.

The late effects of polio are threatening and upsetting because they change the things people can do and how they do them. Polio survivors who had learned to adjust to the impairments caused by their first illness often quite satisfactorily, are then decades later, unexpectedly faced with new deterioration in functioning. These changes are emotionally upsetting, affect self-image, challenge a person's idea of who he or she is, and push a person into new roles in relation to others roles not necessarily wanted or sought.

Most importantly, you can't do what you used to do. Or, what used to be easy, you now have to work hard to do. Or, what you used to do independently, you now have to have help to do. Or, what you used to do without an adaptive device, can only be done with one. Or, what used to be comfortable to do, you now do only with significant pain. Or, what you used to accomplish in two hours now takes half a day and then you're too tired to do anything else.

In the initial stage of post-polio syndrome there is commonly a period of confusion; new symptoms may be dismissed, minimized, or attributed to something else. Once the true explanation is found, it is common to have a great deal of fear and anger; fear of possible progression of symptoms, fear of the unpredictable nature of the syndrome and fear of how helpless you may become.

And there's anger at being forced to drastically and unexpectedly alter one's lifestyle. People ask, "Why me, or why us?" There is a feeling of being cheated, having already faced the effects of polio and have managed to live with it, now the polio tricked you, robbing you again, forcing more changes.

The old coping strategies of minimizing, overachieving and overcompensating cannot be used in the same way as in the past. Because the physical condition has changed, denial and minimization can be hurtful because now more than ever you need to pay attention to your fatigue level or pain, to avoid exhaustion and worsening the condition. It is a major change to let go of this refusal to give in, of pushing oneself to one's limit.

It is natural to feel a deep sense of loss of one's identity and of abilities. You are forced to accept a new identity, perhaps one you don't like very much. For example, you may feel like a wet blanket who holds everyone back because you can't keep up on excursions, hiking, golf with your buddies. Perhaps in the past you had no physical handicaps or disabilities, that was for other people - but now to your dismay, you find you've joined the club.

A common aspect of post-polio is chronic pain which affects us in many ways. It affects our thoughts, our mood and our relationships. People become more internally focused. Often people feel bad about themselves, inadequate in their usual roles. For example, one may wish to make a dress for a granddaughter, or a gourmet dinner for friends but be hurting too much to do it. This can lead to feelings of guilt and of self-punishment.

Some may feel depressed and discouraged because they can't do the things they used to do.

Pain creates internal stress. Stress in turn affects our perception of pain. When you are feeling down or unhappy, your ability to distract yourself from your pain is decreased. Since the mind and body interact, these emotional reactions lead to increased muscle tension and anxiety, causing physiological changes within the body incompatible with relaxation. You need to learn ways to relax, to regenerate emotionally and physically. Family members may have several styles of coping when dealing with someone with chronic pain. Denial and avoidance is common. You may avoid talking with your partner, pretending not to notice the distress. Others may avoid by taking over their partners responsibilities. These coping strategies are not necessarily bad unless you are unaware of your feelings regarding the change in your partners status.

Why do people hold back from expressing their feelings? Sometimes they are afraid to talk about the current changes as they don't want to draw attention to the fact that the partner is changing.

Many also feel protective of their partner, believing that talking about their own feelings and worries will make their partner feel worse since the partner may already be afraid and demoralized.

Some don't feel they have the right to complain, or resent having to make sacrifices, work harder, do more than the spouse, and give up activities, but they may feel too guilty to express any of these feelings.

Many partners feel frustration at not being able to do more to help, or are frustrated at seeing the polio survivor make mistakes in pushing too hard and not pacing themselves and being unable to stop them.

Loss of control is at the heart of all disabling conditions, and often this loss of control is felt almost as strongly, although differently by the families and friends of the disabled.

PART 2

At the Workshop: What polio survivors had to say, what families had to say.

The group was divided into polio survivors and family members. Each group was asked one question, with discussion lasting 45 minutes. They then reconvened to summarize and discuss what the two groups said. The question posed to each group was:

"What part of the experience of the post-polio syndrome is most difficult to communicate to your spouse/family?"

The Polio Survivors:- by all accounts this turned out to be an intense discussion. Strong feelings were stirred up. Many were moved, some cried. It was clear that the process of confronting the emotions surrounding the experience of post-polio is difficult and painful. Similarly communicating about these feelings to family and even to other polio survivors can sometimes feel overwhelming.

Paraphrased, here are some of the areas of concern:

- We are afraid of what the future holds. In fact, sometimes the future seems so scary we can't allow ourselves to even think about it, let alone talk about it.
- We are afraid that our physical needs will place such demands on our families that they will grow weary and resentful and withdraw support. We wish we had reassurance that we will not become so burdensome that others will leave us.
- We want family and friends to not judge us by our appearance. Appearances can be deceiving. More often than not, we look much better than we are. Weakness, fatigue and pain are less visible than braces and wheelchairs, but no less real.
- When we are tired, we mean it. In fact, it usually means we're exhausted, and it may not be remedied by a short rest. Don't over estimate how much we can do. We struggle enough as it is, to figure out our own limitations.
- Sometimes we need to put ourselves first, which is difficult for most of us to do, as this is a major shift for us. We would like you to help us do this by co-operating when we say there is something we need. We know the difference between a need and a whim. It is hard for us to ask for help, it doesn't come easily.

Conflict within the group emerged when some participants expressed fear and frustration and others reacted with anger. It seemed that both fear and anger were central and universal experiences, but that people cope differently. The anger expressed seemed to grow out of a need to fight feelings of vulnerability and helplessness and instead maintain a sense of control and a positive attitude. Worried that their fears and sorrow will pull them down, and unwilling to let themselves stay down, some people use anger to protect against feeling fear. Other people are afraid of how intense their anger can become and so they inhibit and suppress it.

Partners and families:- All expressed a deep commitment to their partner and a readiness to be a part of their lives, regardless of changes in physical status. This commitment was not naive or superficial, but seemed founded on genuine love and respect for the challenges their partner have faced and will continue to face.

They acknowledged that coping with post-polio syndrome involves a series of compromises, but they adapt by remaining flexible and tolerant. Within this group there was much commonality, but when differences of experience emerged that group was quite respectful and compassionate.

PART 3

Partner and family expressed the following concerns:

- It is difficult to see our partners in pain. We feel helpless to ease physical suffering. Therefore, we'd like our partners to listen to their bodies, slow down and not be so perfectionistic.
- It is hard to see our partners reject changes that would help them cope better (e.g. using a wheelchair or a scooter). We do not view use of an adaptive device as failure, but as an increase in functionality and freedom to enjoy life together.
- Sometimes our partner's anger is hard to deal with. When they are feeling tired and

frustrated they get irritable, if we say the wrong thing, they get upset. We sometimes have to ignore what they're saying so that we don't take it too personally.
- The lack of predictability of the illness is frustrating and frightening. We don't know what our partners will be able to do in the future. Therefore, we feel an imperative to live for today and not postpone doing things that give us pleasure.
- Over time, our role in household responsibilities is getting larger. We accept this. Still, your comment of appreciation is very welcome.
- Some of us feel concern about our own physical ability to provide care for our partners as we, ourselves, age and contend with our own aches and pains. We worry about the possibility of not being able to give necessary help.
- It is difficult to know when to be the cheerleader, when to be comforting and soothing, and when to confront anger or passivity. We'd like to feel we have permission from our partners to express our feelings about this.

CONCLUSION

In conclusion, there was broad agreement that life is all about challenge and response, that amidst all the hardship, post-polio presents an opportunity for personal growth for both survivors and family if the challenge can be faced with flexibility, acceptance and openness.

Reprinted from Florida East Coast Post-Polio Support Group November/December 1999 Newsletter.
Reprinted from Colorado Post-Polio Connections, Spring 1999; reprinted from Southern Alberta Post Polio Support Society #7, Post Polio Echoes, May 1997; reprinted from (Mt. Diablo Post Polio Network) MDPPN Newsletter, Volume 6 #01

Anita from Wichita, Kansas writes..
"Anita Bjorling" <anitabjorling@hotmail.com>

I think anyone who thinks PPS is not progressive is uninformed. There are plateaus, but even though we are pacing, at least for me, my strength level is less than a year ago and my fatigue level is higher. I don't think it's depressing to talk straight about PPS, it is harder for me when everyone pretends nothing has changed.

Please Use Your Headlights

by Millie Malone.

Published in GLEANINGS, Nebraska Polio Survivors Association.

Have you ever been talking to someone when your train of thought jumped the tracks? How about having someone come up to you in a public place, pump your hand and ask heartily how you are, mentioning that haven't seen you in ages and you have not changed a bit? Do you think, "Either you've changed a lot, or I never clapped eyes on you before in my life!"? Perhaps you start to go upstairs to get something, sit down to try to remember what that something was, and then forget if you were going up or coming down? If these things happen to you, my friend, you may be a victim of Polio Brain Fog.

Dr. Richard Bruno has mentioned in some of his articles that polio survivors get brain fatigue. I have noticed this in fellow polio survivors as well as in myself. If I start a project after 8:00 PM, it had better be a no-brainer or I will certainly have to do it over again the next day. When I am extremely tired, I find I can't even hear properly, I cannot concentrate, either.

When I am very fatigued, my brain sort of runs on low beams. Bright enough to barely function, but certainly not something you would want to depend on in a crisis. This is particularly frustrating for those of us who got along by using our intelligence instead of our non existent or non-functioning muscles. As children, we could not run and play with the other kids, so we were the ones curled up with a good book. We were the ones who got all A's and were teased by the other children for being Brains. Those same teasing children were usually the ones leaning over our desks copying our answers.

Now, when we try to learn something new, we find we've overworked our brains, too. Bummer! Walking has always been difficult, sometimes breathing has given me a problem, but my brain was my saving grace. I learned quickly, retained it all and earned good grades. Even when I took some College classes after my husband died, I earned a 3.85 grade point average. I cheated though. No, I didn't copy anyone's work. I scheduled all my classes for times when I was well rested. Middle of the day stuff. Very early evenings as opposed to the one class in which I only got a B and which ruined my till then perfect 4.0 GPA -- the dreaded Algebra class. The only available time to take that one was from 6:00 PM till 10:00 PM. I struggled with that class. It was simply too long and too late in the day. I have since figured out that I need fog lights after 8:00 PM. That's when my brain goes off duty.

I have tried taking various supplements that are supposed to help with memory retention. Ginkgo Biloba, Vitamin E, all those herbal things. I didn't notice any dramatic changes in my memory loss. Perhaps that was because I kept forgetting to take them. If you, like me, suffer from Polio Fog, don't be alarmed. It is not necessarily senility, Parkinson's Disease or Alzheimer's. Try scheduling your thought-intensive tasks for the time of day in which you are most rested and see if that doesn't help. And remember to use your fog lights after 8:00 PM.

Millie Malone <milmal@FRONTIERNET.NET>

Email from John Harper in Stockholm received 4th December 1999

> To LincsPPN
>
> My wife had polio as a toddler in 1944, right leg shorter and weaker, a slight limp. No real trouble until weakness/tiredness started slowly coming a couple of years ago and now diagnosed with PPS earlier this year.
>
> Here in Sweden there are rehabilitation centres for exercises, healthy living, learning to live with PPS, usually on a weekly basis. I guess you have a similar set-up in the UK.
>
> My wife has been offered a week in Sweden, or abroad if she can find something.
>
> So my question is: could you please let me know if there is something available in the UK for foreigners. This would be paid by the Swedish medical authorities.
>
> John.

I replied and asked if john could give me more information and this is his reply...

> Hilary,
>
> My wife phoned one of the major hospitals, and in April saw a physiotherapist and occupational therapist. In August she saw a PPS doctor, and again last week. Here is

what has happened so far:

- she had an EMG, showed some recent loss
- has been classified as 25% disabled
- now works a four-day week (previously full time)
- gets 25% disability benefit
- has water gymnastics once a week, run by a physiotherapist
- has been offered foot-care
- will be getting an ankle support
- has been invited to a one-week rehabilitation programme in Sweden, with specialists running the whole programme.

Most of this is free or low-cost. It's really been an eye-opener for both of us. In Sweden we are very critical of the national health service, and in many cases that is justified. But this has been fantastic.

"john f harper" <john.harper@swipnet.se>

Boots

by Christine Ayre

It's strange how a simple thing can bring back memories, the simple thing which set off a string of memories for me was when I decided to buy a new pair of boots.

Trying on the new boots set me looking down the years to the time when I was a child of about eight and at that time I was forced to wear the most awful boots.

I remember a man coming to my school, me being called out of class and sitting in the cloakroom being measured for the boots.

The school I attended was of the Dickensian type, bleak, cold and old, with teachers to match. The classroom was heated by a large pot bellied stove. The kids sitting next to the stove were always red and shiny with the heat, but those sitting the farthest away were covered by a thin coat of ice.

The cloakroom where I sat in misery being measured for my boots, was cold and cheerless. With its quarry tiled floor and the rows of damp coats hanging all around me, it echoed my mood as I contemplated my new boots.

Looking back on this time I realize that I must have looked a sight. My mother tended to dress me in a rather old fashioned way. I ask myself now why did I have to wear those large pink knickers with a pocket in the leg? What was I supposed to put in the pocket? What would people think when they saw me put my hand up my skirt and scrabble round getting whatever it was out of the pocket?

Did I really need the hand knitted wool vest with sleeves, which when I was wearing it made me look as if my body was trapped in a concertina.

And of course the liberty bodice, who can forget that. Putting it on in the morning was like being put in a straight jacket and did it need all those rubber buttons which after being ironed a few times were squashed flat and sticky.

Next I wore a flannel petticoat, then a blouse and gym slip, brown lisle stockings, cardigan, coat, a hated red pixie hood, scarf, gloves and of course on the ends of my sparrow like legs were the brown boots and a knee length calliper. I was even promised a pair of white boots for the Summer. Thankfully they never arrived.

I remember once my grandmother turning up with a pair of brown leather gaiters, which she said would be ideal for Christine to wear. That was when I started to become a rebel and told grandmother what she could do with her gaiters. From that time on I was classed as an ungrateful and cheeky little brat.

My next memory of boots is rather delightful, at least I think so. I will tell you the story and you can judge for yourself.

It happened a few years ago when I visited the Lincolnshire Show. At that time I was still able to walk about quite well. I had been wandering about looking at the animals. The pigs in their polished pink perfection. Sheep who must have spent hours in front of the mirror, combing up their wool. The friendly goats with coats so white, horns polished for the show, and the cows with their beautiful brown eyes and long eyelashes owing nothing to the mascara brush.

I started walking round the trade stands and at last came to a very large tent which contained nothing but shoes and boots. They were displayed in tiers as in a grandstand and I was quite some time looking at the display. One pair of boots caught my eye. They were standing on the bottom tier and although they were seemingly just a normal pair of brown leather ankle boots, when I looked at the price, I realized they must be special. They were priced at £125.

I was standing gazing at these superior boots when a woman came and stood next to me. She was also looking at the boots. She had with her a standard poodle, a very large dog of the most delicate shade of apricot, much beribboned, perfumed and primped, with pom poms on every available limb. He wore an expression of bored disdain. I smiled at him as I tend to do with all dogs. He looked at me in a scornful way, as if I were the lowest form of life.

The woman moved off with her exalted hound, he with his high stepping gait and his nose in the air. As he passed the £125 boots he lifted his leg and with exquisite accuracy he pee'ed in one of the boots. The only evidence of this was a little spurt of steam issuing from the lace hole of the boot, which proved to me that the boots were worth the money as they were completely watertight.

Now I come to the warning in this story, when you next go to buy footwear ask the shop assistant if anyone has been in with an apricot poodle. Before buying the shoes or boots look for steam issuing from the lace holes, put your nose inside and have a good sniff and most important feel inside to see if they are wet.

I know the question you are all asking. Did I tell the shop owner about the poodle peeing in the boot? Well think about it. Would you have been able to do it and keep a straight face?

This is the last time I will be writing for the LincPIN this year. I will be back in the next century with some more lurid tales. It just remains for me to wish you a happy Christmas and a healthy and painfree new year.

Christine Ayre Chairperson LincsPPN catley@tesco.net

Rosemary had been in love with basil for quite some thyme. Basil was regarded as a sage, and was thought to be worth a mint. And rosemary decided he would make an idill husband. So, when one day he proposed marriage, she accepted gladly.

But on the wedding day, he did not turnip. For he had been leading her up the garden path, and had run off with a swede-ish au pear. When rosemary discovered she had been jilted, it cut her to the marrow, and she fled from the church with a face as red as a beetroot.

Daisy her bridesmaid tried to comfort her, and told her she was well rid of basil. Because he was nothing but a pansy, and only last week he had aster for a date, and when she refused, he tried to kiss her on the tulips.

But her friend lily who was a martial arts expert, came to her rescue, and laid basil out with one carroty chop. But this only made rosemary more angry, and she made such a scene, she was arrested for disturbing the peas. Meanwhile, basil and the swede-ish au pear decided to do a runner to Brussels and even though there was not mushroom, they stowed away in the hold of a steamer. But on the way it sprang a leek and sank, and they were never seen again.

And that shallot, because that is the end of this tale.

By DANNY NORMAN, Southampton UK
forwarded with permission by Steve Carrett <steve@CARRETT.FREESERVE.CO.UK>

Treat Yourself at Christmas
WheatSoothe and BranSoothe

Why not treat yourself and your friends this Christmas to a wonderful warming "WheatSoothe" wheatbag or a "BranSoothe" branbag.

WheatSoothe and BranSoothe are invaluable for people with aches and pains. Just heat up the bags in either the microwave, in the oven, or on a radiator, then slap the warm bag on your important little places and experience the sensuous warmth crawling over your vital parts. Great for around the neck and to ease shoulder pains, aching muscles, backache; wonderful on legs and to warm feet; the feeling can be summed up in one word, ecstasy.

The bags can also be used straight from the fridge or freezer. Just right for those black eyes and cauliflower ears one might receive at wild millennium parties. Also just right for the hangover headache.

These soother bags are being made and marketed by the LincsPPN Committee. All proceeds will go to the LincsPPN. Made from the finest wheat and bran and covered in a tasteful dark green tartan fabric, they measure 27 ins by 6 ins and are pocketed to ensure the filling stays put. If you would like one of these bags made by Christine Ayre and Myra McManus then please order early for Christmas.

WheatSoothe are £7.50 Inc postage (**UK only**), this is half the retail price in the shops.
BranSoothe are £4.99 Inc postage. (**UK only**).

Please send orders with cheque to LincsPPN

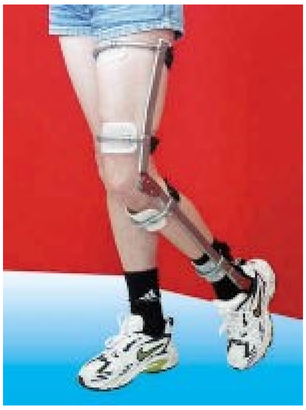
also
Books available from the LincsPPN

Healing the Blues - Drug Free Psychotherapy for Depression
by Dorothea Nudelman Polio Survivor and David Willingham, MSW
A hardback autographed book of 235 pages LincsPPN UK price is £10 inc. post & packing.
USA/Canada please contact Dorothea Nudelman <dnudelman@earthlink.net>

Managing Post-Polio A Guide to Living Well with Post-Polio Syndrome
Edited by Lauro S. Halstead, M.D.
(Paperback 6 x 9 - 256p)
LincsPPN UK price is - Members £8.00 inc. p&p; Non Members £10.00 inc. p&p
Published by NRH (National Rehabilitation Hospital) Press Washington, D.C. 20010-2949 U.S.A. - (202) 877-1776.

Have you heard about the revolutionary new callipers now available in the UK?

by Maggie Fuller (Basingstoke)



These radically new intelligent callipers are made by Dutch manufacturers. Ambroise Holland bv. They supply orthoses and prostheses for both upper and lower limbs and are gradually penetrating the UK market.

I was lucky to have been chosen to try the new style caliper but, have to admit that, when I saw the first sample I thought, "you must be joking!" However, the proof has been in the actual wearing and my orthotist has asked me for my comments. As I am not familiar with the correct medical terms, I hope you will excuse my 'layman's words'.

I contracted Polio at the age of 6 and will be 59 next year. I do count myself fairly lucky, the Polio affected only my left leg, although my thigh, knee and ankle muscles were greatly weakened.

In these 53 years have seen little change in caliper design until the production of the cosmetic version. I have been wearing a partial cosmetic model for a few years and have found it lighter and more comfortable than the earlier design.

However, this new design from Ambroise Holland is totally different. It's so light I can lift it with my little finger, yet it still gives me the same support as my old model!

The main difference is in the frame. With only one side support, with a strong spring at the ankle, have much greater flexibility when walking, especially up and down slopes.

In the past I have always worn a leather knee cap - with this new design there's no need. Instead of the main cross bars being at the back, they are at the front with an easy, secure, velcro fastener at the back. The old, bulky, knee release cable has been replaced by a small button at the top of the side support. It doesn't get caught up like the old style and it is so easy to use.

I also suffer from hyper extension of the knee, a common problem for Polio patients and this new style caliper helps stop this happening.

This new caliper sits much closer to my leg, with the knee joint level with the bend of my knee. Not only is it much more comfortable, there are no protruding bars to wear holes in my trousers, which was a big problem with the old design.

It is still very new to me at the moment, but I wanted to share my experience with you. I know this new design is not suitable for all types of disability but, do ask your local orthotist about them.

Their Managing Director and Chief Clinical Advisor, Ken Spooner, has been extremely helpful to me throughout. I have included a picture of the 'right leg' style, which I hope can be clearly reproduced in this news sheet. *[Note. The illustration at the top of this article in the Web edition of this newsletter is sourced from the Ambroise UK Ltd web site and is not the original picture supplied by Maggie.]* I hope my letter has given you an idea of how delighted I am with 'my new leg'!

October 2005 Update. Ken Spooner and Ambroise UK Ltd are no longer the UK contact. The UK supplier for UTX is RSLSteeper and their web site has full details of the UTX. According to their web site "for information on our range of orthotic services and products, please contact Mark Tomlinson on 0113 2070435 or email mark.tomlinson@rslsteeper.com". The Dutch manufacturer's web site can be found here (primarily Dutch language).

NB. - Len, whose story is next, like Maggie is very impressed with his Utx. Much to my surprise as I had not put a caliper in my near-future needs, I will be fitted with one later this month on my weakening left leg. Orthotists are interested in the benefits of using this lightweight revolutionary caliper and other members are now being assessed. Please write and tell us how you get on with any new aids or treatment you receive so that other Polio Survivors can benefit from your experiences. Hilary.

LEN'S STORY.

I have decided to put pen to paper (or fingers to the keyboard) and spill the beans on some good progress I have made during the last year in trying to live with PPS in a more positive manner.

I contracted Polio in 1957 at the age of 16 months in a remote part of South Africa. My story is not unlike most, from the initial paralysis in my lower body, the recovery, a number of surgical procedures to finally discarding my legbrace.

I have been a "driven" person all my life and was fortunate to have had major business successes. I was hardly 40 and invincible and had not been back to see a Doctor re polio for over 23 years. Over a period of almost two years I picked up disturbing changes in my health:

1. I fell down in our bathroom at home and broke some ribs when I crashed into the hand wash basin... My right leg just gave way and that was the beginning of many. I became more concerned when one day I was walking around my car to get into it, when my leg gave way and I fell in front of an oncoming car. When I heard the screaming brakes stop I found one of the front wheels inches away from my nose. All of this was beginning to get to my confidence.
2. Over a period of time (the creeping effect) I had more aches and pains. This was at first only muscular and joint pains. Then came the agonising cramps/spasms. I had days where I could not breathe properly due to spasm of my diaphragm. Sonya, my wife, using her very best persuasive tactics, got me to see an Osteopath. When I saw Phillip the first time, he was actually appalled at the 'state' I was in. Shortly after my first visit (October last year) I hit the Polio Wall.
3. All my working life I woke before 5a.m. and was at my office by 7a.m. Leaving before 7p.m. was unthinkable. During my early career I would work 17 hours a day for a month during projects. I would never tire. I would normally sleep between 1-2a.m. and 4.45a.m. which was all I needed.

October last year this all changed rather abruptly. No warning at all. I was now fortunate if I got past 11a.m. each day. I had to stop driving myself as I fell asleep a number of times on the M25 doing 70mph! I now had severe physical and mental fatigue. I was scared out of my wits. I thought at first that my “mind” was going. I could not remember what I did and said barely hours earlier. Names, incidents, facts I have known all my life suddenly became a challenge.

I now KNEW that something was wrong. No, I knew earlier and in retrospect... I finally ACCEPTED that something was wrong. Therein lies the difference! Once I accepted the fact, being my normal driven self (about the only thing left at the time), I planned to do something about it.

I went to my GP and she referred me to a neurologist. An utter waste of my time and NHS funds. I fired him! At this stage I suspected it might have some connection with my Polio. I used the Internet. I typed in the word "Polio" on Yahoo and I found reference to PPS. The only UK reference I found was that of the Lincolnshire Post Polio Network. I spent days researching and learning. With the exception of respiratory problems, the basic list of symptoms described my situation to the Big T.

I felt so elated, I now had control as I had something to follow up on. What a bad mistake. I now hit the second WALL. Those of you who know me well, will know that I see red when I get onto this subject. The general ignorance I could deal with, but the smug attitude of "I am the Doctor and you just the mere patient and what do you know" had me desperate. Our supposed one-stop-shop Centre of Excellence, The Lane Fox Clinic finally stripped me of all hope of getting help in the UK. Because I believed, rather naively (as one would) that Lane Fox would help me move forward yet they were in my opinion a waste of time and yet again NHS money. This had me feeling down for a short while, that is until Mama Hilary (oops she was not meant to know) said something that made me realise that I am the best person to look after and fight for myself.

I have since then taken to a power chair at work. I now manage to last until 3p.m. before I leave my office. This has singularly been the best move I have made even if it cost £6,000 from my own pocket.

I have also started using the Utx KAFO from Ambroise UK Limited shown on the previous page but I have the version with the intelligent knee lock that is locked as I heel down and unlocks as I toe off so that I walk normally. I dreaded this but as it turned out it has become a "friend" and on two occasions when I wanted to have a break from it over week-ends, I lasted no more than two hours and I put it back on. I am sure mine is the same story as with others. "If only I knew" what difference the brace would make, I would have had one earlier. Rather than restrict me, the brace has made walking, standing and driving easier!

Where to from here? I simply do not know. What I know is that I regularly have spasms that hurt badly and at times I struggle to breathe because of it. What I know is that I cannot work 5 days per week any longer. What I do know is that I am planning to speak to my MP and present a case that the NHS neglects me. I feel entirely isolated from it.

In the mean time I am having a battle with my local authority, the Royal Borough of Windsor and Maidenhead. They will not let me have an Orange Badge unless I have been successful in my application for DLA. It is bizarre that I am being forced to take money from the State in order to get the Orange Badge. I know of many local authorities that will provide this without DLA yet mine insists that it is following guidelines from the State.

Len Van Zyl
lvz@compuserve.com

Hints for hygiene - or The Fanny Pack

by Maggi Barwick McElroy.

For years I took for granted the fact that I popped into the shower every morning, wafted a flannel over relevant parts in the evening, sprayed a little of this and rolled on a dash of that here and there, now and then, and went through life, fresh as a daisy.

It took me YEARS to acknowledge to myself, let alone to a close friend, never mind mentioning it to a doctor, never *dreaming* of talking about it openly — to say that I now find keeping myself clean and sweet-smelling a struggle.

The late effects of polio has meant that I don't walk (no fresh air getting to the private parts); I use an electric wheelchair (plastic seat); my arms are weak (so I have difficulty getting my hands, with a soapy flannel and then with plenty of rinsing water to the delicate bits).

And more often than not, I'm too tired to manage a thorough bath or shower, anyway. Don't worry , you can come near me without a face mask on - I won't suffocate you with my stink!

But, I DID have to face up to the possibility that if I didn't examine this problem and find solutions, I was going to feel pretty grotty and less than socially acceptable.

And here are the results of MY problem-solving exercise, given to open up the subject and encourage other people to present their tips for getting round similar problems, and perhaps to pose problems that they are having to which someone else might have a possible solution.

First: Pacing. Pacing. Pacing... (Oh, how often do we "post-polios" hear that?) I realised that I could wash a bit of me at a time and dress a bit of me at a time.

Second: I found the best place to wash - and it wasn't the shower or bath. For me, sitting on the loo, with the handbasin beside me, is much less tiring than the effort of getting into the shower. I also need some assistance with the shower, but I can wash myself when I'm sitting on the loo when I want to, and do as much or as little as I can manage at a time.

Third: Interesting cassette tapes to play whilst washing - so I can sit and rest in between washing my armpits and washing my bum and feel as though I'm doing something constructive. (I get novels on tape from the local library, and the occasional opera and improving tape - a bit of positive thinking does a lot of good.)

Fourth: Soap isn't the only thing for washing. I've now settled on using Clinisan wash cream in place of soap. It is used in hospitals, is very mild, is slightly deodorant and - importantly - it won't be the end of the world for your skin if the last bit isn't rinsed off. I just put a small handful on what I delicately refer to as my "front bottom", leave it for a bit, and wipe it off with a wet flannel. I don't need to use a scrubbing action, which my hands/arms just won't permit.

Fifth: Deodorant. Yes there are things that can be safely used on delicate female bits. I used to use Femfresh Spray, but didn't find it enormously effective. I now use a product that I actually sell (as a health and beauty consultant) as part of a dental care range... It is called Eliminator and it is an alcohol free mouthwash ("and all-purpose odour control" - it's American.) It's as safe as houses, everso gentle - I've even used it on skin that has eczema on it - and stops even dire pongs in their tracks. (A friend of mine - a pub landlady - uses for her smelly feet and says it works where nothing else does.) I don't use talc (a gynaecologist friend says it causes so many "down there, doctor" problems), but Vagisil powder is talc free and I waft it all over anywhere that I might feel sweaty.

Sixth: I sit on thick cotton towelling on the wheelchair seat, not plastic or nylon, and change it often. (Just an ordinary towel)

Seventh: *Cotton* knickers - when I wear knickers... Yes, admission time. It is often easier NOT to wear panties, particularly if I'm wearing ski-pants as it is one less thing to pull up and down. However - I wear COTTON ski pants, as cotton next to the skin is an absolute essential.

Eighth: I think it is about time I stopped! Product details are as follows: *Clinisan* can be got on prescription (save money if you have a prepayment certificate or don't have to pay charges) and/or can be got from your chemist, though they will probably have to order it. *Femfresh* and *Vagisil* are also available from a chemist, but not on prescription. *Eliminator* is made in the States by a firm called Neways and is a sold by distributors (a bit like Avon is). If you can't easily get hold of it, we can provide it by mail order: Collective Ability, 194 Cator Lane, NG9 4BE, UK. Email collective.ability@ic24.net Tel: 0115 916 6453.

Oh - there is a ninthly: I'd value comments and additions to the issues and solutions we can support each other with. Remember - there are no problems, just issues awaiting solutions!

Maggi Barwick McElroy
<collective.ability@ic24.net>

A Post Polio Christmas

by Bob Lantrip

When I was asked to write something "Christmassy" for this newsletter, I did what I usually do and took a few days to think it over. I always like to make a mental outline before I commit anything to paper. Since, as a Polio survivor, I've been adapting to things all my life the question I kept asking myself is how have I adapted Christmas to fit my life as a post polio? Much to my surprise I discovered that I hadn't done Christmas any differently than most others, until 1997.

After our children were born, we adopted the habit of driving the 100 miles from our home in Texas to my mother in law's home in Oklahoma on Christmas Eve and then driving another 75 miles on Christmas morning to my parents house, leaving there just in time to arrive back home, put the children to bed, and get rested enough to return to work the next day. Even after we moved from Texas back to our hometown in Oklahoma our Christmas routine remained the same.

But, after spending most of 1997 clearing 5 acres of land so we could move into a new home in the country, I was hit hard by Post Polio Syndrome and decided it was time for everyone to start coming to us for the holidays. My father had long since passed away and my mother had remarried and moved several thousand miles from us, so we informed my mother in law, children and grandchildren, that from then on Christmas Eve would be spent at our house and they could spend Christmas Day with their other families. I also told my wife, Sue, that we weren't spending time or energy cooking for everyone. Instead we bought a meat and cheese tray from a local deli and let everyone make sandwiches as they wanted. My daughter even came out a couple of weeks earlier and helped Sue decorate. I was determined to make this the easiest and most enjoyable Christmas Sue and I had ever had.

On Christmas Eve our house was invaded with children, grandchildren, spouses, girlfriends and boyfriends. Before the evening was over we had 14 people visiting. I was able to talk my oldest grandson into handing out the gifts and my daughter into acting as the family photographer. I spent the whole evening in my wheelchair, sans braces and crutches so I could be comfortable and both Sue and I were waited on hand and foot by our grandchildren. We both had a wonderful evening and even though I stayed up later than usual, I went to bed almost pain free and was able to rest comfortably all night. The next day, everyone went their separate ways, just as we had planned, and Sue and I spent the whole day lounging around in our new gown and pyjamas that our daughter had made for us.

So, a new tradition was born in the Lantrip family simply because I decided it was time to adapt my life for PPS. Last Christmas we did the exact same thing, only with the addition of a new great grandson, and plan to spend Christmas in exactly the same manner for the rest of our lives. Even though PPS is making most of us change our lives to fit this new headache, those changes can be positive ones if we make up our minds to make it so and if we have the co-operation of our loved ones.

Robert M. (Bob) Lantrip
http://home.earthlink.net/~blantrip/
⚠ *Currently Unavailable* ⚠
mailto: blantrip@earthlink.net

Three Wise Women....

Think what would have happened had it been been Three Wise Women instead of three Wise Men.

They would have:
asked directions,
arrived on time,
helped deliver the baby,
cleaned the stable,

made a casserole, and,
brought practical gifts.

Author Unknown.

Some Dietary Advice by Jann Hartman
Polio Survivor and Nutritionist

Some very wise women that I was fortunate enough to meet as a young mom summed up their nutrition advice into one easy to remember sentence: "Eat a variety of food in as close to their natural state as possible." That made a lot of sense to me them, and it still does. When I first studied nutrition in high school there was the Basic 7; then in college there were the Four Food Groups; and finally, we ended up with the Food Guide Pyramid. They all cover the same variety of foods all our bodies need each day, and basically the only difference is in how the fruits and vegetables are grouped or divided up. But, all these years later, natural and fresh is still the best!

Try to get as many fresh fruits and vegetables into your meals as possible. Take advantage of the many fruits coming in to season, not to mention all the fresh vegetables. Have an orange for breakfast. Eat an apple for a snack. Toss a salad to eat with lunch. Raw vegetables (with a low fat dip) make a nice snack. Two vegetables are recommended for supper. And, you can't beat a banana (dipped in peanut butter) for an after dinner snack, if you need one. It's pretty easy to get the recommended five servings or more of fruits and vegetables. And, if you have access to organically grown food, you are indeed lucky. Eat as well as your budget will allow. Your health and well being is worth it.

Eat beans and other legumes (all kinds of dried beans and peas). They are fiber rich, and are generally health promoting. Most of us dont get the recommended 25 to 35 grams of fiber a day. Add legumes (like cooked lentils) to rice dishes, soups and salads. Many of the whole grain cereals are good sources of fiber (but check and compare labels). Try whole grain breads with rolled oats, whole wheat, rye, and graham flours.

Soy products are a good addition to any dietary plan. Tofu is great, if you know how to prepare it. Since tofu is very bland, it is best used in recipes where it will pick up flavors: try adding some tofu chunks to your tuna salad. Yummy! Tofu can be used in many ways: in shakes with red, ripe strawberries or in a cheesecake in place of the cream cheese. Soybeans can be substituted for beans in any recipe, and they are the only bean that provide complete protein. Dried soy granules (textured vegetable protein) can be reconstituted with water or tomato juice and used in meatloaf, chilli, or spaghetti sauce. You can buy ice cream, cheeses, and a variety of meats (from sausage to bologna) that are made with soy; and soy milk is available, too. Try it, you may like it!

Drink plenty of fluids. 64 ounces of filtered water (or other fluids) is recommended each day. Get in the habit of sipping fluids throughout the day. Keep a sports bottle of water with you. If you really can't stand plain water, try adding a little lemon or other fruit juice just for flavor. If you add sugar, or drink a sugar beverage, you are adding calories, and they generally don't quench thirst as well as water does. Beware of all kinds of sodas, either regular or "diet." They provide empty calories and chemicals that your body doesn't need.

Consume less animal fat. Remove all visible fat from meats, and take the skin off all poultry before cooking. Look for and use vegetable oils. All fats are high in calories, so use them sparingly, but use them to add flavor where necessary. Nuts and avocados provide valuable nutrients that can be part of any nutritious and delicious meals. Unsalted nuts make a great high protein snack.

Be sure to include a good source of calcium in your meals. Many people drink milk, but whole milk and even 2% milk contains a lot of fat. Try the lower fat dairy products: skim milk, low-fat yogurt, and low-fat cheeses. Or, try soy milk in your cereal. Eat dark green, leafy vegetables for extra calcium. Drink a glass of calcium enriched orange juice. And, if you don't get enough calcium each day, you need to ask about a calcium supplement.

- "Boost" vanilla flavor, with a scoop of ice cream, blended fruit, for improved flavor.
- Try "Carnation Instant Breakfast" with or without additions...
- Freeze a protein supplement and eat with a spoon.
- "Ovaltine" added to milk or supplement for chocolate malt flavor. "Ovaltine" has added vitamins, not in chocolate drink mixes.

Try to maintain a healthy body weight. But, opt for healthy eating habits rather than strenuous and often dangerous fat diets if you need to lose weight. Strive for healthy lifestyle changes that you can live with each day. Make changes slowly: one at a time. Best advice I ever heard was: "Throw out the scales, and learn to eat well!"

Jann Hartman,
JKH <jann@HOME.COM>
Baltimore, MD, USA

Cranberry Relish Recipe

- 1 bag fresh cranberries, washed and berries with soft spots discarded.
- 1 navel orange, preferably organically grown since you use the peel and all, cut into chunks.
- 1 apple, ditto the organically grown bit, cut into chunks.
- 2/3 to 3/4 cup sugar depending on sweetness that you like.
- 1/2 cup chopped nuts, walnuts are good, almonds are OK too.

In a food processor put half the cranberries, 1/2 an orange including peel, 1/2 apple, 1/4 cup chopped nuts and about 1/3 cup sugar. Process until you get uniformly small bits. Remove to a bowl. Put remainder of cranberries, orange chunks, apple chunks, nuts and sugar into processor and whiz till you get uniform small bits. Combine with previous batch and taste for sweetness. Add more sugar if necessary. Best made several hours (or a day) before serving. Keeps well in the fudge for 3 to 4 days. I think you can freeze it too, but I've never tried this. My daughter tells me you can use previously frozen (thawed) cranberries but the texture will be more moist.

Marcia Falconer <ddf@sce.carleton.ca>

Dear Santa:

I've been a good mom all year. I've fed, cleaned, and cuddled my two children on demand; visited the doctors office more than my doctor; sold sixty-two cases of candy bars to raise money to plant a shade tree on the school playground; and figured out how to attach nine patches onto my daughter's girl scout sash with staples and a glue gun.

I was hoping you could spread my list out over several Christmases, since I had to write this letter with my son's red crayon, on the back of a receipt in the laundry room between cycles, and who knows when I'll find anymore free time in the next 18 years.

Here are my Christmas wishes:

I'd like a pair of legs that don't ache after a day of chasing kids (in any color, except purple, which I already have) and arms that don't flap in the breeze, but are strong enough to carry a screaming toddler out of the candy aisle in the grocery store.

I'd also like a waist, since I lost mine somewhere in the seventh month of my last pregnancy.

If you're hauling big ticket items this year I'd like a car with fingerprint resistant windows and a radio that only plays adult music; a television that doesn't broadcast any programs containing talking animals; and a refrigerator with a secret compartment behind the crisper where I can hide to talk on the phone.

On the practical side, I could use a talking daughter doll that says,"Yes, Mommy" to boost my parental confidence, along with one potty-trained toddler, two kids who don't fight, and three pairs of jeans that will zip all the way up without the use of power tools.

I could also use a recording of Tibetan monks chanting, "Don't eat in the living room" and "Take your hands off your brother," because my voice seems to be just out of my children's hearing range and can only be heard by the dog.

And please don't forget the Playdoh Travel Pack, the hottest stocking stuffer this year for mothers of preschoolers. It comes in three fluorescent colors and is guaranteed to crumble on any carpet making the In-laws' house seem just like mine.

If it's too late to find any of these products, I'd settle for enough time to brush my teeth and comb my hair in the same morning, or the luxury of eating food warmer than room temperature without it being served in a Styrofoam container.

If you don't mind I could also use a few Christmas miracles to brighten the holiday season. Would it be too much trouble to declare ketchup a vegetable? It will clear my conscience immensely.

Author Unknown,
Forwarded by Mary-Lou Whitaker
<Mary-Lou.Whitaker@kinfolk.org>

Lincolnshire Post-Polio Network
If you have or get an email address then please let us know
so that we can send your information on
Our free to all Email updating service of additions to our WebSite
and
Members Only "Polio-Network-Lincs" Discussion List

Sylvia Dymond - a member from Hampshire is often in touch. She is now 65, catching polio at the age of 15. She was in a Milwaukee Brace for 2 years following her polio and has been having problems since 1991 as her body - shoulders to hips is failing her. Trying to get appropriate medical help for her deteriorating condition has been extremely difficult and continually frustrating which has impacted on the rest of her life. She has had to resort to finding her own therapists and buying aids and equipment. Even with all this she rarely fails to include a funny story, or hint that might be helpful in her phone calls and letters.

Sylvia from Hampshire writes

I can only have one hours help instead of two on Christmas Day as there is a shortage of care help available. Do you think I should be clean and have turkey soup or stay dirty and have Christmas Dinner? Hilary told me about only needing to wash the bit that the Doc was going to see and it reminded me of the time I wore some new knickers for a doctors appointment and after the examination the doctor said would you like the price sticker back... £1.99 stuck on the side of his hand.. !!!!! Yes, it was some years back.. you can only get half a knicker for that now.

As I did not seem to be getting anywhere with the medical profession I decided to organise things myself even though it means paying privately out of my benefits. I found an excellent Body Orthotist - Sylvia Foster - who has made me body supports and some comfortable bras. She has told me that I should have had these years ago. However, I must not sit up for too long even in my body support as its tiring and I still have to pace and rest. Another thing I purchased is an adjustable massage bed from Bakare. To get onto the bed I have it at bottom height and sit on it, then I take it down low so that I can get my legs on, then back up again, and I am fairly comfy. I use the massager to relieve aches and pains. If I did not have this bed I might have to have to stay in bed till a carer came. I also bought an electric rise leg raise chair. These items have given me more control of my life. All I have been given by the NHS is an electric wheelchair. If only the doctors had listened to me back in 1991 and I had had these items earlier then I am sure I would not be so disabled now.

Although I seem to have more and more problems as I get older and older, I would feel so much happier if I could be seen by someone who really understood.

I listen to relaxation tapes or find some music or a radio play to listen to, I rarely hear it all but it helps relax me and diverts my thoughts. Local Radio is especially good when it's on specialised subjects and I love the late evening Phone-Ins and have been on a few times. I even got some new members for the LincsPPN. Radio is great for keeping my mind off niggling worries and waiting for my pain killers to work. I was listening to the radio a few months ago and heard that people who had polio can have Viagra. I did laugh as I wondered where we would get the energy from to make use of it. When watching TV I often turn my video on as well. This is a good idea in case you nod off or miss something, you can just wind it back. I have my phone set to answer machine in case I can't get there in time, and tell all my friends to please leave a message, don't just ring off.

I have my bed in my lounge next to my kitchen and bathroom - it's not ideal but as I have poor cold tolerance it saves me heating an extra room, and everything is round me. I always rest when my carer is here to do my meals so that I have the energy to eat it. I have also just been for Respite Care and they collected my bed which made the stay much nicer and the staff were very keen to hear all about my polio and photostated lots of the information that I had taken in with me. One carer's father has polio and he came and visited me just before I left to say thankyou and told me he had had a long chat with Hilary on the phone and she had sent him some information and the book Dr. Halstead has edited, Managing Post Polio.

I have found that being in touch with other polio survivors by letter and by phone has really helped me. It's so nice when you say, this is hard for me and you get a reply from someone who truly understands. You get to be the talker and the listener and you can share funny stories and tips that might help. Instead of taking the carton of milk/juice out of the fridge and pouring some into a mug and then putting it back, take the empty mug and stand it in the fridge door next to the carton and you only have to tip the amount in you need.

If anyone would like to write to me then please send it do the LincsPPN address and I will write back.

Wheelchair and Car Neck Cushion idea.

Linda Myers, Virginia <myersl@EROLS.COM>

I've found a wonderful trick that makes my Jazzy (make of electric wheelchair) even more comfortable than before and eases my rib pain. found a pillow that is about 6" in diameter and about 15" long. The cover is gathered at each end with a shoelace. I could tie the ends together and slip the pillow over the headrest of my w/c and I also got one for my van. Now my headrests are really headrests, not just something too far back to be really useful. See if you can find pillows like these, or take any round pillow or foam of this size and make your own cover, It's absolutely amazing how much less painful my ribs are when my head is really supported. I adjust the pillow so that my head hits it right at the bottom of my skull and top of my neck.

You won't believe the relief that comes from truly supporting your head.

PS - A Draughtsman's chair can be useful in the kitchen.

Those dreaded multi page forms.

Hilary <linpolio@legend.co.uk>

I received my Disability Refurbishment Grant Form. Umpteen pages of questions and 5 pages of notes. I started to read it, technical jargon, and more financial information for another organisation. I will be honest I burst into tears. My daughter arrived home soon after and could see that I had been crying. She picked up the form and said "I will fill this in for you." Before I had time to say that I could do it myself etc., she started. Name, Address, Date of Birth, Age... Scanning through the pages of the form she asked, "How old are you mum?" "52," I replied. She wrote and said "52, and 63 by the time I get to the last page of this form." Well I laughed, in fact I got the giggles. Instead of stopping her I let her carry on. She turned the page over and read *"glebe of an ecclesiastical benefice"* "Oh why can't they use plain English! What on earth does that mean?" She turned to the relevant note and said, "Well let's assume you haven't got this because I am still none the wiser." On she went through the form. "Do you have an in-valid carriage?" "What on earth is that?" "Invalid not in-valid" I say through my giggles. "Are you going to do the work yourself? Oh yes my mum is going to go up the ladder in her scooter." She got more and more uptight and all of a sudden I realised that she had taken the sting, the pain out of this form.

Here was I laughing not crying. So when one of these arrives, why not get a family member or friend to go through the form with you in the first instance. It's not giving up your independence and capabilities if it takes the initial sting out of answering all those questions for the umpeenth time, and allows you to go through the form afterwards seeing it in a different light.

Turn CD's into Decorations.

Sent by Jann Hartman, Baltimore.

Neat idea for those CD-ROMs like the ones from on-line services many of us have received. You can glue two together with the printed side in. They make unique gifts as they reflect all those pretty Christmas lights.

To make: Take ribbon and make a loop, glue it to the printed side of one CD then glue the printed side of another CD to the CD with the loop. (Be sure the loop is large enough to hang on tree limbs.) Then take photos of the kids, grandchildren, the pets and cut them into circles just large enough to cover the clear circle and hole in the CD. Do the other side with another photo. Or, you can use old Christmas cards if you don't want to cut up your photos...

Carers

by Kathleen Perkin

Taken for granted, many work a 36 hour day. Carers do not apply for the position of being a carer and they do not need to pass examinations or go to university. There is no age limit, and carers can be as young as 5 years old. Recently research showed how many children of school age and under looked after a parent, not just as a one off, but day in day out, till something gives way, and then they cry for help.

There are many different aspects of caring and changes in lifestyle and relationships are large issues. To help carers cope with these changes in lifestyle there is an organisation called Carers National Association (the Voice of Carers). CNA have offices in London, Scotland, Wales, N. Ireland and N. England. They have a Carers Help Line Mon.-Fri. 10am-12md. & 2-4pm. Tel: 0808 808 7777 so give them a chance to help you. Carers Christian Fellowship are also there to help, and can be contacted in Cumbria on 01229 585974. Do not try to be a carer alone, do ask for help, even a little help and a chat with someone who understands does ease the load. Best wishes for the future and remember, do ask for help.

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Accessible Kauai

by Marcia Falconer

We've just returned from a 10 day trip to the Hawaiian island of Kauai. It was a business/vacation trip - business for my husband, Dave, and vacation for me (and a bit for him too). Tropical paradise sometimes feels out of reach and this is made even more so by the need to consider accessibility problems. But don't despair! Kauai is attainable and (reasonably) accessible!

Before you rush out to purchase discount tickets to explore Kauai, I'd better tell you where my perspective about accessibility is coming from. I had polio at age 7 and recovered completely. PPS appeared in my right arm about 1985 followed by drop foot in my right leg and serious fatigue in 1990. With some difficulty and reluctance I've learned that mobility aids minimize fatigue and pain and compensate for muscle weakness so I've begun to use them. I wear an AFO, or when I need to stand for long periods or my quads are very weak, I wear a KAFO. I use a scooter for shopping and other 'long distances'. This summer I discovered that forearm crutches are useful for balance when I am fatigued. When we travel, I use a manual w/c that is mostly pushed by Dave.

Accessibility on flights departing from any major city to Honolulu is no problem. Airports can be another matter. Arm weakness prevents me from propelling me w/c any great distance so Dave has to push me in the w/c while coping with our luggage, his laptop computer (vital on a business trip), carry-on bags. To transit an airport requires he have at least 3 hands, even after we've loaded me, sitting in the w/c, with the carry-ons and the heavy laptop. Sometimes Dave manages but he is finally learning that the **easy** way to do this is to use a porter!

Flying from Honolulu to the very small airport on the island of Kauai by either Aloha or Hawaiian Airlines is fine. In addition, when you fly with your own w/c they take your disability seriously and, if possible, will seat you in first class! Of course the flight is only 30 minutes long, but it's a nice way to arrive. The small airport terminal on Kauai is open to the tropical trade breezes and right away you're inundated with warm, humid air carrying smells of tropical flowers (and jet fuel). The ground around the airport is green and red - grass and dirt. All the Hawaiian islands have red volcanic soil and you'll have red dirt packed into the treads of your w/c by the time you fly home!

We picked up our rental car at the airport and drove off to locate the B&B, 'Alohilani', I'd reserved on the Internet. Located near the town of Kapa'a, on the rainy side of the island. it was wonderful and the mountainous scenery with the ocean in the distance was magnificent. Unfortunately, like most B&Bs, it was not w/c accessible. However, if you describe your needs to the B&B owners (by email, phone or letter) they will try their best to accommodate you or help you find another place that is accessible for you.

To get to our private cottage, we walked down a short, flagstone path between huge tropical plants (the kind that we only see growing in pots in a sunny window!) and climb a few steps. The cottage was partially built on stilts over a forested ravine, which meant that as we slept air carrying wonderful smells would drift over our heads from the open windows. Every night I lay awake sniffing the scents as they wafted past my nose - first a sweet floral aroma and then a heavy, dank smell that reminded of wet leaves with an unusual undertone. Just as I would drift off to sleep another scent would float through the room. Before dawn we were awakened by the sounds of the ubiquitous Hawaiian alarm clock - the rooster! There are wild chickens on all the Hawaiian islands and before daybreak the roosters do their best to establish their territories. The near and distant crowing goes on until sunrise but after the first few nights you learn to disregard the sounds, just like the natives do.

The next morning, following a breakfast of fresh papaya, warm croissants with guava jam and wonderful coffee, we headed off to explore the northern reaches of the island. Kauai is small, only about 60 miles in circumference, so getting from 'here' to 'there' isn't much of a problem. Our hostess suggested that we stop at a Guava Kai Plantation on our way to the end of the road at Ke'e beach. Totally w/c accessible, it has a huge guava orchard where you can pick as many guavas as your heart (or stomach) desires, a small manufacturing plant where they produce guava jams, jellies and juice (free, unlimited tasting of everything!) and a small, but lovely tropical arboretum. As well as a friendly cat. We drank lots of free, fresh guava juice but placed reluctantly restrained ourselves in buying jams and jellies packed in glass jars that could break in our luggage.

We continued north to Kilauea Lighthouse and National Wildlife Refuge which has w/c accessible paths leading to spots where you can watch redfooted boobies (birds!) nesting on the cliffs across a small bay. Here, where the ocean currents supply plentiful fish and the high cliffs provide protected nesting grounds, all sorts of tropical birds can be seen. When we tired of looking at unusual wildlife we watched the crashing surf and the wind blowing through feathery green trees. At the right time of year you can watch for whales as well. We drove a short distance back to the main road, stopping at the Kong Lung Store. Formerly a general store for sugarcane workers, it's now a wonderful 'gift shoppe' with beautiful things but not the kind I'd buy as a casual souvenir. Behind it there is a small bakery selling pizza and other delicious things for lunch. If this isn't enough, there is also a small store where they make tropical scented candles and soaps. I couldn't resist and bought a bunch of plumera (that's a flower)-scented candles poured into coconut shell halves. The candles float when you put them in a big bowl of water and give off a fantastic aroma, reminding me, as I sit at home on a dark winter evening, of our trip to a tropical island.

Ten miles down the road brought us to the town of Hanalei. The nearby beach is where "South Pacific" with Mary Martin, was filmed! Most of the shops and restaurants in Hanalei are w/c accessible and people cheerfully (and unobtrusively) help with carrying food and drink to tables on the lanai (which is 'terrace' or 'porch' in Hawaiian). Most beaches, because of the problem with sand and wheels, are not w/c friendly, but in Hanalei there is a completely accessible pier that goes way out into the bay. From here you can look inland to the nearby mountains with sharply eroded ridges covered in lush vegetation. Bring binoculars to appreciate the ribbon-like waterfall that drops 2000 feet straight down, from the top of the mountain to the plains below. And bring a camera to record the local Hawaiian kids who dive off the pier and generally run around having fun. There is also a paved boat ramp, suitable for a w/c, where you can get down to the water edge (and probably go swimming if you want to - the water is lovely and warm).

To get to Ke'e beach, literally the end of the road, we drove over a narrow road with many, one-lane bridges. Waiting for our turn to cross the bridges we examined the local scenery and listened to the radio playing Hawaiian music. Granted that this type of music doesn't travel well, and any tapes or CDs brought home will sound bizarre and out of place, nevertheless when heard while driving to Ke'e beach it is wonderful and entirely appropriate!

Not looking for anything in particular, we marveled over more waterfalls and incredible beaches that appeared at random as we drove. A parking lot with cars suggested there might be something of interest to see, so we pulled into it. There was a beat-up old pick-up truck, loaded with fresh, yellow, smooth-skinned coconuts (not the brown, hairy things we see in our stores). A Hawaiian man, with a very large cleaver, was chopping off the tops of the coconuts to insert a straw so you could drink the 'coconut water' inside. Who could resist? We shared a coconut and drank the slightly sweet tasting clear fluid then took it back to him to be hacked open so we could eat the fresh coconut meat. Delicious, and not the time to worry about saturated fats!

Across the street was a 'dry cave'. One of the natural sights of the island, it was a lava tube through which molten lava flowed a hundred thousand years ago when Kauai had active volcanoes. (Now the active volcanoes are only found on the southernmost island, Hawaii.) The entrance to the cave is shaped like a mouth, about 30' high and 70' across. The floor is hard-packed, uneven dirt and the ceiling is solidified lava with only a few, tiny, stalactites. I'm mildly claustrophobic but the cave held a strange power that drew me in. At first there were other tourists in the cave with us but by the time we'd reached the middle of the cave, Dave and I were alone. If you've ever wondered if the earth is 'alive', being in this cave will make you decide that it definitely is. As I turned around to look back towards the mouth of the cave, I had the feeling that the earth might decide to 'close its mouth and swallow' me. Still, I wanted to reach the back of the cave. Walking further into it, my eyes accommodated to the increasing darkness. At the back of the cave, where the throat would be, was a narrowing and then a blank wall. Although there were no signs of it, I felt that the ancient Hawaiians must have had an altar at this spot. We turned to leave the cave. Going out was as dramatic as going in. Now the bright light from the entrance essentially blinded me so that all I could see was the brilliant light at the mouth and all around me was blackness. The uneven ground meant that I had to go slowly and the presence of the earth all around was overwhelming. It was an awesome thing.

To be continued...

Post-Polio References

1. Kauai, Hawii's Island of Discovery http://www.kauai-hawaii.com/
2. Hawaiian Airlines http://www.hawaiianair.com/

Travel & Transportation - Kauai

Marcia Falconer PhD an[illegible] Bollenbach MA co-wrote the article "Non Paralytic Polio and PPS" featured in LincPIN Volume 2 Issue 3 February 1999 and on our WebSite at http://www.zynet.co.uk/ott/polio/lincolnshire/library/falconer/nonparalytic.html.

They are soon to have another article published. **"Late functional Loss in Non Paralytic Polio"** will be in the next issue of the American Journal of Physical Medicine and Rehabilitation. There will also be other articles on Non Paralytic Polio in this issue. Two we know about are one by Dr. Lauro Halstead and another by Richard L Bruno PhD. Both have many articles in the Lincolnshire Post-Polio Library. More information in our next issue.

N.B. - If you have been prescribed Mestinon/Pyridostigmine the following article will be of interest to your Doctor.

Medical article recently published Neurology 1999 Oct 12;53(6):1225-33 (Abstract only included here).

A multicenter, randomized, double-blinded trial of pyridostigmine in postpolio syndrome.

Trojan DA, Collet JP, Shapiro S, Jubelt B, Miller RG, Agre JC, Munsat TL, Hollander D, Tandan R, Granger C, Robinson A, Finch L, Ducruet T, Cashman NR

Department of Neurology, Montreal Neurological Institute and Hospital, Quebec, Canada.

BACKGROUND: Postpoliomyelitis syndrome (PPS) is likely due to degeneration and dysfunction of terminal axons of enlarged postpolio motor units. Age-related decline in growth hormone and insulin-like growth factor (IGF-I) may be a contributing factor. Neuromuscular junction abnormalities and decreased IGF-I levels may respond to the anticholinesterase pyridostigmine, with consequent improvement in strength, fatigue, and quality of life.

OBJECTIVES: To determine the effect of pyridostigmine in PPS on health-related quality of life, isometric muscle strength, fatigue, and serum IGF-I levels; and to assess the safety of pyridostigmine in PPS.

METHODS: The study was a multicenter, randomized, double-blinded, placebo-controlled trial of a 6-month course of pyridostigmine 60 mg three times per day in 126 PPS patients. The primary data analysis compared mean changes of outcomes between treatment and control groups at 6 months using an intention to treat approach. Secondary analyses included a comparison of outcomes at 6 and 10 weeks, and in compliant patients.

RESULTS: The study showed no significant differences in pyridostigmine and placebo-treated patients with regard to changes in quality of life, isometric strength, fatigue, and IGF-I serum levels at 6 months in the primary analysis and in compliant patients. There were no differences in outcomes at 6 and 10 weeks between groups. However, very weak muscles (1 to 25% predicted normal at baseline) were somewhat stronger ($p = 0.10$, 95% CI of difference -9.5 to 73.3%), and in compliant patients IGF-I was somewhat increased ($p = 0.15$, 95% CI of difference -6.4 to 44.8 ng/mL) at 6 months with the medication. Pyridostigmine was generally well tolerated.

CONCLUSIONS: This study showed no significant differences between pyridostigmine and placebo-treated PPS patients on measures of quality of life, isometric strength, fatigue, and serum IGF-I.

Publication Types:
Clinical trial
Multicenter study
Randomized controlled trial

Comments:
Comment in: Neurology 1999 Oct 12;53(6):1166-7

PMID: 10522877, UI: 99450712

Lincolnshire Post-Polio Library

Articles added since last newsletter with grateful thanks to the authors

Title: Changes in Post-Polio Survivors Over Five Years: Symptoms and Reactions to Treatments.

FULL TEXT HERE

Author(s): Mary T. Westbrook, PhD
Original Publication: Proceedings of the 12th World Congress, International Federation of Physical Medicine and Rehabilitation, Sydney, March 1995.
Abstract/Extract: A group of 176 people with post-polio syndrome, identified using Ramlow et al's (1992) criteria, took part in a 5 year follow-up survey. Most reported increased muscle weakness (91%), fatigue (91%), muscle pain (80%), joint pain (64%) and changes in walking (60%). Increases in other symptoms occurred in less than half the group. Cramps, sensitivity to cold, muscle atrophy and muscle twitching were the symptoms most likely to have stabilised. The average respondent reported greater difficulty in carrying out 4 of the 8 activities of daily living investigated. Respondents were significantly less anxious and depressed about their condition at follow-up. Degree of post-polio changes reported at the time of the first survey was a better predictor of decline during the five years

than were initial polio histories or psycho-social variables. Health practitioners most likely to have been consulted were general practitioners and physiotherapists. Specialists in rehabilitation medicine were rated as providing more beneficial treatment than other medical practitioners. Treatments reported to provide good symptom relief included massage and water activities but not exercise. Life style modifications associated with pacing, reduced activity and rest were particularly effective. Overall 68% of respondents considered there was much they could do to control post-polio symptoms.

Title: Dr. Henry writes about "You Were There"

FULL TEXT HERE

Author(s): Henry Holland MD.
Original Publication: Central Va PPS Support Group (PPSG)'s newsletter, The Deja View, in 1999.
Abstract/Extract: Do you remember the popular TV show of the 1960s entitled "You Are There" narrated by Walter Cronkite? The show would typically allow the viewer to be an eyewitness to a significant time in history. Let me take you back to March 1954. Summer Polio epidemics had been spreading fear and terror across America and much of the world for several decades. In 1952, only two years previous, a record 60,000 cases of polio had been reported in the USA. Another summer was approaching, but finally, as reported in the news, there was hope for a successful vaccine. Much of the hope ironically depended on monkeys.

Title: Polio Biology VII - Holistic Polio

FULL TEXT HERE

Author(s): Eddie Bollenbach, MA.
Original Publication: The Lincolnshire Post-Polio Library - 17th October 1999.
Abstract/Extract: On reflection, it is quite obvious that everything in the body works together. Put another way: nothing can happen inside the body without an effect on all parts of the system. After reading some recent articles on nerve and muscle function I started thinking about Post-Polio Syndrome and how closely a skeletal muscle fiber and attached nerve work together.

Title: Polio Biology VIII - Post-Polio Pathogenesis

FULL TEXT HERE

Author(s): Eddie Bollenbach, MA.
Original Publication: The Lincolnshire Post-Polio Library - 27th November 1999.
Abstract/Extract: Ever since the writings of Copernicus we, in the Western Hemisphere, have used reductionism in our thinking to the extent that we think problems must always have a single cause. So we say this, not that. And we seek until we find a single simple explanation. Nothing but a single understandable cause, it seems, will relieve the nagging uncertainty about what is going on inside our bodies. I don't think things are this simple, especially inside the nervous system.

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The Lincolnshire Association of Physical Disabilities are looking to increase their membership. Full membership is open to anyone who is 18 years of age or older and has a disability.

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Articles for publication by January 20th - Publication date February 5th 2000

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