

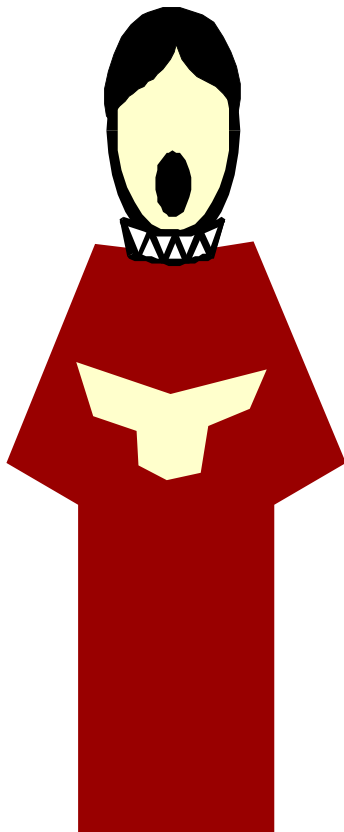


# The LincPIN

The **Lincolnshire Post-Polio Information Newsletter**  
Volume 3 - Issue 2 - December 2000

*The Lincolnshire Post-Polio Network  
wish  
All our Members and their Families  
All our Contributors and Readers  
Seasons Greetings and A Happy New Year - 2001*

*Lincoln has far more places to visit than you might have first imagined.*



Top of most people's itinerary is the Cathedral. A truly inspiring and majestic building, commenced in 1072, but largely rebuilt in the 12th and 13th Centuries in English Gothic style. The vast nave with its limestone and marble columns, vaulted roof, and colourful stained glass windows is an exhilarating sight; whilst in St Hugh's Choir, the intricately carved wooden stalls offer an intimate setting for the daily church services, led by the resident Cathedral Choir. In the Angel Choir see the shrine of St Hugh, and locate the mischievous Lincoln Imp. An innocuous stone carving much featured in local folklore.

Sharing the Cathedral's hilltop setting is Lincoln Castle. Built on the site of the former Roman fortress, this defensive stronghold has long been the centre of the City's judicial and penal systems. The crown court still sits here, upholding the principals of justice established by Magna Carta, and Lincoln's original copy of this famous document, sealed by King John at Runnymede in 1215, is the centrepiece of a special exhibition. You can also visit the Castle's unique prison chapel with its coffin like pews, tour the towers and dungeons, and walk on the walls to enjoy terrific views across the City.

Lincoln boasts some fascinating museums. These include the Museum of Lincolnshire Life, which depicts domestic, social and industrial life in the County over the past two hundred years, with the emphasis on authentic room re-creations and hands on activity days.

**WebSite - <http://www.ott.zynet.co.uk/polio/lincolnshire/>**

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. Although it does not provide an endorsement, it is provided as a service to those seeking such information. ALWAYS consult your doctor before trying anything recommended in this or any other publication. **Lincolnshire Post-Polio Network - UK Registered Charity No. 1064177**

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### First Smell of the Holidays

It was getting near Thanksgiving and the time to think about making fruit cakes for Christmas was up on us. They need a long time to mature and

become delicious so they were always baked early in November. As I got off the school bus one day, the air had a cool crispy breeze and the sky was a creamy blue with marshmallow clouds. It was cold enough so you could see your breath in front of your face. The maple tree in the front yard was showing all of its fall splendor with its red, yellow and orange leaves floating above my head. This was my favorite time of the year.

I always knew when my mom and grandma would be getting ready to bake. As I reached the kitchen door the smell of cinnamon, raisins, dates and spices were in the air. These were the smells of the holiday season to come. The kitchen felt so warm and inviting with its golden mahogany cabinets and the multi burgundy braided rug that lay under the table. An oil painting that hung on the wall, with its bowl of red apples and oranges seemed like it was ready to become part of the baking.

Grandma was sitting at the table with pecans and black walnuts in front of her. She was picking out pieces of shells and getting the nuts ready to put in the fruit cakes. There were candied cherries, pineapple, oranges and apples on the table that had been cut up to put in the cakes. The kitchen always smelled of ginger and spices, Red Jonathan apples were on the cabinet looking even better than the ones in the painting. The golden brown cakes with the big red cherries and raisins were cooling on the racks. Mom was mixing batter for another cake.

Mom had the radio playing "Home for the Holidays," softly in the background. Taffy, my little Chihuahua mix, lay on her rug watching with big brown eyes and a wishful look hoping that someone would drop just one bite for her. She wagged her tail excitedly as I looked at her and smiled.

Mom sliced one of the fruit cakes for us to taste. The sweet, soft cake was warm as I put it in my mouth. The taste of the cherries, dates, and raisins mixed together had such a scrumptious burst of flavor. Mom put a glass of milk in front of me, it was creamy and icy cold as it hit my warm throat.

We then took the nuts that Grandma had hulled and put them and half cherries on each cake to make them so very pretty and inviting. These would be gifts for family and friends. Everyone looked forward to Mom's fruit cakes with great anticipation, and these were the best she had ever made.

Linda S. Booth, Springfield, Missouri  
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## Editorial by Hilary Hallam

Seasons Greetings to all our Members, Families and Friends. I hope you enjoy the content, a mix of information, great tips to help us and a few funnies.

At our AGM it was agreed that the post of Vice Chair would be decided by the Committee. I am pleased to tell you that Janice Eary is now in post. Janice has worked for a Charity in the past and her experience will be invaluable to us. She writes *'If I had known what would happen, when I tentatively put my hand up at the A.G.M. I think I would just have sat on it. I didn't know then about Hilary's powers of persuasion. Anyway here I am Vice-Chair, with responsibility for dealing with the Charity Commission, The National Lottery, and The Long-Term Medical Conditions Alliance. I will do my best and hope you will all be patient with me while I find my feet.'* Chris Salter remains as Vice Chair with specific responsibility for the WebSite, without whose high quality work we would not have progressed to the level we have. Thankyou Chris. The Committee are gradually taking on the responsibility of co-ordinating various tasks which will give me more time for research and giving talks. Wendy Grimmitt is the new Secretary and Frank her husband the Treasurer. All membership, requests for leaflets and information packs to now go direct to them. Address on back page.

We receive requests for help from Lincolnshire, the UK and across the World. Last week a phone call from Reno, Nevada. The story is the same. It does not seem to matter which country you live in, if you do not have a PPS clinic or recognised PPS specialist in your area then you continually do the rounds of hospital departments getting absolutely nowhere. Such a waste of money. Despite the statement from the Dept. of Health on 25th September about PPS, we continue to have calls saying my doctor told me it does not exist and the latest 'there is no reason why you cannot continue working for years.' Where do we get the most help to manage our condition? From other Polio Survivors. Hints tips and bits and requests for help in this newsletter. Send yours to us for the next issue.

By the time you read this I will have winged my way Stateside again. I have to thank my family and PPS friends in Florida for their continued support without which this would not be possible. December 8th to 10th will find me in Daytona Beach for the East Coast Florida PPS Conference. A chance to meet PPS specialists old and new and to discuss with them the problems Polio Survivors are having with physical assessment. We have now had confirmed that what we have been saying for eighteen months, that assessing us using Manual Muscle Testing in a single discipline assessment most often does not confirm the functional decline that we are reporting. We now know that a limitation of Manual Muscle Testing is that it does NOT examine the ability of a muscle to participate in a functional movement pattern. For instance I have been reporting left arm weakness since 1988 that has increased. I am asked, 'Grip my hand, pull against me, push against me' and I can do

that on a one off basis and I am told that my upper body is strong. However, I can lift a teapot but not pour it out, I cannot carry even something light for more than a few yards, etc. Had I been assessed in the first instance by a physio and OT actually doing the tasks I reported difficulties with then all this would have been seen. A saving on NHS money, appeals for benefits, stress on me, and a reduction on the speed of deterioration as they would have been advising me instead of me having to search for the information.

I am also visiting Dr. Carol Vandenakker at the University of Miami PPS Clinic later that week and will be finding out what is involved in assessment, how much it costs and what treatment is offered.

This trip I will also be taking a holiday break - in touch daily through my email - although living on benefits means we do not have money for more than our daily living. The alterations agreed by Social Services last January will be starting just before Xmas. They are going to extend the room I am sleeping in so that there is room for wardrobes, put heating in here and the rest of the bathroom/utility extension, and provide disabled access at the front of the house. I am already struggling to cope with living in this cold area and relieved that I won't have to be here whilst this work is done - my daughter also needs a break and her life will be much easier if I am not around whilst the work is being done.

The DHSS sent me a 5th Anniversary Present of my finding that PPS existed. How wonderful, till you find out that it was a fourth Incapacity for Work Questionnaire. I am going to admit, I burst into tears, to show that whilst I can deal with others problems when it comes to my own its not so easy. It does not matter what small thing happens to us it opens up the whole can of worms. When you do this you are not alone. I regrouped!, and phoned the local DHSS Office to find that Post-Polio Syndrome is not on the exemption or exemption check with GP list, so they will continue winging their way to us till we get this altered. Needless to say another letter went post haste to the DHSS. The last thing we want is the stress of seeing in black and white the difference between what we could do last time they sent us one and now.

### December and January contact information.

Whilst I am away the LincsPPN line - 01522 888601 - will take messages collected daily, plus give a message with the following numbers. Janice Eary Daytime - 01663 743870 and Wendy and Frank Evenings - 01400 282546.

### POLIO PEN/EMAIL/PHONE PALS

We have members and swap newsletters with other PPS groups around the world if anyone would like a polio penpal contact Wendy. Plus now there are cheap rate calls to other countries you can ring now and then and 'hear your new pals accent'.

**Post Polio Syndrome A Critical Review  
St. Thomas' Hospital, October 26th 2000**

I attended the above seminar and was able to discuss with some of the health professionals what I believe is the main stumbling block in the UK. The use of single action Manual Muscle Testing which does not confirm the functional decline we are reporting. If only we all had the opportunity of the multi-disciplinary approach given to the 27 polio survivors who took part in the recent St. Thomas' PPS research project.

Tony Gould - Author of 'A Summer Plague' - Conference Talk pages 22 - 23

Some of the statements made by the speakers were:-

**We do not know how she is walking.** We do, we understand substitution of muscles and using other muscles of our body to assist in our doing actions. We learnt this when we had polio and we are using it again. One of our problems may be that we wait too long before we complain about our problems. For instance, we don't go to the doctor with an aching calf, then knee then thigh, then hip. We wait till our lower back is also affected. The doctor looks at the back as the problem - unless we tell them the course the pain took. My leg pain was from a 'dropped again foot'.

**Arm problems - rotator cuff, carpal tunnel, etc. are not related to polio.** If we had not had polio, we would not have had to use our arms to support weak legs, to use canes, crutches, wheelchairs. We are unlikely to have the level of problems we do now if we had not had to do this, so I disagree and say that our problems **are** related to our polio. The statement can have implications when we are sent for treatments and with Benefits applications, appeals and Tribunal reports. Saying that it is not related means that other health professionals discount that area of our body as being part of our new weakness and functional decline, part of our 'PPS'.

The recent research project found that the **Chronic Fatigue Level dropped but we are not sure why, maybe its the antidepressants prescribed.** Because doctors do not see us before we get new problems they cannot compare then and now. What had not been realised was that by giving patients a full multi discipline assessment, teaching pacing and resting, issuing aids, being able to socialise with other polio survivors for probably the first time and being able to speak those inner thoughts that we all have, that this would allow them to accept a change in lifestyle, manage their days and weeks better with a drop in fatigue levels.

**Professor Windebank talked about his research project at the Mayo Clinic** in Rochdale, Minnesota published in Neurology Jan 1966. They must be the only area in the world that retains virtually all their patients records from 1907. There were only 4

clinical reports missing for the 300+ polio survivors. To do their research they needed 50 people. They started at the top of the list and contacted people in turn till they had found 50 that still lived within a ten mile radius of the hospital. Here lies the problem that was missed by many health professionals. The research whilst important was not representative of the polio population as a whole. As a percentage of any normal population how many people still live within a ten mile radius of their childhood?

I asked about the type of sports these 50 did and it was 'one played some golf.' I asked 'No 5th Dans in Karate, marathon runners, professional sportsmen, lifeguards, rugby referee's and the answer was 'these people had polio!'. I replied 'so did the people I am talking about and they had considerable initial paralysis.' What has not been realised by many specialists - because we are only now coming out of the woodwork - is how many of us recovered to these levels from our polio. It appears to be assumed that if you don't have a thin limb, callipers or some easily visible external sign of your polio then you must have only had a mild case. They do not expect you to say you were paralysed, in an iron lung, wore body corsets, leg and body braces, etc.

Following this in the UK was the article in the Lancet, 'Study throws doubt on PPS.' The rebuttals to this research article are published on our WebSite 'The Mayo, the Lancet and the Revolting Polios' by Helena Edwards of the Leicestershire Post-Polio Network.

Even those who have visibly lived with their polio all their lives have achieved way beyond what was expected of them. Possibly the 'not as great a difference' between their level of ability at best recovery and new symptoms compared with those of us who recovered to looking normal is relevant. This was reflected in the scores listed in their research which were far lower than most polio survivors I have met including myself. Research needs to take in a wider representation of the polio population. All who caught polio in their earlier lives and who had damage to their central nervous system and who are now having or could have problems unrelated to age in the future. It also needs to happen now before too many more polio survivors deteriorate at an unnecessary fast rate due to the lack of knowledge and experience of polio in its first instance and the awareness of this latter stage. I made some excellent contacts and look forward to further meetings with them in 2001.

I stayed with Tony Meladio in south London the nights either side of the seminar, with Ken Spooner stopping off and driving my car with scooter to and from St. Thomas', so that I had the energy to attend. I then travelled across country visiting with other polio survivors. I learned from being with Sylvia Dymond what its like to have Care coming in to help you - an article on this for the next newsletter. I then visited Dr. Emamy who is now looking at some medical articles for us. Then onto south Devon to stay

overnight with Peter Norman and his wife in Budleigh Salterton - a seaside of my childhood. My thanks to all for their hospitality and openness in sharing their experiences and polio lives to help our research.

On the way home I met up with Wendy and Frank Grimmitt and we attended the **South Lincolnshire Healthcare NHS Trust - Specialist Services Department Equipment Awareness Day**. Of note were:-

**Helping Hands** Shoe Helper lengths 26" or 32" a helping hand but with a long shoe horn attached so that you can pick up the shoe and then slide your foot in easily. Another item was a Soxon Sock/Stocking Aid. Difficult to describe, but here goes, its made of a foot long U shaped foam covered metal frame. This is then covered by a soft fleece material. It looks like an upturned bicycle saddle. The top ends of the U nearly touch so you can easily put a sock or stocking on this. You then drop this to the floor, put your foot on the back 2/3rds of it and using the long tapes with loops pull up and lo and behold my pposocks were on.

Another company was **Mountway** with two items that impressed me. The first was the *Mountway Solo Toilet Lift*. *It is a new concept - slimline and battery operated, it is both neat and discreet. Specially designed to lift you on and off the toilet, it blends into its surroundings, causing no embarrassment to you or any member of your family. This allows you to retain independence and dignity.* That night I woke and chuckled to myself, I had visions of Father Christmas sitting on this reading the paper. A second set of controls were in the kitchen, and Mother Christmas is looking at the clock. Ten minutes have passed and she reaches for the controls calling out 'You won't get all the presents delivered if you don't leave now.' Another item was a pillow lift. *At the touch of a button the Serena Pillow Lift will help achieve this, by gently lifting and lowering you into the ideal position for sleeping, resting, reading and watching television - as well as providing help for getting in and out of bed. Just place on the bed and plug it in. So wherever you go your pillow lift can be installed in seconds.*

Another company was **Welland Medical** who displayed the usual stools/shower and pushing aids. The type of shower stool I need - a comfortable toilet seat that is level on top with adjustable legs is not manufactured. I need it high for me, but my visitors with shorter legs need it lower. My toilet is built on a tiled building block, great for me, but shorter legged folks complain their feet swing in the breeze. One visitor suggested an 'adult' step. They are going to make me one to try.

I talked with many companies about the way their items are presented. Most catalogues and leaflets show equipment that shouts 'This is for the elderly and disabled'. So many people both handicapped and elderly say 'I am not disabled enough or old enough to use **that** yet' when in fact it would make their lives much easier and more comfortable. What we want are

brochures and leaflets that make us read on - the Mountway brochures are excellent - that tell us what this equipment can do. Then we can decide if it might help us. We also would like to see more modern designs, colours.

If you have found any equipment, alternative treatment, hints or tips that help you then why not write and tell us. Not everything will help everyone, we are all aware of that, but I know many have benefited from some of the stories. Since the LincPIN where I told of my 5mg of amitryptaline at night I have heard from four polio survivors whose GP's agreed for them to try the same and all report a 'good nights sleep now'. I need to mention that this is half the smallest tablet made and it is the right dose, FIVE mg.

### **The Helping Hand Company**

Ledbury Limited  
Bromyard Road, Ledbury, Herefordshire, HR8 1NS.  
Tel: 01531 635678  
Fax: 01531 635670  
email: sales@helpinghand.co.uk  
www.helpinghand.co.uk

### **Mountway Limited**

Tafarnaubach Ind. Est. Tredegar,  
South Wales, UK NP22 3AA  
Tel: +44 (0)1495 723000  
Fax: +44 (0)1495 723360  
Email: mail@mountway.co.uk

Sales Advice Team - 01495 71800

### **Welland Medical**

9 Lewisher Road, Leicester LE4 9LG  
Tel: 0116 276 1440  
Fax: 0116 276 4449

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## The Fine Art of Pacing

When first diagnosed with Post Polio I was told to pace my activities. I thought, "that sounds simple enough to do". In actuality, I was practising some forms of pacing since I was still working at the time. I had already discovered that I needed to limit my extra outings to one appointment or one errand during the work week. Nor could I accomplish as much in any one given day. Nonetheless, over the years I have discovered that there is truly an art to PACING in our lives.

Pacing requires a concerted effort to limit daily exertions. If we become overtired then the daily naps or night-time sleep is still not enough to restore our energy levels. Once you learn how to practice the fine art of pacing you will probably feel better and possibly accomplish more of the things that are truly important to you in life.

Originally pacing meant to me that I could not do sustained activity for a long period of time. I thought that simply meant that I needed to rest periodically. And that is true. However, I've since learned that by practising a more controlled schedule in my life I *feel* better and more energetic. That doesn't mean I can actually do more activities, I just feel better doing them and to me that is a gift. The need to pace means something different to each polio patient. We each can only do so many activities each day. But some of us are able to function at a higher level. My goal has been to manage my lifestyle so that I am able to enjoy the activities that are truly important to me. Being organized is a necessity to managing PPS fatigue. I plan not just my day's activities, but also take into consideration what is scheduled for the coming week or even the next few months if I have abnormal social commitments. It is important to consider the consequences of holiday parties or vacations or other special events in order to accommodate the special needs in my life.

For me pacing requires that I not continue a sustained activity for longer than 45 minutes at one time. Then I take a 10-minute break. Even though my original bout with polio seemed to affect just one leg my whole body needs to rest and relax to prevent pain and fatigue. Thus pacing is not just a matter of taking rest periods throughout the day. Elevating my legs slightly when sitting in a chair removes strain from my hips and back. Using a thin pillow to support my upper body also aids in reducing fatigue. Retraining myself from crossing my legs has helped to ease muscle strain as well. Even simple things like

using a neck brace when typing on the computer has reduced the muscle strain for me. Being cautious with my activities, using good posture techniques and taking frequent breaks allows me to feel "human" again.

So many people have shared with me their methods of pacing. Limiting the number of errands that we run in any one given day seems to be a tried and true approach to pacing. Napping and true relaxation time is also required to protect the weakened muscles that we all seem to have. But so many of us seem to forget that we need to allow recovery time after a special event, vacation, or illness. If we schedule in the needed rest time following an active period in our lives we seem to recharge faster and not suffer as much from the debilitating fatigue that often follows an active time in our lives. If we also take into account future events that are planned then we can schedule ample down time to accommodate those drains on our limited energy reserves. It can be frustrating to feel so limited in life, but it sure is simpler if we are aware of the need to recuperate and schedule that rest time on a daily, weekly and monthly basis. Pacing to me doesn't mean just planning my day. It requires thought as to what I may have to accomplish in the coming week or even months. With the holidays before us this is an excellent time to think in advance of the drains that will occur from the extra activity of preparation and family time. If you are organized you may be able to survive the busy period without overdoing. It takes time to decide just what you are capable of and what your true limits are. But I have found that I don't make commitments that I think will over extend my limited energy reserves. So by being aware of future events I usually determine what chores I can not do to allow me time to participate in life or to withstand a busier schedule. I often make sure that I have two weeks between travelling, major outings, company or whatever seems to drain my energy.

What have I learned about the fine art of pacing? First and foremost is to get adequate rest daily. A good nights sleep and an hour (or more) nap or rest period is vital to feeling good with PPS. Second, I try to cease activities before I get over tired. And a third key for me is to take a "shut down" day at least once a week. My shut down days mean that I do the bare minimum of physical activity that day. And finally being aware of how I sit or recline makes a world of difference in pain levels and fatigue. I am sure that others can expound on their methods of reducing pain and fatigue with their own versions of the fine art of pacing, so

ask others in the support group what works for them and share your own successes. We can all benefit from new and improved methods until we manage to fine-tune the art of pacing. Remember to rest, allow recovery time and to plan for as many activities as possible. Enjoy the holiday and don't overdo!

Linda VanAken, Richmond Virginia,  
<ChatnLinda@aol.com>  
Central Virginia PPS Support Group.

Marti adds...

Rest before you need to is so important because once you need to, the body has already been overwhelmed. It is so hard to do though. I find myself overdoing and not even realizing it because I am so absorbed in something.

I tend to plan my day around one big thing and then maybe a few little things. I definitely do not like to have a doctor's appointment and then go out to dinner because it is too much for me. Or go out shopping and then go out to dinner. I will spend the next day in bed.

I never thought about using my neck collar when typing and decided to try it this time. It used to be that I could type, uninterrupted for about 15 minutes but now that has changed to about 1 minute and then rest. I cannot peel veggies either, only can do one and then rest. I cannot do any repetitious activity with my hand.

Back in June, I started making watermelon balls and then realized I couldn't do this because my hands started hurting. I got my nephew to do it but I really don't think my sister recognized that this was a problem for me even though I said it was. The comment was that I was trying to get out of work said in a joking way but of course I knew that they believed there was some truth to it.

I can also drive for more hours but only if I have cruise control on the vehicle. If I don't the driving is limited to less than an hour. I have bought a cart for home that I can carry large packages in, like groceries. I also use it to take the recyclables out to the curb.

Cleaning is a whole another thing. I do a little bit everyday. When I can get someone to vacuum for me I do that, otherwise I can do 1/2 of a room a day. Sometimes if really energetic I can do one room. Most of the time I don't vacuum at all, about once every 6 weeks.

Marti <MistiqBlue@aol.com>

**Editor** - As Linda explains the amount of time spent on each activity and the amount of rest needed is individual. You have to assess each activity that you do and work out your own optimum levels for work and rest times.

Exercise is necessary for healthy living but for some daily living will be the most one can manage. From experience and talking with other polio survivors there can be no set pattern because we are all so different. Moving joints, gentle stretching, relaxation and diaphragm breathing are all very important. Hydrotherapy is excellent if you have a pool near you and can have this or afford it. The only person who can really decide on how much is right for each of your muscles is you. How often you repeat any action can vary from muscle to muscle, limb to limb, person to person and day to day. Start low, even one repeat is OK, and increase the number of repeats when you are ready. The help of a PPS knowledgeable physio or other therapist to work with you would be ideal.

Remember the best advice is to pace and rest all activities and exercise. Taking your body to and beyond the fatigue level is likely to cause you more problems earlier in your life. You must stop before you are fatigued and let your muscles recover. Put this into practice, use aids so that you don't waste unnecessary energy and DO MORE of what you want to do. Overdoing daily is out, overdoing now and then to do something you really want to do is good for you.

## PPS SURVEY

A PPS Survey is being undertaken by members Marcia Falconer PhD and Eddie Bollenbach MA, authors of articles on Non Paralytic Polio and PPS and Polio Biology that we have featured in our Newsletters and can be found on our WebSite. Marcia and Eddie are both members of the Lincolnshire Post-Polio Network.

They really would appreciate some more UK ones for comparison with other countries. If you are not on the Net then please ring Wendy on 01400 282546 to obtain a copy or email Marcia for an editable text version.

Marcia Falconer for a <ddf@sce.carleton.ca>.

## **I personally opted for a permanent trach. The best decision I ever made.**

I got polio when I was 7 months old from the vaccine in 1959. I am 41 yrs old. Anyway through my childhood I was active, attended regular school, and treated as my other siblings were, only I just used a chair and had leg braces.

As years passed I had a series of respiratory infections, pneumonia's, etc. Somehow I always bounced back. In the early 80's I attended college here in southern Illinois in which I still reside with my partner Jim.

In about the late 80's I started hearing about PPS but none of the medical community here really had heard of it. I would ask my doctor about it, and he would just ignore that concept. Usually out of ignorance or lack of knowledge. But somehow knowing my own body and what I was experiencing I knew it was something similar if not actual PPS. It was just trying to get someone to understand. Breathing was more difficult, fatigue was intense, and my brain seemed foggy.

So, I just kept going on with my everyday activities but tiring by the evening, and having more frequent respiratory infections, etc. Finally in 1994 around January I started feeling constantly fatigued and panicked. My sleeping patterns were erratic or I slept all the time. Then from the end of Feb till about the end of March... life was a bit cloudy. I remember some things but not others. It was almost like I was living in a cloud. But not really sick enough to go to the doctor.

By the beginning of April 1994 my boyfriend Jim, and friends knew something was wrong. I didn't sleep, eat, and just laid around. When I did go to my GP he sent me home with tranquilizers. That's the worst thing you can give someone with respiratory problems.

By mid April I don't remember a thing... finally my friends convinced me to go to the hospital via ambulance. Once I arrived at the hospital I don't remember a thing. My CO2 (Carbon Dioxide) was so high the oximeter did not read my saturations. They didn't give me much time. I had respiratory failure.

Luckily enough one of the best pulmonologist's in our area was in ER that nite. My doctor at the time asked him to take over. He literally saved my life. He diagnosed me with post polio syndrome and did many tests to tell me that I needed ventilatory assistance at night.

We tried everything the Cpap and Bipap machine with mask. It was something I just

couldn't tolerate. I become aware enough of the situation that I personally opted for a permanent trach. You know, that is the best decision I have ever made. Since then I have had less hospitalizations, less infections, and I am thinking and processing much more clearly. I have almost become smarter because my system is filled with CO2.

I am not saying the transition was easy. I need more daily assistance with care, but we all live with what we have and make the best of it. That has always been my philosophy.

Please go see a polio and PPS knowledgeable pulmonologist... get sleep study tests. It would be the best move you could make to have a greater quality of life. We all know that with PPS our muscles have just got tired from the extra work they have had to do over the years... and if we can get assistance to give the muscles some rest then we must do it.

If I can be of any assistance, answer questions, be of support...please email or write to me.

Annette Hanna, Illinois.  
<nete1@ONEMAIN.COM>

<http://www.eskimo.com/~jlubin/disabled/ventuser.htm>  
Ventilator Users List.

### **Orange and Cranberry Chutney**

1 cup chopped orange  
4 cups fresh cranberries  
1 cup canned pineapple  
1 cup chopped apple  
1/4 cup chopped walnuts  
1.4 cup raisins  
2 cups sugar  
1 tablespoon cider vinegar  
1/2 teaspoon Ginger  
1/2 teaspoon Cinnamon

Bring all ingredients to a boil and boil until cranberries begin to pop. Chill before serving

Ms Que <qbanh@home.com>

**r**



## EXPLAIN GOD

One of God's main jobs is making people. He makes them to replace the ones that die, so there will be enough people to take care of things on earth. He doesn't make grown-ups, just babies. I think because they are smaller and easier to make. That way He doesn't have to take up His valuable time teaching them to talk and walk. He can just leave that to mothers and fathers.

God's second most important job is listening to prayers. An awful lot of this goes on, since some people, like preachers and things, pray at times beside bedtime. God doesn't have time to listen to the radio or TV because of this. Because He hears everything, there must be a terrible lot of noise in His ears, unless He has thought of a way to turn it off.

God sees everything and hears everything and is everywhere which keeps Him pretty busy. So you shouldn't go wasting His time by going over your Mom and Dad's head asking for something they said you couldn't have.

Atheists are people who don't believe in God. I don't think there are any in Chula Vista. At least there aren't any who come to our church.

"Jesus is God's Son. He used to do all the hard work like walking on water and performing miracles and trying to teach the people who didn't want to learn about God. They finally got tired of Him preaching to them and they crucified Him. But He was good and kind, like His Father and He told His Father that they didn't know what they were doing and to forgive them and God said "O.K."

His Dad (God) appreciated everything that He had done and all His hard work on earth so He told Him He didn't have to go out on the road anymore. He could stay in heaven. So He did. And now He helps His Dad out by listening to prayers and seeing things which are important for God to take care of and which ones He can take care of Himself without having to bother God. Like a secretary, only more important.

You can pray anytime you want and they are sure to help you because they got it worked out so one of them is on duty all the time.

"You should always go to church on Sunday because it makes God happy, and if there's anybody you want to make happy, it's God. Don't skip church to do something you think will be more fun like going to the beach. This is wrong. And besides the sun doesn't come out at the beach until noon anyway.

If you don't believe in God, besides being an atheist, you will be very lonely, because your parents can't go everywhere with you, like to camp, but God can. It is good to know He's around you when you're scared in the dark or when you can't swim and you get thrown into real deep water by big kids.

But...you shouldn't just always think of what God can do for you. I figure God put me here and He can take me back anytime He pleases.

And...that's why I believe in God.

This was written by 8 year old, Danny Dutton of Chula Vista, California, for his third grade homework assignment.

## Who says Christians ain't funny?

Come in and pray today,  
beat the Christmas Rush !!!

"FIGHT TRUTH DECAY -  
STUDY THE BIBLE DAILY"

"How will you spend eternity?  
Smoking or Non-Smoking"

Searching for a new look?  
Have your faith lifted here.

"THIS IS A CH - - CH. WHAT IS MISSING?  
(U R)

An ad for one Church has a picture of  
two hands holding stone tablets on which  
the Ten Commandments are inscribed  
and a headline that reads

"For fast, fast, fast relief, take two tablets"

"Come work for the Lord. The work is hard,  
the hours are long and the pay is low.  
But the retirement benefits are out of this World"

Did you hear about the Buddhist who refused his  
dentist's Novocain during root canal work?  
He wanted to transcend dental medication.

Tommy <tlcon@webound.com>  
Branson PPS Reunion Organiser  
ppstersandjesus@egroups.com

## POST-POLIO DOWN UNDER by Dr. Mary Westbrook

Like other western countries Australia experienced frequent polio epidemics in the last century. These continued for several years after the introduction of vaccination, although at a reduced level, until the early 1960s. One of the worst epidemics was in 1937. Community fear was so profound that the state of New South Wales petitioned the Federal Government to quarantine the badly affected neighbouring state of Victoria. When the petition was refused the NSW Government stationed police at railway stations, wharves and border crossings between the states, to turn back children under 16 years of age who did not have a medical certificate stating that they had had no contact with polio in the past three weeks. Australian Nobel prize winning immunologist, Macfarlane Burnet, accepted the then current view that "polio struck through the nose" and advocated nasal sprays and nose clips. Although doctors were encouraged to set a good example and wear clips these campaigns failed. The island state of Tasmania had the highest ever per capita rate of polio (421 per 100,000) that occurred in a polio epidemic apart from the Iceland epidemic of 1924 (1). (This does not include so-called virgin-soil or zero immunity epidemics e.g. the St Helena epidemic, 1945). Epidemics flared up again after a lull during the Second World War, peaking in the early fifties. When the Queen visited Western Australia in 1954 there was a ban on shaking her hand or personally giving her flowers or gifts. She resided on the royal yacht instead of Government House and was not served local food.

Australian polios' experiences were more similar to that of their British than North American counterparts. This is hardly surprising as Australia still regarded Britain as the mother country and many of the orthopaedic surgeons and senior nurses who cared for us did post-graduate training there. My doctor, Lawrence Macdonald, had spent five years at Oswestry and adopted many of their practices. Sister Bennett who ran the orthopaedic ward was impressed with the British practice of putting young patients in the sun. So we were sunned and sunburnt, wearing bikini type outfits, in the height of the Sydney summer. While Sister Kenny was an Australian she was driven from the country, to the American and world stages, by the condemnation of Australian doctors. Relatively few Australians were treated by the Kenny method so most did not encounter the ubiquitous steaming hot packs described in American polio biographies. Usually Australian polios were treated by lengthy hospitalisation, splinting, daily physiotherapy and some hydrotherapy. Our parents were given little

information, visiting was usually once a week, younger siblings were not allowed to visit, and many of us experienced emotional and, at times, physical abuse from staff.

**The advent of post-polio.** Like our British counterparts we got on with our lives. There was no organisation like the British Polio Fellowship to keep us in contact with each other. As the decades passed the strange symptoms many polio survivors were experiencing only began to make sense as rumours filtered through from the USA in the eighties. In my own case, I picked up a copy of the Rehabilitation Gazette in the University library, read an article on the late effects of polio and realised what was wrong with me. In 1988 American sociologist and polio survivor, Irving Zola, visited NSW to lecture on ageing and disability. During his visit he presented a workshop on the late effects of polio. As a result of this a group of survivors met and established the Post-Polio Network (NSW). The Network's Committee decided that research was one of its priorities and as I was a psychologist teaching health practitioners and researching disability issues, I was assigned this task. The Network felt that it needed to establish whether the facts emerging from North American research were replicated in Australia. Most polio survivors who contacted the Network, following media publicity, complained of health practitioners' lack of knowledge of the condition. If the Network was to convince practitioners of the reality of post-polio problems publications were needed in Australian professional journals. Eventually the research findings appeared in medical (2), physiotherapy (3), occupational therapy (4,5) and chiropractic (6) publications. This followed protracted battles in several instances because editors were hard to convince that post-polio existed.

**Research program.** Essentially my research consisted of an initial survey of over 300 Australian polio survivors. Five years later I followed-up 176 people from the first survey who met the criteria that Ramlow et al (7) reported were valid criteria of physicians' diagnoses of post-polio syndrome. The initial survey revealed that Australian survivors were experiencing the same late effects, with a similar time of onset (33 years after original infection), as North American survivors. An unusual aspect of the questionnaire developed for the initial survey was the open-ended questions. These asked about people's reactions to the onset of late effects, treatments they had used and their efficacy, strategies that they found helpful in coping with post-polio and advice they would give to someone who developed post-polio. Their answers provided some new insights into the post-polio experience, many of which were explored by more detailed questions in the follow

-up survey. I will focus on some of these findings rather than on those that mirror North American research results.

### **Changes over time in physical and psychological well-being.**

At the time of the follow-up survey survivors' answers revealed that significant deterioration had occurred in their physical health status since the initial survey (2). Survivors were questioned as to whether 15 symptoms had developed, or become worse, over the past five years. The average respondent said eight had done so. New, or increased, muscle weakness and fatigue were reported by 91% of the group and 80% had developed new, or increased, muscle pain. Symptoms that remained most stable over the five-year period were cramps, sensitivity to cold, muscle atrophy and muscle twitching. Respondents were asked whether they had experienced new difficulties in eight activities of daily living. On average, four activities were harder to do. Survivors were more likely to use aids or assistive devices at follow-up and to use more aids than they had previously. In both surveys survivors were asked to write an account of their feelings about having late effects from polio. These two accounts were scored for their emotional content. Over the five years respondents emotional distress had diminished significantly. They were experiencing much less anxiety, depression, helplessness and uncertainty at follow-up (5). Thus survivors' psychological well-being tended to improve as they moved on from the initial crisis of the onset of post-polio even though, objectively, they were more disabled. Of course post-polio problems still caused survivors emotional distress but for most people this had lessened.

### **Types of coping strategies used and their value.**

In the follow-up survey survivors were given a list of 20 coping strategies involving either a lifestyle, personal or social change (5,8). They were asked to check the strategies they had used and also how helpful each strategy was in relieving post-polio symptoms/problems. Personal strategies were the type of strategy most likely to have been adopted. Personal strategies included:-

- Became more involved in interests I can still pursue,
- Developed my philosophy of life,
- Became a more spiritual person/developed my inner life,
- Used time I'm resting or alone more creatively
- Developed new interests and leisure pursuits.

Seeking enjoyment and spirituality are rarely discussed in the rehabilitation literature as ways of enhancing life with a disability but they have much to recommend them (8,9). Overall, personal type strategies received the second highest number of "very helpful" ratings from survivors.

The second most frequently adopted coping strategies were lifestyle changes. Virtually everyone who adopted a lifestyle change found it provided at least some help. These strategies included:-

- Employing household help,
- Purchasing special furniture and equipment, Home modifications,
- Pacing, Planning and Resting.

Overall, lifestyle changes were judged as more helpful in reducing symptoms than were other groups of coping strategies or the medical type treatments discussed in the following section (8).

Strategies involving social change were those least likely to be used and they were least likely to be rated as helpful. Survivors found it hard to ask for help from family (only 39% did so) or friends (19%). Of those that asked, just over half found it "very helpful". While three quarters of survivors had talked to family or friends about their post-polio only about 40% of those who did so rated it as "very helpful". These findings are disturbing given the research evidence that social support reduces stress and facilitates adjustment among people with chronic conditions including post-polio. There are many legacies from polio survivors' pasts that make it particularly difficult for them to either seek or accept support from others (8,10).

### **Health practitioners and treatments.**

In the initial survey only 13% of respondents said that a doctor had identified polio as a possible cause of their new symptoms (3). Most people made the connection between their symptoms and having had polio as a result of media reports. Almost one in five respondents wrote unsolicited comments on their questionnaires about their bad experiences with doctors. Almost all survivors had consulted their general practitioners who, if they referred them, were most likely to send them to a physiotherapist. While many physiotherapists were rated as helpful, about one fifth of their clients gave "no help" assessments. These seemed largely due to inappropriate vigorous exercise programs which exacerbated existing problems. Chiropractors, who are rarely mentioned in the post-polio literature, received more favourable ratings than did physiotherapists (2). In the 1980s a new medical speciality, the College of

Rehabilitation Medicine, was established in Australia. Its members are the equivalent of North American physiatrists. At follow-up the doctors rated as most helpful were specialists in rehabilitation medicine. However many survivors only saw them because, at the advice of the Network, they requested a referral from their general practitioners. While 56% of respondents rated the rehabilitation specialists they consulted as "very helpful" only 33% gave this rating to neurologists, 32% to general practitioners and 25% to orthopaedic specialists. Among specific treatments tried, those rated as particularly helpful were massage, hot baths, special shoes, drugs for pain relief, and counselling. There was a mixed response to certain treatments with some survivors finding them very helpful and others no help e.g. swimming, hydrotherapy, exercise programs and stress management courses (2).

### **Stress from the past.**

The two major sources of information from the epidemic days are the publications of health practitioners who treated polio patients and the biographies of people who contracted polio. These, I have argued (10), gave rise to two myths. The gross underestimation by health practitioners of their patients', particularly children's, distress led to a myth that: *Contracting polio is not very upsetting for children: They soon get over their distress unless they are spoilt.* Survivors' biographies also downplayed the stress associated with having polio and contributed to the belief that polios should: *Ignore their distress. Hard work and cheerful acceptance overcome polio.*

Do survivors' memories support these beliefs? At the end of the questionnaire I asked survivors to write an account of their early memories of having polio. Overall, 84% of their narratives expressed anxiety. The most frequent type of anxiety related to separation e.g. "I can still see my parents leaving the hospital and myself screaming".. Most accounts contained depression (70%), 45% expressed anger and only 17% registered any feelings of pleasure or happiness. The social interactions described in survivors' stories were categorised as negative (e.g. someone harms or upsets the narrator, "They cut off my plaits. I still cry to think about it") or benign (these interactions ranged from positive e.g. "I enjoyed my parents' visits" to neutral e.g. "The nurse wheeled me to the ward"). Negative interactions were described in 57% of accounts and benign in 56%. My research into people's experience of other events indicates that these polio stories have extremely low rates of benign and very high rates of negative interactions. Some health practitioners writing at the time of the epidemics believed that contracting polio was more

upsetting for adults than for children but I found little difference between the emotions expressed by survivors belonging to these different groups. Survivors who were older at the onset of polio were more likely to report anxiety about dying. Those who had been young children were more likely to express anxiety about guilt, often attributing their polio to punishment for bad behaviour. Survivors who had been in iron lungs were more likely than other survivors were to express feelings of death anxiety, non-specific anxiety, uncertainty and anger. Such memories, and the social attitudes that denied their reality, have added enormously to survivors' problems in facing a second round with polio. They fear they will be abandoned once again while at the same time berating themselves for finding their "small" problems so difficult to deal with (8,10).

The last decade has seen many achievements by Australian polio survivors. There are now support groups in all six states. The Post-Polio Network (NSW) has about 800 members with nearly thirty support groups across the state. The Network receives queries from survivors around the world via its WebSite [www.post-polionetwork.org.au](http://www.post-polionetwork.org.au). It publishes four 16-page newsletters and four information bulletins each year. It has produced a medical alert card and an information booklet (11). The latter is included in the information pack sent to enquirers. Many enquirers make no further contact while some wait several years before joining the Network. We have more female than male members, some members never attend meetings and several send their wives to meetings to gather information. Four afternoon seminars with guest speakers are held yearly. We try to make one of these a mini-conference in a large country city rather than in Sydney. An important task of the Network is informing polio survivors about post-polio and increasing health practitioners' and the community's awareness of the condition. The Network participates in a nation-wide polio awareness week each year and in community education programs on immunisation. It persuaded two medical soap operas to produce an episode about post-polio. One woman contacted the Network after being phoned by her general practitioner at nine one evening. He told her, "I've just watched 'Country Practice' on TV and now I know what's wrong with you".. Three national conferences have been held at which American and Canadian experts, Drs Cashman, Yarnell and Elizabeth Dean, were keynote speakers. However while post-polio clinics have been established in some state capital cities, appropriate health care often remains hard to find and support groups frequently act as informal referral networks.

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\*These papers are in the library at the Lincolnshire Post-Polio WebSite:  
[www.ott.zynet.co.uk/polio/lincolnshire/library.html](http://www.ott.zynet.co.uk/polio/lincolnshire/library.html)

**Christmas Present Idea  
with percentage of profits to our funds.**

**Member Pat Hollingworth  
and David Clark - Snickers Workwear**  
offer White Polo Shirts  
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Prices are £10 with just the Logo on, £13.50 with embroidered First Name below logo.  
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Ambroise UK Limited is a partner company of Ambroise Holland who are the developers of the Utx Swing and Stabil braces that some of our members are now wearing. Dr. Robin Luff speaker at the Seminar at St. Thomas' Hospital mentioned these calipers in his talk on Orthotics.

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<http://www.ambroise-uk.com>

## **POLIO SURVIVORS DRUGS and ANAESTHESIA**

It is important that **ALL** Polio Survivors are aware of the fact that we tolerate some drugs and anaesthetics to a different level than that of non polios.

When you received Information from us we included leaflets about Drugs and Anaesthesia.

### **\*\* What you should know about your medications?**

#### **A guide for Polio Survivors.**

Joan M. Walker PhD, PT and A M Whelan, Phar D  
(Uk version) A F Forde MRPharm. B.Sc.Hons

### **\*\* You are going to have surgery - A Guide for Polio Survivors**

by Joan M Walker PhD, PT

### **\*\* Polio Survivors as Patients - Guide for Emergency Care & Surgical Health Workers**

Joan M Walker PhD, PT., C. McGowan & G. Vardy

In earlier LincPINs we have published

### **\*\* Preventing complications in polio survivors undergoing surgery.**

by Richard L Bruno PhD.

### **\*\* Be true to your PPS and your teeth won't be false to you: Preventing complications in Polio Survivors undergoing Dental Procedures.**

by Richard L Bruno PhD

In our August LincPIN following her speaking at the GINI Conference in St. Louis in June, we published the article

### **\*\* Summary of Anesthesia Issues for Post-Polio Patients**

by Susan Harrison Calmes MD,  
Chair and Clinical Professor of Anaesthesiology,  
UCLA

The British Polio Fellowship Bulletin latest issue contains an article on page 22 entitled

### **'Anaesthesia Considerations for Polio Survivors'**

Geoffrey T Spencer, OBE, MB, BS, FFARCS,  
which is a summary of the conclusions of  
'Perioperative care in restrictive respiratory disease'  
by Patrick HA, Meyer-Witting M, Reynolds F,  
and Spencer GT. Anaesthesia, 1990, Vol. 45,  
p390-395.

Geoffrey Spencer is a Former Consultant, Department of Anaesthetics, Lane-Fox Respiratory Unit, St. Thomas' Hospital, London.

Those marked \*\* can be found in the Lincolnshire Post Polio Library and in Newsletters on our WebSite.

Most of us thought that we only had polio where we were paralysed and have made comments like 'I only had it in one leg' or 'waist down' or 'just in my right arm'. The majority of us show little external visible

sign of our polio damage until we have functional decline. What we did not realise was that at least 90% of the anterior horn cells were in some way affected during the polio infection. When examining us health professionals did not see any clinically evident weakness in any area until we had about 45% nerve damage with paralysis being evident at 60%+ nerve damage. This explains why we are having problems in areas we did not realise had been affected by our polio.

Many earlier medical articles to this year stated that you had to have had paralytic polio to have 'PPS'. Excluding those with a diagnosis of non-paralytic polio 45-59% and those with under 45% damage. But the articles also stated that they were seeing problems in areas not thought to be previously affected. The areas of our body that had non-paralytic polio. Dr. Halstead and Dr Silvers article 'Nonparalytic Polio and Postpolio Syndrome' in the Special Feature on PPS in the Jan/Feb 2000 American Journal Of Physical Medicine and Rehabilitation states

### **A history of remote paralytic polio or findings on history, physical examination results, and laboratory studies compatible with poliovirus damage of the central nervous systems in earlier life'**

This article referenced The Lincolnshire Post Polio Library Article 'Non Paralytic Polio and PPS' by Marcia Falconer and Eddie Bollenbach's which we published in January 1999. There were two other articles in the PPS Feature, one by Marcia Falconer PhD and Eddie Bollenbach MA 'Late Functional Loss in Nonparalytic Polio' (Survey information page 8) and 'Paralytic vs. "Nonparalytic" Polio. Distinction Without a Difference' by Richard L Bruno PhD.

Most of us were children, some of us have no memory of our polio, and the years have passed. To err on the safe side if you are going to have any anaesthesia even for a minor procedure (including local anaesthetic) you should inform health professionals that you had polio and have copies of the leaflets/articles available for them to read if they are unaware.

Your new membership card - will be with your shortly, delay with manufacture for which we apologise - contains a medic alert statement on the reverse. You could also purchase a medic alert bracelet. It is also a good idea if you write or type out some details about yourself, your polio and the drugs you take, and carry this with you in your handbag/wallet.

See easiest 'filing cabinet' to find on next page. Richard L Bruno, PhD is undertaking a PPS Anesthesia Study. You will see that he would appreciate a copy of the Anaesthesiologists report. In the UK, unlike the USA, we are not given copies of our medical reports and records unless we request

them and pay for the copies. Having talked with many polio survivors I wonder how many of us have been told if there was any problem with our anaesthetic? If do not have email you can either write directly to him or send the information to us and we will forward it.

### PPS ANESTHESIA STUDY

**All of this information will help us be better able to convince anesthesiologists and surgeons that the type and amount of anesthesia and pain medication must be tailored to the individual polio survivor and not be determined merely by body weight.**

We are collecting case histories of polio survivors who've had frightening, dangerous or good experiences with anesthesia. The anesthesia could have been a gas, intravenous or oral (or some combination) and used for a diagnostic procedure (such as a colonoscopy), minor surgery (such as dental surgery), laporoscopic surgery or an open procedure.

We would like to hear about the effectiveness of the anesthesia and any side effects you may have had, including:

- \* Waking up during the procedure;
- \* Vomiting after you received the anesthesia;
- \* Not being able to wake, breathe or swallow for hours or days after receiving the anesthesia;
- \* Feeling sleepy or fatigued for days or weeks after receiving the anesthesia;
- \* The amount of PAIN you experienced after the procedure, whether you received pain medication and the type of Pain Medication you were given.

Please include:

- \* The AGE at which you had polio;
- \* If you had BREATHING PROBLEMS when you had polio, what they were and if you used a respirator or an iron lung;
- \* Your AGE and DATES when you had the anesthesia;
- \* Breathing problems you had AT THE TIME of the procedures (including sleep apnea and whether you were using a CPAP or BiPAP machine);
- \* Any medical problems that might make you more sensitive to anesthesia (such as liver or kidney disease).

Please e-mail the above information if at all possible. Don't include any childhood surgeries where you were given ETHER.

We would also very much appreciate your mailing the ANESTHESIOLOGIST'S REPORT that describes how much anesthesia you received, the type of anesthesia you received and your response before, during and after the procedure.

As always, many thanks for your assistance!

Dr. Richard L. Bruno  
Chairperson International Post-Polio Task Force  
and Director, The Post-Polio Institute  
Englewood Hospital and Medical Center  
Englewood, New Jersey, USA.  
<HarvestCtr@aol.com>

### MEDIC ALERT INFORMATION STORE IT IN YOUR REFRIGERATOR

Now this may sound weird, but for a couple of months now I keep a copy of my current computerized medical information sheet in a tall, wide-top plastic water bottle (it looks like a big prescription bottle) in my refrigerator. I got fancy and put a red cross on the bottle. I did this after a nurse friend of mine told me the EMS folks for our region are implementing a program to have everyone in our part of western Oklahoma keep a medical information sheet in a bottle in the refrigerator. When fully implemented, large prescription bottles will be provided free by participating local pharmacists.

The concept is this. Of all the storage places in your house, the refrigerator is easiest to quickly locate compared to desk drawers, filing cabinets, laying on a table top, hanging on a wall, etc. or even on your person. In an emergency call by EMS, you may be in a coma, passed out, faint, and so on, so the EMS people look in the fridge and find your medical information sheet you don't need to tell them. Or if you are conscious but weak, feeble, panicky, etc. you can just say "look in the refrigerator" to the EMS people or anyone else coming to your aid, if you need to say anything at all. If calling 911, the person answering 911 can be told emergency information is in the refrigerator.

The idea is not fully implemented yet by all people concerned. But I like the idea so much that I made up my own "medical information refrigerator bottle." I figured the idea is really good for people living alone such as myself and it is a simple thing to do. Luckily, no need for anyone to find the bottle has come up yet.

Sincerely, Cactus Jack in Oklahoma  
Jack\_Schwartz@ITLNET.NET  
(Polio 1943 at age 4, PPS 1988, pacing, AFO,  
Neurontin 300 mg, 3x/day)

## HINTS TIPS AND BITS from PPSERS world-wide

I could not agree with you more on **making things look as wonderful as possible**. I am on my second scooter, the first was a three wheeler that tipped on the lawn, I was spared. I loved it as it could go more places than my four wheeler and it had a fabric seat and was a pretty pink. This one that I ended up purchasing is a four wheeler with a bright red metallic finish and I do use a gorgeous plaid throw on it to assist with the sweat from the leather/vinyl seat.

I have also learned to carry a plastic cover up that you can see through in case it rains.....when it rains and the main board on my computer gets wet it will only operate in reverse and we have no control over it, we learned this the hard way.

I treat my scooter with the same respect as I treated my feet, it is mine and I have my name on the front. A friend sent me some decals that were holographics in my name " Linda ", and I chose to put them on so that anyone who did not know my name and was talking to dear husband or my darling daughter would also speak to me and it has worked.

Linda B.

You know, most survivors would balk at going into a power chair. I must be nuts cause I can't wait. **7.5 mph is faster than 5.5mph**. And I figure anything that requires a seat belt must be fun to drive!! It will also take up less room in the apartment.

Jo <KellyK10@aol.com>

Just wanted to let you know about the ONLY cushion I can tolerate, it is the **Roho air-bubble, and is comfortable for hours "on end"** <grin>

I have a tendency to sort of list to one side therefore placing more weight on one side than the other, so I have the model called the "Enhancer".....it has two air valves which allows for one side of the cushion to be pumped higher than the other so you sit square.

Ree in MA <debbiesmom@webtv.net>

Try a **Speakerphone** or **headphone attachment** if you find holding a phone up to your ear is getting harder. Sustaining muscle action to the point of fatigue is not a good idea, try aids and give your muscles a rest.

Get some **Voice Recognition Software** before you need it all the time so that you can give yourself a break from typing some of the time.

Hilary <linpolio@legend.co.uk>

It has been three and a half years since I had to retire on SSDI and hit the post polio wall and life got changed totally. I have been an RN [registered nurse] for 30 years and had no idea how much of my own

identity was connected to what a HUMAN DOING I have been. **NOW I am working on a new job... HUMAN BEING**. And making memories everyday. Enthusiasm is so very important.

Today it rained here in the desert and we had BIG TIME lightening and thunder. I saw a full rainbow... and just sat in my van gazing at this beautiful site in the sky! Then after it got dark, had an amazing light show of lightening for a couple of hours... seeing it flash from behind the mountains surrounding this valley. IT was wonderful. NEVER have seen lightening quite like this. I grew up with great storms; they have good light shows after dark in Puerta Vallarta... but I was so aware of that Power so much greater than ourselves today as I enjoyed all these beautiful things of nature! The air smelled so different and it was so up lifting for me. Restful you know?

Linda Dempster <DEMP12@AOL.COM>

Anita received this note from her daughter.

"When I was little, I called you Mommie. When I was older I called you Momma. I never called you Mom because that's what we called Grandma. Today, as I see how you've handled all the trials and triumphs in your life, **I just call you Amazing.**" Love Lori.

Anita Bjorling <anitabjorling@HOTMAIL.COM>

At the doctor's office,  
the PPSer had to fill out a questionnaire.  
One question was, "What kind of exercise do you do?" "None," he wrote.  
The next question read, "How often do you do it?"  
He quickly filled in, "Every day.

Forrest Gump is wrong!  
Life is NOT like a box of chocolates.  
It's like a jar of jalapeno peppers  
you never know when it's going to burn your arse.

Marsha in Texas <marsha@ccms.net>

**ON FOREARM PAIN**, I solved this by making sure my chair was at the correct height. I now sit in the chair so I can position my forearm on the armrest of the chair while I use the mouse of the computer. This gives my forearm support and keeps the stress off the forearm muscles.

Ed Keohan <ekeohan@fiam.net>

I've learned that you shouldn't go through life with a catcher's mitt on both hands.

You need to be able to throw something back.  
**LEG WARMERS and going to bed with cold feet:**

1. Plunk your cold feet on your spouse. But what if you have twin beds?
2. I had a Cornish Rex cat. As you know, that breed is practically hairless. So when I went to bed, Smoky would nose his way under all the blankets until he found my bare feet. There, he would nestle comfortably (and no comments about



“smelly” feet from anyone!) and both of us kept warm all night! Alas, when we moved to a condo, Smoky was not allowed to come. I hope his new owners are keeping him warm. But, my feet missed him so much!

3. Using a hot water bottle might sound like the obvious solution, but hot water bottles get cold in time, and I don't like the feel of them.
4. Electric pad or blanket? Sorry, I love to scrunch the blankets around me, and that is a no-no with an electric blanket.
5. Well, wear socks to bed, you say. I tried this and it worked the best, but socks still had a drawback: with wearing hose all day and socks all night, my feet didn't have a chance to be “free” so to speak.

Aha, the solution for me was this. I had purchased a loosely knit pair of leg warmers to use when we were in the motorhome. On cool days, the floor is cold, so I would don these leg warmers and my legs were kept warm. Leg warmers are like those dancers wear when they are exercising - open at both ends, and quite long. I stitched up one end of the leg warmers, and I pull them on at night - they reach up to my knees; my feet have plenty of room to wiggle my toes; there is absolutely no constriction on my legs to cut off circulation. At last - I can do without those 5 things listed above. No, wait. I'm not exactly truthful. I still miss Smoky - he was the best!

and

It might be interesting to hear how you take **safeguards against crime** since we are physically vulnerable. Just last week, a lady who wears braces because of polio was out on the streets in the Vancouver, B.C. area to sell poppies for our Remembrance Day on November 11. Several very young teens came along and set out to snatch her contribution box - about \$80 in it. She tried to resist, got a slashed hand which required stitches, but the thieves made off with the money. A most despicable crime.

When I am on crutches, standing outside a building and waiting for my husband to bring the car around, I feel very conscious that I could well be the victim of a purse snatching incident. I often give my purse to my husband to carry with him to the car. When I am shopping in the malls, I tie my purse by its handle to the basket and cover it up with a plastic bag or whatever. Should someone try to grab my purse from the basket, they would inevitably pull the wheelchair over. I need my purse for hanky, glasses, etc. Often I take out any credit cards and put them in a zippered pocket on my person. Nothing, of course, is 100% safe - but for sure, we're not able to defend ourselves. If I am on crutches, I just need to get a shove - even a gentle shove - and I am flat on my face. How do you approach your vulnerability to crime?

Joyfully, Viola Pahl <violapahl@iname.com>  
White Rock, British Columbia, Canada  
<http://www.pahls.com/books.html>  
(Viola has written six books - some of them include stories from physically disabled people.)

A man entered his local paper's pun contest.  
He sent in ten different puns,  
in the hope that at least one of the puns would win.  
Unfortunately, no pun in ten did.

**The Eastern Polio Support Group in Australia** is made up of approximately 45 "Polio's", their families and friends. We meet on the third Saturday of each month in a church hall in Box Hill, which is an eastern suburb of Melbourne, Victoria, Australia. We are incorporated and mainly self funded, other than small grants from local councils and the State government which is used to pay printing and stationary costs. We are currently applying for registration as a charity.

Our aim is to provide advice and mutual support to people who have had polio, and/or the late effects of polio (PPS), to educate the community on the need for continued immunisation and to provide a focal point for discussion on issues affecting one or more members of the group. We also enjoy each other's company and look forward to the social content of our meetings.

Victoria has a centralised service, Polio Services Victoria, funded by the State Government which provides access to doctors, physios, orthotists and occupational therapists who are familiar with Polio and the needs of "Polios".

We are sure that the issues which face us are universal, particularly as we are an aging population. Our youngest member is aged 46 and the average age is 65. We are concerned about adequate funding for equipment, suitable housing, access to quality medical care and maintaining our independence.

Personally, I contracted Polio at the age of 4 months in 1954. I have been having problems with PPS for approximately 10 years. I have moved from no aids to calipers, crutches and an electric scooter over the past three years. I have had to dramatically reduce the number of hours I work due to PPS and am now in the process of retiring from the workforce. I hope to take a more active role in PPS research once I have more time available.

We would be happy to answer any questions you may have and look forward to hearing from you or your members.

"Trish Malowney" <tmal@planet.net.au>  
Editor - Eastern Polio Support Group Inc.

**DRIVING** - Are you getting more pain in your right ankle, knee, thigh and hip when driving? Have you checked to see if your right foot is weaker - now dropped again - can you lift that foot up to 90 degrees still and if you can, can you sustain this? Using the accelerator means having to hold your foot in a certain position with a little up and down movement for speed changes for a long time. As the muscles that do this weaken other muscles up your leg and back

come into play and try and help. You then get pain in the knee, hip and back.

Do you get more pain in your right leg when you are driving in town or on windy roads compared to when driving on the motorway? You are doing more accelerator to brake movements. Have you been lifting your left leg onto the clutch? Is this leg now weaker and is it time to change from a manual to automatic? Does your arm ache at all when driving? Would an arm rest or different controls take the strain off your arm?

I was fitted with an Ankle Foot Orthosis and 95% of the pain in my right leg when driving went. It took two months of endless getting, or trying to, in and out of cars to find one that fitted me. A Motability VW Sharan 2.0 Automatic. No more lifting my left leg onto the clutch, no more struggling to get in and out of a normal height car, much reduced pain and strain on my left arm as I now have an arm rest, room for my scooter in the back and a hoist to get it in and out.... Driving is once again an enjoyable experience and I have control of that part of my life back. The only drawback for me is being six foot tall with very long legs and having a scooter. The Sharan was the smallest vehicle that fitted my needs and I had to pay a hefty deposit plus purchasing the hoist on top of handing over my mobility allowance.

You can apply for a grant for this but I was told this can take about six months and you need a doctors report stating why you need this particular model. In the summer of 97 I could not get a doctor to fully assess me let alone write a report. Hopefully this will not be a problem for the change of vehicle in October 2001.

Hilary <linpolio@legend.co.uk>

### Sticky Situation

A movie thriller was just zooming to its climax when an elderly woman began searching under her seat, disturbing the man next to her.

"What have you lost?" the man demanded.

"A caramel," she replied.

"You're going to all this trouble for one caramel?" he hissed.

"Oh, yes," she replied. "It has my teeth in it."

Joan in Oregon <ladybugs66@juno.com>

**After a two-year long study,**  
the National Science Foundation announced the following results on corporate America's recreation preferences:

The choice for unemployed or incarcerated people is basketball.  
for maintenance level employees it is bowling.  
for front line workers it's football.  
for supervisors it's baseball.  
for middle management it's tennis.  
for top management/directors is golf.

Conclusion: The higher you are in the

corporate structure, the smaller your balls are.

Here are **some of the letters/emails** that we have received to give you some idea of the questions we are asked. If you can offer suggestions then please get in touch.

The first asked:-

1. I seem to have continuous pain...are there ways to manage this?
2. I am having trouble with balance. Unexpectedly it seem as if groups of muscles are just 'not there' (i.e. the outer side of my left foot, or the muscles in my thighs), causing me to stumble or fall. Are there ways to avoid this?
3. I have been told to exercise by one doctor, yet have been told by the physical therapist and other doctors that any extra activity would only add to my fatigue, and diminish the time I will have to live a "normal" life before the effects of p.p.s. are debilitating. How do I determine who is right?
4. It seems that every day brings a new type of pain, in a new set of muscles in my feet or legs. Does this mean that the disease is progressing, or just the "nature of the beast"?
5. In my profession I am required to be on my feet most of the time. I find that it is easier to move around once I have been on my feet for a while, although I become very tired much more quickly than even last year. Is this typical?
6. I have been told by another p.p.s. victim that if I were to wear a brace, it would help me walk and to climb stairs more easily.

How do I find out about this? To whom do I talk?  
Royce Ruther <rrut@bright.net>

Another:-

**When I fell down the stairs** a few days ago I was quite reassured by the speed which my brain worked. In a split second that seemed like ten my brain said "do not fall forwards, do not go down in a sitting position jarring your spine on each step, pull all limbs in so you don't knock anything on the way down, just lie back think of England and pretend you are a toboggan on the Cresta Run." Amazingly I managed this including the as yet unnamed 90 degree turn half way down which made it very exciting. The most difficult part was breaking at the bottom of the stairs - a brick floor.

I slid to a stop in a sitting position with legs out in front of me on the cold floor. I gingerly moved each limb and everything seemed to work to the same level as before which was a great relief. I then burst into tears wondering if the next time I fell I would be as lucky. I sat there for some time collecting my thoughts, wondering why the medical profession just do not seem interested in addressing themselves to my latest symptom 'internal' numbness on my left side that started seven months ago.

On May 1st I woke to find the left side of my body

was numb just like a dental injection. I could move so I made the decision it was not a stroke and contacted my GP. I have seen seven doctors - two of these Consultants - since that date yet no one seems to be able to say what is causing this, why it happened, what they can do to help me.

My own research has shown that I do not have full information on body and limb position called disturbed proprioception. It started feeling just like a dental injection and is gradually going through the 'wearing off' stage. When I walk I put my right foot forward as normal and I hope my left leg will follow as normal but I don't know what it is going to do. Sometimes it does and sometimes it goes off in its own direction. Which is why I fell. When I bring a fork to my mouth to eat I am never sure if its going to make it. However as that side of my face is also affected it doesn't hurt much if I miss.

Worrying as this is whenever I tell another polio survivor we laugh our way through this story and I hope you have had a few smiles as well. There is of course a difference in telling someone who can relate to your situation which is why I believe contact with other polio survivors with PPS is so important. It really does lighten the load on some days.

I can feel touch on my skin and pain in the muscles but the inside of my leg feels 'numb'.

I have a well recorded history of 20 years muscle weakness and gradual functional decline. I now have confirmation that I had type 1 polio as a child. I can remember being in bed for many weeks and am assuming that I did not reach the paralytic stage. My parents were middle class and the 'doctors always visited the house' with my varied childhood illnesses. In those days parents did not tell children what was wrong with them. I believe I have late effects of my polio but also have other problems. I have many diagnoses including 'do not have' what others say I have.

Hilary described a similar 'internal numbness' to her doctors about her left leg. In February 1995 when she developed severe pain from hip joint down the back of her leg under her heel to the left side of her foot. She told me 'It is difficult to explain but in the same path where I had pain I have been left with skin where the feeling of touch is different to skin nearby and an 'internal feeling of numbness' as if part of the inside is not working as it used to. '

Does anyone else experience this or have any ideas what could be causing my symptoms?

Jean Murdoch <jean@murdocha1930.fsnet.co.uk>  
Lincolnshire

**HELP REQUIRED  
for calliper users wearing trousers.**

One problem I haven't cracked is how to stop the callipers from ruining my trousers! It may seem

ludicrous but I have to dress smartly for my professional life and the damage is proving costly!! Do you have any hints on how to protect my suit trousers or at least to increase their life span?

Any advice would be appreciated.

James McKillop  
<james.mckillop@beaumont1.demon.co.uk>

Editor - I am six foot tall and finding trousers long enough, wide enough to go over calipers, strong enough yet smart enough material is difficult.

Any other problems with/tips/ideas on clothing would be appreciated.

**See Bean Fudge Recipe on page 23**

**Idaho's Pinto Bean Pie**

(This is supposed to taste like Pecan Pie)

1 heaping cup of mashed Pinto beans  
1/2 cup sugar  
1 cup brown sugar  
1/2 cup butter  
2 eggs, beaten  
Unbaked pie shell

Blend sugars, eggs, and butter until creamy.

Add beans and blend well.

Pour into a 9" unbaked pie shell.

Bake at 375 degrees F for 20 minutes,  
then at 350 degrees F for an additional 24 minutes or  
until inserted knife comes out clean.

Each serving provides 427 calories:  
5.74 grams protein, 20.5 grams fat,  
57.25 grams carbohydrate.

## UPDATING YOUR CHILDHOOD By Lloyd J. Thomas, Ph.D.

In India, they use grown elephants for logging. At night, they tie down each elephant's leg with a small twine and a small wooden stake. The elephant could easily walk away, but never does. It believes that when there is pressure on his hind leg, that it is impossible to move beyond the limits of that string. A strong animal that has been lifting tons of logs during the day, is held back and limited by a small stake and string. How did it get that way?...hobbled by such a seemingly small thing?

When the logging elephant was very young, he was chained (with a large, heavy chain) to a large tree. He would struggle against the limits of the chain until he was exhausted. It seems that he finally learned "when my hind leg feels the pressure of the chain, that is as far as I can walk." So he quits struggling. He makes an immature cognitive conclusion about his limits and his ability to move beyond them, under certain circumstances. As the elephant grows, the chain is replaced by a rope, then the twine. The tree is replaced by a smaller tree, then a large stake, then a small one. The elephant never updates the conclusion he made as a youngster. By the time he is fully grown, he still does not struggle against the puny twine that keeps him tied down. He never challenges that conclusion made in childhood about what he can and cannot do when his hind leg is shackled.

All of us were born into a rather chaotic world. Children are bombarded by new and meaningless stimulation of every one of their senses. Some of that stimulation is pleasurable, desirable and safe. Other stimuli are painful, repulsive and dangerous.

Gradually our brains and nervous systems develop sufficiently so we can begin organizing the chaos into perceptions and assigning meaning to them. We begin to make immature cognitive conclusions about ourselves, others and the world in which we live. These conclusions are generally made by the time we are 5 years old. We decide that certain actions will result in what we want, while others are likely to get us into pain. We develop a kind of "working hypothesis" that says, "This is who I am, who the others are, and how the world is." We conclude that our experience and perceptions are universal and "this is what life is like." Just like the young elephant concludes he can't walk beyond the limits of his tether.

Trouble begins when we grow older, gain more experience, and never revise or update our original conclusions. We keep fitting new experience into old familiar perceptual patterns. We paint new events with old color. We massage new relationships into shapes and roles with which we are most familiar, and with which we are most comfortable. We often carry our childhood conclusions about ourselves and our abilities right on into adulthood, without ever challenging them.

In our rapidly changing world, almost all of our immature cognitive conclusions have become obsolete.

As grown-ups, we are no longer helpless, dependent, incompetent. We are no longer children. And the childhood conclusions we made have usually become irrelevant. But we tend to keep them and continue to behave as if they were still accurate, still true and still useful.

To ease the anger, pain, and fear about giving up our childhood beliefs, as well as all the behavior based upon them, we first need to realize that it was precisely those conclusions, now mistaken and inappropriate, which got us through the first 20 years and allowed us to survive the way we did. We were clever enough, perhaps even brilliant, to have made it through childhood, albeit with a lot of help from parents, teachers and friends. But now, RIGHT NOW, those conclusions may not work. They may now be mistaken. A grown elephant could easily pull up the stake tied to his leg and simply walk away.

For example, the person who feels angry or threatened about being abandoned as a child, feels very justified as an adult in his anger, jealousy, and controlling behavior. And he gives himself, and others all kinds of examples and details of how unfairly he was treated (or is being treated.) And he is right...he was treated unfairly and was cheated as a child. But now, RIGHT NOW, he is cheating himself! As long as he continues to spend his energies being angry at the people who left him or deprived him at one time in his childhood, he has precious little energy left to spend on getting for himself what he needs NOW by way of closeness and happiness. His rage isn't hurting his parents (chain), because they are no longer his parents. They are no longer crippling him. His immature childhood conclusion is. He is crippling himself!

Happiness in life lies not in trying to change your history or your childhood experience. Happiness lies in challenging all of your childhood conclusions, letting go of those that are no longer relevant, and experimenting with new ones. To update your life, you need to identify childhood guilts, grievances, resentments, pain and fears. By updating your childhood, you can prevent it from limiting you today. You can stop your childhood from robbing you of your entire life. As an adult, you can simply walk away from limiting conclusions, and get on with living now. You can update who you think you are. You can choose to experiment with new ways of functioning. You can freely say "goodbye" to your childhood and walk into your future as a free and fulfilled adult.

Lloyd J. Thomas, Ph.D. has 30+ years experience as a Life Coach and Licensed Psychologist.  
Telephone 001 (970)568-0173  
E-mail: <DrLloyd@CreatingLeaders.com>

### CONFERENCE TALK by TONY GOULD Author of 'A Summer Plague'

I've been asked to talk about the patient's perspective. Well, if you look at the timetable of this conference, you'll get some idea of how high a priority the doctors give it. Now I don't want to bite the hand that cares for me, but who has been allocated the notoriously

## TAKING TIME OUT

When people come to visit me they usually comment on how relaxing it is in my company. There I am reclining on the sofa, they get comfy in an armchair and we have a good old chat. The thing is, it occurred to me quite some time ago that I'm really not very relaxed at all. Even when I'm lying down resting I've found that my body can be quite tense, and having spoken to others with polio, it seems I'm not alone.

I'd like to explore the reasoning for this tension another time, but for now I'd like to talk about ways we can help ourselves and conserve our precious energy by learning to relax more. The reason I feel this is very important is that if we're tense, we're using a lot more nervous energy than if we're relaxed, wasting energy in fact. Also our breathing can become very shallow and the amount of oxygen we're taking in is reduced. (More about this later). All this will contribute to fatigue, weakness and aches and pains.

I think it's fair to say that most people with polio like to do the very best they can from day to day. Even when we're pacing ourselves, we probably plan what we can do that's useful during our 'rest' periods. It might be sorting through the post, dealing with household bills, making phonecalls (and we all know how frustrating they can be these days). In fact anything to keep busy and productive. So even though we are sitting or lying down, we're not really resting completely. At times like this we're still active mentally and this can use up quite a lot of energy.

So what I'm suggesting is that you set aside time for a **real** rest, preferably twice a day for at least fifteen minutes, and use the time to practise relaxation and breathing exercises. 'Practise' is quite an appropriate word for it, because it doesn't come that easily for some. You'll probably be lying there thinking; 'I'm sure this works for other people, but it really isn't doing anything for me' and your mind will wander. It's worth persevering though, as it won't be that long before you do notice benefit and you'll understand why relaxation exercises are recommended so much'.

There isn't the space here to give a lot of detail on specific exercises but there are plenty of books to choose from. There are also relaxation tapes you can listen to that will help you focus and stop your mind from wandering. It really is a matter of trial and error to see what works for you - there are no hard and fast rules - so you might like to check out the local library before you buy anything. The only word of caution I would like to mention is that one well known relaxation exercise involves tensing muscles and then relaxing them. This is probably not a good idea for us, as it puts too much stress on the muscles. I particularly like an exercise that involves imagining the whole body

feeling warm and heavy and sinking into the bed. I also find having one or two hot water bottles really cosy and comforting.

Earlier on I mentioned breathing exercises and I appreciate that some may be concerned about this. The need for good breathing cannot be overemphasised but I've purposely used the word 'breathing' instead of 'deep'. You can improve your breathing even if you can't breathe very deeply. This is important as we need to improve oxygen intake to help our nervous systems and our muscles, in fact every system in the body needs oxygen. The trouble is most people breathe with just their chests and this uses only about 20% of the lungs. To get more air into the lungs we need to let the midriff area expand as we breathe in. If you put your hand on your tummy at waist level you need to feel that area swell gently as you breathe in gently, and every so often you may find you can take a deeper breath or two. For some, this midriff area can become quite tense, even affecting digestion, so breathing like this will help to prevent this happening.

Getting some fresh air into the room is helpful too, even though we may not feel like having the windows open at this time of the year. Just opening them for a short time a couple of times a day would be worthwhile.

I hope these suggestions will be helpful to you. Once these periods of relaxation become a habit the knock-on effect can be that during the rest of the day you'll be more aware if you do tense up and you'll find it easier to control this. Hopefully this will result in a little more energy and fewer aches and pains. With the coming few weeks being a busy, sometimes stressful time for many, leading up to Xmas, it's perhaps a good time to try for yourself.

Write to: Vivien Holland  
32 Green Lane,  
St. Albans  
Herts AL3 6EZ

In Lincoln, run by Adult Education, some of us attend a **'Gentle Exercise Class with Laughter'**. Kathy is our tutor and we are a motley crew with Polio, ME, MS etc learning how to relax and gently stretch our joints. We repeat any actions/ exercises to our own limits, sometimes only one or two repeats. We are no longer alone with our problems and our chuckle muscles are the most exercised.

For more information contact Hilary.

soporific, post-lunch spot and been given a mere ten minutes, when everyone else gets at least twenty minutes? I'm not complaining, of course; it's an honour to have been invited to speak at all in such august company.

We polios – if I may be allowed this very politically incorrect formulation (one gets sick of constantly talking about polio victims or polio survivors or even patients, or is it clients these days?) – we polios discovered very early on in our illness that in some ways we were both lucky and privileged. Lucky, because unlike those poor unfortunates with wasting diseases like muscular dystrophy and multiple sclerosis, our recovery, though finite, was absolute in the sense that what we gained we held. This amounted to an article of faith. However frustrating and slow our progress might be, it was irreversible. Even the most severely disabled among us, even those who were quadriplegic and ventilator-dependent, more often than not had a remarkably sanguine outlook on life. Of course there were those who fell by the wayside and died, but they were in the minority. It may be incomprehensible to non-polios but we did, for the most part, think of ourselves as lucky.

But privileged? The late Professor John Vaizey, an economist, suffered as a boy not from polio but from osteomyelitis. He wrote a rather bitter but very interesting hospital memoir, and this is a quote from it:

The social class of the boys with polio was on average considerably higher than that of the boys with osteomyelitis or tuberculosis... [They] carried an air of aristocracy about them... their bodies were lean and hard and clean, and did not fester and smell; quite fortuitously, too, they carried with them the glory of President Roosevelt.

Lord Vaizey (he made good in the end) was writing about Britain during the Second World War. But the elitism of polios – their sense of being something special – was probably even stronger in the United States, the home of President Roosevelt.

The third facet of polio – after luck and privilege – might seem contradictory; and that was that essentially it made no difference to your life. No matter how disabled you were, you went out into the world and got on with living – and making a living – just like everyone else. The importance of this can hardly be over-emphasised.

I don't think it was just because I was in the army when I contracted the disease – and was therefore treated in military hospitals and rehabilitation centres – that I see something militaristic about the way we were trained, as it were, for life after polio. Rehabilitation was undoubtedly a toughening-up process, one in which you were pushed to the limits, encouraged to go through the 'pain barrier' in pursuit of physical fitness, physical wholeness.

Nobody then hinted at the possibility that too vigorous exercise might ultimately damage severely weakened nerves and muscles. But don't get me wrong: speaking personally, I was a more than willing accomplice in this boot-camp approach to rehabilitation. As far as I was concerned, the tougher the better – I would've done anything that would get me walking again minus calipers and crutches, or sticks.

Physically, like most polios, I was obliged to compromise and accept that I would be moderately-to-severely disabled for the rest of my life. But psychologically I was – to use the dreadful jargon – into denial. Me disabled? Try me. I over-compensated wildly, learning to fly a small plane, though my enfeebled legs could scarcely control the rudder-bar, and driving my brand new Austin A40, complete with hand controls and 'Disabled Driver' signs, round Devon lanes at such life-threatening speeds that locals were heard to mutter into their pints, 'Disabled driver? Sterling Moss more like.

The polio mentality – as I've tried to demonstrate in my own case – might be characterised as a combination of optimism and self-confidence spilling over into bravado, a readiness to take on the world with no allowances made for any handicap.

The last thing most of us wanted, when we finally escaped into the big wide world, was to come up against any of our own kind. We rejected other disabled people as ferociously as we rejected our own disability. That rejection, indeed, was about the only thing we had in common.

All this was forty or more years ago. Things are very different now. The impact of post-polio syndrome or – as I prefer – the late effects of polio, has been profound. With people living so close to the edge physically, a minute loss of muscle power can mean the difference between walking, albeit with sticks or crutches, and becoming wheelchair-dependent. Or more distressing than that, it can force people who thought they were finally shot of the iron lung forty years ago back into it, or on to some other form of mechanical respirator. And any loss of independence, that hard-won and most cherished of conditions, can have a devastating effect on morale. The truism (as we thought) that had been dinned into us, that in polio what you gained you held, has turned out to be false. With the central pillar of our creed – the mainstay of our characteristic optimism – removed, our whole world has been overturned.

This has brought about a revolution in the behaviour of old polios, particularly in the United States, where most of the post-polio discoveries have been made. Yet polios – being polios – have chosen to accentuate the positive.

The most obvious behavioural change has been that instead of shunning one another, old polios have been actively seeking each other out and getting

together in groups to discuss not just the new threats to their health and peace of mind but also their past polio experiences and strategies for coping with disability. For many, this has been a revelation. Most polios have been locked into lives of unremitting struggle for decades and have tended to regard their own situation as unique. Now no longer isolated, they're amazed to discover that, far from being unique, their experience conforms to a common pattern. The huge relief that particularly the more crushed among them feel on finding fellow sufferers with whom they can share their experiences, past and present, is sometimes touching to behold. Never was there a better illustration of the old adage that a problem shared is a problem halved.

Disability is of course universally stigmatised. But in America – land of youth and the body beautiful (at least in theory) – deformity seems to be a matter of even greater shame than elsewhere. When I was writing *A Summer Plague*, one not-very-disabled woman I interviewed in the United States was so ashamed of her condition that if she ever encountered another handicapped person in the street, she told me, she 'died of mortification'. The very word handicapped was unacceptable. The American equivalent of our Orange (now Blue) Badge disabled parking scheme is Handicapped Licence Plates; this woman voluntarily went without them for twenty years because she couldn't bear to be labelled handicapped. Now she happily sports handicapped licence plates and goes to meetings of the local polio society. The post-polio debate has brought her in out of the cold; it has socialised her and replaced her shame with pride – disability pride.

Of course one can go from one extreme to the other. In my view, an obsession with being disabled is quite as bad, if not worse, than a denial of disability. There's an obvious parallel here with the gay community: there's nothing wrong with gay pride, but an in-your-face attitude, one that sees everything in terms of what used to be called the 'homintern', is ultimately sterile and stultifying.

My ten minutes are nearly up. If I may be allowed a last word, I would appeal to those GPs who may never have encountered polio but still think they know what's right for post-polio patients. I have been told too many stories of misdiagnosis and patronising dismissal of symptoms as psychosomatic to doubt that there is a lot of ignorance about the disease and its late effects even in the medical world. That is understandable: we polios have outlived our disease, we are like the survivors of some forgotten war. But the fact that medicine has succeeded in rendering polio virtually obsolete doesn't mean that the continuing health of its survivors should be a matter of indifference to medical practitioners.

Thank you.

26th October 2000.  
Seminar on PPS at St. Thomas' Hospital, London.

*A Summer Plague - Polio and It's Survivors*

by Tony Gould 1997.  
£14.95 at [www.amazon.co.uk](http://www.amazon.co.uk)

Long Standing Members will not have a copy of our 30 page Information Pack that includes self assessment charts. If you would like a copy please contact Wendy. We would appreciate a book of stamps to cover the printing and postage. Thankyou.

At our AGM Jann Hartman told us about Idaho Bean Fudge and Idaho Pinto Bean Pie. You should have seen the expressions on our faces. Here are the recipes, the proof really will be in the eating.

### Idaho Bean Fudge

1 (15 oz.) can pinto beans, drained and rinsed  
1 cup cocoa powder  
2/3 cup butter  
1 Tablespoon vanilla  
4 cups powdered (caster) sugar  
1 bag chopped nuts (walnuts)

Puree beans in a food processor  
(or mash by hand).

Add cocoa, butter, vanilla, and mix well.  
Gradually add the powdered sugar,  
and mix thoroughly.  
Add nuts. Spread into a 9" by 13" pan.  
Cut into squares.

Each of 24 squares contains approximately:  
144 calories but also provides:  
2 grams protein, 5 grams fat, and  
23 grams carbohydrates.

These recipes are compliments of the Idaho Bean Commission. Neither of these recipes are for everyday. But, they can add a little more nutrition to holiday foods.

JKH - Jann Hartman <[jann@home.com](mailto:jann@home.com)>  
Baltimore, Maryland, USA.

## IDEAS FOR XMAS

### Pinecone Firelighters/Decorations

Pinecones  
wax crayons  
scented oil (cinnamon, bayberry, apple jack, etc)

Gather large pinecones. I use old candles and also pick up used candles at garage sales and thrift stores. Sort candles by color. You want to end up with shades of red, green, burgundy, etc. I put wax in a large coffee can and sit it in the electric skillet until wax is just melted. Add the appropriate crayon color for the color you want. Add fragrance. Cover kitchen counter or work table with waxed paper. With kitchen tongs dip pinecone into wax. Hold over can and let excess drip off. Place on wax paper to harden. Redip cone until covered with a thick coating. If the wax is too hot it will melt the first layer off. Practice will make perfect.

These pinecones are for firestarters, but smell wonderful and look great on the fireplace or by a stove in a basket with large bow and green pine needles. I've seen the very large cones in gift shops for \$9.00 each.

MarySue "msb1037" <msb1037@msn.com>

More pinecone ideas...

- tie metallic ribbon/rope around pinecones to make a string of cones leaving enough ribbon on the ends to tie and use this as a curtain tie-back - very country and festive, only do this if your pinecones are completely dry or else the sap may ruin your curtains

- take a Styrofoam ball and glue small pinecones all around, wrap ribbon around to cover the empty spaces, tie at the bottom. Take some mistletoe and tie that to the bottom of the ball, attach ribbon to the top for hanging and you've got a kissing ball!

- glue small pinecones to wire ribbon, bend ribbon into circle shape and you've got a napkin ring; I like to go the extra step and bend the ribbon into a bow shape

- tie string to pinecone, cover pinecone in peanut butter, roll in birdseed, attach red/green ribbon to top for a festive birdfeeder

Ms Qué <qbanh@home.com

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