



# The LincPIN

**The Lincolnshire Post-Polio Information Newsletter  
Volume 2 - Issue No. 2 - December 1998**

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Seasonal Greeting from  
The Right Worshipful the Mayor of Lincoln  
Councillor Bud Robinson

Dear Friends,

It is my pleasure to extend Seasonal Greetings to all readers of the Lincolnshire Post-Polio Network Newsletter the LincPIN.

I was pleased to be able to open the Lincolnshire Post-Polio Network AGM in September 1998. I experienced at first hand the work that is carried out by the organisation and, whilst I am pleased that the Network actually started in the City of Lincoln, it also distresses me to learn about the difficulties Polio Survivors are experiencing in receiving medical attention in this Country.

I hope, and am confident, that one day society will recognise the problems and make sufficient funding available, not only for the provision of treatment, but also to enable support groups to function without having to think where the money is coming from.

However, to finish on a more positive note, I was truly inspired and am full of admiration for the way Polio Survivors are coping with the new problems they face.

I enjoyed my visit to the LincsPPN and despite all the problems I heard about, it was a happy occasion.

I would like to take this opportunity of wishing you all A Very Happy Christmas and A New Year

that will bring recognition to all Polio Survivors.

Bud Roy Robinson  
Mayor of Lincoln

Visit Lincoln City Council Website - <http://www.lincoln-info.org.uk/>

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*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 for those seeking such information. ALWAYS consult your doctor before trying anything recommended in this information or any other publication.*

**Lincolnshire Post-Polio Network**

### Editorial by Hilary Hallam, Polio Survivor

So much has happened in the last two months that it's difficult to know where to start. However at this time of the year, may I on behalf of the Committee wish each and every one of you the **Best Wishes for the Coming Season** and hope that all who read this will come together with us to increase the awareness of the problems that Polio Survivors throughout the UK are having in

getting holistically assessed, the correct advice and treatment.

Fundraising is a must for us to improve on the service that we provide. Finance is needed for the basic day to day running, for improving the services of our WebSite and for attending Conferences. If you have any any ideas, suggestions of sponsors or would like to donate funds for specific areas of our work then please get in touch.

Since our last newsletter we have joined the Neurological Alliance - which is an association of Neurological Support Groups coming together - Speaking with One Voice. We have to thank a Polio Survivor in Australia for not only making us aware of the work of the Alliance but also donating our first years membership fee.

There are also two British articles on PPS that have been published in the last two months - one in a publication for GP's, *Update*, 4th November written by Dr. Paul Ballinger - and the other in the *National Association of Fundholding Practices Yearbook 1998* written by Dr. John Shneerson. We have obtained copyright permission to add them to our library and would like to express our thanks to the authors and the Editors of both publications. We have enclosed them with this newsletter.

I attended the Bundesverband POLIOMYELITIS e.V. PPS Conference in Jena Germany accompanied by my daughter Alison and was able to meet up with Polio Survivors not only from Germany but Holland, Switzerland and Austria. I renewed contacts with [Dr. Trojan](#), [Dr. Parker](#) and [Wendy Malisani](#) from Canada and made many new contacts including Dr. Agre from USA and Dr. Nihal Fahey from Egypt and the many German and Czech Doctors that were present and I brought back more medical articles to add to our Library. See the [story of my trip](#) on the next page.

Phil and I attended the fourth meeting of the Neurological Patients Forum at Queens Medical Centre where we were able to bring to the attention of the meeting - which included a panel of neurological rehabilitation specialists - that those of us with chronic neurological conditions who do not come into hospital as an in patient do not see a multi disciplinary team. We are not getting the same level of care by attending outpatient clinics. These meetings were started to give Patient Support Groups a voice in how services are run in the Neurological Wards D10 and D11. So far the Patients Information Room has been retained, improved on, with more information. Patients information and satisfaction forms have been refined. The role of the Primary Nurse has been implemented and the team gave a paper at the recent Neurological Support Group Conference at QNIC where we had a stand. The team are ready to listen to all the points and are concentrating more now on the problems of outpatients and will be bringing this to the notice of the hospital. One fact that impressed us all was their honesty in telling us what is achievable. We all agreed that dialogue like this is necessary to improve on services.

Dr. Alan Whiteley now runs a [PPS Clinic at QMC](#), holistically assessing polio survivors and following elimination tests diagnosing. However as yet there is no follow up of an assessment by a Physic, OT and Social Worker for advice and treatment. Dr. Whiteley met with Hilary after the meeting and told her that he is having further discussions with the hospital management and we have our fingers crossed. Obtaining a correct diagnosis is important but this must be followed up with a treatment plan that can be case managed back to our local areas.

The LincsPPN were invited by Ann Proctor the regional representative of Scoliosis Association UK to share a stand at the Disability Awareness Forum held in Barnsley on Thursday 3rd December. The Mayor Fred Wright and Mayoress Rita Hunt and other professionals who attended were very interested in the work that we are doing. Most being totally unaware of the existence of PPS. Five polio survivors visited the stand and once again the story of doctors not knowing and understanding about the symptoms of PPS was related. If you have scoliosis and would like more information then Ann who has scoliosis herself would be happy to talk to you. 01226 206409. or ring SAUK - 0181 964 5343 Mon. - Thurs. and speak to Pauline the Information Officer.

Gentle Range of Movement and Relaxation Class for those with restricted mobility starts Mon.
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## HAPPY HOLIDAYS

### GRACE R YOUNG, MA, OTR

Many of us benefit from using energy conservation techniques during the year but just don't implement them between Thanksgiving and New Year's. We seem to feel that we must comply with all the demands made on us during the holiday season. Because we have a history of warm and gracious hospitality, we succumb to other people's expectations that nothing has changed.

Are there ways to savour the holidays, welcome people to your home, share in gift-giving and generally partake in the joy of the season without having to expend your precious energy resources? The answer is - of course! Here are a few suggestions. Enjoy!

### GIFT-GIVING

1. Order your gifts from catalogues. If some recipients live out of your area, have the catalogue company ship directly to them.
2. Gift certificates are always very welcome, whether to a particular store or to an entire shopping mall.
3. Go shopping on the Internet.
4. Gift wrapping uses a lot of repetitive motion. Wrap gifts in tissue paper and put them in gift bags.
5. Order postage stamps by mail or telephone. Request a postage-free order form from the post office or your carrier, enclose a check and mail it back or give it to your carrier. Stamps by Phone takes Visa or Mastercard orders 24 hours a day at 1-800-782-6724 (USA).

### ENTERTAINING

Spread socializing throughout the holidays. Extend invitations to couples or small groups of friends over a period of several weeks, allowing two days or more between events to get yourself rested and recharged.

Use holiday paper plates, cups, napkins and tablecloth. Let your guests empty their utensils into a large plastic trash bag and ask a nondisabled person to carry it outside. Have a potluck.

Order a party tray from a supermarket - lots of choices from cold cuts and sandwiches to fruit and vegetable platters. Large discount stores like Price/Costco (USA) carry containers of appetizers and hors d'oeuvres.

Many supermarkets offer complete holiday dinners with all the trimmings for a very reasonable price. Choices include turkey, ham, or prime rib, and you only need to heat up the items.

### DECORATING

Invite your friends to decorate the tree and help make your home festive. Extend invitations to a "Deck the Halls" party and serve refreshments from the above suggestions.

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Grace Young [gryoung@pacbell.net](mailto:gryoung@pacbell.net)

WebSite <http://www.reocities.com/HotSprings/4713/>

See also the Lincolnshire Post-Polio Library catalogue entry for

[Young, Grace R., MA, OTR](#)

1. Quadruped With Crimson Proboscis
2. Eight PM to Six AM Without Noise
3. Minuscule Hamlet in the Near East
4. Ancient Benevolent Despot
5. Adorn the Vestibule
6. Exuberance Directed to the Planet
7. Listen, Aerial Spirits Announcing
8. Trio of Monarchs
9. Yonder in the Haystack
10. Cherubim Audited From Aloft
11. Assemble, Everyone Who Believes
12. Hallowed post meridian
13. Fantasia of a Colorless December 25th
14. Tintinabulations
15. A Dozen 24-Hour Yule periods
16. Befell During the Transparent Bewitching hour
17. Homo Sapien of Crystallized Vapor
18. Desire a Pair of Incisors on December 25th
19. I Spied My Maternal Parent Osculating
20. Perambulating Through a December Solstice Fantasy

Test Results:

15-20 Correct: You don't need any Yuletide spirit.

10-14 Correct: You could use something in your stocking!

5-9 Correct: Are you sure you have the right holiday?

0-4 Correct; Where have you been the last 1900-odd years?



## My Trip to Jena, Germany in my new Motability VW Sharan

Having visited two PPS conferences in American and Canada and met many Polio Survivors en route it became obvious that having a scooter was a marvellous way of saving energy, but without transport to take it where I wanted to go meant that I did not have control of my life. I therefore embarked on the long process of finding a vehicle that I could sit in, drive and would take an electric scooter. Easy you might think, but not when you are six foot tall and have very long legs with weakness that need to be out in front of you. Eventually I found not one but 3 vehicles all virtually the same but with deposits from £3,700 to £2,400.

I went to DC Cook in Lincoln and they arranged for me to test drive a VW Sharan automatic - the lowest deposit. I was able to take it for a long run and it was lovely to drive. However, there was one big hiccup. I found that I did not have the required amount of DLA time and had to apply for a review. I was very disappointed as I had hoped to go the PPS Conference in Germany in my car. I requested a review of my DLA and asked for a quick reply and much to my astonishment got it. I then applied to Motability with the same request and they completed the paperwork very quickly so that I was able to take possession of my VW Sharan 2.0 SE late on Monday 27th October 1998. Tuesday saw East Lincs Mobility fitting the hoist - a Bruno Space Saver and Bruno Mobility Europe loaned me a Supercub scooter for the conference. Wednesday and my daughter and I drove to Hull to catch the P&O North Sea Ferry to Rotterdam. P&O customer services were wonderful and making the reservation, paying for it, and being parked right next to the lift on board was just part of their normal service. We took our bags to our reclining seats and then visited the Duty Free Shop. On the way back to my seat I checked out the Disabled Toilet, plenty of room and well laid out.

Back in my seat and the Captain made the welcome announcement that half way across we would be in a Force 9 Gale. Not something we wanted to hear, but a seasoned traveller behind us said it will be OK. Alison and I had the food we had brought with us and settled down to chatting with the other passengers and were given much information about driving on the Autobahns. The fast lane in roadwork's is only 2m wide, take care. If someone comes up behind you fast then get out of their way. Good advice we found out later. Alison went off to the Bar and the Live Acts and Disco and I settled down for a sleep. I woke later and went to the toilet to find myself halfway across the ship walking up hill. I looked at my watch and realised that we were over half way and this must be the Force 9 Gale. It was nowhere near as bad as I had expected and I was soon back in my seat and asleep. We docked and it was not long before we were on the road, my daughter insisting on driving and she took to the right hand side of the road with no problem. One thing we had not thought of was the fact that the first 100 miles would be in Holland, and with not one word of Dutch between us we had to guess at the information roads signs. We arrived at the Holiday Inn in Jena just as it was getting dark, and after visiting our room which was very comfortable and plenty of room for the scooter we went for a meal. Much fun was had in trying to work out the menu. It was not till the fourth night there that they produced an English version. Following this I crashed and every now and then opened my eyes to see that my daughter was watching American TV. Next day we joined the others in the foyer and were transported to the Freidrich Schiller University by Red Cross Transport with the help of some very good looking German lads! As we were in what had been eastern Germany we realised that for many their second language was Russian, and much fun was had in conversing in a mixture of German, English and Russian.



Universitätsstadt Jena, Schiller-Hause, 07743 Jena

The University was an old building and due to stairs we were not able to go much further than the foyer and the main auditorium and thankfully a Disabled Toilet. There were many stands in the foyer and great interest was shown in the two Orthotic Stands. Otto Bock showed lightweight callipers with carbon fibre of vibrant and multi coloured patterns and one polio survivor demonstrated them wearing her calliper outside of her leggings. Translation was provided by earphones and the two translators were working constantly. They had transcripts from some of the speakers but as you know it's easy for speakers to change what they are going to say, and they took some articles from me to read to help with the terminology. We did not get handouts as I had expected and although I did take some notes, moving from one speaker to another it's not easy to retain it all. (See [points](#) at the end of this article.)

On Monday Alison and I left for Berlin to stay with Klaus and Renate Kunert ([KlausinB@aol.com](mailto:KlausinB@aol.com)) who I had been in touch with on the internet. A wonderful couple who took us on a tour of Berlin,

through the Brandenburg Gate, down roads and past places that had just been names. We saw where the Berlin Wall had been, even a place where there was still some damage from the war. We saw the extensive renovation work being done to apartment blocks. Those not yet done were dull and grey and then there were those that had been finished with new facades of all colours, new balcony's and lots of flowers. It was a very informative experience and we had a lot of fun talking in a mixture of languages with the aid of a couple of very good dictionaries and much laughter. We spent a couple of hours in a Supermarket, where I scooted round and saw it all. Some foods we recognised but there were so many German sausages and meats, different cheeses, cakes, we could have spent a fortune.

On the Wednesday we left Berlin after an early German breakfast of meat, cheese, honey and rolls - we look forward to Klaus and Renate visiting the UK in 1999 and sampling a full English breakfast. We drove to Rotterdam keeping well to our schedule and did not get held up till 4km from the docks, where an accident at some roadwork's held us up for over an hour; would you believe behind a lorry from Lincoln. We were ahead of most of the passengers and boarded immediately. We were late leaving but there is plenty of leeway in the timing of this run. We had a very enjoyable time in the bar watching the live acts. There is a cafe, an excellent restaurant, two bars, a cinema, a roulette table, a shop, Duty Free shops, cabins and reclining seats. The staff were extremely helpful all the time. P&O North Sea Ferries overnight service is definitely a good way to travel to Europe. They also do various short excursions at very reasonable prices.

We got home and I left it to my daughter to unpack the car, do all the washing and I sat in the chair for the rest of the day and did absolutely nothing. The next day I managed about 10% of my normal daily life and gradually was able to increase this over the next few days.

Using an electric scooter makes a great difference as you don't have to stand to talk to people, you have a comfortable seat, you can get on and off when ever you want to and it carries all your books and bags. It saves a huge amount of energy making attending possible. If you want to attend Conferences, go on holiday, etc., then you must plan ahead allowing - and insisting on - down time to rest. Finances permitting I would recommend arriving a day earlier to allow one full day relaxing before the Conference. Whilst attending conferences, being on holiday, you run on adrenaline. Once home you need many days doing very little to catch up again.

I am indebted to DLA and Motability for completing the paperwork on time and to Bruno Mobility Europe for loaning me a Bruno Mobility Supercub - a three wheel scooter that will take up to 21 stone - with plenty of room for me to put my legs out in front either side of the control column. It is light enough for me to lift it on their Space Saver Hoist and guide it into the back of the VW Sharan. Without energy saving devices like this I would not be able to do as much as I can now. They have given me control back of my life.

### **The main points from the Conference were:**

That there are polio survivors all over Europe with the same symptoms and the majority have the same difficulty in getting the correct medical diagnosis and treatment.

That it depends where you live in finding a doctor who has learned enough about polio, accepts that there are late effects to having had polio, and knows enough about it to give you the a holistic assessment, the correct diagnosis advice and treatment. We really need regional Centres of Excellence but at the very least one Centre of Excellence in each country case managing back to your local area.

That the criteria for polio is that you had nerve damage to your body from the Polio Virus. The distinction between non-paralytic and paralytic polio is the degree of nerve damage to an area of your body. If the nerve damage gets to 60%+ in any area of the body, then you get paralysis. Less than that, it's only a weakness. It is accepted that polio survivors who had a diagnosis of paralytic polio are now having symptoms in limbs not thought to have been previously affected. The problem is in proving that you had polio in the first place. You need to be able to provide as much evidence

as you can of your condition before polio - of your diagnosis at the time and treatment - of how you have been in the mean time and your current problems. If you have no records then you need to ask relatives - bearing in mind that discussing this after all this time can be extremely stressful for all concerned. Many parents blame themselves for your getting the polio. It was no-one's fault. If you can, then search local papers, hospital history, where you were staying at that time to see if there is any mention of a polio outbreak.

There are no tests for PPS. It is purely a clinical diagnosis after a thorough examination and tests to eliminate any other condition. Just because we had Polio does not mean that every symptom we have is Post Polio, we can have every other condition instead of or as well as.

EMG studies can show old polio damage but a negative result does not mean that you did not have polio. It is accepted that those nerves that did not die sprout and take over orphaned muscle fibres so different results will be found depending on where the needles are inserted.

There have been some drug trials and as many of us are concerned about the immediate suggestion that we take drugs. I asked when should drugs be considered. Dr. Trojan answered and it was confirmed by other doctors on the panel that drugs are only used once all other methods have been tried. A change of lifestyle, the use of aids and assistive devices to conserve energy, and pacing and resting must be tried first.

Professor Stück, President of the Green Cross, gave a talk explaining that Germany has changed its policy and has not used the live oral vaccine from January this year to eliminate the cases of vaccine related polio.

From talking to many polio survivors the consensus of opinion is that we all want to do as much as possible for as long as possible within our current limitations given the right advice and treatment. That we want to succeed in this phase of our lives as we did in all the other phases but we need the understanding and help of the medical profession to be able to cope with this unexpected and often traumatic change in our lives.

Contact details for services and suppliers mentioned in this article:

DLA, Blackpool	0343 123456	
Motability Customer Services Info.	01279 635666	<a href="http://www.motability.co.uk/">http://www.motability.co.uk/</a> See also <a href="#">MOTABILITY by Joy McDuff - Erith in Kent</a> LincPIN Vol 1 Issue 11
DC Cook - VW dealers - Lincoln	01522 531881	<a href="http://www.volkswagen.co.uk/">http://www.volkswagen.co.uk/</a>
Bruno Mobility Europe	01455 554242	<a href="http://www.bruno.com/">http://www.bruno.com/</a>
East Anglian Mobility	01621 843344	
P & O North Sea Ferries	01482 377177	<a href="http://www.po-ferries-uk.co.uk/">http://www.po-ferries-uk.co.uk/</a>
Holiday Inn		<a href="http://www.holiday-inn.com/">http://www.holiday-inn.com/</a>





## Shopmobilty in Southampton

I would like to talk about a scheme called Shopmobility for people who have permanent or limited mobility which has just started up on 1/12/98 in Southampton, England where I live. It has been running in other areas of the country for a while, and when I heard about it from a friend of mine, I thought to myself I shall have to find out more as I have difficulty in getting about with the aid of 2 canes in the City Centre of Southampton and thought that this would be ideal for me and save my legs getting too tired.

Well I went and visited the Centre office to find out more and they supply Electric Scooters and Wheelchairs which you can hire from £2.50 if non-member and £1.50 if you join for £5 per year. Hire times are from 09:30a.m. to 4:30p.m. so it makes sense if you join up and become a member. For your one hire fee you can use your scooter for the whole hire time, so you can have the scooter for 7 hours and it is well worth the money. A few personal details are taken down and then once you paid your hire fee you can take a electric scooter out and about the city centre straight away if you so wish.

This Shopmobility is a great idea so you can travel about in style without ever getting tired and I had great fun and thoroughly enjoyed steering myself through all the crowds of shoppers. This is the life for me in future when I get to the city centre. Also I thought that I would never see myself using one as I was afraid of swallowing my pride, but now I have used one I won't ever feel that way again, I'm a converted Electric Scooter user now.

This was the first time ever that I had tried using an electric scooter and would recommend it to anyone who has difficulty in getting about. The good thing is that anyone visiting Southampton can hire one but you are reminded through guidelines what you can and cannot do with the scooter and a map is provided to show you where you can travel to within the map boundary of the City Centre. I found the staff very friendly and helpful you also get a quick lesson in how to use one, if you have not used one before like me. My driving skills are not too bad for the first time and I feel quite confident about using a scooter.

The Shopmobility scheme is run by Southampton Voluntary Services and is funded with the support of Southampton City Council and many local businesses. If you would like more information then you can contact Southampton Shopmobility on 01 703 631263.

Steven Carrett - LincsPPN member Southampton.

[<steve@CARRETT.FREESERVE.CO.UK>](mailto:steve@CARRETT.FREESERVE.CO.UK)

## Shopmobility in Lincoln

Shopmobility in Lincoln has been running for nine years. They only have manual wheelchairs for use for which there is no charge - they have plans for electric scooters and wheelchairs but as with many things funding is not yet available. Bookings are taken from 1.30 to 4.30 each day and up to 2 weeks in advance. The earlier you book the better, especially at holiday time. They are open from 8.30 to 4.30. Parking spaces are also available and must be booked. Their base is in Tentercroft Street Car Park near the exit alleyway to the High Street. Their telephone number is 01522 544983.

01522 544983 is also the number for Lincoln Dial a Ride. Specialist taxis that take wheelchairs. Membership is £5 for one person and £7 for Family. Radius is 6 miles of Lincoln.

If you would like a Directory of Shopmobility's and the services they provide, then contact the National Federation of Shopmobility, 85 High Street, Worcester, WR1 2ET. Telephone and Fax. 01905 617761.

A Sunday School teacher told the story of Adam and Eve in the garden, and how they disobeyed God and had to be driven out of the Garden of Eden. Then she gave crayons and paper to her little

ones and told them they could draw a picture of something in the story.

One little boy drew a car. In the car was a man in the front seat, and a man and a woman in the back seat. The teacher tried to think of why he would have drawn a car. Finally she asked him, "Could you tell me about your car?"

"Sure," replied the little boy, "This is God driving Adam and Eve out of the garden!"

Tom Conrad / Judy Conrad <[tlcon@OZCOOL.COM](mailto:tlcon@OZCOOL.COM)>



## Trip to India November 1998

We had been told that the biggest waterfalls in India were to be found in North East Goa. We made our way via what passes for a road in India to a point where we could only proceed in our 4 x 4's. Goa was gripped in the middle of winter so the temperature did not drop below 100 degrees. This also meant that the track was passable! We spent about an hour and a half following riverbeds and jungle trails with a numb bum and white knuckles from hanging onto kit and the 'Lany' (Landrover). Not really the place to fall out.

Our first sight of the falls from the Lany was quite spectacular, a clear blue sky, the green canopy on the mountain, and the white of the falls cutting down through the foliage, seeming to appear out of the very side of the mountain in places.

We pulled into a clearing, it was obvious that during the monsoon the riverbed we travelled would be roaring avenues of destruction. The rocks carve swathes of the ground cover away. However the baked earth provided massive ruts and India's red choking dust covered everything and got everywhere, and I do mean everywhere!!! From this point it was Shankseys, tighten up the boots, secure the Bergen, grip the stick, head down and go for it! I walk in my own style, watch where I place every step, cover a few metres, stick in the ground for balance, stop lean on it and look round. This way I don't fall over by looking at the scenery, and I don't miss the scenery by watching where I'm going all the time. Friends are used to my 'obs stops' (observation stops) and have found that they have started to see and hear more by joining me.

On reaching the rock pool below the falls we stopped and the view was truly breathtaking, the spray formed a myriad of tiny rainbows which shimmered in the water mist. The roar was not unpleasant, and the cool atmosphere most welcome, breathing was easy.

Fluid stop, food, keep a grip on everything as we had now been joined by the smaller of the areas Mackak monkeys who wanted a feed. These inquisitive little guys were great fun, the pouches under their mouths were soon full with food. I made the mistake of not leaving enough banana in the skin I gave to one little chap, he inspected it, looked at me, then lobbed it on my head!

After an hour or so we decided to climb the falls, this is not as mad as it seems, as I enjoy Hill Scrambling in the Lake District. Again I have adopted my own technique, it may not look nice, but who gives a toss? I get there, just takes longer. We did not go into the falls but took an easy route to the East, again after an hour or so of steady climbing we stopped for fluids and to look around. On the way up I had been careful where I put my hands, feet and knees. (I use knees more than most). I was aware of cobras, centipedes and nasty stingy things of the Indian sub-continent. I was not prepared for what happened next. Sighing in satisfaction I perused the view. I looked down at my kit and noticed some droppings. "What's this?" I asked of one of our guides. "Tiger" he smiled "but only small". Tigershit, bullshit! I was sat in its toilet, not being Sabu I could not guess how old it was, things age quickly out there! I still have some ageing to do myself and tigers large or small don't equate to prolonged life. I'm off this rock! Chance the falls, go for the rock pool, hope its deep

enough. Discretion being the better part of valour, my arms took the brunt of my descent. We got down a \*\*\*\* sight quicker than we got up.

Embarrassed laughter and a good yarn for the pub in Blighty. We did not see the noble beast, nor hear it, however, the nearest I ever want to get to a tiger is sitting next to its droppings! It seems to me that as the dry season cuts down the flow of the falls in its upper reaches, the tigers come lower for water and food. Whilst being assured we did not feature on the menu, enough was enough.

John Horan

Polio Survivor from Blackpool

Black Belt 5th Dan Karate.



## **Shaun Hardy**

passed away last month aged 42

Shaun wrote a story [COMING HOME](#) for our second newsletter about his polio at the age of two and a half. He told me how much he cried writing it but also how much it had helped him to put this into words. Many people contacted us and were able to tell their stories after reading his. Thankyou Shaun. Our thoughts are with his wife Debbie and his family at this time.



## **PPS - Crisis or Opportunity. A Chinese view of Disease.**

by Vicki McKenna. Lic.Ac. MBAC, LincsPPN Member, Polio Survivor

Polio Survivors are often Type A's - responding to stressors with a go-getting attitude until the nervous system starts to announce through symptoms of PPS, that it needs a rest from this constant activity. We must now learn to cultivate a different attitude and start to respond with a more relaxed, open approach to life's challenges. Right now we are faced with the challenge of PPS and so we need to let go of the Type A perspective that sees this situation as a dragon that needs to be slain. Instead we can choose to see PPS as an opportunity to learn how to take control of stressors in a more energy conserving way. Thus we will start to live lives that are less exhausting as we protect and nurture our damaged nervous systems.

My perceptions of life and illness have been altered by my experience of being a Polio Survivor and PPS and also by my study of Chinese medicine and its philosophy which is the background to my practise of acupuncture. The philosophy behind Chinese medicine is full of down to earth wisdom which offers us a new perspective on life and these truths can teach us to value our health and well being. They have helped me enormously to cope with and understand PPS.

Chinese medicine has its origins in philosophies that flowered in China thousands of years ago. The body of knowledge that has come down us holds that there is a vital force that permeates all life. This energy is known as "Chi" and when it flows within us steadily and calmly then we are in good health. When Chi is blocked or is deficient, due to physical factors such as viruses or because of emotional stressors, then there will be disharmony and imbalance - in other words disease.

Symptoms of disease as far as Chinese Medicine is concerned, are not to be suppressed or covered up as they are so often in Western medicine. Instead illness and its signs and symptoms are seen as an opportunity to encourage and restore the flow of Chi energy so that healing takes place and hammony is restored. Interestingly, in Chinese character writing the same symbol is used for "crisis" as for "opportunity". Thus the Chinese view is that whatever creates a disturbance in the flow of life, whatever creates a crisis, such as stressors or disease, will also serve as an opportunity for fresh growth. This attitude helped me to perceive my life and PPS in a new light as I began to see the symptoms of we call PPS not as a crisis to be averted or suppressed but as an opportunity to restore

health and balance to my life.

We have pushed ourselves hard in response to trauma, always feeling that we need to achieve and prove ourselves. We now need to learn to respond to life's often difficult events in a different way by altering our perception and remembering that fundamentally we do have a choice - we can see PPS as a crisis that we have to struggle with or as an opportunity to take charge and learn new attitudes and skills that will help us to take better care of ourselves and so feel more at ease in our lives.

This is an excerpt from "*A Balanced Way of Living - An Alternative and Holistic approach to PPS*". It's due out next year. I will let you know in the LincPIN when it's published.



## Encounter in Burgundy

You may have wondered about the origins of my physical disability. I had poliomyelitis, over 60 years ago. I was three years old, and, for all practical purposes my body, as you see it, is the only one I have known. My life is regulated by its condition, and the apparent embarrassment sometimes felt by new acquaintances surprises me, often.

Frequently, I fall over. The difficulty is that the most pain is felt by those seeing me fall. Years of practice mean that the moment I sense something is going to occur, I relax, and I strike the ground 'cleanly'.

However, people seeing the situation always react by rushing to me, aiming to grip any available limb, and pull it. Alternatively, they pick up my walking stick and hold it. Of course, that is the one thing I need to raise myself. It seems that, by falling, I violate one of the basic aims of society - being temporarily horizontal I must be made vertical again, as soon as possible.

I did this once when I was stopping overnight in a French campsite, during a motor caravan holiday. There had recently been a thunderstorm, and the pathways were muddy and covered with gravel washed down by the rain. My wife and I had decided that we would visit the camp restaurant, down a fairly long, sloping roadway. Inevitably, I trod on a small piece of stone, and my foot slipped. I fell, turning on to my back on the way, and ended facing the sky, with my head lower than my feet and my arms spread wide.

There were cries in French, German and Dutch, and a crowd of men, women and children quickly gathered round me. When you fall in this spectacular way you knock the wind from your lungs, and you need to rest a moment, to collect energy for the next stage. My wife has mastered the art of fending off misplaced offers of help, and she stood guard as I checked off the extent of damage. These amounted to grazes on my elbows, mainly, together with a very wet seat to my trousers. I now had to turn on to my front, then turn my body through 180 degrees so that my head was higher than my feet. Fairly quickly I scrambled to my feet, amid cries of relief all round.

I think the main attraction of the event, for me, was provided by a pleasant young German mother, who had the perfect suggestion for curing me. She asked, with a wicked gleam in her eye, if I wanted a kiss!

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Hampshire, England.



Giggles from Donnie  
<[mickiemc@frontiernet.net](mailto:mickiemc@frontiernet.net)>

## MANUFACTURER'S WARNINGS

### TESCO'S TIRIMASU DESSERT

Do not turn upside down.  
(Printed on the bottom of the box)

### MARKS & SPENCER BREAD PUDDING

Product will be hot after heating.

### PACKAGING FOR A ROWENTA IRON

Do not iron clothes on body.

### BOOTS CHILDREN'S COUGH MEDICINE

Do not drive car or operate machinery.

### NYTOL (A SLEEP AID)

Warning: may cause drowsiness.

### A STRING OF CHRISTMAS LIGHTS

For indoor or outdoor use only.

### A JAPANESE FOOD PROCESSOR

Not to be used for the other use.

### SAINSBURY'S PEANUTS

Warning: contains nuts.

### AN AMERICAN AIRLINES PACKET OF NUTS

Instructions: open packet, eat nuts.

## LOSING WEIGHT THE EASY WAY

Here's the guide to calorie-burning activities and the number of calories per hour they consume.

Beating around the bush	75
Jumping to conclusions	100
Climbing the walls	150
Swallowing your pride	50
Passing the buck	25
Throwing your weight around (depending on your weight)	50-300
Dragging your heels	100
Pushing your luck	250
Making mountains out of molehills	500
Hitting the nail on the head	50
Wading through paperwork	300
Bending over backwards	75
Jumping on the bandwagon	200
Balancing the books	25
Running around in circles	350
Eating crow	225
Tooting your own horn	25
Climbing the ladder of success	750
Pulling out the stops	75
Adding fuel to the fire	160

Wrapping it up at the day's end 12

To which you may want to add your own favorite activities, including:

Opening a can of worms	50
Putting your foot in your mouth	300
Starting the ball rolling	90
Going over the edge	25
Picking up the pieces after	350
Counting eggs before they hatch	6
Calling it quits	2



## Catley Priory by Christine Ayre

Nothing now remains of Catley priory, except a few mounds in a field, a moat, and a fish pond. The field is inhabited by sheep, rabbits, and pheasants, instead of the monks and nuns of the Gilbertine order.

St. Gilbert, a priest of Sempringham abbey, a much loved and very popular man, founded the Gilbertine order in 1131. From this several houses sprang up around the Country. One of these was Catley, situated on Catley island, near the Villages of Walcott, and Billingham. Most of the houses of the Gilbertine order were in Lincolnshire, but a few are found in other parts of the Country including Wattam, and Beverly in Yorkshire. Not all the Gilbertine houses were mixed, the mixed ones included Catley, and Haverholme. Canons only were housed at Holland Bridge, Lincoln, and Stamford.

The Gilbertine priory of St. Mary, Catley, was founded as a double house in the reign of King Steven, between 1148, and 1154 by Peter de Billingham. He endowed it with the whole island of Catley, the site of a grange and some arable land at Walcott; the church of Billingham, and the chapel of Walcott; pasturage for 400 sheep in the two townships, and rights of fishing on Walcott marsh.

The number of inmates was limited by St. Gilbert to sixty nuns and lay sisters, and thirty-five canons and lay brothers. A strict set of rules ensured that no contact was made between the sexes, they had separate buildings but shared a church, this was divided by a wall high enough so they could not see each other, but both were able to hear and celebrate mass together. The most beautiful part of the church was for the nuns use. The nuns were guarded at all times, and could only communicate with the monks by two turntable windows, which would only allow a thumb and two fingers through the gap. The windows were also covered by an iron plate.

The order brewed their own ale, but should the sisters run out of ale, the brothers also had to drink water. Any excess ale was sold at the inn in Digby village. The sisters also had to do all the sewing and laundry for the priory. The brothers habit was of blade with a white cloak and hood lined with lambswool, the sisters wore black with a white butterfly type cap.

In 1182 Alexander de Crecy gave to the priory 4 bovates of land in Dunsby at a yearly fee of 10 shillings, 20 acres of land at Cranwell Dunsby and Brauncewell.

In 1184 The priory was given land at Digby, Dorrington, and Brauncewell also the rights to sand, clay, turf and eels from Digby marshes. Fish and eels were the staple food of the inmates of the priory, together with shellfish, and deer.

Catley was always one of the poorest houses of the order of Sempringham, in 1291 it had an income of about £55. In the fourteenth century the average yearly sale of wool was seven sacks, which added considerably to the income of the nuns and canons.

The thirteenth century seal of the priory is a pointed oval, and represents the Virgin, with a crown, seated on a throne, the Child on the left knee; on a base under an arch, the prior kneeling in prayer to the right. The legend is - PRIORTUS . DE . CATTELE

In 1303 the prior held half a knight's fee in Brauncewell, one-third in Dunsby, a quarter in Billingham and Walcott, a quarter in Digby, one-fifth of half in Ingleby, one-fifth and one twenty-fourth in Hemswell, one-eighth in Dorrington, one-tenth and one-sixtieth of one in Glentworth, and one twenty-fourth of another. In 1401 he also held one-seventh in Scopwick.

In 1338 the house was in serious financial straits, and Edward III pardoned the payment of the tenth, £5 11s 3 ¼d. Seven years later the prior, canons, and nuns again petitioned to be excused from tax. They urged that by fires and murrain of their animals they were so impoverished that they had neither crops nor goods for their sustenance. The loss of tenants and the mortality among their sheep after the Black Death no doubt greatly increased the embarrassment of the priory.

The house was surrendered to Dr William Retre by the prior, William Swift, and two canons on 25th of September, 1538. Pensions were also granted to the prioress Margaret Gastwek, and four nuns.

In 1535 the net valuation of the property amounted to £34 18s. 6d., of which £8 4s. 10d. was drawn from the rectories of Billingham and Digby. The demense lands of the priory were only worth £4 a year. In the hands of the crown bailiff four years later the property brought in £38 18s. 11d., and included, besides the rectories, the grange of Scopwick, and lands and tenements in Billingham, Timberland, Walcott, Digby, Ingleby, Saxilby, Lincoln, and Rowston.

Robert Carr of Sleaford, who's father was a rich merchant of the staple, purchased the house and site of Catley, besides several granges belonging to other Gilbertine houses for £400, and a rent of 11s 10d for Catley on December 24th, 1539.

## An Autumn Day

I'm sitting at my computer trying to think of something to write for the LincPIN. Here in my upstairs sittingroom are many distractions, my eyes are drawn to the windows, to look out on a perfect Autumn day. From the front window I can see down the drive to the road, and see the farm traffic passing by, loads of corn and straw being gathered in for the coming Winter. Looking out of the back window I look on the abbey field. The field slopes up from my garden and is inhabited by pheasants, rabbits and hares, also about 200 sheep, all peacefully doing their own thing. The day is peaceful and calm, not a breath of wind, the sheep are sleeping, my dogs are sleeping, Ben woofing in a dream, I start to nod off.

The peace is suddenly shattered by the sound of voices, and the sheep take to their heels. In seconds the abbey field is empty of birds, and animals. From my windows at the side I can see the latest batch of tourists descending from a coach down by the road. A motley selection of people start to wend their way up the track at the side of my house. This is a new approach to tourism dreamed by the Lincolnshire Council. Someone thought it was a good idea to organise trips to all the abbey sites in the area, but nobody told the eager tourists that they would be seeing a selection of empty fields. Today's tourists are the same as all the others. They have obviously been to see other abbey sites before reaching Catley, and have reached a stage of extreme apathy, no doubt thinking longingly of home and wondering why they ever started out on this trip, and would it ever end. I take great delight in watching these people. First today comes a rotund vicar with a beard and a red face, followed very closely by a blonde haired lady past the first flush of youth, wearing a red dress and white stiletto heeled shoes. Next is a snake hipped spotty faced youth wearing skin tight jeans, his legs so long and thin any grasshopper would be proud to own them. He must grease his legs to get them in the jeans. His t shirt bears the legend *I'm anybody's*. I wonder if anyone has taken him up on the offer. His face has a glazed expression as he listens to some music on headphones. Next come a couple who are ready for anything, dressed in check shirts, moleskin trousers and big hiking boots. They have rucksacks, binoculars, cameras, and maps. Why would they want maps to walk round a

field? Bringing up the rear is an elderly lady in tweeds and sensible shoes. She looks rather travel weary.

The first obstacle they encounter is the sheep netting over the gate. The vicar waits to hold the netting down while all the ladies get over. Unfortunately the lady in the tweeds catches her foot in the netting and falls flat on her face in the thistles and sheep droppings. In the vicar's haste to rescue the poor lady he lets go of the netting and leaves the lady with the stilettos straddled over the net. This causes some consternation and takes some time to sort out. The spotty youth has noticed nothing amiss, steps over the netting as if it wasn't there and by this time is halfway up the field, his huge feet crushing the wild flowers as he goes. The couple in the big boots are eagerly consulting their maps and taking photographs. The vicar more red in the face than ever gathers up the ladies, the blonde clinging onto his arm, and they all disappear up the field. After about fifteen minutes I see them again on the horizon, the mapreaders striding out purposefully while the youth wanders along twitching and jerking in time to his music. The vicar shepherds his little band of pilgrims back down to the waiting coach, the lady in red clinging to his arm as she totters along in her once white high heeled shoes, now sadly stained by the grass and spiked along the heels with sheep droppings.

They all wander dispiritedly back to the waiting coach, no doubt wishing they were anywhere but Catley. After a little discussion about who should board the coach first, and a head count, they realise the snake hipped one is missing. The vicar sets off back up the field to find him and after ten minutes he returns with the recaptured youth. Everyone boards the coach and they disappear in a cloud of dust and diesel fumes.

The sheep and pheasants return to the now peaceful Abbey site. I go back to racking my brain, wondering what to write for the LincPIN. Hills will give me hell if I don't come up with something.

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Further Reading:

SAINT for the WEEK February 4th. St. Gilbert <http://www.hullp.demon.co.uk/SacredHeart/saint/StGilbertS.htm>

Catholic Encyclopedia: CANONS AND CANONESSES REGULAR

<http://www.knight.org/advent/cathen/03288a.htm>



## A Polio Christmas Carol



All of us are familiar with The Christmas Carol written by Charles Dickens. As a novelist, Dickens purposely portrayed the plight of the poor and the disadvantaged in many of his works. During the first part of the nineteenth century, Dickens came to Richmond, Virginia and made a point of witnessing a slave auction because he realized the inherent social evil that slavery represented. His writing described in vivid detail the social injustices of his time. In The Christmas Carol, Tiny Tim is the sickly child and might represent a polio child. Tiny Tim's father, Bob Cratchett, is the loving parent who obediently works hard for the miserly tyrant, Ebenezer Scrooge. As the story unfolds, we learn more about Scrooge through a series of ghosts, namely the ghost of Christmas past, the ghost of Christmas present, and the ghost of Christmas future. As grown up Tiny Tims (polio survivors), we may be more like Scrooge than we realize. We have our ghosts of polio past, present and future.



My past polio ghost is an eleven year old boy lying in the isolation ward at MCV in 1950 on the ninth floor, south wing in a room with five other boys, two who were in iron lungs. The rhythmic breathing sounds of the iron lungs were distracting and unsettling. The four or five year old boy in the next bed was able to jump on his bed as if it were a trampoline. Thus, I wondered whether I would soon be in an iron lung or soon be like the boy next to me. Neither happened, but that ghost of polio past is still vivid and real in my memory. Every one of you has some memory of a ghost of polio past, even if you were too young to remember the initial infection. Your past polio ghost might have been a situation that occurred when you could not do something that others did easily, and you felt painfully self conscious. Maybe some of those past polio ghosts haunt you to this day, or maybe you wonder what might have been, "if that polio virus had passed me over." Past polio ghosts probably affected family members over the years as they, along with us, had to deal with the unfairness, the anger, and even the guilt borne with the experience. Have we forgotten those ghosts, buried them or dealt with them, and moved on with our lives? Each of us has to answer for ourselves.

My ghost of polio present began in the summer of 1990 when I first experienced more fatigue than I had ever felt before. The fatigue caused me not to attempt a vacation trip that I had planned. I spent that whole vacation week resting at home. The fatigue became manageable for the next five years because I saved energy by using a scooter, but this current polio ghost was unrelenting, and the fatigue overwhelmed me in the summer of 1996. As a result, I had to make a major life style change. I had to retire from a very fulfilling psychiatric practice and accepted a disability status. This present polio ghost haunts almost everyone in our support group. It can also create feelings of guilt, anger and fear just as the ghost of polio past. No one really knows or totally understands why this ghost entered our lives again. Because there is no positive way to identify this ghost, the medical world does not always believe that the ghost of polio present really exists. Maybe no one can see this ghost, but we can surely feel it and it is real. Fortunately, there are professional post polio experts in the medical community such as the polio clinic at Sheltering Arms here in Richmond. These experts are more understanding of this present ghost. It seems that this ghost of polio present is not going to leave us and we cannot run or escape from it. We have to deal with it in whatever way is best for each of us.

That brings us to the ghost of polio future. In Dickens' The Christmas Carol, Ebenezer Scrooge experienced a remarkable personality transformation in which he became loving, generous, and understanding after his encounters with the three ghosts. As a result, Tiny Tim and his entire family benefited, and Scrooge himself had a brighter future. What is our ghost of polio yet to be? I hope mine is finding a way to use my knowledge, experience, understanding, empathy, and limited energy in a way that fulfills my desire to feel useful and purposeful to my profession, family, friends, faith, and the world of post polio. This future ghost does not scare me as much as resigning myself to the victim role. At our meetings, I have perceived that each of you are highly motivated to deal with this future ghost in similar ways. We have always accepted and met challenges and the ghost of polio future is no exception.

There is one unexpected blessing that these three ghosts have brought. We have found each other. I have met many marvelous, wonderful, caring people in our support group and communicated with many others on the telephone and through e-mail. Without these ghosts, we would have had no reason to find one another. That is the good news in this Polio Christmas Carol.

Most of you have your favorite presentation of Dickens' Christmas Carol, but I must tell you that mine is the "Muppet Christmas Carol." If you have never seen it, I would recommend you rent it at a video store and watch it with a child. Happy holidays everyone.

Dr. Henry Holland  
[Henry4FDR@aol.com](mailto:Henry4FDR@aol.com)

"Scrooge's Third Visitor" comes from the etching by J. Leech. The Dickens Picture Book. A Record

of the Dickens Illustrators by J. A. Hammerton. Volume 17 of the Charles Dickens Library Testimonial Edition. London. The Educational Book. Co. Ltd. 1912.

Further Reading:

A CHRISTMAS CAROL by Charles Dickens - The complete text from 1843

<http://www.stormfax.com/dickens.htm>

Biographical information, Dickens on the Web, Dickens 's Journalistic Career, Literary Giants, Quotations, Discovering Dickens, Works etc.

<http://www.helsinki.fi/kasv/nokol/dickens.html>



*"Muppet Christmas Carol" (1992)* in the [Internet Movie Database \(UK\)](#).

See also the Lincolnshire Post-Polio Library Catalogue

[Dr. Henry writes.....](#)



## L-carnitine and its use in the management of the fatigue of PPS

In an effort to provide more information regarding L-carnitine and its use in the management of the fatigue of PPS, the article below is offered for your review [posted to several polio-centric mailing lists]. I have used Carnitor (L-carnitine) since early this year. I feel that it has helped me. It is not a cure or a replacement for restful sleep, intermittent down time throughout the day or the pacing of energy. I have contacted Sigma Tau Pharmaceuticals, the manufacturer of Carnitor, in an effort to encourage them to do a double blind, placebo-controlled study on Carnitor in the treatment of PPS fatigue. To date, I have not received a response. Judith Hughes of California gathered and organized the information below. Read this information and make your own informed decision.

Dr. Henry Holland

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### L-CARNITINE TREATMENT OF PPS FATIGUE 11/98

The most basic and necessary treatment for the body/mind fatigue of post-polio syndrome is adequate rest (which might even require the help of mechanical ventilation) and the use of electro-mechanical supports such as braces, crutches and wheelchairs as needed.

What else can be done? We know the polio virus killed nerve cells, both in the body and in the brain. For almost a decade neurologists treating PPS have been prescribing drugs developed for other neuromuscular conditions. Examples are Mestinson and Amantadine, used otherwise to treat myasthenia gravis and Parkinson's disease respectively.

Another approach to treating PPS is to look beyond obvious paralysis and nerve cell damage and consider problems which develop secondarily as a result of polio. One way a person with significant polio damage differs from the norm is that he/she doesn't have as much muscle tissue. By the time one has to sit down most of the time, a great proportion of one's body's muscle mass is gone -- even if the rest of the body still functions. In a normal body, the legs and buttocks carry the weight of the body and have the biggest and strongest muscles.

Does a shortage of muscle itself have any effect on the body? Yes, It limits the amount of L-carnitine stored in the body. Thus, when needed for physical and mental functioning, it is not available. Our remaining muscles, which we push to the outer limits of their capacity, do not have the normal physiological support needed to keep them healthy.

In September 1994, M. J. Matheson, MD, wrote about L-carnitine (levocarnitine) and post-polio

syndrome (Polio Network News, and posted later on the Internet). She described the 1993 study in Switzerland done by Dr. Thomas Lehmann who treated 27 persons with post-polio syndrome with 1000 (-3000) mg/day of L-carnitine. Most subjects reported improvement on a range of PPS symptoms like strength and fatigue. In explaining this improvement, Matheson theorized:

"the paralyzed or weakened muscles of the polio survivor are atrophying or atrophied as a result of the late effects of polio. Because there is less muscle, there is less possibility to store L-carnitine. When tissues become acidic (lactic acid from overuse) or there is desaturation of oxygen (due to respiratory insufficiency or bad vascularization) the concentration of L- carnitine is lower in the blood, tissues and cells. The (over)use of muscles (whether atrophied or overused in compensation) has been shown to cause a local fall in levels of L-carnitine. L-carnitine improves the metabolism of oxygen, fat and glucose and inhibits the use (abuse) of muscle proteins for energy production. The deregulation or decompensation of the metabolism of fatty acids, glucose, oxygen, and energy (necessary for good muscle function) because of a lack of L-carnitine could result in fatigue and weakness of the muscles."

(For Matheson's article go to: <http://nonprofits.accesscomm.ca/polio/Carnitine.htm>)

### What is L-carnitine?

L-carnitine is an amino acid derivative which plays a critical role in fatty acid oxidation, the chemical process by which our bodies and minds are energized. In heart and skeletal muscle, the primary fuel source is mitochondrial fatty acid oxidation. L-carnitine has two functions. It is a carrier molecule that transports fatty acids into cellular mitochondria for their conversion into cellular energy, and it also moves potentially toxic byproduct molecules out of the mitochondria after which they are excreted in urine. L-carnitine is known to be important in nerve functioning and in protecting nerves from injury, in part by enhancing the activity of nerve growth factor. Normal muscle cells have a great concentration of mitochondria required to power muscle cell contractions.

### Where do we get the L-carnitine we need?

75% of our bodies' stores of L-carnitine come from dietary red meat and dairy products. We also, in our kidneys and liver, synthesize carnitine from methionon and glutamine (with the aid of vitamin B6, vitamin C, niacin, pantothenic acid and iron). Normal people with an adequate diet do not need to take L-carnitine as a supplement. (Note: infant formulas are fortified with carnitine.) Despite promotion by supplement companies, "carnitine-loading", in which L-carnitine is used by athletes as an ergogenic aid, has not been proven to result in improved endurance performance. There is no known L-carnitine overdosing; excess L-carnitine is excreted from the body.

### What are the established uses for L-Carnitine?

Some people are born unable to synthesize L-carnitine adequately. They have what is called a "primary" deficit. The [Muscular Dystrophy Association](#) recognizes certain conditions caused by the body's inability to make L-carnitine; these result in weakness of the shoulders, hips, face and neck muscles and the inability to sustain moderate exercise without kidney damage. L-carnitine metabolism is abnormal in patients with end-stage renal disease; both the process of dialysis and the dietary changes decrease L-carnitine intake. L-carnitine is being used to treat these conditions. Additionally, L-carnitine is being used experimentally for some conditions which include angina, peripheral vascular disease, dyslipidemia, and diabetes. L-carnitine treatment initiated early after acute myocardial infarction and continued for 12 months can reduce the dilation of the left ventricle that normally follows an MI.

There is considerable, ongoing research into L-carnitine's many functions in the body and brain. Carnitine easily passes through the blood brain barrier (BBB). Researchers are beginning to study

the possibility that L-Carnitine might be useful in helping drugs get through the BBB. Interesting also is the fact that L-carnitine is also a precursor for acetylcholine, the neurotransmitter whose breakdown is inhibited by Mestinson.

While there have been no L-carnitine studies done on post-polio in the United States, there are studies demonstrating L-carnitine's effectiveness in reducing fatigue in patients suffering from chronic fatigue syndrome (CFS). Like PPSers, the level of L-carnitine in CFSers is low. L-carnitine studies have also been done on early Alzheimer's patients and significant improvements in behavior and attention have been demonstrated.

To get an idea about the scope of the serious research being done on L-carnitine, go to "PubMed" and do a search on "carnitine". PubMed is the Medline search service provided by the National Library of Medicine. The site address is: <http://www.ncbi.nlm.nih.gov/PubMed/>.

### Dosage and Usage

Since this drug hasn't been extensively tested on PPSers, there are no guidelines for the treatment of PPS fatigue. We need to use common sense, as always. Lehmann's subjects took 1000 mg / day. There are reports about people in Australia who take twice that amount. When first starting L-carnitine therapy, it would be wise to begin with a moderate amount, perhaps 500 mg / day for a week until you get a feeling for how it is affecting your body. Then you might work up to 1000 mg or even 1500. We are all different. Some people take 1000 mg / day upon waking, on an empty stomach, and have no problems. Others space L-carnitine over the day. If taken too late in the day, some people can't sleep. Other's can. Those who take L-carnitine in the morning may find they are fading in the late afternoon and might want to take an afternoon booster. You need to experiment. If you are taking Mestinson, keep taking it.

### Acetyl-carnitine vs L-Carnitine

Acetyl-carnitine is chemically related to L-carnitine but is not the same. The body converts L-carnitine into acetyl-carnitine as needed. Apparently, there is a metabolic dysfunction which impairs the transformation from L-carnitine to acetyl-carnitine. Bought OTC, acetyl-carnitine is more expensive, said to be "more easily used" by the body.

### Prescription or OTC?

Since L-carnitine is sold both as a prescription drug as well as over-the-counter (OTC). It would seem sensible to get it in prescription form if you can. With less controls on the manufacture of OTC supplements, you might not get what you pay for and, if you don't, you won't get the benefit pure L-carnitine would provide. Medicaid (at least in California) pays for prescription L-carnitine.

### Prescription Carnitine

L-Carnitine is available as a prescription drug under the names: Carnitine, Carnitor, L-Carnitine and Vitacarn. Carnitor, manufactured by Sigma Tau, seems to be the most widely stocked brand. The generic name is levocarnitine. There are no known interaction effects between L-carnitine and other drugs or foods. There are no known diseases for which L-carnitine is known to be harmful. Note: If your L-carnitine comes wrapped in plastic containers, leave them wrapped up until you use them. Out in the air they absorb moisture and can crumple up.

### OTC Carnitine

Dozens of nutritional supplement companies make L-carnitine. Because of a lack of quality oversight, there is great variability in purity in "supplement" L-carnitine. Supplement companies make a distinction between "acetyl-l-carnitine" and L-carnitine, saying that the acetyl form is absorbed more easily.

### D-carnitine

There is a product sold in health food stores called vitamin Bt. It contains a MIXTURE of D-carnitine and L-carnitine. This is NOT the same as L-carnitine and can cause problems. Be sure to take L-carnitine only.

### Note: L-carnitine and Coenzyme Q10

In a study reported in Molecular Aspects of Medicine, 1997, the effects of 100 mg / day of Q10 on skeletal muscle energy metabolism in middle-aged post polios was studied. The results suggest Q10 supplementation improves muscle energy metabolism in post-polio individuals. Q10 is a nutrient that works with L-carnitine to facilitate mitochondria energy production. L-carnitine and Q10 complement each other metabolically and should be taken together.

Further Reading:

Sigma Tau Pharmaceuticals Carnitor ® (Levocarnitine) Home Page <http://www.sigmtau.com/>



Nancy Brotzman USA <[petra@EPIX.NET](mailto:petra@EPIX.NET)> sends us this story...

A little boy about 10 years old was standing before a shoe store on Broadway, barefooted, peering through the window, and shivering with cold. A lady approached the boy and said, "My little fellow, why are you looking so earnestly in that window?"

"I was asking God to give me a pair of shoes," was the boy's reply.

The lady took him by the hand and went into the store, and asked the clerk to get half a dozen pairs of socks for the boy. She then asked if he could give her a basin of water and a towel he quickly brought them to her.

She took the little fellow to the back part of the store and, removing her gloves, knelt down, washed his little feet and dried them with a towel.

By this time the clerk had returned with the socks. Placing a pair upon the boy's feet, she purchased him a pair of shoes, and tying up the remaining pairs of socks, gave them to him.

She patted him on the head and said, "No doubt, my little fellow, you feel more comfortable now?"

As she turned to go, the astonished lad caught her by the hand, and looking up in her face, with tears in his eyes, answered the question with these words...

"Are you God's Wife?"

From Mary Ellen, USA Family Hemby <[mh45745@NAVIX.NET](mailto:mh45745@NAVIX.NET)>

I know it is winter when:

The gel in my w/c seat cushion freezes overnight in the van and I have to sit thru an entire church service completely chilled to the bone!!! (oh, I miss the Texas warmth...)

From Viola Pahl, Canada <[violapahl@iname.com](mailto:violapahl@iname.com)>

The best of all gifts on any Christmas tree - the PRESENCE of a happy family all wrapped up in each other. At Christmas time consider not so much the gift of the friend, but the friendship of the giver.



## When Silence Isn't Golden

By Dorothea Nudelman

'Tis the season full of folly when "performance demands" are reckless for polio survivors with diminished energy. In the U.S., the autumnal harvest and Halloween festivities open this season of abundance. Thanksgiving, Christmas, and New Year celebrations perpetuate the orgy until early January when we whimper a bit before collapsing in exhaustion. This habit of extravagance beyond reason, good health and good sense is difficult to alter. Partly, it is driven by the expectations of others. Partly, by our need to fulfil those expectations at any cost.

As polio survivors, we rarely acknowledge the emotional or physical price of our efforts even when they rob us of enjoyment. The quickest way measure the true cost is to ask ourselves how we feel about the approaching holidays.

- Are we dreading the demands on our physical energy?
- Are we driven to do more to please others or prove we are up taking care of everything- from the Thanksgiving dinner to the Christmas tree, gifts for everyone, cards, entertaining, etc.?
- Are we resenting what we feel we must or should do?

Over the years, media images of the holidays have struck me as replete with happy, energetic people of dazzling material wealth. They sparkle in candlelight and glow with satisfaction. How real people, even able-bodied ones, accept this as the standard of achievement amazes me. But, unthinkingly, they and we do. The result of such unreal expectations is often private disappointment, feelings of inadequacy, resentment and resolution to "do better" next year. For years I wasn't even aware that I was one of these striving people.

During my daughter's early childhood, my in-laws were only too happy to leave all the holiday planning and preparation to me. At the time, I was working outside our home but, since they had only one child and no other grandchildren, I wanted to please them. Year after year, I went all out to make a picture perfect Christmas. The year Kathryn was five, I almost outdid myself. When the in-laws arrived on Christmas Eve, the tree was sparkling, the table was glowing in crystal and silver, the prime rib was roasting, and we were dressed and ready with their gifts. By the time we'd had a cocktail and the food was on the table, my daughter began to cry. "What's wrong?" I asked her, expecting a sore throat or earache. "I'm too tired! I don't want any dinner. I just want to go to bed!" With that she rubbed her eyes and cried some more.

I took her to her room where she undressed and climbed into bed. As she snuggled down she handed me her favorite book. "Will you read me a story?" she asked. I read, and in five minutes she was asleep. No more of this, I thought. I have turned myself inside out to make everything perfect for others but we don't [need] such excitement. My five year old brought me back to my senses fast. I probably should have curled up with her!

After that, our plans for Christmas Eve became very low gear. We ate simple meals, often leftovers or soup, left refreshments for Santa, and went to bed early. It disrupted the in-laws, but they adjusted. We had quiet nights with small rituals and private Christmas mornings opening gifts, and eating special breakfast treats. Now, we rarely dress until midday and then have friends in or go out to deliver Christmas gifts to others.

I used to bake a half dozen different Christmas sweets, but now I choose the best one and make it in

larger quantities. We always had a very large, elaborate tree, but last year our now grown daughter was away and we skipped having a tree. We missed it, but only a little. This year, the kind and size of tree will depend on who wants to participate in chopping it down, setting it up, decorating it, and cleaning up. In short, we look at what we want and make realistic choices that involve everyone's help.

We all enjoy ourselves more when we know our own limitations and honor them. Mine is PPS, yours may be limits of time, money, even inclination. Whether we are looking at holidays or just ordinary days, we can change our behaviors if we remember that silence is not a virtue when it is harmful to ourselves and others we love. We need to learn to tell the truth in lieu of protecting others from what they (or we) may not want to hear: "I'm too tired," or "My legs hurt," or "I have to sit down because I'm losing my balance."

The good news is that most polio survivors have had active productive lives. We passed beyond our initial illness and felt we had "skirted" the edge and gotten free. We learned to cope so well with our polio limitations that we forgot the painful years of struggle and loss. Or, at least we remained silent about them. We learned silence well. Many of us did and still do ignore the growing weaknesses and pains of PPS as if, by silencing them, they will simply disappear. Our families and friends join us in this conspiracy of silence until we are forced to acknowledge that our bodies have changed, that we need help, that our losses cannot be restored by hard work and endurance.

It has taken me years to acknowledge these changes and to learn new coping mechanisms. But the lessons have been richly rewarding. They have increased my understanding of myself and others, and made me more richly appreciate all I have. Most importantly, I have begun to learn how to care for myself now and in the future. Indeed, it is a "noisy" business I have started!

In my memoir, *Healing the Blues*, I told how the story of this new growth began. I can now make physical changes to preserve my strength, flexibility, and safety. But I find that the most complex and far-reaching changes I need to make lie in communication with my spouse, my daughter, and my close friends - people I interact with on a daily basis and who are closest to me. (Ironically, this is probably true for most people regardless of their physical prowess.) I think that for polio veterans to move forward in developing significant relationships with children, spouses, and friends, we must abandon our silences and voice our needs more openly and directly.

While the need to "ask for help" seems self-evident, it is difficult to do when the lessons of silence were tied to independence and self-reliance throughout our recovery years. Though silence served as strong motivation in our initial recovery, it is futile and destructive when used inappropriately. If we now need to rely somewhat on others for the full enjoyment of our lives, not to ask for help exhibits false pride and recklessness. Let me share with you how this has worked in my own life.

Twenty-two years ago, when I was pregnant with my only daughter, Kathryn, I had time for reflection. While I happily anticipated her birth, I was also fearful about how I would manage, physically, since I walked with crutches and a full leg brace. My husband, Michael, and I had worked out many details in advance, such as he being the 'designated floor-walker' at night, and I having childcare help during the day. Yet I knew I would face massive challenges. How would I move the baby about the house? Take her outside? Get to her crib in a hurry? How would I keep up with the daily unexpected events in a world I'd so carefully structured to accommodate me? I trusted those changes would come in time, but I assumed I would be responsible for all of them.

Furthermore, I adopted the view that my daughter should be protected from my fears and special physical needs as a result of polio. It was enough that I'd endured them. I did not want her to feel the burden of my 'differences'. So, before her birth, I had already decided to maintain simple honesty about the surface facts of my life but 'shield her' from my private pain about all I would never be able to 'do' with her. Silence, once again. I didn't discuss this decision with anyone, and never doubted it was right until recently.

In the course of Kathryn's growing up, I recall instances when those silences were broken. When we

took the training wheels off her Strawberry Shortcake bicycle, she rode around on the street in front of our house just before taking off on a ride with her dad. I smiled and clapped. She rode up to me flashing a proud smile and whispered-"I wish you could come riding with us, Mom." "So do I!" I agreed, hugged her, and waved her on her way, grateful that she had a dad who loved to play with her.

To 'compensate' for all I couldn't do with her, I enrolled Kathryn in summer camps and year round lessons in riding, swimming, ice skating, dancing, gymnastics etc. I drove her everywhere, watched, waited, enjoyed her satisfaction vicariously, and ended my workdays by feeling as exhausted as if I'd done the sport myself! My attention to and pride in her developing skills were my gifts to her. I sought to open her world in ways mine had closed and I enjoyed it. I shared these delights with other parents. I never dreamed that there was another gift I could give her.

My practical self spoke again when Kathryn was 17 and I was finishing pre-publication work on *Healing the Blues*. There were many last minute details to take care of that summer and needed to remain focused on my work. Kathryn had just finished high school and the opportunity arose for her to take a six week trip to Europe with her dad. I encouraged them. "You two can go all the places I can't go, walking and hiking, and not worrying about accessibility for me." They agreed but asked if I'd be jealous. "No," I said, "because I'll enjoy it vicariously and you two will have a special experience together." This was true. I didn't allow myself jealousy or small-mindedness, but I never shared with them the feelings of loss and sadness at not being able to do things other families did.

Recently, I asked Kathryn what she feels has been lost through my silences. After a busy day running errands, we stopped for coffee at a local café where we got nostalgic. We began with simple things. I asked how she remembered her growing up years with me, how she had seen my differences. She said she always knew that I was and was not different. "You were really like other mothers, except your differences were particularly unique. The polio had made you walk with crutches and a brace. That attribute of you was different. I always felt protective of you in that I knew you were at a disadvantage from those who didn't need devices to get around. I hated when people stared at you. I gave them dirty looks until they looked away. They made me angry!"

I recalled an earlier conversation about that. When she'd first told me of her anger, I gave permission for her dirty looks. We'd had this exchange when she was eight or nine and I started using handicapped parking spaces. "I wish you wouldn't use those blue spaces, she'd said. "Why?" I asked. "Because they make people stare at you, she shot back. I hate that!" "Well, let them stare," I said. "The blue spots are closer to places I need to go. Let them stare, they've stared for years! I've gotten used to it. I don't even notice it anymore." Recalling this story now reminded me of how I sassed adults as a child when they'd had the nerve to stop me on the street and ask what had "happened" to me or how I got "crippled. I had been just as outraged as Kathryn had been.

"Do you remember the time you won a prize, \$10 I think, in a neighborhood Mother's Day art contest?" Kathryn laughed, "Of course I do! I think I was only about seven!" "That's right - I still have that picture. You drew me as a stick figure standing in a yard with grass and flowers behind me and a table in front piled with boxes of presents. I even remember the boxes had ribbons drawn on them. The best part was that I stood behind the table throwing my crutches into the air. I had a big smile on my face. How I loved that picture. How I loved that you had drawn it!"

"Well that's the way I saw you, whole and happy. That was my world. Simple and full of good things. Things I could do. I was proud of myself. And you, too." Like any other mother, a piece of me lingered over those simple days again.

Offhandedly I asked her, "What memories about my coping with polio are vivid for you now as you look back?" Without hesitation she answered, "Your never relaxing, never stopping when you worked at something until it was done. I always knew when the end came because you'd say, 'Okay. Now I've got to go put my feet up.' It wasn't until recently that I even knew your legs hurt you. It was that, knowing about the pain, that got my attention. I felt bad when I learned it hurt. I



understood 'hurt.' Had I understood earlier, I think I'd have been a lot quicker to do things, to help. At first, it made me angry, that I didn't know. Now it just makes me sad. You never said anything."

I was amazed. I'd never seen it this way. Silence was the very thing I practiced so as not to leave her burdened. But this 'protection' didn't serve her well any more than it had served me. Once I realized that, the floodgates of conversation opened easily. Since then, I have been entirely honest and direct with her. And she has said it's so helpful, all the time, to know what's going on with me. Speaking for herself and her dad she said, "That's the best way for us to help you. The best, the easiest, and fastest way for us to know where you're at - open communication without demanding."

Our conversations were so rewarding that I pushed further, abandoning any defensiveness regarding her experience of me. I just needed to listen with my ears and heart. Maybe I could get some tangible examples of what she meant. So I asked, "Can you tell me of sometime when I was open with you that was very helpful?"

"Education," she said, "is the very best thing. When you found your polio doctor, Dr. Yarnell, and took us with you to see him, that was great. It gave me a context for understanding what was happening to your body. It's not that I didn't or don't believe you, but there's something about us all sitting there together and hearing the informed view of someone you've never met but has credibility. Being there, gave me the context I needed to really understand."

"What impressed you most?" I asked. Her answer came immediately. "The 20% rule - when he explained that you should exercise for only 20% of your capacity. That would keep you toned and flexible but it wouldn't overwork your already overused muscles. I knew right away that if 20% was the right amount for you, then dad and I should be doing the other 80% of the work around the house - at least. I could see that. It was measurable. So, 80% should be a standard, an objective. It gave me something to hang onto, a fact. If I could practice behaving at this standard, you wouldn't have to ask so much or so often. That kind of knowledge is the best kind for me."

"What's bad?" she grinned, anticipating my next question. "What's really bad, the worst, is when you do too much." She slumped across her chair in mock exaggeration that was probably not too far from the truth. "When you get tired and cranky. Resentful and critical. And it's unpleasant for all of us, mom, and worst of all it doesn't help you. We all wind up feeling like hell. And in silent rage, you go on doing whatever you're doing." There was that silence again. "The way I see it is that we all have our responsibility. You, as a polio person, have to speak up, say what you need. We have to listen and do our share. It might not always be 80% but we can do better."

There it was. Speak up, sing out. Kathryn told me - simply and honestly - what I needed to hear. It doesn't matter if I'm in a chair or standing. I'm the same person to her. Being my true self is important. This is true for all of us, our best hope for the future. Learning and living with our individual limits is possible, not simply at holiday time, but each day of our lives.

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Portola Valley, California, U.S.A

For details of Dorothea's book see  
[HEALING THE BLUES - DRUG-FREE PSYCHOTHERAPY FOR DEPRESSION](#)  
in our Library Booklist section.



'Twas THE MONTH AFTER CHRISTMAS  
from Carmel

Tw as the month after Christmas, and all through the house  
Nothing would fit me, not even a blouse.

The cookies I'd nibbled, the eggnog I'd taste  
At the holiday parties had gone to my waist.  
When I got on the scales there arose such a number!  
When I walked to the store (less a walk than a lumber).  
I'd remember the marvellous meals I'd prepared;  
The gravies and sauces and beef nicely rared,  
The wine and the rum balls, the bread and the cheese  
And the way I'd never said, "No thank you, please."  
As I dressed myself in my husband's old shirt  
And prepared once again to do battle with dirt--  
I said to myself, as I only can  
"You can't spend a winter disguised as a man!"  
So - away with the last of the sour cream dip,  
Get rid of the fruit cake, every cracker and chip  
Every last bit of food that I like must be banished  
'Till all the additional ounces have vanished.  
I won't have a cookie - not even a lick.  
I'll want only to chew on a long celery stick.  
I won't have hot biscuits, or corn bread, or pie,  
I'll munch on a carrot and quietly cry.  
I'm hungry, I'm lonesome, and life is a bore--  
But isn't that what January is for?  
Unable to giggle, no longer a riot.  
**Happy New Year to all and to all a good diet!**

### More from Viola Pahl

Little Jimmy was saying his bedtime prayers a week or two before Christmas. He enumerated the many things he would like to have for Christmas in a startlingly loud voice. "Don't pray so loudly," chided his mother, "the Lord isn't deaf." "Maybe He isn't," admitted Jimmy, "but Grandma is."

When in the frosty midnight  
He cruises through the air  
What Santa needs for Christmas  
Is fur-lined underwear.  
But when sliding down the chimney  
Toward the bright grate fire,  
Asbestos pants for Santa  
Would be more SOOTable attire!



## Lincolnshire Post-Polio Library

Articles added since last newsletter with grateful thanks to the authors

**Title:** [Dr. Henry writes about Recovered Memories](#)



**Author(s):** Henry Holland MD.

**Title:** [PPS and Intimacy](#)



**Author(s):** Linda Van Aken and Henry Holland MD

**Title:** [Silicon, Sex and Polio Survivors](#)



**Author(s):** Dr. Richard L. Bruno

**Title:** [Predictive Factors for Post-Poliomyelitis Syndrome](#)



**Author(s):** Daria A. Trojan, MD, MSc, Neil R. Cashman, MD, Stanley Shapiro, PhD, Catherine M. Tansey, MSc, John M. Esdaile, MD

**Title:** [Dr. Henry writes about Reductionism](#)



**Author(s):** Henry Holland MD

**Title:** [Electrophysiology and Electrodiagnosis of the Post-Polio Motor Unit](#)



**Author(s):** Daria A. Trojan, MD, Daniel Gendron, MD, Neil R. Cashman, MD

**Title:** [Anticholinesterase-responsive neuromuscular junction transmission defects in post-poliomyelitis fatigue](#)



**Author(s):** Daria A. Trojan, Daniel Gendron and Neil R. Cashman

**Title:** [Unusual Cases: Postpolio syndrome](#)



**Author(s):** Paul Ballinger MRCP, MRCGP, DCH, DRCOG

*A copy of this above article was distributed to LincsPPN Members with the hardcopy edition of this newsletter*

**Title:** [Poliomyelitis](#) New Problems From An Old Infection



**Author(s):** John Shneerson MA DM FRCP FCCP

*A copy of this article was distributed to LincsPPN Members with the hardcopy edition of this newsletter*

**Title:** [Findings in Post-Poliomyelitis Syndrome](#)



**Author(s):** Jacquelin Perry, M.D., James D. Fontaine, M.D. and Sara Mulroy, PH.D., P.T., Downey, California



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Medical Conference and AGM  
Friday 12th and Saturday 13th March 1999  
Green Isle Hotel, Nass Road, Dublin 22.

More information will be available by the time of the next newsletter.

**Jim Costello, Chair-person - "Jim " [<jjcos@indigo.ie>](mailto:jjcos@indigo.ie)**



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