

The LincPIN

The **Lincolnshire Post-Polio Information Newsletter**
Volume 4 - Issue 1 - December 2002

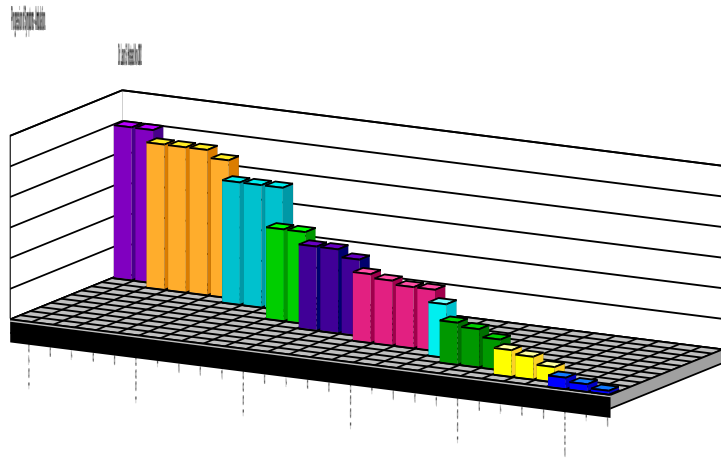
WebSite - <http://www.lincolnshirepostpolio.org.uk>

Wishing You All the Best For The Coming Season

Dr. Lauro S. Halstead
is a Polio Survivor.
1954 - aged 18 years.

This chart shows the reduction
in the number of City Blocks
that he has been able to walk
over the last 27 years
showing a decline in ambulation
through Post Polio Syndrome.

- 1983 - He started using an electric scooter at work.
 - 1990 - An ankle foot orthosis.
 - 1999 - A second scooter for home and social use.
- Article Pages 6 - 9



Photograph of Aaron Mattes, MS, RKT, LMT, creator and developer of Active Isolated Stretching: The Mattes Method. Article pages 14 to 16.
Photos 1, First stretch to limit. Photo 2, 10th stretch note increased range. Photo 3 thoracic stretch.



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.

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

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Membership Information

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

Please make cheques payable to 'Lincolnshire Post-Polio Network'
post to Membership Sec, 78 Heron Road, Larkfield, Aylesford, Kent ME20 6JZ, UK

UK Membership - Life Member (LM) £100 or £5 x 20 months S.O. - Member £10 a year.
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Other Countries please contact <membership@ or treasurer@>for details.

Enquiries, items for newsletters, - enquires@ or newsletter@

Next LincPIN Newsletter - February 2003

Articles for publication by January 25th - Publication date mid February 2003.

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Editorial by Hilary Hallam

On behalf of our Committee and team of helpers I would like to wish all our members, their families and friends, and any other readers all the very best for the coming Season and a Happy New Year.

2002 seems to have flown by, in fact it hardly seems any time at all since we celebrated the Millennium. We have been back in Florida now for two months. October saw us playing catch up on the energy expended up to the AGM, packing and the flight. This was in temperatures in the high 80's and low 90's with very high humidity. 10 degrees above normal for the time of year. Doubly exhausting! We did not do very much other than attend two pps meetings, shop for food, and visit a couple of flea markets.

On the 30th October we set off to drive the 1000+ mile trip to Atlanta in Georgia to attend the Atlanta PPS Associations One Day Seminar with Dr. Halstead as the main speaker. The first PPS conference I attended back in 1997 was organised by APPA so it was good to renew old acquaintances. I also met up again with member Phyllis Eckert who is the current President of the First Coast PPS group in Jaxonville, Florida. It was an excellent conference. Dr. Anne Gawne from Warm Springs was there, and Dr. Leslie from the Shepherd Center next door. I did get a chance to speak with all three doctors but there is never enough time to talk with all the people for the length of time you want to. APPA introduced me to the audience and were very complimentary about our organisation, work and our WebSite and its Library of Articles. Report pages 6 - 8.

Less than three weeks later we set off for north Orlando travelling on back roads to avoid the notorious I4. It does take longer, but its less stressful. We arrived at our hotel just after 3 p.m and crashed out for the rest of that day. We were rudely awakened at 1.a.m with the fire alarm going off, the noise was horrendous. Luckily there was no obvious fire and we were able to remain in our ground floor room with the door open so we could get out quickly if necessary. A fireman joked with me 'you folks sure do book early early morning calls' Which leads me into an important reminder. If you wear callipers, special shoes, walk slowly, in fact anything that could delay you leaving a building in the event of a fire, then you must PLAN ahead. Before booking ask the layout of the hotel, ask for the lowest floor room. On arrival ask if there any special instructions and tell them what your problems are. Not everyone - as we know - is disabled aware and knowing we have electric wheelchair and scooter we have been seriously offered the end room on the seventh floor right next to the fire escape.

Dr. Julie Silver, from Boston, was attending a conference in Orlando and had been asked to speak by

the Central Florida PPS Support group. Dr. Silver kindly came a little earlier to our hotel which allowed us time to talk about the UK problems before going to the meeting. Report on pages 10 - 13.

I would like to thank Linda Priest and the APPA committee and J. Ann Singleton for organising these meetings. Having the opportunity to meet and hear highly respected and knowledgeable health professionals passing on their knowledge of Post Polio and sharing information with other Polio Survivors is a great experience. These and the other conferences and meetings I have attended since our formation has been our backbone and enabled us to become a spoke in an International Wheel of information providers, accessed by polio survivors and many health professionals worldwide.

This newsletter also contains information from Denise and Jenni, committee members. Another 'Ask Linda' item from Greater Boston PPS Groups newsletter about undiagnosed respiratory problems. Active Isolated Stretching: The Mattes Method. Read about this treatment method that opens up our stiffening joints promoting better circulation. Joints that move freely again allow muscles to work more effectively. Marcia writes about West Nile Virus and Polio. Marcia and Eddie start a series of questions to us so that we can join in the 'research'. Another person I 'found' on the Net was Derek Paice, a polio survivor who has type II diabetes. He has done some amazing personal experimentation on the blood glucose levels from different foods and published the results. His article is at the end of the Newsletter with a chart on the back page.

Yet another email has introduced us to Ms Laurie. Mitchell, an 80-year-young great grandmother. Now retired, she spends her time writing and painting. She has published essays and articles in major newspapers as well as smaller publications. She is currently working on

a collection of her short stories. She has kindly given permission for us to publish some of her work. See the story of her polio on page 18. Finally have fun on the Xmas page 20. Name those Carols, answers page 23.

Lincolnshire's Neurologist Update - Dr. Bowen is in the military and due to the current issues in the Middle East his starting date in Lincoln has been delayed.

Denise Carlyle, Vice Chair.

Hi there. I'd like to briefly introduce myself -
Denise Carlyle, your vice chair,
polio class of '54 at age 2,
PPS confirmation 1999 (Papworth, UK).

I studied piano at college, becoming a music teacher in a city secondary school. I soon found teaching the full ability range wasn't much fun! Being on my feet all day was very demanding and within a few months I was prescribed tranquillisers to help me cope! It never occurred to anyone that one of the reasons I couldn't cope was physical, just as it was never discussed why I couldn't use the piano pedal well (I used my left 'good' leg), or gain full tone with my right hand. Everyone just assumed I ought to be left-handed.

Married life took me into the farming world. As the boys were growing up, I was bored, and did an OU degree in sociology/psychology, as well as feeding lambs etc, teaching piano, doing voluntary work as a trainer in the Citizens Advice Bureau, and looking after agricultural student boarders. In 1990 I started to experience sustained fatigue, pain in joints etc, [after hysterectomy and appendicitis/peritonitis operations]. I was given a calliper again and told to use a stick – which I refused to do ☺. I still walked two miles daily with our retriever, Susie.

The psychological effects of the polio experience became apparent ten years ago when I attended a Transactional Analysis module as part of a counselling course. As a group, we were put into a calm state where we were taken back through our lives to childhood. In retrospect, it was a very dangerous thing for any leader to do without the resources to cope with the fallout. I got stuck at age two. He brought the group back to the present but I remained stuck, silent for the rest of the session. Although the leader noticed this, he did nothing about it. I got myself home, and cried for much of the next three weeks with no understanding of why. I can still feel the tears at the back of my mind now as I write this. I needed counselling to understand that the child in me was still crying.

Soon afterwards, my marriage broke up. Needing full-time work, I went into research, working in clinical audit, introducing Total Quality Management to General Practice teams, then returned to teaching for more money and housing provision, teaching sixth formers psychology and GNVQ Health and Care, which I very much enjoyed. I found full-time teaching impossible. I

obviously had not learned from my previous experience! I lasted seven weeks before 'hitting the wall'. A GP advised that teaching was too stressful and I needed to find an alternative career (still no mention of the late effects of polio). Through the years, social factors influencing health had become a major interest. Stress was an issue with farmers, doctors and teachers, so I returned to research to examine teacher stress. I found doing a PhD full-time and raising two teenagers alone very stressful.

I had read in a **BMJ article that PPS was 'all in the mind'**, and so, like many polio survivors, I put my deteriorating functioning down to lack of fitness and joined a gym! Bad idea. Within a year I could no longer do my job. I began to hit the wall every three or four weeks. Then had to have a three week break when an interview with a distressed teacher brought the past flooding back to me again.

The Open University was very good, extending my contract, paying me for an extra year. They gave me a computer plus an overbed table so I could work at home, paid my internet bill, and enabled me to buy a subscription to use the pool at my local hotel (it's warm) to keep me supple. With their encouragement and support, and that of my young GP, I completed my doctorate in Emotions and Stress.

So, like many of us then, I was the typical 'A' type, enduring several years of denial ☺ before I finally hit the wall big time and had to admit there was something very wrong. Now early retired, I am adapting to living on benefits. My house and garden are being reorganised for wheeling (five year plan!). I still swim (very short distances), sing in a choir, and have four piano pupils. I look forward to keeping my brain active through working with LincsPPN.

denise.carlyle@lincolnshirepostpolio.org.uk

If any other members would like to introduce themselves in a newsletter then we would love to hear from you. If you do not write letters for the Letters page then we cannot include that section.

TREASURER'S THOUGHTS

When Hilary inveigled me into doing the job of treasurer, and after I had reluctantly agreed, I told her I would do the following:

- keep the books and prepare the accounts
- prepare some budgets and
- write a piece for the newsletter.

Three days before Frank formally retired as Treasurer Hilary told me “there isn’t much involved work-wise”. It is with sadness that I have to tell you she was wrong, and as is the way of things all jobs expand.

However she did kindly let me off writing a piece for the last magazine (since it was only a couple of weeks after the AGM and I don’t think even Hilary was willing to chance her arm to that extent!) but there has been no such respite this month.

The main advantage of the job is that I no longer think about my own money, I am too busy worrying about the small amount of cash LincsPPN has.

Fundraising

Last year our total income was £5,544 of which £2,000 (36%) came from donations (15% from U.K. and 21% from U.S.A.).

If we are going to:

- continue to issue six magazines a year (the main way we keep in touch with members)
- update our Web Site (the way we get the majority of our new members - as well as being a world renowned information source)
- increase our lobbying of the Health Service Professionals

we need to raise more money. In the first instance the easiest way is through the membership, principally because you are aware of our aims and will be among the beneficiaries.

To this end I am asking all of you to give consideration as to how money could be raised (lots of small amounts e.g. raffles, sponsorships

etc. soon mount up) and also to tell me what, if anything, you yourself are able to do to help.

Robin (the membership secretary) is looking into the cost of stickers we could sell next Christmas to raise funds.

In the meantime I am also investigating charitable funds that give money to other charities, but it is only fair to say that previous fund raising efforts have been unsuccessful. However that is no reason not to try again.

Gift Aid Declarations

So far I have received 29 of these and the amount I can reclaim from the Inland Revenue this year currently stands at £189. If you haven’t returned your form could you please do so?

Gremlins in the 2002 Accounts

As last year’s accounts whizzed backwards and forwards across the Atlantic gremlins sneaked in.

The figures should have been:

- Income over Expenditure \$1,413.75
- Expenditure over Income -£861.86
- Combined (at \$1.55 to £1) Income over Expenditure £50.25 (i.e. we had a small surplus).
- In addition the total of sterling expenditure should have been £4,819.06

Your Views

I would be very grateful to hear your thoughts as to how our financial affairs can be improved. In the next magazine I will give you an idea on how the day to day costs are met and controlled.

jenni.paulger@lincolnshirepostpolio.org.uk

The next issue will also include more information about the day to day running of our organisation. All work is voluntary, most expenses are waived. We will give you an idea of what this would cost if all this was paid. We will let you know how many people contact us by phone/letter/email and how many of those join and more.

**ATLANTA POST-POLIO ASSOCIATION
ONE DAY CONFERENCE
NOVEMBER 1ST 2002
SHEPHERD SPINAL CENTER,
ATLANTA**

Main Speaker, Dr. Lauro S. Halstead.

Report by Hilary Hallam, and Phillippa Eckert.

Phillippa Eckert is a USA member of the Lincolnshire Post-Polio Network and has just retired as President of the First Coast Post Polio Support Group, Jaxonville, Florida. Hilary Hallam the Founder and Chair of the Lincolnshire Post-Polio Network.

Dr. Lauro S. Halstead is Director of the Spinal Cord Injury Program and Director of the Post Polio Program at the National Rehabilitation Hospital in Washington D.C. He helped to organise the 1984 and 1986 Research Symposia on the Late Effects of Poliomyelitis in Warm Springs Georgia. Dr. Halstead is internationally known for his work on the late effects of post polio, and a polio survivor himself.

Additional Speakers were Dr. Donald Peck Leslie, the attending physician at the Shepherd Spinal Center which specialises in neuromuscular disorders and Dr. Anne Carrington Gawne, Director Post Polio Clinic and Brain Injury Program, Roosevelt Warm Springs Institute for Rehabilitation, Warm Springs, Georgia.

Linda Priest, President of APPA opened the event and introduced Dr. Leslie who in turn introduced Dr. Halstead. The following is a report of his presentation

Living with PPS: A Personal Perspective.

Dr. Halstead gave his presentation whilst seated in his scooter. He wanted to discuss his problems in the spirit of interaction with the audience and invited questions. He fully admitted that he did not have 'all the answers' but using his experience of polio and PPS he would give us an insight into how he manages his life as a physician and polio survivor.

Living with PPS is an ongoing battle. This is not a static disease. Often the adjustments made by the polio survivor in the past, which worked then, will not work now. Dr. Halstead admitted that he used all sorts of subterfuges to fool himself and others, while his limitations became progressively more

apparent.

Dr. Halstead was infected with the polio virus - incidentally six months after visiting Lincoln in the UK - in 1954, aged 18, a sophomore in college. All four limbs were affected and he spent two to three weeks in a respirator. He had no dysphagia. He was in hospital for five more months used a wheelchair for five more and an ankle foot orthosis for one year. Between 1957 and 1961 he had nine reconstructive surgeries. Recovery took three years. He taught himself to write with his left hand as his right hand and arm were paralyzed. An avid walker, he climbed to the top of Mount Fuji (12,000 feet) as a testimony to his full recovery. An achiever, he did not think of himself as disabled.

His condition was stable for twenty five years. In 1979 he began to experience extreme fatigue and new leg weakness. He considers this as the beginning of his PPS. In 1983, although he could still walk, he started using an electric scooter along the very long corridors of the hospital in order to save strength and energy. This scooter was left just inside his entry point to the hospital for him to use the next day. In 1990 he was fitted with a right ankle foot orthosis supporting his dropped foot and enabling him to carry on walking. When Hilary visited with Dr. Halstead in Washington just prior to the Toronto PPS Conference, four years ago, he was just about to get a scooter for home and social use.

Dr. Halstead illustrated his progressive decline in walking ability with a chart. See front page. This shows on the left side the number of Blocks he could walk, starts in 1975 and ends in 2002. The downward slope goes from a maximum of walking over ten city blocks down to almost zero.

Dr. Halstead then showed us slides of his home and work. Illustrating the changes that he has made, aids that he uses, so that he does not waste energy, so that he can do more of what he wants to do.

He lives in a house although from the front it looks like a bungalow. All the main living areas are on the one floor, and he has installed a stair-lift (stair glide) to the basement area. This stairlift fits directly onto the stairs, not the wall, and can be, and has been moved from house to house.

In the kitchen he uses tall stools or stands leaning one knee against the cupboards for extra support. In the lounge he has had his couch raised on four six inch risers so that it is easier to rise from. In his office at home he has a cushion on the seat, all

the important documents that he needs are in a box under the desk so that he only has to lean down to get at them. All the things that he needs are within short arm reach.

His bathroom has rails fitted to hold onto. He advises that if possible delay deciding where the rails for the bath should be fitted until you are wet. He has a small stool in front of the vanity suite so that he can kneel on one knee, place his arm on a cushion and leaning his head down he moves the shortest possible distance. Clothes that are on rails means raising your arm up to get them down so he has a 'butler' (stand with hangers and places for other clothes). Some years ago he found shoes with Velcro straps and that was the end of struggling to tie laces.

He made us laugh with his photographs of eating. This started with two spoons, a 5ml and a 15ml. He then showed a dinner plate including carrots and using the 5ml spoon, three carrot slices. But with the 15ml spoon he could get 15 carrot slices on board. He places his left arm on a cushion on the table and by leaning his head down there is less distance to the spoon. Better biomechanics and saved energy.

He then showed slides of how he stands up from chairs by placing his legs at a distance apart and his knees closer together. There are many tricks that we evolve to do what we need to.

He then told us about a time in his clinic when a patient said that she used pillows to support her when resting or sleeping in bed. He asked her "how many" and was surprised at her reply of five, that is till he got home and counted his six! He uses pillows to support the parts of his body that need it and so rests more comfortably. He has a fused shoulder.

He has had to reduce his work to part time and uses a headset and voice activated software to dictate reports. All his needs at short arm lever distance. He takes an hours break during his working hours, using a recliner chair and listening to soothing tapes. The next slide showed a sign taped to his office door. Therapy Session. Do not Disturb.

He uses a small suitcase on wheels to 'carry' his laptop and office papers around. He has a Bruno Kerbsider hoist in the back of his SUV for his electric scooter.

When out and going into a shop without his scooter he uses a seat stick so that when he gets to the counter he can sit and deal with his money

etc. comfortably.

He likes playing the piano and is trying to figure out a way of playing with only his left hand that would sound like he is using two hands.

Dr. Halstead does some stretching exercises every day, eats a good diet of white meat, fish, fruit nuts and vegetables. He does not smoke, but does drink socially. He takes a few basic pills necessary for his health and one multi vitamin.

Dr. Halstead emphasized that we should avoid using pain pills unless at night to help with getting a good nights sleep. We can eliminate muscular pain by doing less. He said we should regard our energy, as Hugh Gallagher had said in his book...

"My muscle power and endurance are as coins in my purse: I have only so many and they will buy me only so much. I must live within my means, and to do this, I have to economize: what do I want to buy and how can I buy it for the least possible cost."

Dr. Halstead defined muscle pain as pain that will subside with rest. Pain that does not respond to rest has some other origin.

His open sharing of his feats and foibles resonated with us all.

This was then followed by a short question and answer session. Most of the questions in the time allowed were about exercise and pain. Dr. Halstead said that exercise for some is just getting up and dressed, but for most others, he recommends a limited program worked out with a doctor or physical therapist with pps knowledge and experience.

During lunchtime we renewed acquaintances. Roger came up to me and thanked me for the reply to his email just a couple of months ago. He had done as I suggested and joined APPA, started to get more help with his condition and was thoroughly enjoying the conference. It is so nice to meet the faces behind the words on the screen. I spoke with Dr. Gawne, Dr. Leslie, Myrna Whittington, Jo Caywood, and Phillippa Eckert. Professor Jack Smith, a Medical Librarian, from the University of Alabama, who has been in contact with Len Van Zyl and myself drove over from Birmingham Alabama. We also had opportunity to view the stands of mobility aids and local organisations. There is never enough time to do all the talking we want to.

After lunch Dr. Halstead told us a little about

current medical research, although sadly funds for research are hard to get.

A. Brain Fatigue

Dr. Daria Trojan and others at the Montreal Neurological Institute doing research with ten patients with fatigue have found neuronal loss in the brainstem but not elsewhere for ↓N-acetylaspartate/creatine ratios versus normal controls.

A Modafinil Study to treat brain fatigue is starting in the Fall of 2002 in five centers. It is a central nervous system stimulant that is used to treat narcolepsy, and MS and is double blind, cross over, placebo controlled.

B. Spinal Cord Pathology.

Gonzales H, et al Stockholm 2002. Has found an increase in cytokines in cerebro spinal fluid in 13 post polio patients. The level found is similar to that found in M.S.

C. Potential New Therapies.

IGF1 was most studied in post polio patients with no major benefit.

Stem Cells. The breakthrough of the year in Science 1999. There are a lot of issues such as where they are collected from, e.g. discarded embryos, and most likely the patients own cells, or those from a twin could be used. Whilst this has been accepted in the UK, Japan Sweden, and many other countries there are political issues in the USA. Still its Research to watch out for, for polio and other conditions like Parkinsons, Spinal Injuries, Stroke, Alzheimer's, Corneal Disease, and M.S.

D. Bracing.

He also covered new brace technology with computer chips, which let the brace bend as needed - even enabling some of the wearers to run. This technology along with newly developed very light weight materials should be available in about two years.

E. The Polio Mouse!

Jubelt B. et al. SUNY Upstate Medical University.

We were surprised to know that they have now developed a Polio Mouse under the direction of Dr. Burk Jubelt and we look forward to learning

how 'they' deal with their PPS and any research that they want to test. One of the novel therapies being tested is with stem cells. A mouse infected with the polio virus will develop PPS in 6 - 8 months. Perhaps through these studies, they will find out more about how the virus attacks the body, and what happens that causes the later decline in functionality. The majority of the work, to date, has been funded with private money.

Of interest, the one day conference took 13 days out of the month for Hilary and Richard. Day 1, to buy food for the 13 days. Day 2 to prepare food and pack clothes. Day 3 to pack computer, truck and rest. Day 4,5 to drive 500 miles to Atlanta. Day 6 Conference. Day 7,8 to drive back. Days 9 - 13 recovering. Day 14 go food shopping again. Many chores get left to do this, its either/or.

Finally here is another quote Dr. Halstead used from Hugh Gallagher.

"Growing older with polio is a matter of economics... How much limited expenditure of energy for how much satisfaction. Minimise the exertion, maximise the pleasure."

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Phillippa Eckert <REckert551@aol.com>

Reprinted from the Greater Boston Post Polio Association Fall 2002 Newsletter. <http://gbppa.org>

Ask Linda.
by Linda Wobeskya, M.S. P.T.

Dear Linda,

I've heard a lot of polio survivors have undiagnosed respiratory problems. I never needed to be in an iron lung, so I think I'm O.K. How can I find out for sure? Wondering in Weymouth, MA, USA.

Dear Wondering,

Many polio survivors do in fact have respiratory problems that may go undiagnosed. Polio survivors may be at risk for respiratory problems, regardless of the prior use of an iron lung. To understand the relationship between polio and breathing let's first look at the muscles we need to breathe. WE have muscles for inhaling (inspiratory musculature) and muscles for coughing (expiratory musculature). Weakness in either or both can lead to problems.

The main inspiratory muscle is the diaphragm. When the diaphragm contracts, it actually flattens, creating more space in the rib cage, which causes the lungs to expand. There are also small muscles between the ribs, called intercostal muscles, which aid this process by lifting or separating the ribs. If your inspiratory muscles are weak, the lungs may not fully expand with each breath. This problem can be increased by scoliosis, a common problem among polio survivors. Scoliosis, or curvature of the spine, changes the positions of the ribs and decreases their motion such that the actual size and therefore the volume of the rib cage is diminished. Scoliosis alone can cause respiratory problems, even if the inspiratory musculature is undamaged.

So one source of respiratory problems is not getting enough air in. Another source is not being able to exhale with force, or cough. Under normal circumstances, exhalation is passive. In other words, it does not require muscles. However, if there is anything blocking or irritating the airways, you need to cough to expel it. Coughing requires strong abdominal muscles. If you place your fingers on your belly and cough, you can feel these muscles working. A strong cough is crucial for keeping your lungs clear and healthy.

In the article Pulmonary Dysfunction and its Management in Post-Polio Patients. Drs. Bach and Tilton discuss the fact that many respiratory problems are missed because the symptoms do not seem respiratory in nature. Common symptoms are fatigue, headaches, anxiety, depression and nightmares. It is easy to attribute these symptoms to other causes. It is important to note that shortness of breath or difficulty breathing are usually NOT symptoms.

If you have any concerns about the health of your lungs, I recommend that you talk to your doctor or perhaps see a pulmonologist. I also recommend you take a copy of the Bach and Tilton article to your doctor. The article contains recommendations for evaluating and treating polio survivors. The article is available online the Lincolnshire Post Polio Network Library at <http://www.ott.zynet.co.uk/polio/lincolnshire>. The full reference for the article is Pulmonary Dysfunction and its Management in Post Polio Patients. Bach, JR, Tilton, Margaret. NeuroRehabilitation.8 (1997) 139 - 153.

Swallowing Problems.

Peter Ellis, Nepean, Ottawa, Ontario, Canada.
<ellispc@sympatico.ca>

Peter Ellis, a retired engineer and polio survivor whom I met after the Toronto PPS Conference has changed his email address. Peter has written up his problems/experiences/ongoing treatment regarding swallowing and is happy to share this with anyone. These articles are highly detailed and for that reason I decided not to include them in a newsletter, but have passed the information on to anyone enquiring. If you would like copies then please email, write or phone.

Hint, Tip or TitBit
CROCKPOT RECIPES ON THE NET.

<http://www.clark.sh/subs/>

scroll down to CROCK POT Recipes, write your eMail address in box to join the free eList and click on join.

NANA NEEDS A NAP - New children's book
written by a Polio Survivor Grandmother with PPS.
www.nananeedsanap.com

Yum Yum Cake

*2 eggs 2 cups of flour, 2 cups of sugar,
1 cup walnuts (chopped), 2 tsp. baking soda,
1 20 oz. UNDRAINED can crushed pineapple,
1 1/2 tsp. vanilla essence.*

*Mix together and pour into a greased and floured 9 x
13 cake pan. Bake 350* for 35-40 min.*

*Icing: 1 1/2-2 cups icing sugar, 8oz cream cheese,
1 stick butter - 4oz., 1 tsp. vanilla essence
1 cup of chopped nuts.*

Mix and spread over cake. Sprinkle with nuts.

Central Florida PPS Support Group Reception for Dr. Julie K. Silver.

[Our last newsletter included another groups report on Dr. Silvers Talk as I was unaware at that time that she would be speaking in Florida. Dr. Silver does not use slides so whilst the content of the talk is the same there are variations. There was also an extensive questions and answer session following the talk.]

J Ann Singleton, President of the Central Florida PPS Support Group welcomed all to the meeting and introduced Dr. Julie Silver. Julie is the Founder and Medical Director of the IRCP in Spaulding Massachusetts. Author of many articles and books on PPS. {Esperanza Boorman, one of our UK members whose daughter lives in Boston sees Dr. Silver when she is over in the USA]

The title of my talk is Polio Myths and Half Truths.

One of the first things asked of me, is how did I become interested in PPS. The answer to that is that my mother, her father and her brother all had polio. Polio was part of what we did each day, part of my life. Grandpa would sit in the car with us taking us out to lunch and ask us to look for the 'Paralysed Parking Spot'. It was many years before I knew it had another name.

During my training I had the great honour of working with Dr. Lauro Halstead, a polio survivor himself, and my knowledge of polio and its problems increased. Later at Harvard Medical School I mentioned I treated polio survivors and they came out of the woodwork. It is polio survivors that have motivated me. I have learned not only from my own family, from other health professionals but also from my patients and from polio survivors like yourselves. Every day brings more information to add to the pot.

One matter has caused me increasing concern and that is where I see statements that Polio Survivors should not take this drug, or not do this action. Some of these are not what I would recommend, and I call them polio myths and half truths. I would now like to correct some misconceptions. What medical doctors know and don't know and put this into perspective.

The biggest one. Exercise! A lot of people are confused about exercise. Which muscles should they exercise and for how long and how often?

This talk is for most polio survivors – there are always exceptions and it is for you and your health professionals working together to come up with a plan that fits your particular needs. However, Heart disease is more likely if you do not exercise. In fact not exercising can be more disabling, you can become weak from disuse. What we promote at our clinic is a good exercise program, with three components, stretching and flexibility, strengthening and

cardiovascular exercises. For cardiovascular training we recommend that you use your best muscles, that you do not use your weakest muscles.

We promote cross training. That is a variety of different forms of exercise so that you vary the program as much as possible. The idea is to use muscles in different ways. For instance if you swim then do not just swim front crawl, vary it with other strokes. Another day ride a bike or stationary bike.

I cannot tell you what is a perfect program as each of you will need a different plan. Whatever the exercise and level it must be non fatiguing. An exercise program is not doing a lot of walking, going up and down stairs because they are there. It is not daily activities, not running errands, not pushing a manual wheelchair. These are exercise but this is not a program. This is using the same muscles in the same way over and over again.

The regimen worked out for you will consist of a number of repetitions for a length of time and against a level of resistance. Alternating ways of exercising. There should be consistency in the program and the starting level will be worked out by your therapists. Increases in levels will only be introduced at your pace.

Daily activities should be limited to conserve your strength and managed by using aids and assistive devices. [This is extremely difficult if you live alone, or your partner less able, you have children at home, elderly parents to look after.]

Hugh Gallagher, polio survivor and author of *Splendid Deception and Blackbird Fly Away Wrote* - *"My muscle power and endurance are as coins in my purse: I have only so many and they will buy me only so much. I must live within my means, and to do this, I have to economize: what do I want to buy and how can I buy it for the least possible cost."*

Think about your day and the week ahead. What is really important to you. Write those activities down. These are the things you should spend your coins on. Grocery shopping, if you love it then do it, if you don't then have a delivery service. Cut back on what is not meaningful to you and do what you care about. Sitting to have a shower is not giving up. New showers in homes have seats and rails, my ten year old son always sits, if you suggested he should stand he would say why? It is all perception. If you love to stand to shower then that is fine, but if its tiring then try different seating to find something that suits you. Then you can enjoy your shower. If showering totally wears you out, then go visit the grandkids instead.

You do not have an infinite number of coins. You have to think what is best for you. Make a three day log of activities. Rate them as low, medium and high energy.

Colour them green, yellow and red. If you have a lot of red and not much green, then you need to make changes. Have more greens, less yellows and few reds.

When you pick a form of exercise to do then you must remember to look at all that goes into doing this activity. Swimming is a good example. Polio survivors often tell me that swimming is the best exercise. Florida has a lot of water, a lot of pools, warm weather and if that fits into your lifestyle then that is fine. However, you must take into account all the steps that you have to take to go and return from the swimming session. There are 13 steps – although I was told at a recent conference that I had missed one and that is Rinse off after being in the pool – so we are now at 14 steps. [These were itemised in the last newsletter]. Only one of those steps is the actual swimming exercise, the other 13 are actions to get to and from the pool, all taking energy tokens. If they take away too many of your energy tokens from your daily allowance then maybe swimming is not for you. Its fine if you want to do it, but it's a lot of work, so keep in mind what's involved. It's a great cardiovascular exercise but there are other ways.

[Editors note - Using this you can also look at other areas of your daily activities and think about how much energy you are going to expend doing them. Is the amount of energy it takes, coins from your daily amount, worth the result. It is very hard when you have always done an activity like mowing the lawn for 30 years to make the decision that it is time you got someone else to do it. It's your job, you have taken great pride in how good it looks, so you must keep on doing it, despite ending up exhausted and in pain. Look at your weekly log, this is a RED activity. Look at the greens, how many other things could you do in place of mowing the lawn. It is possible that the person who now mows your lawn is not doing as good a job as you did, BUT what is important is the quality of your life.]

Another myth is Medication. There are some articles in newsletters that state Do NOT take Statins for cholesterol because one of the side effects can be muscle weakness. Do they cause weakness? The testing that was done found that only one percent, the same as the placebo group, had muscle weakness. What is most important is to look at each individual situation.

Why is it being suggested that you take a certain drug? Because you have a problem that needs treating. If this problem is that you have a very high cholesterol and therefore you are at risk for heart disease, stroke then this is more important than your PPS. Together with your doctor you must weigh up the risk and benefit ratio. Ask your doctor about all the medications, what side effects can they cause. If you take a drug and you feel that it is not helping you, making you worse, or you have a bad side effect from it, then its time to be discussing this with your Doctor. Maybe taking a 'drug

holiday' to see what happens if you do not take it. Do not do this on your own as stopping drugs without advice can be dangerous. If that drug did not work then look at other drugs, other ways of treating the problem.

Questions and Answer Session.

Do we always recognise where the pain is coming from and why? I ask because I had pain in my neck and jaw, spasms and contractions, for some time. I put it down to PPS. I had myofascial release which helped short term but the problem continued. I never thought of going to the dentist. When I eventually went I found I had a bad tooth and now its pulled the problem has gone. I never recognised the pain I had as toothache....

A. As a general rule pps pain is muscle pain, burning and aching usually in big muscles and frequently at night. It is never associated with numbness or tingling. Lots of people are attributing all symptoms to pps and that is dangerous. Try and work out where the pain is coming from, what are you doing or were you doing before.

Q. My question is perhaps the same song but a different verse. Periodically I get burning deep muscle pain but this is always after a sugar load, after cheesecake, jelly donuts. If I stay away from dense sugars then its ok.

A. The sugar blues. 5 to 10% of the population have adverse reactions to sugar. If your self assessment has found this then 'no more jelly donuts'. [See article page 22 - 24]

Q. Statins, and the drug Lipitor. I had been taking Lipitor for at least eight months. I was losing capability rapidly. I came across a report about a side effect of this drug being muscle weakness and immediately stopped taking it and the losses slowed considerably. The tv commercials for this drug actually state if you have muscle weakness then talk with your doctor.

A. As I said earlier if you have a reaction from a drug then you must discuss this with your doctor and weigh up the pros and cons of taking it. You took the right action, what is your cholesterol level now and how are you managing it? R. I have managed it with diet being very cautious about what I eat. JS. All drugs list side effects and if you get a side effect then maybe this drug is not for you. Its fine to be educated about your medications, but remember to work WITH your doctor and weigh up the advantages and disadvantages.

Q. Are steroids harmful to the body, and could my loss of hearing be from polio damage?

A. No on loss of hearing. Oral steroids are very detrimental to bones and one of the big risks when taking them. At a medical conference today we had a lecture on osteoporosis which is a terrible disease. If

you are diagnosed with most cancers then you have a chance of surviving, but if you have a hip fracture and you have osteoporosis then you have a 25 to 30% chance of dying within the year. There are some new and exciting things coming out soon so watch out for them. In terms of steroids again it is discuss this with your doctor and weigh up the risks and benefits of taking the drug. Staying on them repeatedly is not a good idea.

Dr. Zilioli [local PPS doctor] – Injectable steroids are not as much of a problem. Q. How many shots can you have in a year? A. As a general rule, not based in real science, come up with three a year. It depends on where you are injecting, a joint, or a bursa. If a bursa then I can be more liberal, but you have to take more care with joints as steroids can be toxic to cartilage.

Q. Exercise, how many times a week, for how long, what is a general rule?

A. What we usually do is to alternate days. One day do strengthening with the legs and the next day the arms. In terms of how long, repeats, this has to be worked out with you and your physical therapist. If you do not have someone available then do not do anything to the point of fatigue. Stop before fatigue. One thing that has been shown is that even small amounts of cardiovascular exercise are beneficial. Five minutes is better than none.

Q. I have found an interesting exercise that might help others. I have always used diaphragmatic breathing. I lie on my back with two phone books on my belly for half an hour and do slow deep breathing and watch the books go up and down. JS. That's helpful, a good idea.

Q. If I was wanting to do pelvic tilts to strengthen my back but because of my severe scoliosis I can only do say 15 at a time is that ok. I have been told by my physical therapist that when working with abs that I have to get to a certain burn level. If I do it to that level then I am FRIED! Is it ok to do little spurts, is it still going to be of benefit?

A. Pelvic tilts are fine to do. Again at the osteo lecture today I learned that they have done some studies on elderly people who are very osteoporotic who cannot do a lot of exercise. An exercise worked out for them is to use an inflatable beach ball. Which means its easy to take with you as you can inflate it when needed.

You take the inflated beachball and place it against a wall and just lean against it or push against it. Its an isometric sustained contraction. For your neck just lean against it, for your hips turn sideways and push your leg out against it. There are many variations you can try. They have measured strength and bone density and both have increased. It's a safe way to exercise. Its very low level and it seems like you are not doing anything, but you are, it's a very gentle isometric contraction.

Q. If you are borderline osteoporosis should you start taking Fossamax – the once a week kind – Does that increase bone density or do you have to accompany it by weight bearing exercises.

A. Fossamax is one of the best drugs. It does not exactly increase bone density by making new bone, it decreases bone reabsorption so bones can increase in density and fracture risk decreases. Audience. What about the stomach problems you can get from Fossamax? JS. As I said before, discuss this with your doctor. If it causes you stomach problems then maybe its not right for you, but try it. There is a new study that parathyroid hormone injections may make new bone and that could be available soon, but again there may be some risks, so weigh the risk against the benefit. Audience. On Channel 2 a few weeks ago there was a report that the Space Coast have been testing something on astronauts but its not under trial for the general population. JS. I have not heard about that.

Q. What do you recommend for diet?

A. Generally we advise three small meals a day with two good snacks. Keep blood sugar level. [Article pages 22 - 24] High protein and low fat. Creatine 3g a day is good for the kidneys. Vit D and calcium.

Q. What is creatine?

A. Creatine has been tested in some conditions like ALS (Motor Neurone Disease) It looks like it maybe interferes with one of the mechanisms that causes cell death. Keeps motor neurones alive longer.

Q. I have a knob on my foot, does that come from pps or arthritis?

A..Spurs of bone are most likely linked to arthritis.

Q. What thoughts do you have on shoulder joint replacement, in shoulder that already has torn rotator cuff.

A. It all depends on the person. I would be worried about joint replacement in arms where people are using their arms to transfer, to weight bear. You cannot weight bear through a prosthetic joint. When doing a transfer you are using triceps, not rotator cuff. If you need to use your arms a lot then I do not advise joint replacement. If you can stand easily and do not need your arms to do this then it's a different situation.

Q. Vaccines. What is recommended for Infants Salk or Sabine.

A. The CDC [Center for Disease Control in Atlanta] now recommend 2 of Salk, the killed vaccine and then two of Sabine, the live vaccine.

Q. I have heard or seen that there can be an increase in breast or other types of cancer for polio survivors. Can you comment?

A. There is a study from a Japanese group that connected an increase in breast cancer in girls that had scoliosis. Response. Could it have anything to do with

the number of x-rays taken? JS. This is not my field, so I can't really answer this other than to say I do not know of any studies to confirm if polio survivors get more cancer than the norm, although this is a question that I am frequently asked.

Q. I have lymphedema and inject my leg once a month. Can repeated injections cause muscle damage?

A. I suspect that the vit B 12 injections are not a problem..

Q. Memory loss, do you have any techniques. What should we do so we go not get super spacey?

A. Get properly assessed, ensure you have your thyroid and blood levels checked. If you have any respiratory or swallowing problems or were in an iron lung you should have a sleep study done to see how you are breathing at night. Ensure that you do not push your daily actions to the point of fatigue, do the actions in sections taking short breaks. I hear many of you talk about the POLIO WALL, stop before you hit it.

Q. What about alcohol?

A. Avoid alcohol as much as you can. It is toxic to nerves. Too much can increase your risk of falling. It can make you tired and contributes to depression. Either do not drink or reduce the level.

Q. I have breathing problems, if I lay flat on my back I don't breathe. I also have swallowing problems if I am tired. I am concerned that not all docs and emergency room people are aware of enough facts about polio. I have had my life saved by respiratory therapists stepping in with advice on more than one occasion.

A. Swallowing. Basically we recommend that anyone who has swallowing problems is assessed for that and sees a speech therapist who can teach you a variety of tricks to help. My grandpa had severe swallowing problems and so far I have not seen any patient as bad as he was. I do recommend that you ensure that your family and close friends learn how to do the Heimlich manoeuvre in the event that you get food stuck and cannot swallow. Tricks that can be taught are things like relaxing the shoulders, tilting the head. If you have any problem like this then talk with your doctor, get properly assessed and learn the tricks that can help you. [See Peter Ellis information page 9]

Respiratory problems. If you are overly tired during the day, wake with a headache, snore badly, etc. then you need to have a sleep test to find out what problems you have. If your body is not getting enough oxygen, or not getting rid of the carbon dioxide then this needs regulating. These can be easily rectified by machines, Bi Pap, C Pap, etc. If you have severe breathing problems then it is important to get a lifeline that you can press in the event that you need help.

Q. I had polio at the age of 10 and was in an iron lung for three months, in hospital for two more. I had a very weak voice. After a year I led an almost normal

physical life. I was left with residual weakness on the right but only docs can tell that. I have severe swallowing problems. I now speak nasally all the time. I have slight lung problems. I have had some excellent advice on how to take pills, like putting them in apple sauce, and other tricks. I now seem to have less of a problem because I know how to manage it.

A. When you can't breathe or swallow you panic. So learn some tricks so that you can manage it. Relax and take your tensed neck and shoulders out of the equation.

Ann Singleton then introduced the meeting to Dr. Zilioli from Winter Haven, Florida, and to myself giving information about our WebSite and how to access it.

Hint, Tip or TitBit. Try relaxing each muscle in turn when you can't sleep at night. Jeanne, Annandale VA.

Active Isolated Stretching The Mattes Method

by Hilary Hallam - Lincolnshire Post-Polio Network

Carol Vincent of the Southern Hillsborough PPS Support Group told me that the Sports Medicine and Rehabilitation International Clinic not far from Richard's home in Florida had an excellent reputation and asked if I would go and see what the treatment involved. I rang and was immediately invited to visit and watch the work.

The Clinical Director is Aaron Mattes, MS, RKT, LMT. For 37 years, Aaron L. Mattes' training and education of functional anatomy and kinesiology provided a basis for his innovative therapeutic technique, Active Isolated Stretching (AIS). This has been incorporated into a therapeutic myofascial technique termed 'The Mattes Method'. This promotes functional and physiological restoration of muscles, tendons, vertebrae, ligaments and joints facilitating healthier superfascial and deep fascial planes. **The primary obstacle to flexibility is the tightness of the surrounding muscles and fascia of a joint.**

Medical articles in this and previous newsletters have advocated exercise for polio survivors, with the first emphasis being on stretching to retain good range of movement. We are told that more problems will arise with disuse of our muscles and joints causing us further deterioration. In the UK we have great difficulty in finding anywhere that will give us a multi-disciplinary comprehensive assessment, let alone treatment. When we are offered therapy many of us have found that the level and number of repeats we are expected to do has caused us increased pain and fatigue. The consequence of this can be that we stop exercising.

So far since my fall in 1988 I have been offered exercise therapy a few times, each only time 4 - 6 weeks. Until I found PPS and learned that I should not exercise beyond the point of fatigue I pushed myself hard trying to complete the numbers of repeats that I was being asked to do for each exercise. The overgrading of my muscles ability led therapists to believe that I should be able to do what they were asking of me. When I complained that it was too much, causing me increased pain and fatigue I was told that I was not trying, was being wimpish. Try harder. Many of you have told me that you have had similar experiences and how disheartening it is not to be able to do what you could only a few years ago.

Do we realise how much range of movement we are losing as we experience new weakness and unexpected functional decline? I certainly had no idea till this week.

Having watched Aaron and his other therapists working - and listening to two of the clients telling me that their improvement at this clinic exceeded all expectations - I

asked whether this form of therapy could be of help to polio survivors. Aaron said come tomorrow and I will get rid of the 'dowagers hump' on your back. Those words were on my GP's records and I hated them! Those of you who have met me will remember how round shouldered I am, and how very quickly the curve of my back increases as I walk, making me look more like a '99' year old than 55.

Nothing ventured, nothing gained. I went the next afternoon and Aaron explained that the stiffness of my joints was preventing me from using my muscles in an effective way. He also explained that anyone with weakness from a medical condition is started with Passive Isolated Stretching. This means that all the work is being done by the Therapist. Normally the action is Active, i.e. the person being worked upon is asked to start a movement and the therapist takes it just that bit further. This meant only a small amount of fatigue from an extensive therapy session.

First we need to understand the workings of the fascia. This is a three dimensional fibrous tissue that provides interconnections throughout all cells of the body. Fascia surrounds muscles, bones and joints, which gives our body structural integrity and strength. Being continuous throughout the body, fascia encompasses the sensory organs of the nervous system, blood vessels and lymph channels. Fascia also serves as an extensive water storage system. Oxygenation of the cells and tissues are regulated by the fascia. Furthermore, this fascial network facilitates the removal of our body's toxins. Distortion of the fascial matrix by trauma, aging, posture, hormonal or metabolic imbalances, injury and toxins disrupts the homeostasis of the body. These conditions left untreated promote detrimental contractures, inflammation, lymphatic congestions, peripheral vascular obstruction, hypertension and a host of other disease states.

The Mattes method incorporates a key concept, which states that only relaxed myofascial structures will allow themselves to be optimally stretched. Adhering to Wolf's and Sherrington's Laws, the Mattes Method facilitates optimal myofascial stretching of isolated muscles without activating a protective myostatic reflex contraction.

The Mattes Method utilizes a gradual stretch of NO GREATER than 2 seconds promoting full range of motion and flexibility without activating antagonistic muscle group contractions.

There are obstacles to optimal flexibility. Underlying medical or physical problems. Inflammation, neurological injuries and conditions can promote fascia, muscle, tendon, ligament and joint tightness resulting in contractures. Chronic abnormal posturing. Muscle imbalance, Effects of aging (and we age every second so we cannot get away from that). Aging promotes

atrophy with lost elasticity of muscles and connective tissue. Inactivity leads to further muscle weaknesses. Weaknesses lead to strength and flexibility imbalances between antagonistic muscle groups, which create adverse strains on the skeletal system and result in postural abnormalities.

As Aaron worked on me he told me exactly which muscle he was working. He first isolates that muscle by the way he holds you and then he asks you to move in a certain direction. Even though he is actually moving that limb or your head, he asks that you think 'doing it', as this helps your brain to learn the pathway. He extends that movement to its limit for two seconds and releases. Repeating actions a few times, changing to another muscle and then moving to the other side. Then he goes back to the first side and does the same movements again and I could see the increases in my range of movement in the mirror. See Photo 1, 2 on front page.

As an idea. If you hold your hand flat palm down and now try and lift your first finger. How far does it go up, 20 degrees, 45 degrees? If I told you that its optimum is 90 degrees I am sure you like me would say, 'No Way', but we are wrong. Now lift the finger again and with the other hand push that finger back a little further for two seconds and release, breathing out as you do this. What degree did it go back to now? It does hurt a little, but the pain is very short lived. Believe me I, and the other clients, were grimacing and making faces. However, today I noticed so were the therapists as they expend their energy to provide this therapy. See Photo 3.

I am sure you can guess by my writing about this therapy that I have had some good results. My first session was one hour forty minutes. I can hear you say, I could never have done all that time, but remember I was not doing most of the work, it was Aaron who was moving my limbs for me. Passive Isolated Stretching. If I had felt at any time that the therapy was not doing me any good or could cause me problems I would have stopped it.

However, I could see the range of movement increasing and I could feel the stiffness loosening. At the end of the session I was asked to look at my back in the large mirrors. My back was straighter, my 'dowagers hump' hardly visible. I took a drink and could drain the can as I now had some neck extension - something I have not been able to do for 14 years. I left and got into the truck to drive home and was stunned when I turned to check behind me and did not need to hitch my body round to see. My neck goes far enough again! Later that night I put my arms behind me and I could reach up and undo my bra again, no more twizzling, thank goodness.

Ah! but I can hear you say what about next day I bet you ached. I bet you were exhausted. I slept very well, I

woke and gingerly stretched and then turned on my side and sat up, stood up, walked to the bathroom and back again, I did not ache at all. I was amazed.

About ten minutes after waking I sneezed a couple of times and another surprise. Before the therapy I had been going to visit my GP on returning to the UK as I was unable to cough or sneeze fully without considerable pain. It was almost as if I had lost all movement of my ribs intercostal muscles. Now when I breathe in and out my chest wall is moving again. The relief at not having to go through another round robin route for this symptom is wonderful.

Aaron explains with every breath in and out, the body responds in synchronicity with that movement. Muscles expand and contract pumping blood to the heart and pumping lymph throughout the body. Each vertebrae in the spine moves in synchronicity with the breathing cycle in order to maintain integrity of the spine and spinal cord. Remember the comment in the last newsletter about putting your feet up four inches above your heart a few times a day, also recommended at the Atlanta Conference. This was because the pump to get the blood with its waste products, toxins, etc from our feet back to our heart is our feet and lower leg muscles. If they do not work very well now then that pump is faulty. Getting your legs up will help reduce the burning pains that we experience when we have had our feet down too long.

Correspondingly, cranial bones make very small movements that alter the pressure inside the cranial vault promoting cerebrospinal fluids circulation. This proper cerebrospinal fluid circulation nourishes and provides optimal neurological functioning.

I returned from having a second session with more of my muscles being worked on. I never knew we had so many. I made the mistake of saying my right wrist was weak and for the next few minutes Aaron moved my wrist and fingers in ways I did not even know they could move. There are still some muscles that he has not worked on but that's for next time, he said with Glee. Aaron said that I had come in there like a large tornado without any wind! I was just one solid lump. I hate to say it but he is right.

Here is what he says about me. "Hilary walked into the clinic, a tall lady, almost my height and overweight. Immediately I noticed her kyphosis and what is most commonly termed as a 'dowagers hump'. I knew that I would be able to help and explained my work on two of my clients, a spinal cord injury and Parkinsons. Being honest, I could see that she was sceptical so I offered to 'get rid of that dowagers hump' which I knew would be something that she could not refuse.

Here is an idea of some of the ranges of movement that you should have (1), what she now has (2), and what

she had before I commenced therapy (3)
 These are the five I's of Active Isolated Stretching.

- Identify the specific muscle to be stretched.
- Isolate the muscles to be stretched by using precise localised movements.
- Intensify the contractile effort of the agonist muscles opposite to the antagonist muscles that are reciprocally relaxing and lengthening on the opposite side of the joint. Reciprocal innervation of the muscles to contract will also simultaneously reciprocally inhibit the opposite side muscle to relax and lengthen.
- Innervation. Reciprocal innervation (tissue signalled to contract) contracting action of a muscle or muscle group (agonist) which is neurologically encouraged to contract while the opposite side (antagonist) muscles are neurologically prepared to relax.

	1	2	3
Neck Extension	+50	+30	-10
Neck Lateral Flexion Right	60	30	5
Neck Lateral Flexion Left	60	30	10
L Shoulder External Rotation	145	105	60
R Shoulder External Rotation	145	115	70
L Shoulder Internal Rotation	85-90	85	45
R Shoulder Internal Rotation	85-90	85	10
L Shoulder Flexion	180	175	110
R Shoulder Flexion	180	165	130
Thoracic Extension	+45	+30	0
Hamstrings L	100	90	45
Hamstrings R	100	85	55

- Inhibition - Reciprocal inhibition reaction of a muscle or muscle group which is neurologically signalled to relax, while the opposite side (agonist) muscles receive nerve signal to contract.

I have rehabilitated thousands of subjects including famous politicians, entertainers, and hundreds of Olympic and professional athletes. I have worked over 175,000 clinic hours, which is equivalent to two people working a normal 40 hour week! I have treated people with all sorts of injuries and neurological conditions. I also lecture nationally and internationally.”

Words have not been invented that can express how grateful I am to Aaron for his treatment and time. I consider myself to be **very** lucky to have had this

opportunity to experience the treatment.

I believe this is the **missing link** between being correctly assessed for PPS and having an exercise plan worked out for us. If we have stiffened joints, muscles that could work but are being restricted, limited energy levels that reduce the amount of time we can give to exercise, then we need a plan that will provide the most effect for the expenditure of our energy. This method of opening up our joints, increasing the range of movement of our whole body, regardless of its ability, means improved circulation and better drainage of waste products and toxins and gives us greater flexibility to perform our actions of daily living. Now my body is loosening I have noticed that I can stand a little longer, get up from a chair a little easier, and for some actions can see a slight increase in the amount I can do per energy token. After fourteen years to see an improvement instead of continual steady decline is very heartwarming.

I know it is not going to be easy for us in the UK but Aaron has published highly comprehensive workbooks and videos, which can be ordered through his website. Ask your doctor/physiotherapist/massage therapist/etc., to contact Aaron for more information.

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POLIO - by Laurie Mitchell

When I was little I lay in bed and wondered what I did that was so bad I had to go to the hospital all the time where doctors operated on my legs and put them in casts and made me hurt so much I would lie awake nights to plot my escape but of course I could not get out of bed by myself and no one would help me but the nurses did bathe me and rub pretty smelling lotion on my back and change the sheets and bring me prune juice to drink but I still wanted to go home and that made me sad because my brother and sister taunted me about being crippled and made me cry but I guess kids don't know any better and now I am an old lady and my legs hurt again and I have a hard time walking and turning over in bed with no one to help and no one rubs pretty smelling lotion on my back and no one brings me prune juice to drink or change the sheets and I wonder what I have done that was so bad to make this happen again?

I wrote this piece several years ago when I was feeling particularly low. I hurt all over, couldn't get a decent night's sleep, and literally dragged myself through each day.

After living with the residual effects of Polio most of my life, post Polio crept up on me ten years ago, to change the rest of my life. As my mobility diminished, using first one crutch, then two, and after that a walker, I now depend on a motorized wheelchair to get around. I see life as constant change, requiring one adjustment after another.

On the wall of a rehab center, I remember a poster that said, "Don't let what you can't do keep you from doing what you can." Unknowingly, I've followed that philosophy all my life.

Thinking back, I feel I've lived my life in a murky state of denial. Having suffered Polio at the tender age of two, I grew up never fully acknowledging that I was so unique.

Through the years, I wanted to do what my friends did, but when I tried to get up on water skis, I didn't have the strength, and fell kathunk in the drink. When I tried to bowl, the normal stance of landing on the left leg resulted in a visit to my orthopedic doctor. Once, when friends and I went to the ice skating rink, I rented two pairs of shoes. Because Polio has resulted in one leg being shorter than the other, and one foot being two sizes smaller, I still wear two different size shoes. Could I skate on ice skates? No! My ankles caved in to let me down.

My favorite film stars were Fred Astaire and Ginger Rogers. Oh, if I could only learn to dance like Ginger! So I enrolled in a class of ballroom dancing, but never quite turned into that beautiful swan, gracefully gliding

around the mirrored room.

My efforts at extra curricular activities petered out. But I did marry and raise three children, even though surviving their teen years was a challenge. I also worked as a graphic artist for many years.

At age 62 my then-husband traded me for a younger woman. Undaunted, I was faced with reinventing myself. To rebuild my shattered self-esteem I enrolled in college to earn the degree that had eluded me during child-raising and working years.

I graduated at age 66 with a Liberal Arts Bachelor of Science degree. It didn't do much for me in the way of employment, but it did salve the pain of a late-life divorce.

The saga of my life's experiences reminds me of the story about the little bee. Aeronautical Engineers insist it is impossible for bees to fly, based on the ratio of wingspan to body. But bees don't know this and continue to fly anyway. A state of denial?

I've read that many Polio sufferers are over-achievers, that they live their lives in states of denial, as I have.

But now in my later years, I've come to terms with my disability (finally own up to it as a disability), and see it as an inner strength. I'm happy now to jet around in my Jazzy, red electric wheelchair (thanks to Medicare). I no longer think about having less than perfect limbs. I'm no longer embarrassed when people stare at me and no longer wince when someone asks me what is wrong, or why?

I've come to terms with who I am, and where I am, Polio or not.

© Laurie Mitchell - lauriem@acrnet.com
Bachelor of Science, Eastern Oregon State College,
1989 Business Administration, Psychology, Creative
Writing, Journalism, Art

Any member not on the Internet that would like to write to Laurie please send via our office and we will pass it on. Her family came from Lincolnshire many centuries ago which she says is a strange coincidence. If I hear back from her before I finish this will add whereabouts.

Marcia writes... Dear Readers and Friends,

In my last letter I talked about doing one unexpected, random act of kindness. This time I thought I would look at poliomyelitis caused by the West Nile Virus, a topic that has been in the news here in Canada and in the U.S.

West Nile Virus (WNV) is mainly found in birds and is spread by mosquito bites. A mosquito bites an infected bird, sucks up some of the virus along with bird blood and then squirts the virus into the next animal (bird, human, horse, dog, etc.) that it bites.

The WNV is a Flavivirus and is not related to the poliovirus. However, the genetic material of both WNV and Poliovirus is made up of RNA. What is important to know is that RNA viruses, like WNV and Poliovirus, have the ability to mutate or change their characteristics and to make new strains of the virus. We believe this is what happened in North America and why a minor illness can now lead to paralysis.

The WNV has been around for a long time and was limited to semi-tropical areas of the Mediterranean. In 1999 the first case of WNV was identified in New York City and the following three summers it spread across the U.S. and Canada. It probably will spread around the world. The most recent report of the Communicable Disease Surveillance Centre in London (June, 2002), says WNV has not been reported in the UK. However it is found in birds in northern Poland and Germany and these birds migrate to the UK so cases of WNV, either in birds or humans, may have occurred here but not been diagnosed.

The West Nile Virus in North America appears to be a new, more serious strain than the one that has been known in the Mediterranean region. It is producing cases of poliomyelitis with a frequency approaching that of the Poliovirus! *Poliomyelitis* is a medical term meaning "weakness or paralysis of muscles" and it can be caused by viruses other than the Poliovirus; in this case it is caused by the West Nile Virus.

Over 2000 cases of WNV have been reported in the US with at least 98 people dead. (To put this in proportion, keep in mind that the ordinary flu causes over 20,000 cases every year with 400+ deaths.) As in polio epidemics, most cases of WNV go undetected and the person develops immunity for life. 30% of WNV cases result in a mild, flu-like illness from which the person quickly recovers. However between 1% and 5% of people with flu-like symptoms go on to develop encephalitis. A large percentage of these people will develop some degree of muscle weakness that is, in all respects, identical to poliomyelitis caused by the Poliovirus. Iron lungs have been replaced by respirators and people are being left with weakness and paralysis of limbs. Doctors are now told to suspect WNV when

they see muscle weakness rather than Guillain-Barre Syndrome.

Since the symptoms of paralytic WNV are identical to those of polio, it is probable that these people are now at risk of developing Post "WNVPolio" Syndrome! In the case of polio survivors, major symptoms of PPS develop 30 or more years after the acute illness. It will be interesting to see if people with "WNVPolio" develop similar symptoms much sooner. We have always wondered at the relationship between aging and PPS - it appears we now have a vehicle to examine this question!

There is a major difference in poliomyelitis caused by WNV as compared to that caused by Poliovirus. With WNV, the people affected are mostly between the ages of 45 and 75 rather than under 2 years of age as was the case for the Poliovirus. Children do contract WNV but their immune systems are better equipped to fight off the infection and most cases are very mild. Older people, and those with compromised immune systems, are the people who develop WNVpoliomyelitis.

Symptoms of WNV develop 3 to 15 days after the bite. Most people won't notice any illness, a few will feel mildly ill. Unlike polio, people with WNV are NOT contagious; the only way to contract WNV is through a mosquito bite, or possibly through a blood transfusion or organ implant - but these are clearly not common circumstances.

There is a big push to develop a vaccine and it is expected to be ready for human trials within 2 years.

What does this mean for us? Well, it means that we need to avoid getting bitten by mosquitoes! It is the common *Culex* mosquito that is the major carrier of WNV. Everyone should take precautions such as wearing long sleeves and trousers outdoors, using insect repellent lotion, staying indoors during dusk and dawn (the optimum feeding time for mosquitoes) and using screens for your windows.

If you get a mosquito bite, don't panic. Most bites will NOT infect you with WNV. In Canada and the U.S. the number of birds infected with WNV is monitored and used as an indicator of how likely you are to be bitten by

.....continued at bottom of next page, 11.
New Project - Marcia and Eddie Ask - Nov. 2002.

Marcia Falconer and Eddie Bollenbach will be picking a different item each month and posing a question/asking for your experiences/etc. At the end of each month they will collate the information and present the results. These will appear first on our Members Email List. Any member who does not have access to the internet can either write to us, or if what you want to say is short then ring and our 'Phone Team' will pass it

on.

Firstly let me introduce them to you.

Marcia Falconer has a Ph.D. in cell and molecular biology. Her original area of specialization was that of the differentiation and development of nerve cells. More recently she did research in the field of virology using a virus quite similar to the poliovirus. She had polio at the age of 7 and PPS developed approximately 35 years later. Marcia is now officially retired but continues to monitor scientific literature concentrating on virology, the poliovirus and PPS. She and Eddie Bollenbach have published several papers in respected journals. They also conducted a survey on PPS and are currently working on articles related to this survey. Marcia discovered the Lincolnshire Post Polio Network website in 1997 when she experienced a sudden increase in the severity of PPS symptoms. She is a life member of the LincsPPN.

Eddie Bollenbach holds a BA and MA in Biology and Certificates in Holistic Health, Origins of Life, and Cryptogamic Botany from the University of Tennessee. He has worked as a lab researcher with organophosphate pesticides at the Boyce Thompson Institute for Plant Research and as a Field Researcher in Fungicide Research for Cornell University. Eddie has taught Microbiology, General Chemistry, Anatomy and Physiology, General Biology, and a number of other courses over 30 years at Northwestern CT. Community College in Winsted, CT. Currently he is Professor Emeritus in Biology after retiring from the College last June. Eddie has had PPS for 20 years and uses a power wheelchair to get around, and is a member of the LincsPPN.

Hello Folks: Every month we thought it might be productive and fun to pose a question to the Lincolnshire group about Post-Polio Syndrome. Members of the mailing list can then post answers back and we can assemble and evaluate them as a whole. This way, we thought, we could learn more about PPS and develop a valuable database.

This month we thought we would plunge into the area of fatigue. Some types of general fatigue caused by muscle overuse results in the sufferer having an elevated pulse at rest. Some types result in a pulse, at rest, slower than normal. We don't know what polio fatigue does in this regard. As far as we know nobody has studied pulse rate and polio related fatigue.

If, over the next month, you can take your pulse at rest when you are feeling ok and record it. And then if you overdo and feel bad with fatigue some day take your pulse again while you are at rest and report this to the List, we may be able to learn something about Post-Polio fatigue. We can compare the data set for the entire group and see what happens to heart rate during

PPS fatigue.

When all the information is in Marcia and I, along with members of the group, can have an on-line discussion and analysis of the results and what they may mean.

The best time to take your pulse is in the morning when you first get up. Count the number of beats for 15 seconds and multiply by 4. Use the illustration at: <http://my.webmd.com/encyclopedia/article/4115.11390> to help you find your pulse either in your lower arm or at the carotid artery in your neck.

We hope you feel this will be both interesting and worthwhile.

To help you record the results why not draw up a two column chart. Column 1. Pulse rate when you are at rest and feel fine. Column 2. Pulse rate when you are at rest but feel PPS fatigue.

Eddie Bollenbach and Marcia Falconer
<edward.bollenbach@snet.net>

continued from previous page.. Marcia writes...
a mosquito carrying the WNV. I don't know if there is a similar program in the U.K., but I would assume there is or shortly will be one. However we are in the age category where the most serious cases of WNV occur and the best precautions are to avoid getting bitten (as best you can while still enjoying life!) and knowing about West Nile Virus - which is why I've written this letter.

With kind thoughts to you all, Marcia Falconer

*If you would like to contact Dr. Falconer, she can be reached by email at: marcia.falconer@sympatico.ca or by regular mail at:
Dr. Marcia Falconer, 33 Abingdon Drive,
Nepean, Ontario, Canada K2H 7M5*

NAME THAT CHRISTMAS CAROL

- | | |
|---|--|
| 1. Bleached Yule | 12. Jehovah Deactivate Blithe Chevaliers |
| 2. Castaneous-colored Seed Vesicated in a Conflagration | 13. Red Man En Route to Borough |
| 3. Singular Yearning for the Twin Anterior Incisors | 14. Frozen Precipitation Commence |
| 4. Righteous Darkness | 15. Proceed and Enlighten on the Pinnacle |
| 5. Arrival Time 2400 hrs - Weather Cloudless | 16. The Quadrupeled with the Vermillion Proboscis |
| 6. Loyal Followers Advance | 17. Query Regarding Identity of Descendant |
| 7. Far Off in a Feeder | 18. Delight for this Planet |
| 8. Array the Corridor | 19. Give Attention to the Melodious Celestial Beings |
| 9. Bantam Male Percussionist | 20. The Dozen Festive 24 Hour Intervals |
| 10. Monarchial Triad | Answers page 23. |
| 11. Nocturnal Noiselessness | |

ALL I NEED TO KNOW IN LIFE I LEARNED FROM A SNOWMAN

It's okay if you're a little bottom heavy. Hold your ground, even when the heat is on.
Wearing white is always appropriate. Winter is the best of the four seasons.
It takes a few extra rolls to make a good mid-section.
There's nothing better than a foul weather friend. The key to life is to be a jolly, happy soul.
It's not the size of the carrot, but the placement that counts.
We're all made up of mostly water.
You know you've made it when they write a song about you.
Accessorize! Accessorize! Accessorize!
Avoid yellow snow. Don't get too much sun.
It's embarrassing when you can't look down and see your feet.
It's fun to hang out in your front yard. Always put your best foot forward.
There's no stopping you once you're on a roll.

RECIPE FOR A HAPPY NEW YEAR

Take 12 fine, full-grown months;
see that these are thoroughly cleansed from all
old memories of bitterness, rancor, hate, and jealousy.

Cut these months into 28/29 30 or 31 equal parts.
(This batch will keep for one year.
Do not attempt to make more than one batch at a time
many people spoil the entire lot in this way.)

Prepare one day at a time as follows:

Into each day,
put
12 parts of faith,
11 of patience,
10 of courage,
9 of work
(some people omit this ingredient
and spoil the flavor of the rest),
8 of hope,
7 of fidelity,
6 of open-mindedness,
5 of kindness,

4 of rest,
(leaving this out is like
leaving the oil out of the salad-don't do it),

Add 3 parts of prayer,
2 of meditation,
and 1 of well-selected resolution.

If you have no conscientious scruples,
add a teaspoonful of good spirits,
a dash of fun,
a pinch of folly,
a sprinkling of play,
and a heaping cupful of good humor.

Pour love liberally into the whole, and mix with vim.
Cook thoroughly in a fervent heat.

Garnish with a few smiles and a sprig of joy.
Then serve with quietness,
unselfishness,
and cheerfulness
and then a Happy New Year is a certainty.

from "Leaves of Gold"

Hints, Tips & TitBits.

I have to say I am slowing down due to more muscle fatigue. Have to rest a lot more - which, to me, is a waste of time - but not when it comes to maintaining every shred of strength. I have likened saving our polio strength to this:

For years, we polios were living on the "interest" money; now we are drawing on the "principal" - but we do not know how much "principal" we have left - so we have to be very careful not to withdraw too much at a time, or else we will end up bankrupt. So while I don't like the extra time I take for the rest, I know that I have to watch over my "bank account" of strength with a lot of diligence so I won't be bankrupt.

Who am I? My name is Viola Pahl, married to Fred Pahl. We have a married son with four grandsons, and a single career daughter who, after teaching in four different countries, is back in Canada to live with us. At age 22 in 1948 when I was seven months pregnant, I was stricken with polio. At the onset, I spent several weeks in an iron lung, and in the ensuing years, I use crutches and/or a wheelchair.

Life has been good to me. As a clergyman's wife, I was kept busy with entertaining, travelling, music, public speaking, and writing books. I worked in the offices of many government officials, including the Premier of the Province of Alberta. For several years I was a relief instructor at a college in the field of Business Administration. We are retired in White Rock, British Columbia, a small city two miles from the US border. From our condo we see the ocean, the Gulf Islands, the Olympic/Washington peninsula, and a view of magnificent sunsets. I enjoy e-mail correspondence, so drop me a line at: viola@pahl.ca

WebSites: Book information: www.pahl.ca/books
Photos: www.pahl.ca/fredandviola

Items of Interest to Polio Survivors posted on the Internet by Lili Guerry - sophia_7777@yahoo.com

SUPPLEMENTS MAY HELP MUSCLES

Patients confined to their beds may want to consider taking a nutritional supplement, as new research shows amino acid may lessen muscle atrophy brought on by space travel, prolonged bed confinement or immobility.

The University of Texas at Galveston enlisted healthy subjects to stay in bed and take supplements for 28 days during a National Space Biomedical Research Institute study. Researchers say results suggest an amino acid supplement can maintain synthesis rates and body mass. While it was studied in the scope of space flight, the data have implications for the elderly, kids with burns, patients in intensive care and those who have

had major surgery and are not very mobile.

METHOD COULD LEAD TO TREATMENT FOR SPINAL CORD INJURIES

Scientists have found how to direct the growth of nerve cells using a laser. The technique could provide a way to treat spinal cord injuries or to connect nerve cells for other purposes- poses, they said. By using low-energy laser light placed at the edge of growing nerve cells, the investigators nudged the cells, called neurons, to extend their appendages in new directions. "Small proteins within the cell that participate in growth would be attracted to this light, and would start drifting in the light's general direction," said Dr. Mark Raizen, physics professor at The University of Texas, Austin. The results appear in the journal *The Proceedings of the National Academies of Sciences*. Using the kind of lasers that dermatologists work with to remove tattoos and blemishes, the investigators changed the general direction of growth for most neurons tested and increased their speed of growth up to six-fold. They found they could even change the direction of growth by more than 90 degrees. In the future, the laser guidance technique may lead to semiconductors that include nerve cell components, or neural networks, that resemble structures in the brain, among other possibilities, Raizen said.

TRYPTOPHAN AFFECTS MOOD, MEMORY

If you have the urge to nap after Thursday's big Thanksgiving meal, it's because of a chemical in turkey that also plays a role in maintaining good mood and memory. Wlm J. Riedel and colleagues at the Brain and Behavior Institute at the University of Maastricht in the Netherlands examined the effects of the body's depletion of an amino acid called tryptophan on mood and cognitive function. Tryptophan, known for its presence in turkey and commonly blamed for creating the sluggish post-meal feeling, is a metabolic precursor to the chemical messenger serotonin. It also is found in milk, bread, cheese and bananas. Tryptophan depletion decreases serotonin levels in the brain, which in turn can lead to depression and other problems. Researchers say while the study does not offer a solid conclusion that eating more tryptophan will enhance memory or mood, it does indicate a possible connection.

LIFE AFTER POLIO (See chart on back page)

When Hilary Hallam asked me if there was anything helpful I might share about my polio experiences I struggled at first on how to be suitably positive. As yet, there are no “cures” for damaged muscle nerves, but on reflection, neither are there “cures” for aging. The best we can do is age at a slow rate. The same thing applies to polio. With that mindset here is something helpful that I can contribute.

First let me use an analogy. A glider has no power and sooner or later falls back to earth, but it can glide slowly and gracefully for a long period, or precipitously for a short period, depending upon the pilot’s skill. The same thing applies to polio; with care, skill, and a bit of luck, we can keep going for a long flight.

I had polio in 1949 when I was a 20-year old Royal Air Force pilot and went from being 100% fit to 95% disabled in about five days. Sound familiar? After two years of convalescence I was discharged from the RAF with 60% disability.

My residual disability gave me a probable advantage that I didn’t realize at the time. I was forced to have a sedentary occupation. For this reason I could not/did not unduly stress my muscles, and post polio effects came on slowly. I married my high school sweetheart and after going to night school for five years graduated in electrical engineering. I had a successful career in engineering research in the UK, and eventually emigrated to the USA in 1964 with my wife and three young children. I retired in 1993 at age 63 when I found it difficult to do the even the small amount of travelling that my job required. However, about two years later, I found a way to extend my ‘glide.’

In 1990, three years before I retired, I was diagnosed with type 2 diabetes, a disease that causes elevated blood glucose (BG) levels. Initially I did little about the problem, but my BG levels got worse, and so did my muscle fatigue. By 1995 I decided that at least I could do something about the diabetes. Over the next two years I read many books about diabetes, researched for ways to control blood glucose, and did hundreds of self-experiments. The solution for me became obvious; **don’t eat foods that rapidly convert to glucose.** Using that approach my blood sugar came under much better control AND I got an unexpected benefit. My muscles tired less quickly.

I tried to find the reason for muscle improvements, and found a possible, but unproven theory. During experimentation with various supplements I noticed that 10 mg/day of DHEA had little effect on my BG, but somewhat reduced the rate at which my muscles fatigued. Further reading of a scientific paper (2) showed that DHEA increases the amount of a hormone

called IGF-1 in the blood. That seemed like a possible clue, and one day I came across a research paper that to me suggested a relationship between muscle fatigue, blood glucose, and DHEA. The paper, titled “Cells That Die Too Soon.” (3) showed that **muscle nerve cells grow more slowly and die more quickly in a high glucose environment** AND the effect is mitigated by IGF-1.

I believe that DHEA gave me a minor improvement in muscle stamina, but the most significant factor was my improved BG levels. These results motivated me to **control blood glucose levels, not only to prevent the awful side effects of diabetes, but also to reduce the rate at which muscles tire.** I was pleased with my results and continued ‘gliding.’ But stormy weather was ahead.

About 18 months ago I developed a disabling disease called Polymyalgia Rheumatica, (PMR). It causes tremendous pain in muscles, especially neck, shoulders, buttocks, and legs. Fortunately it does not seem to weaken the muscles, however, I could barely lift my arms or get out of bed, and thought I was having polio all over again. It took a while to diagnose the PMR, but the treatment, I believe it’s the only treatment, is a hormone called prednisone. The prednisone is dramatically effective. In my case it practically eliminated the muscle pains in 72 hours and I was once again mobile.

Not surprisingly, there are trade-offs involved in the use of prednisone. It has some nasty side effects, one of which is to increase insulin resistance. This in turn increases BG levels and I found it necessary to add insulin injections to help control my BG, whereas previously I was controlling with diet alone.

I’m told that the PMR is self-limiting and will go away in two to six years, but in the meantime I take prednisone to stay on a good ‘glide path.’ My goal is to be one of the old polio survivors. I’m 73 right now and have a ways to go, but I’m working on it.

My contribution from all of this is to recommend that you check your blood glucose levels. If you are diabetic, then **control your blood glucose** by diet and whatever other means are necessary, as recommended by your physician. My dietary method is to eat only those foods that cause a slow increase in blood glucose. This includes all proteins, and carbohydrates with a low glycemic index.

The above discussion reflects my experience and opinions, but you should note that **I am not qualified in the field of medicine, and the comments I’ve made do not represent medical advice.**

Good luck and good ‘gliding.’
Derek Paice (DEKEP@aol.com)

References.

<http://www.mendoza.com/paice.htm> (More about the author's approach to diabetes)

(2) Morales, J. Arlene, et. al. Effects of Replacement Dose of Dehydroepiandrosterone in Men and Women of Advancing Age, *Journal of Clinical Endocrinology and Metabolism*, 1994.

(3) Feldman, Eva. *Cells That Die Too Soon* Diabetes Forecast, January 1997, pp 53-55.

See Chart from the front cover of his booklet on the back page.

Derek has kindly given us a couple of copies of his booklet - 58 pages - and also permission to photocopy extra copies.

Here is an idea of Glycemic Index based on fixed amount of available carbohydrate - NOT the amount of food.

Mercy Ships.

Whole-wheat bread	105
White Bread	100
Pumpernickel bread	71
Ice cream low fat	71
Milk full fat	39
Baked beans	69
Kidney beans	42
Soybeans	25
Pretzels,	116
Popcorn	79
Potato chips	77
Peanuts	21
Shredded Wheat	99
Special K	77
All Bran	60
Honey	104
Sucrose (table sugar)	92
Fructose (fruit sugar)	32

Polio Survivors
with Interesting WebSites, etc.

Life Member Jann Hartman
Jann's Pennsylvania Dutch Kitchen
<http://www.geocities.com/arojann.geo/pages.html>

Gwen Varga, BS, RN.

HTTP://home.earthlink.net/~celticwings
Wheelchair Weight Control
From a bodybuilder perspective!

Contact Member John Finlay
Mablethorpe Computer Services
for great prices on
Printer Ink Cartridges
and more
mabcomp@btinternet.com

Answers:

1. White Christmas
2. Chestnuts Roasting on an Open Fire
3. All I Want for Christmas is My Two Front Teeth
4. O Holy Night
5. It Came Upon a Midnight Clear
6. O Come, All Ye Faithful
7. Away in a Manger
8. Deck the Hall
9. Little Drummer Boy
10. We Three Kings
11. Silent Night
12. God Rest Ye, Merry Gentlemen
13. Santa Claus is Coming to Town
14. Let it Snow
15. Go, Tell It on the Mountain
16. Rudolph, the Red-nosed Reindeer
17. What Child is This?
18. Joy to the World
19. Hark! The Herald Angels Sing
20. The Twelve Days of Christmas Carols for the Psychiatrically Challenged

IN MEMORY OF JOHN BOWLES

We would like to express our grateful thanks to Bernice Bowles,
her family and friends
for the sum of £402.00 donated in memory of her husband John.

It is with sadness that we have just heard of the death of another member.
G.T.L. (Tim) Rose on November 16th.
His wife has asked us to thank everyone for their help and kindness.

Donations have also been received from Winifred Hyam, Graham Baker,
Olive Mowat, Stuart Murdock, M. Parin, Mrs. I. M. Meade, Jean Simm, Vic Gabriel,
Monthly donations come from P.M. Stokes-Smith, G & MA Thompson,
Sylvia Fortune, and G.N.A.L. Martin.

Bob Price from Jacksonville, Florida needs a special mention.
Over the years he has found us the donations to purchase a computer,
paid in all our US \$ checks and often added \$100 to the payment.

Substance Response Test - on front page of Diabetes and Diet: Type 2 Patient's Successful Efforts at Control

See article pages 22 and 23.

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'I think that your experiments on yourself and what you have written about them are a great service to
the diabetes community. Rick Mendosa, a journalist specialising in diabetes.'

