The Lincolnshire Post-Polio Network
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THE LINC-PIN

Issue No. 8 - November 1997
WebSite http://www.zynet.co.uk/ott/polio/lincolnshire/
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Promoting the Awareness

that Polio Survivors are experiencing
new medically noted
but otherwise unexplained symptoms
is of paramount importance
to the wellbeing of Polio Survivors
not only in the UK but around the World.

Every time we speak to a Polio Survivor,
and see the look of relief on their faces,
see their frowns disappear and hear the words,
'You mean I am not the only one,
other Polio Survivors are having the same problems,
there is a possible explanation for my symptoms,
I am not going barmy, its not all in my mind.
You have information that I can give to my doctor,
that might explain all this....
We know how they feel, 50% better immediately,
How do we know?
Because that's how we found out as well.

If you can help us in any way,
with introductions to anyone in the media
or medical professionals;
with practical help here in Lincoln;
with financial help by way of sponsorship or grants;
then please get in touch
and help us help the Doctors put the smiles back on
the U.K's 250,000

and the World's 12,000,000 Polio Survivors faces.

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*Remember the opinions expressed are those of the individual writer(s) and do not necessarily constitute an endorsement or approval by the Lincolnshire Post-Polio Network. Although it does not provide an endorsement, it is provided as a service for those seeking such information. **ALWAYS** consult your doctor before trying anything recommended in this information or any other publication.*

Lincolnshire Post-Polio Network

Seasons Greetings to all
(editorial)

So much has happened since our last newsletter its difficult to know where to start. I was still putting newsletters into envelopes on the way down to Gatwick Airport in the early hours of the 5th September prior to flying to the States, and if by any chance you did not get your copy, then sincere apologies and if you care to ring one will be in the post to you straight away. LincsPPN members not on the Net will find the story of my travels enclosed.

This newsletter contains more information from around the World and we hope you will find it informative. Our Web Site continues to grow, especially the Online Library. We would particularly like to thank a small group Americans for their generosity in providing finance for a new high spec computer to assist the LincsPPN in improving it's Web Site even further. It will be used by our Vice

Chairman and Web Site Administrator, Chris Salter, to automate and/or speed up many of the administration tasks involved in operating a web site. However, we still urgently need more donations to fund improvements in all our services including our Web Site and to cover day to day operating costs of those services.

For non Internet members we have included a complete list of all the full text medical articles currently in our online Web Site Library and will provide list updates in subsequent issues of the Linc-Pin. A small selection of those articles have appeared in past issues of our newsletter and we will continue to include a number of medical articles in each new issue. However, if you would like copies of any specific articles from our Web Site Library then send a large self addressed envelope with the appropriate amount to cover the cost.

US Bank Account and Treasurer - We welcome Denise Mealy from Ohio, USA to our Team. We now have a non-profit Dollar Account in the States and Denise has kindly agreed to oversee this account and will be liasing with Jean Tapper our UK treasurer. This will save us exchange rates for transactions where we need to pay in US$, and we are already receiving US$ checks as donations and for payment for Dorothea Nudelman's autographed book 'Healing the Blues' into this account.

The **Atlanta Post Polio Conference in the USA** was very good and I had hoped to do a report with this Newsletter but the Conference Tapes I ordered have not arrived yet. I did not take notes at the six workshops and two keynote speeches so as to be able to concentrate fully, and as with most Polio Survivors my memory is not what it used to be, and I need to hear the talks again to do them justice. Sonny Roller MA, and Dr. Fred Maynard of the University of Michigan gave the keynote speeches and Sonny - a Polio Survivor and Project Manager of the Wellness for Women with PPS Project - has kindly allowed us to reproduce her speech in this issue.

Canada - Sally Aitken from Polio Quebec has given us permission to use information from the recent Grand Rounds at the Montreal Neurological Institute and Hospital with Dr. Neil Cashman, Dr. Richard Bruno and Dr. Robert Miller and the Questions and Answer session with Dr. Cashman at their AGM.... **Australia -** we are now in touch with four PPS support groups.... **New Zealand**, Dr. Les Simpson has contacted us, see his article... **Finland**, Seppo Utrianen has contacted us.... and we have been contacted by doctors and polio survivors in **London, Canada, India, Pakistan, Italy......** letters and emails arrive daily. Come on English readers - Medical Professionals and Polio Survivors - lets here more from you please for our next newsletter.

Hilary Hallam

Let's Sleep With Our Nightmares and Follow Our Dreams

Sunny Roller, M.A.

Project Manager, Rehabilitation Psychology and Neuropsychology
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Keynote speech given at the Atlanta Post-Polio Conference,
"Been There, Done That, Movin' On" in Atlanta Georgia,
September 12-14, 1997

This presentation is dedicated to my Dad who passed away 2 days ago.

Good Morning. I'd like to begin by introducing you to the man who has been my partner in the post-polio experience for the past 12 years. Dr. Fred Maynard is my physician. He is the one who had to give me the desolate news in 1984 that I had post-polio syndrome and that there was no cure. Five years ago he faithfully saw me through the onslaught of a broken leg and 9 months of careful rehabilitation. He also dragged me through the transition from walking full time to using a wheelchair more often. But even more important, he taught me over the years that health means balance in my daily life and that my own creativity and flexibility were the two qualities that would help me achieve balance and wellness. His openness to new ideas - especially my ideas, along with his ingenuity and his compassion as my partner in wellness have made him the most influential person in my post-polio healing and growing process. I have asked Dr. Maynard to take part in my presentation this morning because as my physician-partner, his contribution to what I want to share with you is natural, essential and pertinent.

The title of our presentation today is "Let's Sleep With Our Nightmares and Follow Our Dreams." Living with polio for 40, 50, or 60 plus years has filled each of our lives with a generous supply of both nightmares and dreams. I believe that from time to time it is important for us to reflect on our very private nightmares and dreams, if we are to live an abundant and healthful life in the years ahead. As we take time consider this dual challenge today, thinking about following our dreams or being led by our hopes is one thing. We've been doing that successfully for years, but sleeping with an array of nightmares - now that is quite another thing! How could I suggest such a thing? Well, let's stop and contemplate. Maybe I shouldn't ask, but have you ever slept with a nightmare? Well, I'll tell you a secret, I've slept with a few horrible nightmares during the course of my adult life and I highly recommend it. It can be liberating, rejuvenating and VERY good for your mental health!

In order for you to more clearly understand what I'm trying to say, I'd like to share a children's story with you. You probably know it. It's called *There's a Nightmare in my Closet* by Mercer Mayer... (Editors note, Sonny then showed slides of the different pages)

"There used to be a nightmare in my closet.
Before going to sleep,
I always closed the closet door.
I was even afraid to turn around and look.
When I was safe in bed, I'd peek...
sometimes.
One night I decided to get rid of my nightmare once and for all.
As soon as the room was dark, I heard him creeping toward me.
Quickly I turned on the light and caught him sitting at the foot of my bed.
"Go away, Nightmare, or I'll shoot you." I said.
I shot him anyway.

My nightmare began to cry.
I was mad ...
but not too mad.
"Nightmare, be quiet or you'll wake mommy and daddy," I said.
He wouldn't stop crying so I took him by the hand
and tucked him in bed
and closed the closet door.
I suppose there's another nightmare in my closet,
but my bed's not big enough for three."

The late effects of polio started for me about 15 years ago. It was at that time that the monster that I called polio came out of my heart's closet and scared me half to death. All my life I had been running away from the nightmare. I was living in spite of my polio, not with my polio. As I was growing up with my nightmare monster called polio, my mom would tell me I was a normal girl who just walked a little slower than everyone else. She also told me that a wheelchair was not acceptable in our house. A wheelchair would make me feel sick and I was not sick. I remember as a

4-year old the unique stench of hot wet wool in the hospital those Sister Kenny hot packs. I remember the fear and pain when a nurses aid accidentally scalded my leg with one of those hot packs and I had to lie limp and take it because I couldn't jump away. I was completely helpless as [a] paralysed little girl under her outreached arms. I remember being accidentally dropped off a stretcher into a huge tank of water by the therapists and almost drowning at the age of five. I didn't want to swim again until I was in high school. I remember complex orthopedic surgeries when I was 7 ... when I was 11, 12, 13 and 14. Bedpan after bedpan after bedpan - cold, white enamel. Black cat gut stitches in my leg skin. Ether that made me vomit over and over. Mom and dad walking away leaving me to lie there in the bed sheets by the window week after week after week. They bought their first car so they could come and see me across the city. But I couldn't go home with them. They just left me there every time. I remember being trapped in the prison of those old inner city hospital buildings. And I had to take it. Rooms with white walls ... metal frame beds with side rails that were arbitrarily clanked up around me ... windows that looked out onto brown brick walls. I remember the hospital sound of long lonely boat whistles on the Detroit River as I lie awake gazing from my bed through the screen window into the dingy inner city night. I remember a little girl in the bed next to me who had been burned from head to toe. She was in agony. She screamed in such pain. A little boy had set her on fire as she was swinging at the playground. I never saw her face. I remember the creamy complected teenage girl with long shiny black hair who was forced to lie in the bed next to me stuffed into a hot, unmoveable, itching full body plaster cast all summer long.

In a book by Tony Gould, the voices of other children and adults with polio herald their old monsters:

> Jean remembers her experience as an 11 year old girl: "I was put in a bed on the second floor. A nurse came in and gave me a plate with spaghetti on it, and I was totally paralysed, except I could move my right hand and my left foot. And I could breathe all right. She said, 'We're not going to coddle you here. You'll have to eat your dinner. And I couldn't reach it. There was no way I could even get one strand of that spaghetti. I'll always remember that. And she came in and took it away.

As she grew into womanhood Jean describes another nightmare: "In this kind of culture - in most cultures - men like perfect women; they like their arms and legs to match. And that was quite a shock to me, because I still thought of myself as quite a catch! And yet I came out into a culture which gave me much more resistance. Right away, you knew where you stood with men and it was just devastating. I mean; it was terrible. And nobody ever talked to me about it, nobody ever said, 'this is what you should expect."

Lennie who got polio in 1944 mentions the hot pool therapy he enjoyed but the salt tablets he had to take: "Even today, more than four decades later, I still shiver at the mere thought of those salt tablets. Sometimes the hospital orderly would literally have to pry my mouth open to force me to swallow them. dreaded the nausea that the taste of salt inspired in me." He goes on to describe getting his first pair of double long-leg braces with a pelvic band: "At first, all I could feel, as I stood hanging like dead meat on the shoulders of John the Barber and Charley the Bracemaker, was a sudden surge of new consciousness, frozen for a moment, in a dark corner of my terror. The legs are dead, it whimpered, boring into some quiet alley of my twelve-year -old mind." In many ways, we were American children who suffered atrocities like concentration camp victims in the 1940s and 1950s.

That was during the first half of our lives. I recovered, went to college, taught high school English for 10 years and began to work on my Masters degree. Then, As a woman with the late effects of polio 30 years later in the mid - 1980s, with new pain, weakness and fatigue. I was reluctantly forced to return to a hospital building to see Dr. Maynard. I had to smell the old smells, witness the therapists and nurses and watch the sick people who were lined up in the hallways in wheelchairs waiting for their next treatment. I was compelled to face those old fears and nightmares of childhood. It was totally horrifying. I was told to use a wheelchair. God no! I was told swimming was the best exercise for me. How ironic! I was told that I had some fine skills to offer to other polio survivors, but I would have to come to the hospital building to work everyday and interact with the nurses aids and therapists. I had to return to my old prison. The thought was repulsive. But my whispering intuition told me I needed to do this ... that it was time to reframe my old memories from the vantage point of a reasonable adult. Old nightmares needed to be yanked out of the closet and intimately embraced. And as many of us continue to experience the late effects of polio there are a variety of new fears breeding ... I sometimes worry what will happen to me in five years? Ten years? Will I have to use a wheelchair full time? Will my right hand go dead from carpal tunnel syndrome? Will I develop sleep apnea? What horrible thoughts. But acknowledging these nightmares is my own calling to wholeness. It's me embracing all that I am and claiming it. I'm not running away anymore. Our fears are real parts of us that grow when we ignore them too much. I remember Dr. Maynard saying that it is important to acknowledge the fears and nightmares, but not get stuck in them! So I need to take time to pay attention to the monsters in my closet. Sometimes in my mind I take one nightmare out separately or in little pieces and set it beside me and I sit very still with it and I observe the creature in detail and see what it looks like, sounds like, even smells like.

I say to the nightmare,"Who are you?
Get closer and show your face!
Let me see where you came from! What gives you life? What's your name?
I think I'll call you Sherman!
What are you doing?
Are you a real fear or are you FEAR - false evidence appearing real?
Now that we're out of the closet and the room is bigger
I see you more clearly in the light.
Look! You're getting smaller
because you are simply a minor part of my whole life and I see that.
I can live with you!
You can't kill me! Sherman, you're like a tiny bug on the wall.
You can't destroy my happiness!
You're just another part of my life's tapestry and I can live with you.

When I really took a look like that at some of my nightmares I even saw for the first time many of their positive qualities and characteristics that I hadn't noticed as a child. Making friends with our past and current fears can help free us to pursue our dreams for the future. I remember 10 years ago, when I was going to my first GINI conference. I was petrified because I had never been with a large group of people with disabilities. I had spent my time running away from such encounters. As a teenager and young adult I would literally cross the street to avoid a person who used a wheelchair because I didn't want to be associated with the group in our culture called handicapped. I practically threw a friend out of my apartment one day when she suggested that I might want a job working with people with disabilities. But on a warm weekend in May in St. Louis, Missouri, I made myself leap braces and crutches first into that horrifying situation - a hotel full of polio survivors. After 2 days with hundreds of people who were like me in many ways and unlike me sometimes, I was calmer and saw things in a completely new light. Embracing this embarrassing fear offered me a huge freedom. I don't race to avoid myself and people like me. I have a choice to join in if I choose. And love it, if I choose! It's part of that coming to wholeness.

If we aren't wasting our time being haunted or scared by old nightmares, we can move on to the good stuff in life. We can put the negative behind us or at least next to us and we can say "we've been there, done that and now we're movin' on", at least for the time being. What are some of your fears? I bet we all have a few left in there. The nightmare of a doctor's examining table ... the threat of being abandoned ... having to wear a brace? What scares you? I'd like to invite you to use this conference as an opportunity to talk about and confront a nightmare or two. **Do what scares you!** Learn to manage those pesky nightmares! It can be done. It has been done! As Daniel C. Steere has said, "Life is very manageable. It is intended to be. Life is exciting and positive and rewarding. Life is the most marvellous tool God has created for you. Everything on earth has been put here at our disposal. God intends for you to use life. He wants you to take advantage of all the things he has put here, and to use them as resources and opportunities.

We have a wonderful array of resource speakers here who will give us new insights from their learned perspectives. Dr. Leslie will share information on fatigue and post-polio, Roberta Todd will discuss adaptations and innovations for easier living, Dr. Alba wants to share her expertise on breathing and sleeping well with you. That's just to name a few! We have an opportunity to discover the most recent knowledge in the post-polio field and then think about how to apply it. Dr. Maynard will discuss his paradigm called the life-course perspective[1] in his presentation tomorrow. His very relevant frame of reference shows us that we have always been adapters with our polio disabilities and we continue along that path even now as we grow older with polio's effects. Life is a never-ending series of adjustments and our highest priority must be to be flexible and adaptive. Adapting is one of the things we do best!

This month I turned 50 years old. This birthday for me has been a reflective one. I have grieved over past omissions and felt pride in many of my achievements. I thought about life before polio, after polio in my childhood and teenage years, and life with the late effects as I mature. I reflected on being part of the polio survivor population in America. I reflected on how some so-called scholars have referred to us as medical dinosaurs. I'm concerned about how so many physicians and therapists are inadequately applying the post-polio information that now exists in the literature. Because they can't seem to apply it, many polio survivors are still saying that they cannot find physicians that really know how to help. We still feel abandoned and isolated especially in many doctor's offices. I thought about the important legacy we will leave behind us that will forward all civilized societies - we started the disability rights movement opening doorways for moving and living more freely in the world, we are participating in medical research that will help generations to come, as polio patients we have been the catalysts for huge developments in the field of medical rehabilitation. We have provided many success stories for our parents, employers, physicians, teachers and clergy to tell.

I know that as I commence into the next 50 years of my life, it is my personal vision for the future that will direct me. What dreams do I want to work toward and follow now? What dreams are leading you along your way? I want to flourish in the years ahead! I want to feel economically comfortable and to be very mobile - no matter what that looks like. I want to contribute to my society and make a positive difference in the world. I want to love and help people. I want to be physically and emotionally close to bright, loving people. I want my friends to want to be close to me. I want to do the things I choose. I want to do the things that scare me and feel more free than ever. I want to be pain-free and to stay clever and creative enough to figure out how to get things done during the day - successfully. I hope to stay connected to a large number of resources - people and things. It was great to travel to India, Europe and New Zealand to teach about polio. I want to always feel that life is an adventure and that there is more excitement just around the corner. It was a proud moment when I quit smoking 8 years ago. I want to know more about what wellness is and how to incorporate it into my life. We are developing a program at the University of Michigan called "Wellness for Women with Polio: A Holistic Program Model." It is a research study to investigate what will help polio survivors optimize our health as we grow older with our disability. I want to live in a constant state of wellness. I want the personal power to grapple with difficulties and fears and know that I will come out a winner. But most of all I want to stay optimistic. I want enthusiasm and hope to be my minute-by-minute companions.

How about you? What are your dreams for the future? Have you any new ones? To accomplish and important task? To be a great grandmother? To travel to Alaska or South America? Have you written them down?

We're not done yet. We're never done. Each of our personal stories continue. How we play our story out is our choice and our responsibility. I say bring on the next monster! We know struggle and we know victory. We have created new knowledge about polio's late effects, when there was none 15 years ago, and merged it with established medical facts. Professionals have now heard of post-polio syndrome. Look around. We have created networks of caring friends and helping professionals. We have individually developed new adaptive skills and techniques in the past and know how to do that. We draw from the wisdom our past generously offers. We also leave behind the outdated and the useless. There is hope and there is help. We are smarter and wiser now than ever before. Remember that last line in our Mercer Mayer story?

"I suppose there's another nightmare in my closet,
but my bed's not big enough for three."

Look what Mercer Mayer shows us at the end of his story

> "There is always another nightmare to befriend, another fear to diminish."

I believe that we actually have the power to turn our monsters into genies and to help others based on our important polio experiences. Good things are waiting for us behind the next door.

Let's sleep with our nightmares and follow our dreams.

[1] *Dr. Maynard's article "Managing the Late Effects of Polio from a Life-Course Perspective", Ann NY Acad Sci 1995, can be found in our Library.*

Lincolnshire Post-Polio Library - Copy of above article with links to referenced full text and abstracts where available.

POST-POLIOMYELITIS FATIGUE WHERE IS THE LESION? THE CONTROVERSY - THREE POINTS OF VIEW

A REPORT OF A SPECIAL NEUROLOGY ROUNDS AT THE MONTREAL NEUROLOGICAL INSTITUTE AND HOSPITAL SEPTEMBER 26, 1997.

The origin of post-polio fatigue is controversial. Thanks to Dr. Cashman's initiative, there was a respectful discussion about the cause and source of Post-polio fatigue at the Neurological Grand Rounds of the Montreal Neurological Institute on the morning of September 26 attended by physicians, other health-care practitioners, students and a few members of Polio Quebec. The speakers were

Dr. Richard Bruno (Psychophysiologist and Director of the Post-Polio Rehabilitation Research Service, Kessler Institute for Rehabilitation, New Jersey Medical School) spoke about the role of cerebral abnormalities on post-polio fatigue.

Dr. Neil Cashman (Co-Director of the MNIH Post-Polio Clinic with Dr.Trojan)

Dr. Robert Miller (Chair of the Department of Neurology, California Pacific Medical Centre) who flew in for the occasion.

A lightly edited resumé delivered by Dr. Cashman at Polio Quebec's Annual General Meeting the following day appears below for those who were unable to be with us or who would like to "hear" it again.

"Post-polio fatigue is probably the most common and certainly one of the most disabling symptoms that occur after polio. There is a great deal of controversy in the field as to what is causing the fatigue. The stakes are very high, because if we were to understand what is causing the fatigue then we could design a treatment or therapy that would help counter it.

"Dr. Bruno has spent a great deal of time working on an idea prompted by early pathological studies done by David Bodean who did post-mortems and found that an encephalitis existed in the brains of people who had acute polio. Because about 10% of those who had polio actually died from the illness, their brains and spinal cords could be examined to try to figure out what the polio virus was doing to the nervous system. We all know that the polio virus affects and destroys motor neurons, or motor nerve cells in the spinal cord and in the brain stem. This is what accounts for weakness and muscle atrophy. What the original investigators were finding, and Dr. Bruno has capitalized on this, is evidence of destruction of nerve cells outside of the motor system. One area that is commonly affected in people who have had polio is the reticular formation, i.e., a group of nerve cells that seem to support consciousness, so to speak. Dr. Bruno has taken this and said - what if there is a post-polio syndrome of the reticular formation, and how would that manifest itself? Dr. Bruno's theory would present as a disorder in arousal, retrieval, attention, and it may account for some of the troubles people have with concentration, with memory and with fatigue. This is the crux of Dr. Bruno's argument that, in fact the fatigue that people with PPS have is actually brain fatigue - nothing to do with the nerves and muscles. Rather it is a disorder in concentration and memory. He presented some data that suggests that medicines such as bromocryptine that increase the function of the reticular formation can actually improve fatigue and attention in people with this type of post-polio syndrome.

'Then I (Dr. Cashman) added that, yes, there is involvement of other parts of the brain and the brainstem, but the obvious and clear area of involvement by polio is the motor neurons, and when motor neurons die, remaining healthy motor neurons sprout extra branches to try to supply the muscle fibers that have lost their branches in the polio - a great recovery mechanism for say 10 or 20 years, but ultimately the motor nerve cell which is designed to support approximately 1,000 muscle fibers may, after polio, support 10,000 muscle fibers. Eventually the motor neuron starts to say this is too much. I can't keep this stability up forever, and these extra branches begin to degenerate. This is not a motor neuron disease like Lou Gehrig's disease. It's at the other end of the motor unit - it's a terminal axonal disease. The evidence we have of this is from muscle biopsies and a number of electrophysiological tests. We're certain - I'll put it that strongly - that there is degeneration of terminal axons. Everyone who has done these sorts of experiments in the world, agrees there is degeneration of terminal axons in PPS. But Dr. Trojan and I have tried to take this a step further. When you think about it, a terminal axon is not normal one day and gone the next. There must be an intervening period of poor function - of disfunction. And this may account for some waxing and waning symptoms of PPS, like fatigue. What Dr Trojan and I have done over the past five years is to collect evidence that there is a problem with the function of the terminal axons. One of the things we found is that one of the defects - one of the ways the nerve terminals are disfunctioning is that they have decreased release of a chemical called acetylcholine. This chemical accounts for the nerve talking to the muscle. If there isn't enough acetylcholine, the muscle doesn't get stimulated and doesn't work properly - doesn't generate a force. So we have tried to increase the communication between the nerve and the muscle by giving a medicine that prolongs the effect of acetylcholine in the junction between the nerve and the muscle. This is the basis for the use of Mestinon. We believe we have good preliminary results to show that Mestinon does work, and trust this will be demonstrated in the report, to be released in November, of a large multi-centred double blind Mestinon trial. [*See preliminary report in NewsBites*]

"Dr. Miller, well-versed and very knowledgeable about post-polio syndrome and other neuro-muscular diseases, defines fatigue very tightly as a decrease in muscle strength with exertion and a return of normal function with rest. He argued that the fatigue in PPS acts more like muscle fatigue than central or neuro-muscular junction fatigue. He has done studies demonstrating the problem with the role of calcium in the muscle. Calcium is used to stimulate a muscle contraction, and if the muscle depolarizes without the release of calcium, then a good force isn't generated for the effort the nerve has put into it. He believes that all of these ideas about fatigue, whether it be central from the brain, at the neuro-muscular junction, or whether it is at the level of the muscle fiber itself, fail to explain the severity of fatigue experienced by people with PPS. His major idea for therapy of this type of fatigue is to engage in exercise. Dr. Miller believes that a great deal of PPS fatigue is due to deconditioning, and that non-fatiguing exercise, or even fatiguing exercise, can lead to an increase in strength and a decrease in fatigue. I find this a bit hard to swallow, (said Dr. Cashman) but given Dr. Miller's love to run marathons and sailboard in San Francisco Bay at every opportunity, I can see where he's coming from.... If you're tired you go and exercise....

"So, there are at least three camps when it comes to understanding fatigue. People are paying attention and doing a great deal of work to understand the underlying physiology of fatigue and post-polio syndrome. The debate has now been formulated. We'll see which theory prevails over the next few years. It could be that we're all right. It could be that some people have one type of fatigue and others another type. It could be that we are all wrong.

Video and Audio Cassettes (English only) are available of the Grand Rounds Contact Sally Aitken (514 932 6092) - or write the Association. In UK contact LincsPPN. Prices not available at time of going to press.

Lincolnshire Post-Polio Library - Copy of above article with links to referenced full text and abstracts where available.

DR. NEIL CASHMAN ANSWERS MEMBERS' QUESTIONS

POLIO QUEBEC AGM - September 1997

1. Have you ever considered what the chiropractor can do to help the pains and the general condition of the spinal cord?

A. I now feel that chiropractic manipulation may be good for some especially if they have acute lower back pain. A chiropractor may even give quicker relief than a traditional doctor in certain cases. But I am very worried when people get their necks manipulated. I've seen too many accidents in this context - nerve roots being pinched or torn - actual damage to the spinal cord or brain stem. I still cringe when there is talk about neck manipulation.

2. (a) When do you decide to prescribe Mestinon to a patient?

A. We think that Mestinon helps with severe generalized fatigue and also with muscle fatigability. Exert yourself, walk the length of a mall, and you may have increased weakness and have to sit down to recover your strength. These kind of symptoms seem to be helped by Mestinon. We think Mestinon improves the communication between the nerve and the muscle. First of all we advise non-medical ways of treating fatigue: activity planning, changes in life-style. If those don't work, we consider trying Mestinon. Even if we prescribe Mestinon, we find only about 60% respond to it well, so we don't have a predictive test as to whether a person will respond well or not. When we have exhausted non-medical ways of treating fatigue, we try Mestinon.

2. (b) Is general fatigue a criteria for the use of Mestinon, or is it more for weaknesses to legs, arms or for pain?

A. There's no physiological explanation for it to be effective for pain. Mestinon might have other uses than just for fatigue, but at present, we're not smart enough to know how it works, or whether it can work for pain.

3. Has there been any research/invest into alternative medicine techniques either using herbal remedies or other healing techniques (Qi-gong)?

A. The use of alternative medicines is a matter of choice for the individual. Although we can't cure post-polio syndrome, we believe we can treat some of the symptoms. Be sure you have good advice before taking them so that you avoid hurting yourself physically or financially. Remember that nobody has the cure for post-polio syndrome.

4. Do you recommend taking extra Calcium or Vitamin E for PPS?

A. The trouble in the muscle is inside the muscle. It's not due to not enough calcium. It's due to the muscle cell physiology, so extra calcium wouldn't help there. However, there are reasons to take extra calcium, i.e., for osteoporosis and health in general, but not for post-polio syndrome specifically. As for Vitamin E., it is a different story. It is a very potent anti-oxidant, and there is apparently no toxic dose of this vitamin. So it is safe to take several hundred units a few times a day. It won't hurt you. Perhaps it will help. At least there won't be a side-effect.

5. Should a PPS person do conditioning exercises, sub maximal exercises or maximal fatiguing exercises, or all three?

A. The role of exercise in PPS is hotly debated at present and is being researched actively. We used to say that any exercise to the point of pain, muscle cramps or weakness in the muscle was too much and that it might actually accelerate weakness in PPS. At this point there are people under carefully controlled research conditions (e.g. Dr. Agre in Wisconsin) who have been able to show that even fatiguing exercise can result in an increase in strength with time. The conventional wisdom is "don't push, it may make things worse." But there are some cracks beginning to appear in the conventional wisdom. As for specific advice, do NOT exercise to the point of cramps or pain or weakness unless you are under some carefully controlled research environment. There has to be a happy medium between some form of activity and over-exertion. And for the time being, I think it is best to stay in that happy medium. Don't just sit and do nothing!

6. What are your thoughts about CPAP?

A. This is a non-invasive machine to assist breathing, especially at night. It can be used if there is a profound weakness of the respiratory muscles or if the patient has sleep apnea.

7. Elaborate on the role of free radicals in PPS?

A. Tough question which would take pages to explain and my answer is based more on an idea than on very specific knowledge. Motor neurons appear to be very sensitive to the effects of free radicals. A free radical is a molecule that can oxidize things in the cell, e.g., lipids, DNA and proteins and make them not function properly. We found that the motor neuron generates a pulse of free radicals when it is about to die. If one can block the action of free radicals then you can prevent or slow down motor neuron cell death. I have wondered whether there is a similar effect at the nerve terminal which is where we think the action is in PPS. What we think is happening in PPS is that the hugely enlarged nerve "tree" with 10 times more branches than it was supposed to have undergoes a loss - a sort of breakdown or PPS pruning. This loss of terminal axons over time after polio, and why these degenerate is not known at present. A possible mechanism for degeneration. involves free radicals that they be oxidizing the lipids and proteins in the nerve terminal. It opens the possibility that some anti-oxidant medicines may prevent or slow down the loss of terminal axons in PPS. Something as simple as Vitamin E, for instance, might slow down the loss of nerve terminals in PPS and other related diseases. More work needs to be done.

8. Does the [Canadian] government recognize PPS? Has any progress been made towards getting compensation for PPS?

A. Yes. We have been able to have people declared disabled with post-polio syndrome. But applications for compensation seem to be automatically rejected, requiring the appellant to go to appeal. If you decide to opt for disability with your doctor, expect a battle of between 6 - 12 months, if indeed you succeed.

9. Given that weight control is a problem when mobility is reduced, what advice would you give given that weight loss is a twofold formula of fewer calories combined with increased physical activity?

A. The Polio Clinic, through Dr. Trojan at the Montreal Neurological Institute and Hospital, can refer you to a dietician, a physiotherapist and an occupational therapist. Together they can recommend an appropriate diet and exercise program.

10. Is there anything new to relieve the feeling of coldness due to polio?

A. Just as there are many reasons for post-polio fatigue, there are dozens of reasons why people who have polio may experience cold in their extremities, e.g., poor circulation, loss of muscle mass in a leg. Some reasons may be related to polio, but not necessarily so. I have been doing some work which is not yet published showing that when one gets nervous or tired or something similar, there can be prominent constriction of the blood vessels which causes a sensation of cold.

11. Are tendonitis and bursitis a sign of PPS? Are there short-term or long-term remedies? Is exercising recommended to regain strength?

A. These conditions are often the result of people overexerting for a long period of time. If arms are bearing weight or being used to get around in a wheelchair, they begin to complain.

12. What impact will Mestinon have on the heart?

A. Mestinon increases acetylcholine everywhere in the body; part of the rhythm control of the heart is due to levels of acetylcholine at a synapse of the heart. Too much acetylcholine in the heart causes a slowing down of the heart. This isn't dangerous; in fact it is barely noticeable. But people who have had heart disease, either myocardial infarction or a rhythm a abnormality should consult their doctor before embarking upon Mestinon therapy.

13. How old is your youngest post-polio patient?

A. Fourteen years old.

Audio Cassette (English Only) and Video Tape (English Only) of the above which includes Dr. Cashman's Annual Report and his resumé of the Grand Rounds on the three possible causes of Post Polio Fatigue are available by calling Canada 514 932 6092. In UK contact LincsPPN. Cost of audio-cassette - $; cost of video-cassette (thanks to Mansour Jabbari) - $ are unknown at the date of going to press. If you would like a copy of the Annual Report, please contact the Association. Sally Aitken aitken@accent.net.

Lincolnshire Post-Polio Library - Copy of above article with links to referenced full text and abstracts where available.

A GOOD IDEA - One we could take up

A member shared how she came to know about Polio Quebec. Her 12-year-old daughter received a report about PPS written by Dr. Cashman through her school nurse. This member then made her doctor aware of the work being carried out at the Montreal Neurological Institute and Hospital and was subsequently referred to the Polio Clinic. We thank our member for recommending that high school students receive information about handicaps and support groups. *Sally Aitken Polio Quebec.*

LincsPPN comment. We should also explore ways of getting young people to know about support groups for people with handicaps. This is a good idea, how about contacting your local schools and asking them if you can talk to the students about Polio, Post Polio and having a loss of ability. Let us know what you think. Would you be prepared to talk to the school nearest you, to the Scouts, Guides, or any group in your area?

If anyone would like to take up the challenge and talk to the School nearest to them, or to any local youth group, then please get in touch with us and we will send you some information that could help. Talks need not be long, fifteen minutes with time for questions afterwards is ideal. We have transcripts of talks already given. Contact Hilary.

* * *

MY GORILLA

I tried to go to work today, I tried my very best,
But, I awoke this morning with a Gorilla on my chest.
Sometimes he's on my chest, my legs and sometimes on my back,
I never know when my gorilla's going to attack.
In battle I've engaged him and thought that I had won,
Only to enrage him and then he had his fun.
Of taking my ability to run, to work, to play
Slowly I am learning that he always gets his way
So I have to learn to live with him And his banana breath
For if I try to beat him he'll Gorilla me to death.
My Gorilla's name is Polio, I've had him since an infant
And everyday he tries his best to make my life recumbent
If you have a gorilla seek help and seek help soon
For with help from doctors and friends, maybe he will be but a baboon.

Written by Edgar L Baker, Dayton Post Polio Group, OHIO
and given to Hilary when they met in Tipp City, Ohio.

A CREED TO LIVE BY

Do not undermine your worth by comparing yourself with others,
It is because we are different that each of us is special,
Do not set your goals by what other people deem important,
Only you know what is best for you.

Do not take for granted the things closest to your heart
Cling to them as you would you life, for without them, life is meaningless.
Do not let your life slip through your fingers by living in the past nor for the future.
By living you life one day at a time, you live all the days of your life.

Do not give up when you still have something to give
Nothing is really over until the moment you stop trying
It is a fragile thread that binds us to each other
Do not be afraid to encounter risks
It is by taking chances that we learn how to be brave.

Do not shut love out of your life by saying it is impossible to find
The quickest way to receive love is to give love;
The fastest way to lose love is too hold it too tightly;
In addition, the best way to keep love is to give it wings.

Do not dismiss your dreams,
To be without dreams is to be without hope;

To be without hope is to be without purpose.
Do not run through life so fast that you forget
Not only where you have been, but also where you are going.
Life is not a race, but a journey to be savoured each step of the way.

Author Unknown
Sent to us by Rev. Karen Utz, Pennsylvania, USA. popette@twd.net

* * *

Australia

"We" are the "Mornington Peninsula Post-Polio Support Group in Australia" and Deirdre and myself together with Vic Oliver and Maureen Smoker try our best to keep this group together.

We meet at the "Mornington Bush Hospital", courtesy of their Board of Management each month and generally have a good time whilst seriously discussing the post-polio problem. We have twenty-seven members at present, though not all attend the meetings. Quite a few pay their dues ($10.00 per year) and are happy to receive our newsletter each month. I try to incorporate something medical i.e. the latest information from Richard Bruno and others, mostly from the USA. Not a lot of research is done here on the Post Polio issue. I also incorporate the general chit-chat that goes on at the meetings and try to keep it light - no doom and gloom.

One of our regular members, Bruce Worme, who lives further down the Mornington Peninsula, is putting on a Christmas Lunch for us on the 7th December. He is providing a big piece of beef on a spit and all the ladies have volunteered to provide either a salad or a dessert. We are all looking forward to the "do" very much. We had a "Christmas in July" lunch at the local hotel last July which was quite enjoyable but the membership requested more social contact so this is our first event since then. We are planning a few outings to the local wineries here on the Peninsula, of which there are many, and I will do my best to stay sober. We still find it odd, after thirty years in Australia to have Christmas in the heat. We are experiencing a bit of warm weather at the moment, today is beautiful at 26 deg and we are expecting 34 deg on Wednesday. When it gets up to the 38 deg (100F deg.) mark it gets a bit much, but as we only live up the road from the beach this is not too much of a problem for us. (Eat your hearts out!)

One of our older Post Polls, Audrey Donehue, has recently undergone a total hip replacement operation on her "good leg". Her surgeon was very worried [about] how she would cope with it and said that she would probably be in hospital and nursing home for at least three months. Seven weeks later she discharged herself and is doing really well. Typical Polio A Type. Her surgeon had never operated on anyone who had had Polio before so he was very relieved at her quick recovery.

Deirdre has helped me by typing this for me as she is a much quicker typist than I am, so I am going to volunteer to wash-up after dinner. (He said "No way" Hils, how about that for gratitude!!)

I will finish now and take this opportunity to wish you and all your group a Happy and Safe Christmas and Prosperous New Year.

Kind regards,
Dennis and Deirdre

Lincolnshire Directory [International/National/Local Support Organizations] - Mornington Peninsula Post-Polio Support Group

From Dennis Hurse Far North Queensland Australia...

Dennis has sent us the following information on a B&B near them which is 100% set up for those of us 'less able', Greg himself is in a wheelchair. Dennis says come visit and meet their PPS support group...

Koah Bed and Breakfast in Tropical North Queensland. Greg and Sandra Taylor offer two double guest rooms in the main house or unique fully self contained chalets with double bed, twin bunks, TV, fridge and ROLL IN BATHROOMS. They overlook native bushland and a large dam stocked with fish. Lot 4, Koah Road, via Kurunda, 4872, Far North Old. Tel/ Fax 070 93 7074 <koah@ozemail.com.au>

Kay Trevan in Adelaide
<ktrevan@adelaide.on.net>

Since April 97, I have bad pain in both lower legs, extreme fatigue, am sensitive to cold. It was 42C here yesterday (Adelaide, South Australia), and I needed to wear track pants. I have had tests: Xrays, CT scan, Evoked response tests, needles with electric wires stuck into my calf muscles, blood tests, MRI, and still no one can tell me what it is. I need to use a walking stick, and we are now going to buy a wheelchair, because I cannot stand or walk for very long. I am 52 and was a mature student studying 2nd year french at Adelaide University when I had to put a hold on this and now believe it might be PPS. Thankyou LincsPPN for putting me in touch with other PPSers in Australia, the internet is wonderful. I would love to correspond with others with PPS, so please write to me. UK members write c/o LincsPPN.

SNIPPETS FROM PPSers AROUND THE WORLD

Helen K Ferguson, Florida, writes
<hkf@tu.infi.net>

According to Gudni Thorsteinsson, M.D.[1], at the Mayo Clinic, urinary problems are not unusual, as well as intestinal problems. For many of us the muscles in that region have weakened/atrophied and our decreasing physical activities can lead to this for some people. For some of the ladies, there is the added strain that was put on the pelvic muscles when we were pregnant, which can lead to urinary problems even for the TAB. Aren't we lucky today that there are aids that help us through this and allow us to continue to be active?

Dr. Gudni Thorsteinsson latest article "Subspecialty Clinics: Physical Medicine and Rehabilitation - Management of Postpolio Syndrome", Mayo Clin Proc 1997;72:627-638, can be found in our Library.

Tom Walter in California writes
<Tomincal@aol.com>

Results of the survey conducted in the early '90s by Jonathan S Vordemark MD, FACS, FAAP, at Texas Tech in Lubbock have finally been published in a peer-reviewed journal in July, 1996, as reported on the MEDLINE service --

TITLE - Urologic manifestations of postpolio syndrome.
AUTHOR - Johnson W, Hubbard D, Vordermark JS
SOURCE - Journal Wound Ostomy Continence Nurs 1996 Ju1;23(4):218-23 UI-97056335 (Medline's "Unique Identifier" number)

The abstract of the article available for viewing online on the Internet is similar to the text made available from a talk given by Dr. Vordemark during the Second Texas-Oklahoma Post-Polio Symposium, September 21-22, 1991, at the Ramada Hotel of Wichita Falls before the study's conclusion -

> Polio survivors may develop progressive functional deterioration years after the acute episode of poliomyelitis, a phenomenon that has been described as Post Polio Syndrome (PPS). This syndrome has been reported to affect bladder function, but nature and frequency of bladder dysfunction in these patients has not been described.
>
> To determine the character and prevalence of bladder dysfunction among persons with a history of polio, we conducted a survey of randomly selected polio survivors.
>
> The survey solicited information on the acute episode of polio and the nature of late-onset neurologic symptoms that could be attributed to postpolio syndrome.
>
> There were 242 female and 88 male respondents to the study.
>
> Symptoms attributable to postpolio syndrome were present in 87.2% of female subjects and 73.9% of male subjects.
>
> Respondents with postpolio syndrome had a significantly greater prevalence of urologic symptoms than seen among respondents without postpolio syndrome, although no dominant pattern of voiding dysfunction was noted.
>
> The early onset of erectile dysfunction was more common among male subjects with postpolio syndrome than among male subjects without postpolio syndrome, and was usually before age 50.
>
> Genuine stress incontinence was seen in 36.3% of the survey population, with pelvic prolapse common.
>
> Sixteen women with postpolio syndrome underwent surgical repair for urinary incontinence, with a success rate of 60.5%.
>
> Bladder disorders are common among persons with PPS, but further clinical and urodynamic data are necessary to define the nature and magnitude of this dysfunction.
>
> Urodynamic evaluation is recommended in any polio patient being considered for surgery of the lower urinary tract.

Ginger Hastings writes
moonwolf@gowebway.com

Adjustment to a disability occurs in stages, and these stages are much like the process involved in grief and bereavement. Hanoch Livneh, Ph.D.. is a Rehabilitation Therapist and researcher/scholar, and has defined these phases as: **shock, anxiety, denial, bargaining, anger, accommodation and adjustment**. I won't go into the emotional content of each phase, but each one raises some very different emotions and is vital to the total adjustment process.

Polio Survivors are people who are in various stages of their adjustment process. Some in the early stages can no more "just get over it" than they can "just get over" having PPS; it is something they will have to work through and come to terms with. What may be seen by some as whining and complaining, may be a very necessary part of the initial healing process. Those who have already been through this and have reached accommodation or adjustment often don't remember what it was like for them in the beginning. At any rate, I see Post Polio Support Groups as places for all PPS-ers to process whatever stage they are currently in, and to receive support and feedback from both those who share their current situation, and those who have successfully adjusted to it.

I hope that you will share your experiences of how you have made any adjustment with all of us, from those who are new to PPS and still struggling with the denial and anger part of it to those who are now using aids, assistive devices and who have changed their lifestyles and improved their quality of life. It's not easy, but helping each other is what it is all about.

El Panadero (The Baker) writes
<EMPANADOS@aol.com>

Let's talk about falling down, and getting up again.... and how we deal with it. Maybe those who have never hit the floor and looked up in embarrassment can get a glimpse at what it feels.

When it happens to me, I immediately yell out, expletives included: "Who the '&^%$... dropped the ^%$@&* banana peel on the floor." While everyone around me unsuccessfully searches for a banana peel, taking their attention off me temporarily, I get up off the floor as my dignity and self-esteem struggle to return to normalcy. This line is somewhat more difficult to use when falling in the snow, but I use it anyway knowing that there will always be somebody who'll take your word for it!. Often down but never out....

England
British Polio Fellowship
New Chief Executive

Congratulations to Andrew Kemp on confirmation of the post of Chief Executive. On behalf of all Polio Survivors we wish him every success in this post.

"When God Created MOTHERS"
Linda Boudreau <sheralee@glinx.com>

When the Good Lord was creating mothers, He was into His sixth day of "overtime" when an angel appeared and said, "You're doing a lot of fiddling around on this one."

And the Lord said, "Have you read the specifications on this order? She has to be completely washable, but not plastic. Have 180 moveable parts....all replaceable. Run on black coffee and leftovers. Have a lap that disappears when she stands up. A kiss that can cure anything from a broken leg to a disappointed love affair. And six pairs of hands." The angel shook her head slowly and said, "Six pairs of hands...no." "It's not the hands that are causing me problems," said the Lord, "it's the three pairs of eyes that mothers have to have." "That's on the standard model?", asked the angel.

The Lord nodded. "One pair that sees through closed doors when she asks, 'What are you kids doing in there?' When she already knows. Another here in the back of her head that sees what she shouldn't but what she has to know, and of course, the ones here in front that can look at a child when he goofs up and say, 'I understand and I love you', without so much as uttering a word."

"You should scrap it and start over," said the angel. "I can't," said the Lord, "I'm so close to creating something so close to myself. Already I have one who heals herself when she is sick...can feed a family of six on one pound of hamburger...and can get a nine-year-old to stand under a shower."

The angel circled the model of a mother very slowly. "It's too soft," she sighed. "But tough, said the Lord excitedly. "You cannot imagine what this mother can do or endure."

"Can it think," asked the angel. "Not only think, but it can reason and compromise," said the Creator.

Finally, the angel bent over and ran her finger across the cheek. "There's a leak," she pronounced, "I told you [that you] were trying to put too much into this model.

"It's not a leak," said the Lord, "it's a tear." "What's it for?" she asked. "It's for joy, sadness, disappointment, pain, loneliness and pride." "You are a genius," said the angel.

The Lord looked sombre. "I didn't put it there."

Letters to the Linc-Pin

Margie Nelson in California writes

I am writing to you to first and foremost thank you for having this WebSite! My three sisters and I have lived with the devastating effects that polio has had on our dad (not to mention our mom!). Our dad contracted polio when he was 17 years old, and that was about 27 years ago. He was born in Nova Scotia, Canada, and was treated at the Halifax Infirmary. He was on an iron lung, and paralysed from the neck down, until a wonderful person came into his life (who became a very close friend) and encouraged him and helped him to learn to walk again. Unfortunately, his parents were only able to visit him once during this stay of one and a half years at the Infirmary (I think how devastating this must have been for his morale).

I am sure this is not a new story to anyone dealing with the unfortunate circumstances of having a loved one suffering from polio and its effects. We (my sisters, mom and I) all knew that post-polio syndrome was a reality before any Medical Doctors acknowledged it (and some still refuse to acknowledge it). Over the years we saw our dad unwillingly relieved of his ability to go for short walks, mow the lawn, drive the car, and after many years of his 'keep on going' attitude, he agreed (most reluctantly) as we did, that a wheelchair may give him more access to is home than walking could.

My most vivid memories of the effects of my dad's polio are of him 'falling'. The doctor said he had 'black out spells'. (So, why didn't he give his best efforts to rid my father of them - he only provided support when my father ended up in hospital). In my exasperation I can only quote a truly Californian expression, 'Whatever!' (as it makes no sense whatsoever!) I can't tell you how many times my dad fell and almost put his head through the TV, the glass table top, or something else that could have killed him. My mom and I would jump at any loud sound, as were programmed to respond to my dad's situations. Many times it was not serious, sadly, sometimes it was. Unfortunately, the doctors shrugged it all off, except until he needed surgery............

Perhaps if more health care providers had experienced this first-hand, they would not be so willing to so callously disregard it... My thoughts and prayers for all post-polio survivors and their families.

Marcia Falconer in Canada writes

I have read your newsletter(s) with great interest and much sympathy. I don't know if you are interested in a somewhat different story.

In the late 1940's my mother, father and I spent every summer at a church "camp meeting" in Pennsylvania. In preparation we hauled carpets, beds, mattresses, a chest of drawers, a table and chairs, a small kerosene stove and an old wooden ice-box to the camp meeting ground located in a small forested area. The furnishings were moved into a large (12' x 12') tent complete with a wooden floor and there my family would spend the next weeks socializing with friends, going to "prayer meetings" and enjoying the relative cool of the camp grounds compared to the sweltering heat of the city.

In the summer of 1949, when I was 7 years old, I became sick with a very high fever while we were at camp meeting. My mother took me on a 45 minute trolley car ride to see the doctor. I remember the ride mainly because the trolley car bell, which sounded at every stop, made my already bad headache intolerable. I don't remember the visit to the doctor but I do remember being sent back to the camp meeting in a taxi - my first time ever for a taxi ride.

After this I have no memory for many days. My mother said I cried a lot from pain in my back, arms and legs and I couldn't eat. Then there are two vivid memories. One is being too weak to get out of bed and so my father carried me from my small bed to the larger bed that my parents shared so that I could be more comfortable during the day. The second memory concerns a baby "potty chair". I was too sick and too weak to use a toilet, so my parents brought my old potty chair into the tent. It had wooden arms and by holding onto them I could move from the bed to the potty chair and lower myself onto the seat. This memory is still colored by the embarrassment that a 7 year old felt for being relegated to using a baby's potty chair.

As I recovered, but still was restricted to bed, my parents would tie the tent flap back so that I could look out and watch my friends playing. These friends could call to me from a distance, but nobody was allowed to be near me except my parents for two (or was it three?) weeks. I spent many long days sitting up in bed, playing with paper dolls and wanting to be out with my friends. Finally camp meeting was over and we returned to our house in the city. Now I was allowed up but I was quite weak and in fact, spent most of the day just sitting on the sofa. Eventually school started - I returned to second grade and things became normal.

So that's it. Except that I went on to university and studied biology. After graduation I worked as a technician in a laboratory where we used polio virus in our research. Before beginning my work I had to have a baseline antibody titer done in case of a possible accident with the polio virus. When I came in for the results, the doctor said "Oh, I see you've had polio." "Not to my knowledge." I replied. "Ah but you did - you have a high level of antibodies to strain 2 of the polio virus and low levels, as would be expected from Salk shots, to the other two strains.

In speaking with my mother, the only possible episode of illness I ever had that could possibly be polio was the one I described above. Still, aside from "weak legs and arms" during that summer, I never had an other effects. I had, I suppose, what might be classified as non- paratytic polio. And in my mind this was just a bit of curious information.

Now I am 55. I have a PhD in cell biology and I am a research scientist with my own lab doing work in molecular biology and virology. And some curious things have been happening. For the past 7 years, after physical stress, my right leg suffers from episodes of "drop foot" which cause me to stumble or occasionally fall. Similarly, after periods of stressful use of my arm - for example, canoeing, - my right forearm will be weak. These episodes have become a bit more frequent, last longer and/or they are incited by less stress. Numbness was never associated with these symptoms and although they regressed, the muscles always seemed to never quite return to the pre-stress state. I could mention other symptoms as well, but I prefer to think they may be related simply to growing older.

Over the past six months or so, the "drop foot" in my right leg has become essentially continuous and my doctor has prescribed an ankle-foot-orthosis which works wonders. It would be nice if I could fix the right arm symptom as easily. The major neuro-muscular diseases have been ruled out and I have "idiopathic muscle weakness with some atrophy". I mentioned PPS but the doctors are unfamiliar with it. I gave them some literature from sites on the Web but have had no "feedback" about the articles.

So there you have my story. It is my opinion that PPS may be causing my symptoms. I am still seeing doctors who have given me no other, real, alternative diagnosis. Curious isn't it? I wonder - are there other people like me, who have had non-paralytic polio and are now seeing muscle/nerve effects which are similar to those suffered by people who had obvious paralysis during their acute polio episodes? I would enjoy hearing from anyone else with a similar story.

GINI - International Polio Network
gini_intl@msn.com

Have a new CD-ROM available. *Post-Polio Syndrome: A New Challenge for the Survivors of Polio*. For additional information, copies, or literature about the late effects of polio, please contact: International Polio Network, 4207 Lindell Boulevard, #110, Saint Louis, Missouri (MO) 63108-2915, U.S.A. Tel. (314) 534 0475 Fax (314)534-5070.

Seppo Utrainen, Polio Association, Finland

Seppo Utrainen would like to introduce himself to us. He is on the Board of the Polio Association in Finland. A Polio Survivor of 1956 in Finland. He is 48 and married with two children and has an M.Sc. (Eng.) and since 1992 has run his own business as a Consultant.

Viola Pahl, Vancouver, Canada writes
Is this what they call at Hot Seat?

In 1977 was chosen along with other handicapped people, plus a doctor and therapists, to tour part of Japan. We were to visit rehab centers and share with staff and patients things we have in common. On a "day" off, we were at a posh resort. I wanted to have a bath (they had western toilets and bathtubs in this particular resort), but the tiled bathroom was icy cold. I could not find a thermostat. But as I was sitting on the toilet, I noticed a control switch and thought "Hey, heat at last!" I turned it on to the "hot" setting. Would you believe it? It was to warm the toilet seal - not the room. (Is that what is called a "hot" seat??) Now that's luxury, folks, sheer luxury! The closest thing I ever got to this was when I was in the hospital in 1948/9 with polio. In those days (maybe they still do it), the bedpans were often warmed before we used them. Just the same, I would have rather had the room heated than the toilet seat.

See our Library Book Catalogue for details of Viola's books GOLD IN LIFE'S HOURGLASS and GRANNY'S LOVE/HATE AFFAIR WITH A COMPUTER.

DO STIFFENED RED CELLS HAVE A ROLE IN PPS SYMPTOMS?

Dr. Les O Simpson, Dunedin University, New Zealand

My primary assumption (Simpson's Axiom) is that "Persistently impaired capillary blood flow is absolutely incompatible with normal tissue function." You should understand that red blood cells are about 8 microns in diameter while the average capillary diameter is about 3.5 to 4 microns which means that red cells must change shape to traverse a capillary system. So capillary blood how will be adversely affected by red cells with the reduced deformability which accompanies a loss of discocyte shape. The effects of stiffened red cells can result in the rate of blood flow being reduced to a point where the rate of delivery of oxygen and nutrients is inadequate to sustain normal tissue function. Physiology textbooks record that when a working muscle is deprived of oxygen it fatigues very quickly.

The availability of oxygen is reduced in anaemic states because there is inadequate haemoglobin to transport available oxygen to the tissues. Tiredness and general bodily dysfunction occur at high altitudes where there is a low oxygen tension. When episodes of low blood pressure (hypotension) occur there may not be a sufficient driving force to maintain flow in the capillary system. Because I have found in a number of chronic disorders associated with chronic tiredness (ME, MS, AIDS, Lupus, Occupational Overuse Syndrome) that there are changed red cell shape populations, I have proposed that the resistance to flow in the capillaries of shape-changed red cells may also result in inadequate rates of oxygen delivery to sustain normal tissue function.

As it seems possible that the health problems of post polio people could be a consequence of shape changed red cells I examined blood samples from 21 female and 10 male post polio patients. The results showed that 8/10 males had at least one abnormal value and the remaining 2 had high-normal values. A similar proportion of females (17/21) had at least one abnormal value, 2 had high-normal values and one had no abnormal values.

Dr.Liz Falkner of Masterton NZ, a polio victim, arranged for me to assess 75 blinded blood samples which included 29 samples from blood donors, with the remainder from post polio persons. It is relevant that in 1993 Chetwynd et al reported that 48% of 694 cases of post polio suffered from excessive tiredness, 30-50 years after suffering acute polio. While it could be expected that changed red cell shape could be involved in the excessive tiredness, in our study 31 of 46 cases considered they were "well" or "slightly unwell." Of the 2 cases who considered they were "severly unwell" one had a normal blood picture. Thirteen cases considered they were "moderately unwell", and 12 had blood changes typical of cases of ME and one had a normal blood picture. At the other extreme, of the 11 cases who considered they were "well with no symptoms" 10 samples showed changes typical of those with ME-type symptoms. Because of this unexpected disparity between reported wellbeing and blood results, the study was not submitted for publication.

Similar problems relating to perceptions of wellbeing were found in a study of subjects with ME who had been diagnosed at least two years before the study commenced. These chronically unwell people attended a meeting every 4 weeks for 40 weeks for blood sampling and there was a significant proportion who considered they were "well" when there were marked changes in their red cell populations. It was concluded that in the chronically unwell, individuals seemed to have lost the ability to recall what it was like to feel "well" and the term now meant that they were having a reasonable day. It seems possible that this could apply to post polio persons as well.

Because red cell shape changes are exacerbated by events which result in relapses (over-exertion, emotional upsets, anxiety) I believe that red cell shape through its effects on blood flow, is a significant factor in the health problems of post polio people.

With that conclusion in mind, I would like to explore the red cell shapes of a larger sample of post polio people. Because my work is unfunded, it would mean that volunteers offering a 3 to 5 drop sample of venous blood would have to pay seventeen pounds sterling or its equivalent for the test. If anyone is interested would they please contact Hilary Hallam at LincsPPN and she will pass on the information to me by email.

Weather Report for Christmas

Turkeys will thaw in the morning, then warm in the oven to an afternoon high near 190F. The kitchen will turn hot and humid, and if you bother the cook, be ready for a severe squall or cold shoulder.

During the late aftemoon and evening, the cold front of a knife will slice through the turkey, causing an accumulation of one to two inches on plates. Mashed potatoes will drift across one side while cranberry sauce creates slippery spots on the other. Please pass the gravy.

A weight watch and indigestion warning have been issued for the entire area, with increased stuffiness around the beltway. During the evening, the turkey will dinimish and taper off to leftovers, dropping to a low of 34F in the refrigerator.

Looking ahead to Friday and Saturday, high pressure to eat sandwiches will be established. Flurries of leftovers can be expected both days with a 50 percent chance of scattered soup late in the day. We expect a warming trend where soup develops. By early next week, eating pressure will be low as the only wish left will be the bone.

Richmond, Virginia, United States of America

Survey of Anxiety Symptoms & Depression among individuals with Post Polio Syndrome

Forms available from LincsPPN

The Department of Psychiatry of the Medical College of Virginia in Richmond, Virginia, USA is conducting a study on the incidence and severity of anxiety symptoms and depression among individuals with post polio syndrome. A survey will be sent to PPSers interested in participating in the study. One does not have to have experienced any anxiety or depressive symptoms to participate. Also, one does not have to have a formal diagnosis of PPS in order to participate. If an individual feels reasonably confident about having PPS, then that individual may certaily participate. This is study is being led by Dr. Rizwan Ali, senior resident in psychiatry and Dr. Henry Holland, Associate Clinical Professor of Psychiatry. Dr. Ali originates from Pakistan where the wild polio virus still exists, and he has a friend with PPS living in Washington, D.C. Dr. Holland is a polio survivor (1950) and has had PPS since 1990. He is essentially retired on a disability from PPS.

LincsPPN Editorial Note:
A selection of Dr. Henry Holland's posts to the SJU Polio Mailing List including biographical notes can be found in found in the "Dr. Henry Writes" catalogue section of our Library. They hope to have 500 PPSers from around the World to take part in this survey.... it would be nice to have representation from Britain.

STOP PRESS

South African Post Polio Syndrome Association has been formed by Priscilla Webster.

* * *

LINCOLNSHIRE POST-POLIO NETWORK
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