The Lincolnshire Post-Polio Network
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The LincPIN

The Lincolnshire Post-Polio Information Newsletter

Volume 2 - Issue No. 11 - June 2000

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Editorial by Hilary Hallam

I am in the last few days before leaving for the USA. This issue is 4 pages smaller than usual and published about 10 days early. The next issue will be a bumper issue with information collected from the trip and also published a few days early.

Complaints - We have realised that we cannot continue complaining about services if we do not inform the relevant authorities of the problems. We do understand - and personally - that to add the stress of complaining to the minefield of getting appropriate medical help does not help our condition. A member has courageously written a full report of her difficulties for her Health Authority in the hope that by detailing the situation it can be seen that most appointments were inadequate and wasting NHS money. A synopsis is provided on the next two pages. If you write or visit with your M.P. then please send a copy or ask that they contact our MP, Gillian Merron. The more MP's that are aware of our particular difficulties and that it is across the UK, we hope the more chance we have of improving the situation. Don't forget to include a copy for us, or write to us with the name of your MP and we will do a letter for you. Pages 4 - 5.

Main Article - Polio Above The Neck. This article has been included because we are getting reports from a few members that they are reliably informed by the health professionals they have seen - including neurologists - that the polio virus does not affect any part of the brain only the spine. There are other articles in our Library. It also gives important information on swallowing. Pages 6 - 9.

Secondary Article - Voice Care. This article has been given to us by Miranda Davis, Speech Therapist with the Speech and Language Therapy Services in Lincoln. Miranda has offered to learn more about Polio and PPS and help by giving talks and writing future articles. Pages 10 - 11.

Dr. Ali Arshad has given us the results of his survey on PPS mostly in the Leeds Area. We are often in touch and he tells me he has been giving talks in Yorkshire trying to promote the awareness of the condition. He also wrote an article in Yorkshire Medical from which we had a call from a 38 year old Registrar in an A&E Department who had polio as a child and had been looking for reasons for his new symptoms for 18 months. His 20 minute call ended with that's the best consultation I have had in years and then laughed saying "and you couldn't even see me". Pages 12 - 14.

Media Events - Two recent Lincolnshire media events. One is the 19 minute broadcast on Radio Lincolnshire. If you know someone with a computer and access to the Internet you can listen to it on our WebSite. A Transcript will be available later on. Pages 16 - 17.

Long-Term Medical Conditions Alliance - AGM and speakers - May 10th 2000. I attended this AGM in the heart of London and was impressed with achievement of this 10 year old organisation. Page 19.

Annual General Meeting - September 30th 2000. For latest information see the back page.

Neurosciences Forum with Lincolnshire Health Authority - A meeting was held on May 18th where I did a 15 minute presentation on Post Polio Syndrome and why we are having difficulty in getting correctly assessed and diagnosed. Much interest was shown by all groups in the fact the single one-off Manual Muscle Testing overgrades our muscle ability giving health professionals a false impression. It would appear that we are not the only condition where this will apply. At the last meeting I asked that all groups reported their ten top gripes as I believed they could be 80% the same. It came out at nearly 100% for the top three. The main issue that we have been trying to get across since we first approached the LHA in mid 1997 is statistics. The specification for Neurology that we discussed in 98/99 showed the top 16 neurological conditions with PPS, ME, Fibromyalgia and many others not included. The bottom condition was Myasthenia Graves with 7 patients when in fact we learned that day there are at least 114. We learned that Statistics used are the National

Figure divided by the population of Lincolnshire. At last we proved our point and Deborah James from the LHA will now approach the Primary Care Groups and ask them to put just one question to their members. How many of your patients have the following neurological conditions?

Roosevelt Warm Springs Institute for Rehabilitation PPS Clinic - With grateful thanks to Dr. Anne Gawne we will be spending two days meeting with her multi-disciplinary team, PPS Support Group and other Polio Survivors from other PPS groups driving across State.

GINI 8th International Post-Polio and Independent Living Conference, St. Louis, Missouri, June 8th to 10th 2000. On the 8th June I do a 12 minute summary following Dr. Gawne and her teams presentation on the roles of a holistic multi disciplinary team and on the 10th June Richard and I share the full presentation - Assessing our activities to more effectively manage our lives and provide the medical profession with information on the changes taking place - which includes audience participation. Another Lincolnshire resident and LincsPPN Member Peter Jay, the Voluntary Welfare Visitor for the British Polio Fellowship is also speaking. The majority of the speakers are medical professionals, so it's a great honour for two polio survivors from the UK to be given this opportunity for which we are both grateful.

PRESS RELEASE IN BRANSON, MISSOURI.

Reunion: Internet Polio Survivors will again meet in Branson for fellowship. Date: June 10-13, 2000 Place: Lawrence Welk Resort, Branson, Missouri, U.S.A.

TV program Monday 12th June 2000 with Steve Grant of the Newsteam. www.ky3.com Millie Malone and I will be representing the over 50 polio survivors and supporters present at this event. Polio epidemics were common in the mid 1900's. Even after the vaccine was developed many people contracted polio from the vaccine or because it had not reached their area of the country. After the vaccine was developed and many survivors recovered some or most of their mobility, medical professionals turned their attention to other diseases thinking this one was conquered. Survivors then started experiencing symptoms such as new muscle weakness, debilitating fatigue, muscle cramps and breathing problems. Even those thought to have mild cases of polio and some who thought they had a case of the flu came down with similar symptoms. After determining there was no other cause the medical profession determined these symptoms were the Late Effects of Polio or Post Polio Syndrome. No standard treatment was determined and not much was being done to help these survivors. In an effort to learn more about these new symptoms and what could be done, many turned to the Internet. A few email lists started where survivors could talk to each other. Through these lists survivors learned about the Late Effects of Polio or Post Polio Syndrome. By joining together they helped spread information to not only Internet users but also many others including medical professionals. Today there are several email lists and many web sites to learn about Post Polio Syndrome. One by-product of the email lists was meeting new people online. It was nice to share with others who knew what you were going through and friendships developed. Out of this came a meeting of the Internet Polio Survivors in 1999. This was such a success that it was determined to meet again. Although this Reunion will not be a conference much information will pass from person to person. The emphasis here will be on fun and fellowship.

Contact: Tommy Conrad, HC 3 Box 3695 Theodosia, MO. 65761
Tel:- 001-417-273-4335 Email:- tlcon@webound.com

We will also be meeting up with many Polio Survivors (some of them USA members of the LincsPPN) and PPS Groups and sharing information. This will be my fifth PPS Conference. Without which I would not have learned so much about the condition or been introduced to so many PPS specialists who freely give us of their valuable time when we contact them for information and who give permission to include their articles in the Lincolnshire Post-Polio Library, now over 100 articles mostly from peer reviewed journals.

Associaçao Pós-Pólio de Portugal. http://www.geocities.com/HotSprings/Resort/4652/ Antonio Cardoza Pinto from Portugal contacted us recently about the new Portuguese PPS Association and is now flying across for the GINI Conference and the Branson Reunion.

POLO SHIRTS with the new Lincolnshire Post-Polio Network Logo on them. David Clark - Snickers Workwear has kindly donated the cost of making the disc for these shirts They are white polyester cotton 65/35%, collar and 3 buttons, with a breast positioned embroidered logo of 13,500 stitches! Sizes available are S 34 -36, M 37 - 39, L 40 - 42, XL 43 - 45, XXL 46 - 48, XXXL 49 - 51 and are priced at £10 with the Logo on, and £13.50 if you wish your Christian Name to appear below this. Please send your orders and cheques, which include postage direct to you, to the LincsPPN.

Almost everyone who contacts us complains that they are not getting appropriate assessments, diagnosis, advice and treatment.

We have realised that if we do not let the doctors, hospitals, benefits agency, appeals service etc., know that we are unhappy with the services we are getting then nothing will be done to put the matter right. The main reason for not complaining is that we are already having a stressful time trying to get medical help and the correct benefits - or fighting to get them reinstated after they are withdrawn for no reason and more stress is not a road we wish to go down. We are also concerned that if we complain we will get less help as the complaints procedure is not to an arbitration service but to the main service provider. We have to address this issue if we want to see changes. There are many choices. You can write to a letter of complaint to the appropriate body and we suggest you copy it to us, your MP and Lincoln's MP, Gillian Merron. If you feel that this is too much for you to cope with then you can write to us, giving us permission to use the information in our quest to change the system for polio survivors and stop the waste of NHS and government money as we struggle through the minefield of getting appropriate help.

You are not alone, and one member has courageously written a full report for her Health Authority and offers us a synopsis for this newsletter. Her letter states:

> I understand why other people have declined to make their dissatisfaction official. I realise that by making these comments I may well be blacklisted from any future medical treatment or disability equipment. It is my personal experience that clinicians do not respond well to criticism and like to wield their considerable power to punish those who voice concerns, and so deter others from doing so. I did however feel that, with my multiple diagnoses, my comments might be of help to others to bring about better clinical care. Because we are not curable we seem to be written off, however, with appropriate clinical care we would function better, have an improved quality of life, and in consequence our long term management would be far more cost effective.

A Lincolnshire Post-Polio Network Members offers us a Summary of Clinical Diagnoses, Comments and Advice given to her.

I spent many weeks in bed with a variety of childhood illnesses including winter bronchitis. At the age of 8 I remember having different breathing problems during a long spell of serious illness. I was off school for a year and when I returned I had a doctors note 'Excused Games, no stamina'. I vividly remember the way I walked was ridiculed by many of my classmates. At secondary school I played in goal so that I did not have to run. My muscle weakness became more noticeable in 1981 and I started my search for a diagnosis. I found the Lincolnshire Post Polio Network in late '98. I had had a polio blood titre test done by my GP but the Public Health Laboratory said the results meant nothing as I had been vaccinated against polio when I was 19. However the results were sent to Canada and read by a Virologist who reported that I had had Type I Polio and been in contact with Type 2. My continual progressive weakness and symptoms remain unaddressed.

As well as cervical spondylitis, progressive muscle weakness, fatigue, swallowing and breathing problems, intolerance to cold and heat, etc, etc., I have recurrent severe pain at the top of my neck with associated drowsiness that puts me to sleep for days. By chance it was found that (usually, but not always) when a physiotherapist tries to relieve this pain with mobilisation of the neck at C2 (unsuccessfully), the muscle weakness, and some other symptoms, noticeably improve for up to three months. I have full range of neck movement and therefore wonder if something like scar tissue from an old neck injury is exacerbating my problems. I wished for this to be investigated and sought help. I did not get any help but I did get a number of diagnoses.

1982 CONSULTANT NEUROLOGIST.

Comment	Fluctuation of effort on both upper and lover limbs on testing.
Physical Examination	Undressed and very lengthy - a full range of tests.
Diagnosis	Cranial nerves are normal. Non specific changes on muscle sampling, probably not significant.
Advice	Reassure patient on findings.

1996 NEUROLOGY SENIOR REGISTRAR.

Comment	Letter sent to my GP. "No speech or swallowing disturbance" - (I had been reporting swallowing problems since 1992 increasing in severity also speech problems.)
Physical Examination	Undressed - adequate.
Diagnosis	Some sort of chronic fatigue.
Advice	Do a bit more each day and you will be back to normal.

1998 CONSULTANT RHEUMATOLOGIST.

Comment	None.
Physical Examination	Undressed - very brief.
Diagnosis	Fibromyalgia (although I did not fit the diagnostic criteria given to me of widespread pain in all four quadrants of the body for a minimum of 3 months and at least 11 of the 22 tender points, that were not tested.)
Advice	None.

1998 CONSULTANT NEUROLOGIST.

Comment	Letter to GP "I dont think well find a pain at the base of the neck."
Physical Examination	Undressed - brief.
Diagnosis	ME (although I did not fit the diagnostic criteria given to me of mental fatigue nor unpredictable fluctuation of symptoms from day to day).
Advice	None.

2000 CONSULTANT NEUROLOGIST.

Comment	"I have not read your notes". "Polio virus does not cause lesions in the brain." **
Physical Examination	Fully clothed - very brief.
Diagnosis	You do not have MS. You have arthritis of the neck and age. (Symptoms commenced when I was 39, and the left side of my body is the same age as my right).
Advice	"You should not read medical research because you do not have a medical degree." "You should not concern yourself with detail." "You should not try to treat yourself." (I replied no one else is attempting to do so).

2000 CONSULTANT NEUROLOGIST - Private appointment one week later.

Comment	"Polio virus does not cause lesion in the brain".** "You do not have extensive muscle wasting and therefore cannot have Post Polio Syndrome." (Wasting is not part of the diagnostic criteria.)
Physical Examination	Fully clothed - very brief.
Diagnosis	You have MS.
Advice	Walk 1½ miles twice a day. See a neurologist yearly. (The Multiple Sclerosis Society was horrified at such advice. I walked my last 1½ miles in 1992.)

My G.P. diagnosed Post Polio Syndrome in 1998 - Which of these clinicians should I believe all, some or none? What about the problem with my upper neck at C1/C2? What about the comment that the polio virus does not cause lesion in the brain?

Editors note - The comment about the polio virus not affecting the brain has been said to four members this year. "Polio above the Neck" article follows. There are other articles in the Lincolnshire Post-Polio Network Library mentioning the polio virus damage to areas of the brain.

* * *

POLIO ABOVE THE NECK

with Susan Perlman, MD

Reported by Mary Clarke Atwood

with editorial assistance by V. Duboucheron & S. Perlman.

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Newsletter April 2000

Neurologist Dr. Susan Perlman, Director of the UCLA Post-Polio Clinic, spoke at the May 2nd 1999 meeting of the Orange County Post-Polio Support Group. In addition to her responsibilities in the Post Polio Clinic, Dr. Perlman also serves at the University of California - Los Angeles (UCLA) as Associate Clinical Professor of Neurology, and Director of the Neurogenetics Clinic.

Previously much attention has been given to post-polio problems involving the limbs - a weak leg, fatiguing arms, etc. These manifestations of Post-Polio Syndrome (PPS) occur in people who had spinal poliomyelitis - the acute infection that affected anterior horn cells in the spinal cord segmentally.

People who had nonparalytic polio, by definition had polioencephalitis. They had involvement of those brain areas above the spinal cord, and could well have had poliovirus changes in the brainstem (bulbar polio). So breathing and swallowing problems may be present even in people who ostensibly had non paralytic polio and also in others who may have no complaints about their legs or arms.

This report focuses on the problems of bulbar polio and other problems that are now manifested in people who have PPS. The cause of these problems is polio damage that occurred in the upper cervical spine and upward. Bulbar is defined as polio involvement of the motor nerves in the brainstem.

Early Studies.

Polio autopsy reports following the epidemics of the 1940's and 1950's showed signs of acute polio infection throughout the body; it was not just restricted to the spinal cord. There were changes found in upper motor neuron pathways and there were changes found in central brain structures that control alertness, central fatigue, and autonomic functions such as temperature regulation etc. There were also many changes seen in the brainstem itself.

Probably greater than 90% of a polio survivor's motor neurons were somehow affected during the acute stage and had some damage, even if it was not paralytic. Autopsy studies have shown that during the acute attack as few as 3 or 4% of the motor neurons remained intact.

There are not many polio survivors seen now who had severe residual effects from the acute bulbar polio infection. This is probably because when there is 50% loss of the motor neurons that control breathing or swallowing, a person is going to be in serious trouble. Many did not survive the acute infection. Those who survived bulbar polio truly are survivors, said Dr. Perlman.

Respiratory Problems.

There are some people who had only mild breathing weakness with the original polio, (chest wall weakness or a little diaphragmatic weakness) but their breathing centres in the brainstem were actually intact. People who had true bulbar polio had involvement that didn't trigger breathing - they needed to be assisted until those centres came back. So when looking at post-polio breathing problems, people who had primary muscular manifestations should be included along with those who had bulbar polio.

In other parts of the body such as arms and legs, surviving motor neurons remodelled and adopted the injured or orphaned ones in order to take over function. However this was not as common in the brain and brainstem. Since the brainstem has less plasticity and flexibility, it was harder for remodelling to occur to the nerves of the pharyngeal muscles and to those of the upper part of the oesophagus. For years, many survivors have been using compensatory strategies, such as swallowing on the other side of their throat. Those who had residual problems such as vocal cord paralysis may also have been able to compensate for this. But when the muscles on the 'good' side of their throat begin to weaken, they become aware of a 'new' problem in that area.

Muscles that control breathing and swallowing are the same groups of muscles that are involved with speech, to some extent. These groups of muscles are located in the throat. So people with PPS who are having problems with swallowing, breathing, or shortness of breath during activities of daily living, might also complain of speech problems. Although facial, jaw, and throat muscles are controlled in the brain stem, they have rarely been thought of in connection with polio.

Are people who had bulbar polio going to be having increasing bulbar dysfunction? The following criteria are used to determine increasing bulbar problems:

1. Severity of residual disability.
2. Residual bulbar or respiratory signs.
3. Later age at onset of acute polio (past age 10).
4. (Possibly) recent falls or injuries; or surgical procedures in the pharyngeal area; or weight gain, because it puts more pressure on the diaphragm and pharyngeal area.

Fortunately our bodies have several safety factors to assure that breathing muscles meet our oxygen and carbon dioxide demands. The primary muscle for breathing is the diaphragm and the secondary breathing muscles are the external intercostals (the muscles between the ribs). So if a person has a fatigable diaphragm that tires out by the end of the day, the intercostals will kick in and the person will begin breathing from the chest. There are also accessory respiratory muscles that help lift the chest from the shoulders.

With post-polio breathing problems, part of the problem is going to be muscular. There may be a diaphragm or secondary assistive muscles not kicking in as well as they should. There can also be central (brain) changes contributing to this, such as decreased respiratory drive, if those centers were affected originally. There may be changes in the chemo-receptors; perhaps the sensors are not sensing carbon dioxide (CO_2) build-up as sensitively as before.

Scoliosis can also cause restriction of breathing. A person who has a scoliotic spine cannot expand his chest as well so he underbreathes because of it. If scoliosis is getting worse as a post-polio symptom, it's going to make that aspect worse and will interfere with breathing.

When doctors are looking at respiratory problems of PPS patients, they should look at not only peripheral problems and muscular problems, but also central disregulation of breathing as well. All these factors are addressed at the UCLA sleep lab, directed by Dr. Frisca Yan-Go.

Recent Findings.

Dr. Perlman cited a report (Epidemiology, October 1, 1992) that involved 77 subjects with nonparalytic polio and 474 subjects with paralytic polio. A change in breathing was observed in 10% of the nonparalytic subjects and 12% of the paralytic ones. Swallowing problems were noted in 6% of the nonparalytic subjects and in 7% of the paralytic ones.

In the larger ongoing studies at polio centers such as Mayo Clinic, Rancho Los Amigos and centers in Canada, possibly as many as 40% of the people with PPS are having new respiratory complaints. (About 80% of PPS patients complain of fatigue.)

Another study of 74 polio survivors who were having shortness of breath found two good measuring devices for patients with increasing respiratory problems:

1. Forced expiration (a pulmonary function test) can be very helpful monitor. This test shows how hard it is for a person with PPS to breath out and it requires the use of some of the intercostal muscles and the abdominal muscles. Dr. Perlman recommends this test every year or so for her patients who have significant breathing complaints.
2. The other very helpful thing is to monitor (CO_2) levels in the blood. The question is not how much oxygen is a person inhaling, but how much CO_2 is a person retaining? Is a patient not breathing fast enough? Is the person fatiguing so that he cannot ventilate? It is the amount of ventilation a person gets that clears the CO_2. So if your ventilating less efficiently, your CO_2 levels are going to go up slowly?

For patients at risk, these researchers felt that anything that was in danger of happening could be detected by measuring maximum expiratory pressure and carbon dioxide levels on a regular basis.

Swedish research on cardio-respiratory parameters in PPS patients found a significant incidence of deconditioning. This goes back to the old thought that everybody should be doing some exercise. Dr. Perlman says doctors are no longer saying people with PPS should do no exercise; some exercise, conditioning or aerobic exercise, is important. Survivors can improve heart function, circulation, and breathing to some extent by doing something that increases heart rate. These researchers suggested increasing the heart rate to 70% of maximum by using a pool or other equipment. They felt these were tolerable levels for their PPS patients.

Researchers in Toronto looked at 3 areas of muscles, (respiratory, diaphragm, chest wall), bulbar symptoms, the control rate, and scoliosis. They found that the control panel in the brainstem was the least important of the group. These people were having problems because of the diaphragm, chest wall fatigue, or due to progressing scoliosis.

A few of Dr. Perlman's patients have experienced increased breathing problems at higher altitudes. Adjustments can be made so those patients can travel at higher altitudes and not feel short of breath all the time.

Swallowing.

The motor neurons that control swallowing are located in the brainstem. In order to have an effective swallow, groups of muscles are used to insure that the food is chewed, forms into a bolus, and goes down properly. The swallowing center coordinates other activities related to swallowing: chewing, licking, gagging, coughing, sneezing, vomiting, belching, and breathing to some extent (when a person is swallowing, he doesn't breathe). It is hard to eat or swallow at the same time as breathing, because the two groups of muscles and nerves are competing against each other.

There are at least a dozen places in the body where a post-polio patient who had some pharyngeal problems or brainstem related swallowing problems could begin to have trouble now with swallowing. For example, people who have weakness in the jaw muscle as a complication of PPS will find it hard to chew when fatigued. Or people who have a weak soft palate will find that food is slipping into their throat before it is fully chewed and food or drink (especially drink) may be coming out of their nose.

Swallowing problems have been identified in recent studies. However, it is rare to see a PPS patient who is having constant choking. Most people can think about it and use their conscious mind to control what is going on, thereby preventing swallowing problems occurring. Any part of the gastro-intestinal tract - from the mouth all the way to the bottom - could be slowed, weakened or not working properly due to PPS. But don't assume that every symptom a polio survivor gets is due to PPS.

Although common pathway are used for breathing and swallowing, not everyone who has swallowing problems has breathing problems and not everyone who has breathing problems has swallowing problems. Bulbar muscles can slowly dysfunction and there can be silent swallowing problems. In a 1991 swallowing study by Dalakas he concluded 'in bulbar neurons there is a slowly progressive deterioration similar to that in the muscles of the limbs.'

Blood Pressure and/or Variable Heart Rate.

Can high or low blood pressure be a result of polio and PPS? Can variable pulse rate be made worse, not because of heart disease, but because of post-polio symptoms affecting the area?

The average internist may be hard pressed to believe it possible for polio to be related to current blood pressure or pulse rate problems. However, vaso-motor centers that control blood pressure and pulse rate are located in the medulla (in the lower brainstem) and also in the autonomic area of the brain. Since polio damage has been seen in the brain and in the brainstem, this is an area that needs further study.

As we understand what was involved in acute polio and the amount of brain that was involved, recovered motor neurons that might have looked quite complete on the surface could actually be functioning on very shaky ground. The majority of motor neurons, in whatever region the poliovirus got to, were probably affected in some way or another,' said Dr. Perlman.

To Contact UCLA Post-Polio Clinic
Dr. Susan Perlman
300 UCLA Medical Plaza, Suite B200
Los Angeles, CA 90024-6975
Phone +1 310 - 794 -1195.

Audio Tape available - A recording of this complete talk is available for $5 + $2 p & p (USA). Contact Ken Baragar, 817 Irving Place, Anaheim, CA 92805-5025 Phone +1 714 - 535 - 2710.

Editors notes:

1. We will be getting a copy of this tape.
2. If I burst out laughing I choke every time. My voice is deepening and if I talk for too long my voice gets hoarse. I started reporting occasional swallowing problems over 4 years ago which was quite worrying. I could not get this assessed no matter how often I asked. The first time I reported it I was told I had not mentioned this before I learned the symptoms of PPS, suggesting that I was making it up. I laugh about it now, but because no one was accepting any of my other symptoms I decided they would think I was really crazy if I mentioned the swallowing as well. Last year my last GP said she had been advised that as there was 'No treatment for PPS, there was no need to send me for assessment as it would not alter the course of treatment.' I did comment that I thought my AFO, electric scooter, house alterations, disability aids, physiotherapy and hydrotherapy were treatment, but she did not answer. As usual I had already researched this and learned that worrying about it makes you tense up and makes it worse. The advice was to relax my shoulders, tip my head forward and to the side and I am able to swallow the second time.

   I changed my GP and as my symptoms are getting a little worse I insisted that these symptoms were assessed and was at last referred to a Speech Therapist from the Lincoln District Healthcare Trust Speech and Language Therapy Services - Miranda Davis. I did not take any medical articles with me this time. I decided that I would just be an ordinary patient. You can't win though as this was a total change from my previous appointments. I was treated like an adult had my problems explained in technical detail with diagrams as she could see I understood the medical terminology. She admitted she knew little about polio and PPS and asked for more information. Because of what I reported I have to be checked by the ENT Department to ensure there is no other reason for my deepening voice, hoarseness, choking and inability to swallow on occasion. She could not refer me directly anymore she had to write to my GP and ask him to do it. Such a waste of time and money!

   Miranda gave me the Voice Care article on the next page which she hopes will be of benefit to our readers and assures us that she will be learning more about polio and PPS and will be happy to speak at meetings and help with more articles at a later date. Why can't more health professionals be like her?

VOICE CARE

provided by Miranda Davis
Speech and Language Therapy Services
Lincoln District Healthcare NHS Trust.

Voice quality is affected by many factors. Awareness of these is essential for good voice use especially if you are a 'Professional Voice User.'

ENVIRONMENTAL PROBLEMS.

Air Quality.

Household dust, pollen and chalk are irritants that cause the air passages to become inflamed and dry. This may affect voice pitch and quality.

- become more aware of air quality
- **drink more fluid** if air quality is poor
- make sure the area is properly cleaned
- avoid using dusty chalk.

Humidity.

A hot, dry atmosphere can be damaging as it dries out the protective mucous membranes of the throat. This can make the vocal folds more vulnerable to trauma.

- place a bowl of water above a radiator or near a heat source to humidify the air
- keep rooms well ventilated, if possible.

Wet, foggy atmospheres can lead to the overproduction of mucous which may affect voice quality.

Background Noise.

Raising one's voice over background noise even of low intensity may lead to strain. Speaking at a high pitch and volume is potentially dangerous because the vocal folds are stretched tightly and move quickly.

- avoid speaking for long periods of time in noisy circumstances e.g. pubs, discos, parties, swimming pools etc.
- try not to shout to compensate
- turn off TV or Radio before speaking
- reduce unnecessary noise whenever possible, e.g. scraping chairs on uncarpeted floors.

Speaker-Listener Distance.

Volume of the voice should be varied according to the distance between you and the listeners.

- remember when the voice is used at a greater volume you need to take more and deeper breaths
- adjust the layout of the workplace or classroom to reduce the distance between speaker and listener
- use other noise-makers to attract attention, e.g. whistles, claps etc.
- if the listener has a 'hearing' impairment ensure you are facing them when you speak and that background noise is minimal.

PHYSIOLOGICAL ASPECTS

Allergies and Infections.

Infections such as laryngitis and pharyngitis cause swollen and inflamed membranes. When you have a throat infection **rest the voice** and **drink extra fluids**. If the voice sounds hoarse, rest it for several days if possible.

- **Inhale steam** if you suffer from catarrh. Also useful for tired and strained vocal folds.

Allergies, e.g. hay fever, can also result in swollen and inflamed membranes of the throat.

Medications.

Some drugs can affect voice quality, e.g. inhaled steroids for asthma, antihistamines.

- Be wary of **over-the-counter throat medications**, these contain antihistamines and dehydrants which have a drying effect on the larynx
- Be wary of **preparations** which contain **anaesthetics** to numb pain
- Consult your doctor if any prescribed medication or drug seems to be affecting the voice.

Recreational Drugs.

Smoking tobacco and other drugs has a profound effect on the vocal tract, both drying and irritating the mucosa. It can cause redness and generalised irritation to the nose and throat. It is also closely related to laryngeal cancer and pre-cancerous conditions.

- Stop smoking, if you cannot, seek help to do so
- Avoid smoky atmospheres.

Avoid other irritants

- dusty, chalky atmospheres
- dry atmospheres, over humid atmospheres (swimming pools)
- banda fluid, fumes from felt tip pens, some solvent-based glues, chlorine etc.

Caffeine.

This substance is another drying agent.

- Reduce excess intake of caffeine found in drinks such as coffee, tea, coca-cola
- Drink more water.

Alcohol.

This is another substance which has a drying effect on the vocal cords and can produce marked changes in voice quality even after relatively small amounts. **Spirits** are the most damaging.

- Avoid alcohol before speaking or singing
- If you must drink, take more diluted forms, e.g. wine with soda.

Tiredness.

Tiredness makes it more of an effort to breathe and speak adequately, therefore there is the possibility of vocal strain.

- Ensure that the **throat is well lubricated** because it becomes drier when tired.

Emotions.

The voice is a reflection of the emotional state. Consider the sound of the voice of someone who is depressed, or very happy. Voice misuse can be the result of increased tension which has emotional origins.

- Identify if you feel anxious or worried
- Talk over any worries or problems you might have with someone who is a good listener.

Fear.

When afraid the breathing rate increases, the **heartbeat accelerates**, the **larynx rises** and the **vocal folds tighten** causing the pitch to rise and the voice to sound tense.

Hormonal Changes.

Women experience hormonal changes premenstrually. Hormone levels change causing the vocal folds to swell and increase in mass causing the vocal pitch to lower and increase, a husky/whispery quality.

- Avoid excessive vocal demands at these times.

Dehydration.

A dry throat sounds strained and lacking in resonance.

- Ensure that there is an adequate fluid intake into the body.

Long penods of talking will require frequent intakes of water. Always have water available during these times.

Speech and Language Therapy Services
92 Newland, Lincoln, LN1 1YA.
Tel: +44 (0)1522 514814
Fax: +44 (0)1 522 513711
29.2.2000

EMAIL UPDATE NOTIFICATION SERVICE: You can receive email notification of changes to our WebSite if you wish. This CONFIDENTIAL service is provided free of charge. You can also choose how often you are notified. Read our LincsPPNUpdate section for full details including an optional form for subscribing (you can also subscribe by separate email if you wish).

http://www.ott.zynet.co.uk/polio/lincolnshire/changes.html

REMEMBER, MEMBERS WHO HAVE A COMPUTER AND INTERNET ACCESS, IF YOU WISH TO SUBSCRIBE TO OUR MEMBERS DISCUSSION LIST WE NEED YOUR EMAIL ADDRESS.

A Qualitative Survey of Postpolio Syndrome in the Leeds area.

S. A. Arshad, St. Mary's Hospital, Greenhill Road, Leeds.

Lincolnshire Post-Polio Library copy by kind permission of Dr. Arshad.

INTRODUCTION.

There were six major polio epidemics in the United Kingdom early this century. In the Leeds area, more than 400 cases of Polio were notified between the years 1940 - 1962 inclusive[1]. After the successful introduction of mass vaccinations with the Salk and then the Sabin vaccines in 1956 and 1961, new polio cases became extremely rare.

It is known that that many people with a history of polio may develop new symptoms after decades of stable functioning. The time lag varies but the usual period between the onset of these symptoms is about 30 years[2]. The risk of developing these symptoms appears to be correlated with the severity of the original paralysis[3].

Most common new health problems reported by Postpolio patients are fatigue, muscle pain, joint pain and weakness. Functional problems include walking, climbing stairs and dressing[4]. The suggestion is that these new symptoms should be labeled as the "Postpolio" syndrome.

Table1 Problems experienced by those who had polio many years ago.

- weakness, pain or cramp in muscles
- increasing arthritis
- increasing arthritis secondary to unusual use of muscles and joints
- increasing fatigue
- skin and circulatory problems secondary to autonomic nervous system involvement

- osteoporotic changes leading to fractures
- increasing deformity e.g. scoliosis
- increased risk of deep venous thrombosis
- increasing respiratory problems, including possibly undiagnosed sleep apnea
- increasing difficulty with mobility
- increasing difficulty with work and activities of daily living
- difficulty in obtaining orthoses
- difficulty in obtaining suitable wheelchairs

A qualitative study was carried out between the months of September and November 1998. Interviews were done on 14 patients suffering from the post-polio syndrome. They were between the ages of 40 and 72 years and eight males and six females. All of them had polio in childhood, before the age of 10 years with various impairments.

The aim of this study was to explore possible influences on the perceived quality of life for people with PPS. This is a pilot case series in descriptive epidemilogy.

METHOD.

A structured interview schedule was used. The questions covered various aspects employment, appearance, social support etc.

The answers were analyzed with NUD.IST software*[5]* using cross-case comparisons *[6]* assessing the similarities and differences emerging as patterns between and within cases.

The interviews were conducted in the patients residences with spouses present in some cases. All questions were answered to the best of their abilities.

RESULTS.

The results of the structured interview was as follows:

1. occupation:	8 were working but had to modify their practices
	4 had to give up work due to post polio syndrome
	1 had retired
2. family relationships:	11 had supportive families and spouses*
	2 lived alone and kept themselves in isolation
	1 had problems with their families understanding their illness
3. activites in the house:	10 needed help from their spouses, family members or home help
	3 managed their own household chores
	1 was wheelchair bound but had the house fully adapted
4. negative feelings:	12 experienced anxiety or depression about their condition
	2 were resigned to their condition (taking it as it comes)
5. sleeping pattern:	13 had disrupted sleep due to pain and exhaustion

	1 no problem
6. personal hygiene:	10 needed help ranging from complete dependence to aids
	3 managed independently with difficulty
	1 was completely dependent
7. leisure/hobbies:	12 were restricted in amount of time or equipment
	2 had to give up their hobbies

* Out of which only 2 reported a satisfactory physical sexual relationship, the rest had difficulties.

CONCLUSION.

It is apparent that these symptoms have significant potential consequences for the individuals experiencing postpolio sequelae in their functional capabilities to cope with activities to cope with activities of daily living (ADL). Obviously reports of fatigue, pain, muscle weakness and atrophy, respiratory difficulties have significant effects on mobility. Individuals experiencing PPS note difficulties in walking, using wheelchairs, transferring in and out of chairs, never mind negotiating stairs. As one might expect, mobility difficulties also potentially affects one's ability to remain employed.

In terms of being self sufficient, individuals faced increasing difficulties in dressing, washing among the activities performed at home as well as sexual functioning. In fact respondents have been forced to alter their activities of daily living, expand their reliance upon mechanical aids and personal assistants. Generally PPS sufferers report having to "slow down" in terms of activities in a day to day basis.

Not surprisingly these changes have an important emotional impact. The anxiety, frustration, uncertainty and isolation must have a significant influence on one's outlook and response to the demands of daily living, particularly in light of the likelihood of a more restricted lifestyle. A concrete manifestation of these changes is a decline in one's capacity to maintain a social life.

There may be comorbid or secondary medical conditions contributing to development or aggravation of symptoms. Being a diagnosis of exclusion, there are no specific tests for the Postpolio syndrome[7]. It is therefore important to compare quality of life with other neurological conditions having a similar set of symptoms, to compare differences associated with disturbance of activities of daily living.

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1. Medical Officer of Health Reports; Archives, Leeds Central Library.
2. Cashman NR, Neurological manifestations of the Postpolio syndrome. Curr Op Orthop 1992;3:224-8.
3. Jubelt B, Cashman NR. Neurological manifestations of the postpolio syndrome. Critical Rev Neurol 1987;3:199-220. [PubMed Abstract]
4. Chetwynd J, Botting C, Hogan D. Postpolio syndrome in New Zealand: a survey of 700 polio survivors. New Zealand Medical Journal Sept. 1997; 406-8.
5. Anon QSR. NUD.IST; 4th ed.; Melbourne, Australia. Qualitative Solutions & Research Pty Ltd 1997 Data Analysis.
6. Miles M, Huberman M. Qualitative Data Analylsis; an expanded sourcebook; 2nd ed., Thousand Oaks, California. Sage Publications 1994.
7. Thorsteinsson G, Subspecialty Clinics: Management of Postpolio syndrome. Mayo Clin Proc 1997; 72: 627-638. **[Lincolnshire Library Full Text]**

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

The Vaccine Victims Support Group will be meeting outside the Departments of Health and Social Services on Wednesday 28 June at 2.00pm to press for a proper vaccine compensation scheme for the children who have been severely damaged by the vaccination program. We will then be marching on to St Stephens Gate and will have a meeting with MP's in the Grand Committee Room in the House of Commons. We would appreciate as much support as can be raised for this very worthy and necessary cause. This will be the fourth time that the group has brought their children to Parliament in order to raise the profile of this issue with the Government. I would like to invite any interested members of the PPS group to join us and increase our show of support.

Should you have any questions please contact LincsPPN Member David Thompson on davidl@freewebaccess.co.uk or phone on 0207 290 1510 (Office Hours)

Reflections by Christine Ayre

<catley@tesco.net>

Life these days is lived at such a fast pace, people don't seem to have time to spend and enjoy the simple things. I expect I am the same, but I do now and then pause and think of a time when life was a bit slower and people had time to spend, which didn't involve cars, mobile phones, computers and the like.

Only twice in my life have I had an experience of the slower pace of life, now past, which I have remembered with delight.

The first of these was in the late sixties when I was working for a photographer, so on Saturdays my work took me out to weddings, many of which were in the Villages surrounding Sleaford.

One such wedding was to take place at a Village named Irnham, near the small market town of Bourne. I was not relishing this wedding as it was a cold and snowy late December day. The Church was not one I had been to before and on arrival I was horrified to find evergreen trees laden with snow growing almost up to the Church door, a photographers nightmare.

We were standing outside the Church door trying to keep warm when a very nice Lady, who was I think doing a bit of dusting, came out and invited us in, saying "there is a good fire in here, come in and get warm". Going in that Church was like stepping back in time, it was a small place with white washed walls, a large pot bellie stove in the centre, which was giving off a wonderful heat. I wandered around looking at the beautiful stone carving and wonder of wonders a tomb with a brass knight on the top. All the time the cleaning Lady was talking, telling of the death of the Squire from the manor, who had passed away only a few weeks previously and how much he was missed in the Village and how he was related to the Knight on the tomb. The Village people were all waiting for the new young Squire to move into the manor from London.

I thought at the time, I will always remember this day and this Village, where time seemed to have stood still, the like of which I was sure, I would never see again.

How wrong I was, last week I had a similar experience and again one I will always remember.

I had arranged to go with my sister in law to a talk, the subject being Queen Elizabeth the first. The talk was to be given by someone from Oxford University, so well worth the trip.

I had about ten miles to drive to the Village of Little Hale, the talk was to take place in the local Chapel. The afternoon was beautiful with the sun shining and the birds singing.

We drove along a narrow road, through a patchwork of fields, some so bright with the flowering rape, others more restful to the eyes, with the soft green of the wheat. We passed meadows starred with daises and buttercups, and hedgerows heavy with the scent and blossom of the hawthorn. A perfect English Summer day.

The Chapel was easy to find and proved to be a small building joined onto a house. The date on the Chapel was 1839, but the building seemed to be older, brick built, of a soft rosy red colour, the windows high, made to let in the light and not for looking out of, nothing to tempt the eyes away from the pulpit.

Imagine the children in days gone by, sitting in the pews, with fire, brimstone and threat of eternal damnation raining down on their heads. How they must have wriggled and squirmed longing to be released from this prison.

On this Summer day all that is past and the Chapel is a place of delight.

One small room with about five pews on each side, a pulpit at the end and a small old fashioned ornate organ at the side by the door. A floral carpet covered most of the dusty old floorboards, vases of lilac and wild flowers stood around and arrangements of leaves adorned the high windowsills.

The door stood open and the sun flooded in. We were the first to arrive, so sat in a pew at the front and contemplated the organ, flowers, pulpit and the china teacups with the Chapel crest in green and the words Little Hale Chapel 1939, these must have been made for the Chapel Centenary. I wonder who thought of buying the teaset and how fitting for a Chapel, how many cups of tea had been drunk from them over the years.

We drank our tea and ate the home made biscuits, the speaker climbed into the pulpit and as if imbued with the spirit of a long gone preacher, delivered his talk with much fire and quite a bit of pulpit thumping.

As I watched the reflections from the blue glass above the door move across the carpet, I found my mind starting to wander. I imagined a Winter evening long ago when the Chapel was young, the congregation glad to be in the warmth given off by the stove in the centre of the room, the oil lamp giving off a mellow glow and the preacher maybe wearing a black tail coat and flat crowned hat, visiting the Chapel to give them their Sunday ration of fire and brimstone.

No cars, radios or jet planes to intrude on the peace, just the voice of the preacher and the singing of hymns.

Little Hale still retains its quiet, slow pace of life, I hope it stays that way.

I have never been back to Irnham Church, thinking to see it again would lose the magic, But I will be revisiting the Chapel next month, this time its a talk on the black death. Will it be such an inspiring visit? Will my imagination be stirred again? Time will tell, but I hope so and I may be able to get another story from the visit.

An © ☺ Email on the SJU Polio List.

ME AND MY SEVEN DWARVES

Achey,
Sore,
Pooped,

Paralyzed,
Fatso,
Drugged
and Smelly,

have not been posting much of late. Too busy keeping each other company. Can't wait for them to pack up and leave. Unwanted house company!

Marsha in Texas <marsha@ccms.net>

Media Events

BBC Radio Lincolnshire, 12th May 2000

Dave Bussey (pictured left) presents the daily *Action Line* program live on BBC Radio Lincolnshire. In the edition of the program broadcast on the morning of 12th May 2000, he discussed various aspects of Post-Polio with Hilary Hallam, Hon. Secretary of the Lincolnshire Post-Polio Network. We intend to provide a full transcript of the broadcast within a week or so. In the meantime we are able to provide a limited access RealAudio stream recording of the broadcast. The recording is unedited apart from the deletion of music segments for reasons of copyright. We are grateful to Dave Bussey for supplying us with a high quality copy of the discussion produced from the program master tape.

IMPORTANT! Our current trial RealMedia server will only allow two concurrent streams of the file below. If the service is busy please try again later.

BBC Radio Lincolnshire 12th May 2000
19m 18.5sec Surestream 28K/56K

British Broadcasting Corporation

BBC Radio Lincolnshire
http://www.bbc.co.uk/england/radiolincolnshire/

BBC

BBC Radio Lincolnshire
Presenter - Dave Bussey
http://www.bbc.co.uk/england/radiolincolnshire/pres_bussey.shtml

BBC Radio Lincolnshire
94.9, 104.7 FM & 1368 AM

Post-Polio
References

1. A Résumé of Polio and Post-Polio compiled by Hilary Hallam. LincPIN Volume 2 - Issue No. 3 - February 1999.
2. Personal Assessment of Your Activity Levels. by Hilary Hallam. LincPIN Volume 2 - Issue No. 4 - April 1999.
3. Post-Polio Syndrome - From learning it exists through to better managing your life by Hilary Hallam. LincPIN Volume 2 - Issue No. 9 - February 2000.
4. LincsPPN World-Wide Conference and Seminar Diary - Eighth

International Post-Polio & Independent Living Conference - Conference Card #0006.

Lincolnshire Echo, 5th May 2000

Sufferer invited to USA

Victim to speak at seminar

A LINCOLN woman who has been experiencing the late effects of polio for more than 12 years has been invited to speak at a medical conference about the condition in the United States.

by Wendy Inkster

Hilary Hallam (53), who has post polio syndrome, will be one of three British speakers at the Post Polio and Independent Living Conference in Missouri.

Like thousands of people across the country, she contracted polio during the 1940s and 1950s before vaccines virtually eliminated it in the late 1950s.

Founder and secretary of the Lincolnshire Post-Polio Network – an information service – Mrs Hallam will be addressing medical professionals and polio survivors about self-assessment of the condition.

"Due to the invention of the vaccine it has been thought polio was a disease of the past," said Mrs Hallam, who lives in Doddington Park.

"When polio survivors find themselves confronted by this unexpected stage of their childhood polio they experience initial horror.

"They find there is an even bigger battle to be fought – finding specialised clinical support."

She said by keeping an adequate diary of symptoms and functional changes, among other things, it would help doctors recognise the condition and treat it accordingly.

Peter Jay (54), who lives in Sutton Bridge and is a voluntary welfare visitor for the British Polio Fellowship, will be speaking at the conference for a second time.

He will be discussing the importance of self-management for people with long-term conditions.

"This is the most important conference for discussing issues regarding people who have survived polio and I am honoured to attend," he said.

"The conference is a good opportunity to discuss these issues and hopefully get polio treatment clinics in Britain."

The conference takes place from Thursday, June 8, to Saturday, June 10.

Lincolnshire Health Authority have donated £100 towards the trip, but Mrs Hallam is still in need of further funding.

She especially requires a second-hand lap-top computer which makes it easier for her to transport information about the charity.

☎If you can help or for more information telephone Hilary Hallam at the Lincolnshire Post Polio Network on (01522) 888601.

SPEAKER: Polio victim Hilary Hallam. Picture reference: 0-1925-9.

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The full text of this article can also be found on the Lincolnshire Echo web site at http://www.thisislincolnshire.co.uk/scripts/edarchdisplay.asp?section=Local+news&ID=4653&source=LINC.
⚠ *Currently Unavailable* ⚠

*LincsPPN Editorial Note: In conversations with the Lincolnshire Echo **before** the above article was published, they were specifically asked by us not to use certain terms including "victim". In our experience of previous newspaper articles, use of such terms can 'switch people off' with the result that those in desperate need of more information may fail to make further contact.*

Post-Polio References

1. LincsPPN World-Wide Conference and Seminar Diary - Eighth International Post-Polio & Independent Living Conference - Conference Card #0006.
2. LincsPPN Directory - International/National/Local Support Organizations - The British Polio Fellowship.
3. The Lincolnshire Echo - this is Lincolnshire http://www.thisislincolnshire.co.uk/ External Link.

Lincolnshire Post-Polio Library

Articles added since last newsletter with grateful thanks to the authors

Title: Dr. Henry writes about "Christina's World"

FULL TEXT HERE

Author(s): Henry Holland MD
Original Publication: Central Va PPS Support Group (PPSG)'s newsletter, The Deja View, April/May 2000 issue.
Abstract/Extract: In David McCullough's Truman there is a recounting of the events that occurred in 1948 during the election campaign between Harry Truman and Thomas Dewey. One paragraph in the biography reads, "It was the year, too, of Christina's World, a haunting portrait by Andrew Wyeth of a crippled woman and a forsaken house on a bleak New England hill…that would become one of the most popular paintings ever done by an American."

* * *

Sent in by Lili <tweety7777@WEBTV.NET>
Author Unknown.

I have just been through the annual pilgrimage of torture and humiliation known as buying a bathing suit.

When was a child in the 1940s, the bathing suit for a woman with a mature figure was designed for a woman with a mature figure: boned, trussed, and reinforced, not so much sewn as engineered. They were built to hold back and uplift, and they did a darn good job. Todays stretch fabrics are designed for the prepubescent girl with a figure chipped from marble. The mature woman has a choice - she can either front up at the maternity department and try on a floral suit with a skirt, coming away looking like a hippopotamus escaped from Disney's Fantasia, or she can wander around every run-of-the-mill department store trying to make a sensible choice from what amounts to a designer range of FLEXIBLE rubber bands. What choice did I have?

I wandered around, made my sensible choice, and entered the chamber of horrors known as "The Fitting Room." The first thing I noticed was the extraordinary tensile strength of the stretch material. The Lycra used in bathing suits was developed, I believe, by NASA to launch small rockets from a slingshot, giving the added bonus that if you manage to actually lever yourself into one, you are protected from shark attacks. The reason for this is that any shark taking a swipe at your passing midriff would immediately suffer whiplash.

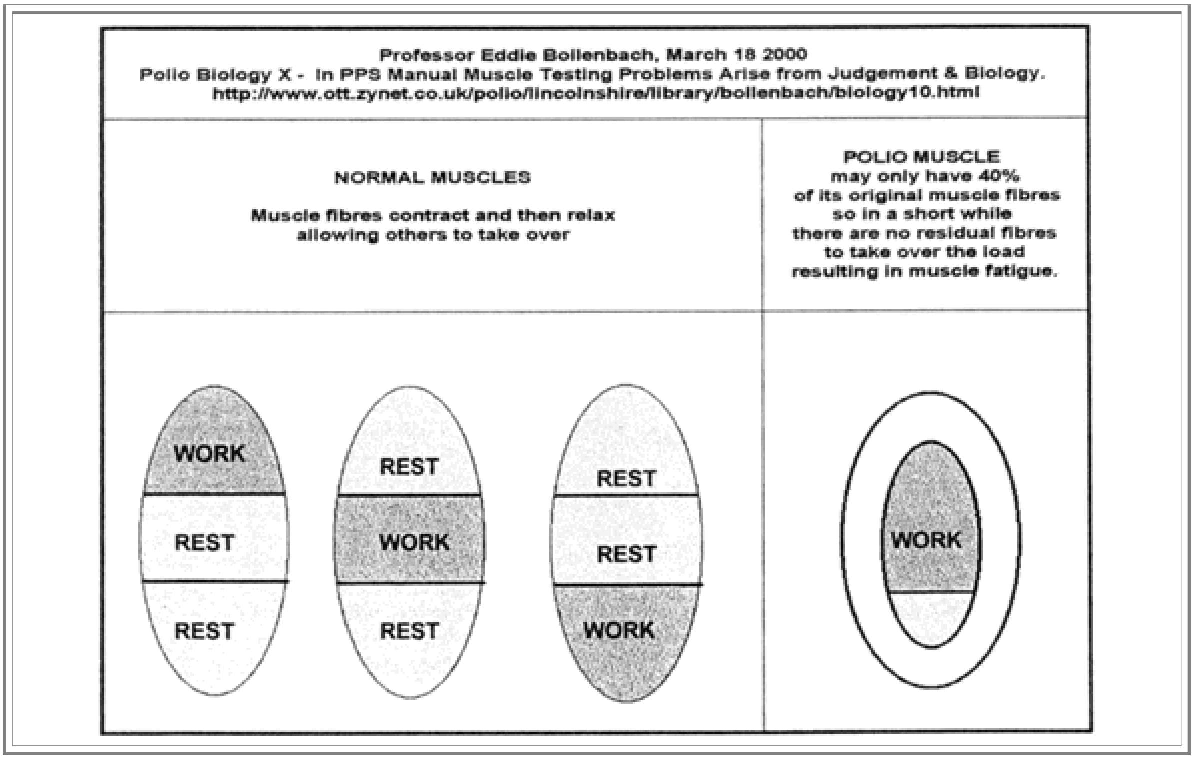
I fought my way into the bathing suit, but as I twanged the shoulder strap into place, I gasped in horror - my bosom had disappeared. Eventually I found one cowering under my left armpit. It took a while to find the other. At last I located it flattened beside my seventh rib. The problem is that modern bathing suits have no bra cups. The mature woman is meant to wear her bosom spread across the chest like a speed bump. I realigned my speed bump and lurched toward the mirror to take a full-view assessment.

The suit fit all right, but unfortunately it only fit those bits of me willing to stay inside it. The rest of me oozed out rebelliously from top, bottom and sides. I looked like a lump of Play-Doh wearing undersize cling wrap. As I tried to work out where all those extra bits had come from, the prepubescent salesgirl popped her head through the curtains, 'Oh, they are sooo YOU!' she said, admiring the suits. I replied that I wasn't so sure and asked what else she had to show me. I tried on a cream crinkled one that made me look like a lump of masking tape, and a floral two-piece that gave the appearance of an oversize napkin in a serviette ring. I struggled into a pair of leopard-skin bathers with ragged frill and came out looking like Tarzan's Jane on a bad day. I tried a black number with a midriff and looked like a jellyfish in mourning. I tried on a bright pink suit with such a high-cut leg I thought I would have to wax my eyebrows to wear it.

Finally I found a suit that fit. A two-piece affair, with shorts-like bottoms and a halter top. It was cheap, comfortable and bulge-friendly, so I bought it. When I got home, I read the label, which said, 'Material may become transparent in water,' but I'm determined to wear it anyway. I just have to learn to do the breaststroke in the sand.

Editors note - If you would like to write something for our newsletter; an amusing tale from your polio past; problems you are having; tips that might help others; then please get in touch.

Last newsletter we included the article - Polio Biology X
In PPS Manual Muscle Testing Problems Arise from Judgement & Biology.
For presentations I have produced the following diagram to explain polio muscle fatigue.



The Long-Term Medical Conditions Alliance.

Improving Lives - Proposals for Change.

Calls for changes in health & social care to achieve better quality of life for people with long-term medical conditions, from the perspective and experience of the people themselves.

Long-term medical conditions are not yet given proper attention in the changing pattern of health and healthcare. Advancements in research and treatment and the fact that more people are living longer have made dramatic changes in their prevalence. The White Paper on Public Health 'Saving Lives: Our Healthier Nation', estimates that one in three of the adult population is affected, with a particular impact on older age groups. A significant number of people have more than one condition.

The NHS, local government, professional and voluntary bodies all contribute to meeting needs but not enough is yet done to help improve the quality of people's lives. Greater recognition is needed of the substantial impact of illness affecting so many individuals: impact on their lives, on their families, on employers and on heath care. LMCA and its 98 (now 112) member organisations propose a broad approach across the wide range of long-term conditions and a more united approach across services in order to achieve changes that are needed.

Five principles should underpin a new approach.

- Address common issues across long-term conditions
- Put greater emphasis on quality of life
- Treat people as people, not patients
- Work towards greater social inclusion
- Use the expertise of individuals and organisations

LMCA proposes nine changes to achieve these objectives.

1. Improve equitable access to specialist services
2. Extend the role of nurses

3. Improve equality of access to the most effective treatments
4. Plan seamless, life-long services
5. Develop and offer self-management programmes, information and support
6. Use the knowledge of individuals in improving professional awareness
7. Put into practice principles of user involvement in commissioning
8. Invest in and use the expertise of voluntary health organisations
9. Ensure real government commitment to making an impact.

LMCA - Unit 212, 16 Baldwin Gardens, London ECIN 7RJ
Tel: 020 7813 3637 Fax: 020 7813 3640 Email: alliance@lmca.demon.co.uk
WebSite www.lmca.demon.co.uk

⚠ ***The Long-term Conditions Alliance and National Voices merged on 17 October 2008 to create one unified umbrella charity representing service users and carers in health and social care policy-making nationwide. For more information see http://www.nationalvoices.org.uk/ltca/page*** ⚠

Editor's Notes - I recently attended the AGM and Members Conference of the LMCA and was able to speak with a number of people from other Support Groups. I gave information to and had a few minutes with Peter Homa, Director of Health Improvement, Commission for Health Improvement and Cliff Pryor of NSF - voted a new Trustee of the LMCA - who is working on the People's Voice for Health Campaign. I emailed him as requested with more information.

In the afternoon at the Workshop - Influencing local health policy makers - I asked 'Lincolnshire Health Authority use the National Figures for Neurological Conditions and divide them by the population of Lincolnshire, do other Health Authorities do the same? If so where do the National Figures come from? Linda Edwards Chief Executive of the National Osteoporosis Society said that they were campaigning for the statistics of wrist injuries to be broken down further so that they can pick up more information on breaks that could be from osteoporosis. Bernadette Maughan, one of this sessions speakers and Head of Consumer Relations at Nottingham Health Authority said she would take this up with her superiors.

LINCOLNSHIRE POST-POLIO NETWORK ANNUAL GENERAL MEETING.

DATE: 30th September 2000

VENUE: Ancaster Day Centre, Lincoln.

This Newsletter was prepared early due to the trip to America. Bookings on Saturdays at Ancaster Day Centre in Lincoln require one of the Caretakers to work overtime and due to holidays it has not been possible to confirm the date requested of 30th September 2000. If this date is not available then the date will appear above. If an alternative venue has to be picked this will also appear above. Full details including a map will appear in the next newsletter.

The rough format for the Saturday will be:- Annual General Meeting 10.40 followed by a break for coffee. 12.00 two talks. 1.00 we will serve a cold meat salad with roll and buffet lunch. Cost to be advised next issue. 2.00 - 3.30 two/three more talks followed by a tea break, raffle and question time. Ending at 4.30 with the building closed at 5.00p.m.

Each talk will be about half an hour in duration and on various subjects related to Polio and PPS with speakers confirmed next Newsletter. We anticipate covering the following subjects. Assessment and Diagnosis, Advice and Treatment available, Orthotics, Breathing and Swallowing problems and problems with getting/losing/fighting for benefits.

As with last year we have checked with the Holiday Inn Express and they have plenty of

vacancies to date on all weekends in September/October. Friday and Saturday nights will be full of fun and laughter if last year is anything to go by. A great way to share experiences of polio, PPS and the medical minefield in general. It certainly was not all doom and gloom, as many will remember the mascara ran down my cheeks! If you wish to book rooms at the Holiday Inn Express, please ring direct to 01522 698333 mentioning the Lincolnshire Post-Polio Network. We will arrange a special rate as soon as the date is confirmed.

LINCOLNSHIRE POST-POLIO NETWORK
Registered Charity No. 1064177

UK Membership - Life Member (LM) £100 or £5 x 20 months S.O. - Member £10 a year.
(All UK Memberships payable by Standing Order - Form on request)
Renewal dates are the First of the Months of Feb, Apr, Jun, Aug, Oct, Dec.
Please make cheques payable to 'Lincolnshire Post-Polio Network'
European Membership - LM £125- Member £12.50 a year- Newsletters by airmail.
USA/Canada Membership - LM US$250 - Member US$25 a year - Newsletters by airmail.
(US$ checks to LincsPPN c/o 4212 Blanding Blvd, Jacksonville FL 32210, USA)
Other Countries please contact for details.

All donations will be gratefully received.

LincPIN Newsletter - August 2000
Articles for publication by July 20th - Publication date August 5th 2000

All enquiries, book requests, medical article requests, membership fees, items for newsletters and donations to
The Secretary, Lincolnshire Post-Polio Network
PO Box 954, Lincoln, Lincolnshire, LN5 5ER United Kingdom
Telephone: +44 (0)1522 888601
Facsimile: +44 (0)870 1600840
info@lincolnshirepostpolio.org.uk

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Last information content change: 26th April 2009.