



The LincPIN

The Lincolnshire Post-Polio Information Newsletter
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WebSite - <http://www.ott.zynet.co.uk/polio/lincolnshire/>

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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 to those seeking such information. ALWAYS consult your doctor before trying anything recommended in this or any other publication. **Lincolnshire Post-Polio Network - UK Registered Charity No. 1064177**

Editorial by Hilary Hallam.

LincPIN. The **Lincolnshire Post-Polio Information Newsletters** are intended to together provide a comprehensive set of articles on post polio issues. This newsletter - No. 30 - contains as promised a long article on respiratory problems. I apologise to those of you who may not want to read it all, however, we have been asked repeatedly for information on this subject - see letters page (twice urgently this week). If you are having symptoms as on pages 6/7 then Health Professionals you are consulting may not be aware of this information. Many PPS groups have requested permission to reprint this in full for the same reason. See other comments on survey results attached.

All details of the Annual Meeting and Afternoon Events are on page 3 with a full page return slip which we do ask that you return whether or not you are able to come.

Polio is a neurological condition, there are only 300 neurologists in the UK and still we hear of neurologists with what appears to be a total lack of understanding of polio and its late effects. Two more in the last four days. One believes that we want to give up working, prefer to live on less money on benefits rather than what we were earning, miss out on the retirement we had planned, because we want to be disabled! Any health professional who really knows Polio Survivors - strong minded, hard working, over achieving, never stopping, don't need any help - would not be making this statement. To help with an article and letter we would be grateful if you could answer the following question added to the return slip. If you have had to give up work early due to PPS, tell us why, what job you had, and has this resulted in a drop in income. The other neurologist has been quite vehement to the patient about the 'bizarre' manner in which she has to get herself about, suggesting that her problems are purely mental!

Meetings since the last newsletter. Lynn Hobday and I attended the Lincolnshire Modernisation Council Meeting as representatives of the Lincolnshire Neurological Alliance. This was extremely interesting where health professionals and user/carers were discussing many aspects of health issues as the changes take place from Health Authority to Trusts etc. Not only did we learn some very interesting facts but our views were being listened to and taken into account. We attended workshops on Primary Care, Access and the Elderly. We have asked for a workshop on Neurology for the next meeting in September. Lincolnshire Neurological Alliance are still in the process of forming an official committee and finalising the Constitution. The next meeting is in September.

On June 20th along with Dr. Betty Dowsett (her report pages 4 - 5) I attended the Neurological Alliance/MS Society Day in Earls Court. Due to PPS, energy levels from travelling and the London Traffic I had to spend part of the morning session setting up

our display of laminated slides on PPS. Many health professionals from different parts of the country visited the stand. A lot of talking and handing out basic information leaflets. The afternoon session with talks from three Neurologists was very interesting, all three have multi disciplinary clinics - MS, MND and ME - and all reported that this was the best way to provide a good service. 'Don't knock neurologists' was the comment, 'morale is low, there are only 300 of us, we have many problems and the largest one is that we do not have enough funding to do the work we want.' Their advice was that we should be speaking to Central and Local Government Health Departments to campaign for greater funding. The evening session where The Neurological Alliance launched their new report *In Search of a Service* - the experiences of people with neurological conditions was excellent. Many meetings are taking place over the next few months and we look forward to bringing you more information in our future newsletters.

The Mobility Roadshow at Crowthorne was very interesting - and sincere apologies to anyone who was there and did not meet up with us due to the rain, although we did make a tannoy announcement of our move. I had the opportunity to look for other automatic vehicles that might fit my needs as my VW Sharan is up for change in October. There are no cheaper high seat automatic vans that will take an electric scooter on a hoist available on Motability. I am therefore having to apply for a grant to pay the £4,500 deposit. One real surprise was that Salesmen were interested in speaking to me when I was standing up but it was a different tune when I was riding on my scooter and one even suggested that it would be better for him to speak to the person who was going to drive the vehicle! I had a lovely opportunity of a chat and cuddle with Polio Survivor Peter Field who has campaigned and worked for many different disability organisations for many years despite his decreasing mobility. I was saddened to hear of his death in an accident only a couple of weeks later. His achievements for disabled people over the years have been incredible. Our sincere condolences to his family.

I gave my presentation to health professionals and polio survivors at Hayle in Cornwall last week. The senior physio told me afterwards that she now had more understanding of polio muscles and that my ideas of pre appointment self-assessment and energy planning could be used across many neurological conditions and she would be introducing some of this in the near future.

**Lincolnshire Post Polio Network Annual General Meeting
and Afternoon Events.**

Saturday 29th September 2001

Ancaster Day Centre, Boundary Street, Lincoln, Lincolnshire.

AGM is 10.45 for an 11.15 start

(Members only - room available for non members)

Buffet Salad Lunch will be served at approx. 12.40 p.m.

Cost £3.50 to be paid in advance if possible.

Afternoon Events will commence at 1.45 p.m.

Tea and Raffle at 3.45 - Question Time at 4.00

Room to be cleared by 5.00 p.m.

**As in previous years join us socially at the Bar of the IBIS Hotel
both Friday and Saturday evening.**

Nominations or Offers to stand for any of the posts of Chairman, Vice Chairman, Secretary, Treasurer, Committee Member are requested. Reply slip is enclosed with this newsletter.

The Afternoon Events will consist of one or two short talks (awaiting confirmation of speaker) and then a choice of half hour workshops where you will be able to discuss your problems. The actual workshops will be finalised upon receipt of your attendance slip - please enter on this any subject that you would like to discuss. There will be a workshop for those who do not have Polio. Question Time - this is open to all members so please submit yours on the attendance return form. Any not covered during the day will be answered and all published in the next newsletter.

Ancaster Day Centre is just after house Number 32 on the left of Boundary Street in Lincoln. Turn in left and drive round the back to the Car Park, entrance at the far end. Boundary Street is west off the A1434. The A1423 goes from Lincoln to Newark from the Roundabout junction with the A15 (Lincoln to Sleaford). Coming from the north Boundary Street is about 100 yards south of the roundabout, after the Esso Station on your right, 15 yards before the Pedestrian Lights. Coming from the South it is past Walkers Crisps and a Gas Station on your left and just after the pedestrian lights.

Rooms have been pencilled in at the IBIS hotel which is behind the Pride of Lincoln (visible on the A46 Lincoln Bypass) and accessed via the first road left off Whisby Road. Please take care at the A46/Whisby Road Junction, it is extensively hatched to allow turning but the opposite road is offset.

Please contact the IBIS Hotel directly mentioning the Lincolnshire Post Polio Network on 01522 698333 All rooms are priced at £35 with Continental Breakfast available at a price of £3.95 each if wanted. They now have a snack and meal of the day menu but inform us that we can still bring in or have a Take Away sent in. A full meal service is available at the Pride of Lincoln about 30 yards across the Car Park. Please ring if you would like us to find you alternative cheaper closeby accommodation.

Families and friends are welcome. We will have leaflets and information available on What's On in Lincoln. Close by to the IBIS Hotel are a Garden Centre with small Animal Park, the Whisby Nature Reserve with Exhibition Centre and Cafe, Doddington Hall and North Kesteven Sports Centre. In Lincoln itself there is the Cathedral and Castle both started in 1068, the Lincolnshire Life Museum, the Usher Art Gallery, the Lawn Visitors Centre, Roman Ruins and many shops.

A return slip is enclosed with this Newsletter. Please help us to organise this event by completing and returning this as soon as possible. We need to know if you can or cannot attend, if you wish or do not wish lunch, if you have any nominations or would like to offer yourself for a post on the committee, and if you have any questions that you would like put at Question Time. Any questions that we do not have time for will be answered and all will be published in the next newsletter.

We look forward to seeing as many of you as possible and will provide a full report with the next newsletter.

The Neurological Alliance / MS Society Day at Earls Court June 20th 2001 One Amazing Meeting!

Introduction. As a Life Member of the Lincolnshire Post Polio Network (as well as of 3 ME charities) I was able to attend the event of this organisation for the first time and found it a truly mass gathering of like-minded people with neurological disabilities and of their professional carers. The audience filled two enormous ballrooms and the foyer of a large hotel in Earls Court, London. The Neurological Alliance now represents some 50 charities supporting a widespread profile of chronic neurological conditions which currently affect over 3 million people in the UK. Their disabilities range from brain and spinal injuries and malignancies to stroke, epilepsy and congenital deformity and include conditions with which I am more familiar such as meningitis, MS, Parkinsons, Motor Neurone Disease, ME and the Post Polio Syndrome.

Patients and Professional Carers Working Together. To my astonishment, many of the smartly dressed, well spoken and obviously professional speakers and chairmen revealed themselves to be sufferers or carers of people with these devastating conditions. The impact of their self confidence and achievement was dramatic and gave us all new hope for the future. However, this hope will demand even closer co-operation between patients and professionals if sufferers and carers are to be given the choice and the control which they need over the services they receive (or hope to receive in the future).

The Patient User/Consumer Movement. This relies upon a long and hard won record of success based initially on the efforts of the keynote speaker (a sufferer from MS who was co-founder with Michael Young of the College of Health). She has long struggled to educate fellow patients about the corrosive imbalance of power between doctors and patients and the insidious erosion of patients' rights within the NHS including the right to second opinion, the tacit withdrawal of the 'patients charter' and the insistence upon reliance on random controlled trials (RCT's) as the gold standard of management while 'quality of life' is far more important in chronic neurological disease, in children and the elderly. We were reminded of the current fragmentation of the voluntary sector, their rivalry for meagre financial support, despite the fact that nowadays more funding for research is derived from volunteers than from the government.

Neurological Appointments should be a meeting between equals. There is a lot of excellent practice in the community and, for the third year the MS society distributed awards for above average performance and initiative to:- a) The Walton Centre, Liverpool, for its education modules on stress management, nutrition lifestyle and prevention of secondary disabilities after diagnosis and hospital discharge. b) Tree Tops Nursing Home, Colchester, for its special research programme which recognises the expertise of patients who contribute to these studies, who educate other patients and who were enabled to attend the conference and contribute to questions from the audience by means of special amplification. Entrance to the Nursing Home proved to be enabling rather than restrictive in the late stages of MS. c) The National Hospital for Nervous Diseases - for its dedication to the emotional and educational needs of newly diagnosed patients.

Medicine is an Art as well as a Science. The afternoon sessions were devoted to innovative medical practice by Consultant Neurologists of whom we were reminded, we have but 300 in the UK compared with some 10,000 in other European countries of similar size!

a) Colchester - where the Consultant Neurologist welcomes co-operation with support groups. He blames the current 2 year waiting list upon management by medical staff trained primarily in 'Public Health' rather than in general medical problems, but has somehow managed to set up efficient NEUROCARE programme for the common neurological disabilities - mainly MS. However, it seems that half his workload is derived from 'medically unexplained' conditions which do not come within his remit and cannot be helped. I very much suspect that the commonest neurological conditions in the UK today (including the late effects of ME and the Post Polio Syndrome) fall within this category! {Editors note - I spoke to this Neurologist later and he said that he would not be able to see Polio Survivors as he knew nothing of PPS and then thanked me for the information that I gave him]

b) Guys and St. Thomas' and Kings College Hospitals - Consultant Neurologists have developed an MND Nurse led outreach service for long term secondary problems including pain, ventilation

requirements, gastrostomy, speech therapy and palliative care.

c) Harold Wood Hospital ME Centre - one of the founder members of the Neurological Alliance, where care for ME patients was initially linked too the pre-existing neuro care programmes for Parkinsonism and Tremor. ME, one of the commonest and most chronic neurological conditions in the UK, has a devastating effect of adolescents and is by far the most frequent cause of long term school absence. Many patients are severely ill and house bound or bed bound but, though they can be managed by conventional methods within the NHS, Harold Wood is the only charity which has taken on an in-patient and outpatient service. The cost of this illness runs into millions of pounds but, as yet, there is no NHS provision for patients. Tribute was paid to the early pioneers of the Harold Wood Centre.

Collaboration with a Wider Medical Audience. The evening session included a wine reception to mark the launch of the Neurological Alliance's new report 'In search of a service - the experiences of people with neurological conditions' to which delegates from the 2001 World Congress of Neurology (held across the road at Earls Court) were cordially invited.

Poster Displays in the Foyer. A special mention must be made of the wonderful display provided by the Lincolnshire Post Polio Network. Despite having no speakers in the main sessions, this was the major focus of attention outside, offering the opportunity to view vivid illustrations of post polio problems, a comprehensive range of literature on the subject and an operative website display. There was also an opportunity to meet and discuss the problems of this illness with Hilary Hallam. As a long term patient she has achieved impressive improvement largely by her own efforts and must be considered one of the most knowledgeable persons in the UK in respect of the management of the Post Polio Syndrome - an illness for which no provision has yet been made by the NHS.

Summary. There are a great many lessons to be learnt from this conference in respect of the management of ME and the late effects of both ME and Poliomyelitis which are indistinguishable and may include secondary problems with Parkinsonism. The attempt to set up and to main specialised ME clinics has merely served to marginalise the disease and has induced many patients to make long journeys to the few geographically distant centres available, with resultant relapse and deterioration.

Only by means of co-operation and collaboration with other neurological charities can a properly conducted neurological assessment, followed by equal right of access to local rehabilitation facilities for all ME, Post Polio Patients and other similar neurological conditions be achieved in the near future.

Dr. E. G. Dowsett, MB ChB, Dip.Bact.
Honorary Consultant Microbiologist Basildon and Thurrock General Hospitals NHS Trust
and member of The Chief Medical Officer's Working Party on ME.

47 Drewsteignton, Shoeburyness, Essex SS3 8BA

THE TRUTH IN JUST 13 WORDS

**Inside every older person is a younger person
wondering what the hell happened.**

Breathing Problems of Polio Survivors

Reprinted with permission
from GINI International Polio Network
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People with neuromuscular disease such as post-polio often need help with breathing, not because there is something wrong with the lungs, but because the respiratory muscles may be weakened or paralyzed and the chest wall is stiff and inelastic. If scoliosis is present, the work of breathing may be even harder. Other conditions such as chronic obstructive pulmonary disease (COPD) and sleep apnea (obstructive, central, or mixed) may also be occurring. And, overlaying all of these factors, is the simple fact of aging.

How did acute poliomyelitis affect breathing? What is bulbar polio? What is spinal polio?

The poliovirus affected, in many different patterns, the nerve cells in the lower brain (bulbar) and spinal cord that control the muscles of the body. Poliovirus does not damage the lung tissue or the nerves to the airway muscle.

When the bulbar nerves were destroyed (bulbar polio), the muscles of the throat were weakened. This resulted in choking during eating and a diminished ability to cough.

When the spinal nerves were affected (spinal polio), muscles of the arms and legs, and trunk muscles needed for breathing and for taking a deep breath for coughing were weakened. Polio survivors may have had some combination of bulbar and spinal polio, so there may be corresponding throat muscle and limb/respiratory muscle weakness. Involvement of the upper part of the spinal cord weakened the key breathing muscles – the diaphragm and chest musculature.

How does respiratory muscle weakness affect breathing?

The diaphragm is the key muscle for inspiration (breathing in). When it is weakened by polio, the work of breathing becomes harder, especially when a person is lying down. With each breath, the abdominal contents have to be pushed down, but when sitting upright, gravity assists the diaphragm by pulling the contents down. Polio survivors, especially those with scoliosis, compensate by breathing faster but more shallowly because they lack the muscle

strength to stretch a stiff rib cage. They may also have smaller lung volumes that further reduce respiratory muscle efficiency and drastically increase the work of breathing. This can lead to underventilation and respiratory failure.

How does respiratory muscle weakness affect sleep?

Respiratory muscle weakness contributes to sleep-disordered breathing. During REM (rapid eye movement) sleep, relaxation of many voluntary muscles, including the shoulder, chest, and abdominal muscles, often occurs. And, these muscles are used to assist breathing when the diaphragm is weak. Consequently, a weak diaphragm has difficulty sustaining adequate breathing, especially when lying down. This leads to a decreased level of oxygen in the blood, or SaO₂ desaturation. SaO₂ desaturations can extend into non-REM sleep and contribute to arousals, inducing sleep fragmentation, and decreasing the amount of time in REM sleep. The quality of sleep deteriorates.

A polio survivor experiencing a combination of any signs and symptoms in the following list should immediately seek a respiratory evaluation, preferably by a pulmonary physician (pulmonologist) with experience in neuromuscular disease.

- Shortness of breath on exertion (dyspnea)
- Need to sleep sitting up (orthopnea)
- Retention of carbon dioxide (CO₂)
 - morning headaches
 - poor concentration
 - and impaired intellectual function
- Sleep disturbances
 - not feeling rested in the morning
 - sleepiness during the day
 - dreams of being smothered and/or nightmares
 - restless and/or interrupted sleep
 - fatigue or exhaustion from normal activities
 - snoring
- Claustrophobia and/or feeling that the air in the room is somehow bad
- Anxiety
- Difficulty in speaking for more than a short time
- Quiet speech with fewer words per breath

Use of accessory muscles to breathe

Weak cough with increased susceptibility to respiratory infections and pneumonias

Are all polio survivors at risk for breathing problems?

No. Individuals who used an iron lung, or barely escaped one, during the acute phase should be aware of potential problems. Those survivors who did not need ventilatory assistance during the acute phase, but who had high spinal polio resulting in upper body weakness and/or diaphragm weakness, and those with scoliosis (sometimes referred to as chest wall deformity) may also be at risk.

Other factors contributing to breathing problems are asthma, COPD, smoking, obesity, and sleep apnea: either central, obstructive, or mixed.

Another compounding factor is diminished vital capacity (VC), which happens to everyone as they age.

Why do these problems often go unnoticed?

The reasons are varied and can be complex. The onset of respiratory problems is insidious, and this gives an individual time to become accustomed to each decrease in function. Thus, one is not immediately aware that anything is wrong, and a treating physician may not recognize the signs or be familiar with the option of home mechanical ventilation. The person's spouse or family should be questioned about signs and symptoms, changes in activity levels and breathlessness, and sleeping patterns.

Additionally, facing breathing difficulties can be frightening, for both the survivor and their loved ones, and there can be a reluctance to address them. Sometimes this fear stems from inaccurate information about the problem and the solutions or from earlier polio-related experiences.

What is underventilation?

The alveoli in the lungs are tiny air sacs at the end of the respiratory tract where gas exchange with the blood occurs. In underventilation (medically known as chronic or global alveolar hypoventilation), the saturation of oxygen in the blood falls due to increased carbon dioxide (CO₂). Normally the alveoli should clear most of the CO₂ out with

each breath. Instead, the CO₂ accumulates (called hypercapnia), and thus there is decreased room in the alveoli for oxygen.

Hypercapnia and decreased oxygen saturation are the hallmarks of underventilation or hypoventilation. The signs and symptoms of underventilation usually appear first during sleep.

Some people seem to suddenly experience life-threatening respiratory failure due to CO₂ accumulation (hypercapnia). They may not have been aware of gradually increasing symptoms and signs, particularly since they are often not physically active nor regularly monitored with simple pulmonary function tests. Polio survivors may think that they are breathing fine until an upper respiratory infection, which makes breathing in harder for everyone, causes serious problems, partially due to an ineffective cough and the inability to eliminate secretions.

Who is the most qualified to evaluate breathing problems?

Astute family physicians will order a referral to a pulmonologist, preferably one experienced in neuromuscular disease. Pulmonologists specialize in all breathing-related disorders, however, most focus on more acute problems such as intensive care. The pulmonologist who focuses on neuromuscular diseases understands that the problem is due more to respiratory muscle weakness and the restrictive nature of the disease rather than the lungs themselves.

The IVUN Resource Directory compiles a list of pulmonologists and respiratory health professionals who are knowledgeable about and committed to home care and long-term mechanical ventilation. It is available at www.post-polio.org/ivun/ or in hard copy from International Polio Network.

What tests will a pulmonologist order?

Pulmonary function tests can be performed in a physician's office with a simple spirometer (an instrument for measuring the capacity of the lungs) or in a fully-equipped pulmonary function laboratory.

Pulmonary function tests should include:

Vital capacity (VC) both sitting and supine (lying down), FVC, FEV₁. VC measures the total volume of air one can breathe out completely after inhaling a full breath. VC is usually done

forced, as fast as possible, and is known as FVC. When this fast forced expiration is performed, the volume breathed out in the first second is known as FEV1. VC is sometimes done slowly and is called SVC. These tests can be done while standing, sitting, or supine. A drop in VC over 25% in the supine position indicates significant diaphragm weakness. When VC declines to <1 L (liter), underventilation often occurs. [LincPIN Editors note, there are two domes to our diaphragms, and it would be advisable if testing is also done with you lying on each side]

MIF and MEF. Maximum inspiratory force (MIF) and maximum expiratory force (MEF) are measured by breathing in and out with maximal effort, through a closed mouth tube attached to a pressure measuring device. This measurement reflects inspiratory and expiratory muscle strength.

Peak cough flow. In people who have had polio, cough is often not effective enough, due to respiratory muscle weakness. A weak cough can lead to poor secretion removal, increased respiratory infections, and pneumonia.

What is an ABG and should polio survivors who suspect breathing problems have one?

An arterial blood gas (ABG) should be ordered when VC falls or symptoms of underventilation develop. An ABG invasively measures levels of oxygen, carbon dioxide, and pH in the blood and assesses pulmonary gas exchange. A non-invasive measurement of oxygen saturation in the blood is pulse oximetry, but it is not as complete or sensitive as an ABG.

What is pulse oximetry?

The blood oxygen saturation can be measured noninvasively using a pulse oximeter. It is a probe placed usually on a highly oxygenated part of the body, such as the finger. Infrared light is released and analyzed by recording its changing absorption in the arterial blood. Nocturnal oximetry is becoming more useful in screening for abnormalities that often occur first during sleep. Some oximeters have a memory module to record 8-12 hours of oxygen and pulse rate data.

What is a sleep study and when is it necessary?

Sleep studies (formally known as polysomnography) are usually performed in a sleep laboratory over one or two nights to record multiple variables simultaneously, such as sleep stages, rapid eye movement (REM),

snoring, airflow at the nose and mouth, arousals, heartbeat, chest wall breathing motion, and oxygen saturation, to assess sleep disorders (such as sleep apnea). These studies include EEG (brain wave), ECG (electrocardiogram), and often a video record of sleep movements.

Sleep studies are recommended for an individual exhibiting signs of nocturnal underventilation, but not daytime underventilation, or for asymptomatic individuals with a VC <1 to 1.5 L.

Sleep studies are often recommended to detect sleep apneas.

What is sleep apnea?

Defined as the lack of breathing through the nose and mouth for at least ten seconds, sleep apnea can be obstructive or central or mixed. Obstructive sleep apnea (OSA) occurs when tissues in the throat collapse and block airflow in and out of the lungs during sleep, although efforts to breathe continue. Central apnea occurs when the brain fails to send appropriate signals to the body to initiate breathing. There is neither airflow nor chest wall movement.

In sleep apnea, breathing ceases, oxygen in the blood decreases, arousal occurs, sleep ends, and breathing resumes. The individual then drifts back to sleep and another apnea occurs, with this cycle continuing throughout the night, resulting in hundreds of arousals from sleep.

OSA at first occurs when individuals sleep on their backs, but eventually apneic episodes are present with any sleep position. A number of factors make snoring and apnea worse, such as obesity and nasal obstruction. Smoking causes the lining of the upper airway to swell, alcohol and sedative drugs cause the muscles in the back of the upper airway to relax, and excessive weight decreases the size of the upper airway.

When there are night-time breathing problems in a person with neuromuscular disease, such as post-polio, they are more likely due to respiratory muscle weakness, rather than OSA. However, some individuals may have only OSA while others may have both respiratory muscle weakness and OSA.

What is the treatment for sleep apnea?

Sleep apnea is best treated with the use of a continuous positive pressure airway (CPAP) device to push the tongue out of the way and

keep the airway open during sleep. If underventilation and sleep apnea occur simultaneously, a bilevel positive pressure device is recommended to help improve ventilation and also keep the airway open.

What is CPAP?

CPAP stands for Continuous Positive Airway Pressure. Air flows continuously into the airway via the nose with use of a nasal mask. CPAP keeps the airway open, but does not adequately assist respiratory muscle activity.

CPAP is primarily used to treat obstructive sleep apnea, and thus is normally used only at night during sleep. CPAP units are not ventilators. Higher pressures may make exhaling uncomfortable and difficult. Newer CPAP units, called Auto CPAPs, automatically provide varying levels of pressure based on the individual's needs during the night. Because OSA is prevalent among the general population, many companies offer CPAP units.

What is mechanical ventilation (MV)?

Mechanical ventilation is the use of machines to help people breathe when they are unable to breathe sufficiently on their own. It is most often used for a few days in a hospital setting, when people are recovering from surgery or during a serious illness. However, some people may be unable to breathe on their own after the acute illness is over and may require long-term MV. Other people may have a stable, chronic condition that prevents them from breathing on their own; they may need to use a ventilator only at night or both at night and during the day.

Assisted breathing through mechanical ventilation can help people sleep better and result in improved lung function during the day. MV can restore the gas exchange and prevent respiratory failure.

When is mechanical ventilation an option?

A general guideline, but not a rule, suggests that mechanical ventilation be initiated when there is a 50% decline in VC or a VC of under 1 L. Each symptomatic survivor needs a comprehensive evaluation by a knowledgeable physician to determine when to start MV. This is especially true of the survivors of bulbar poliomyelitis. Mechanical ventilation helps rest the respiratory muscles, resets the sensitivity to CO₂ of the controller in the brain, and improves pulmonary mechanics by providing more functional lung expansion.

Is exercise a treatment option?

Chest expansion exercises may help keep the chest wall more elastic and avoid loss of lung volume. There are four ways this can be done: with an Ambu-type resuscitation bag, using a volume ventilator for air stacking, using glossopharyngeal (frog) breathing, or using an IPPB (intermittent positive pressure breathing) machine.

If I need mechanical ventilation, what are the options?

The older technology of negative pressure ventilation, which developed during the polio epidemics to keep respiratory polio survivors alive, has given way to the newer technology of positive pressure ventilation.

Negative pressure ventilators apply intermittent negative pressure (like a vacuum) to the chest and abdomen by means of an iron lung or Porta-Lung, a chest shell (cuirass), or a form of body jacket or wrap. Some polio survivors still use the iron lung, Porta-Lung, or cuirass.

The pneumobelt is also still used. It is an inflatable corset around the abdomen which acts by pressing on the abdomen to augment exhalation. Inspiration is not assisted. The pneumobelt can only be used in the upright, seated position and does not work if one is either underweight or overweight.

Positive pressure ventilation uses a bilevel pressure support device or a volume ventilator to deliver air noninvasively via a face mask, nasal mask, nasal pillows, mouthpiece, lipseal, or oro-nasal combination, called noninvasive positive pressure ventilation (NPPV). Positive pressure can also be delivered invasively through a tracheostomy tube (TPPV).

What is the difference between a bilevel device and a volume ventilator?

Bilevel pressure devices continuously deliver air, but the inspiratory pressure can be adjusted separately from the expiratory pressure. Bilevel devices are also used with a face or nasal mask or nasal pillows, and, like CPAP, used mainly at night. However, bilevel devices can only deliver a certain amount of pressure that may not be enough for people with respiratory muscle weakness and underventilation. There are many bilevel pressure devices on the market, but the only one that can be truly called BiPAP® is from Respirationics.

Compared with volume ventilators, bilevel

devices are lightweight, less expensive, easier to use, and adjust better to leaks. However, disadvantages include not being well-suited for tracheostomy ventilation, having no internal battery, not as commonly used with an external battery, may be noisier, and the expiratory pressure is unnecessary for some people and may cause thoracic discomfort. Examples of bilevel devices include Respiroics Bi-PAP® S/T and BiPAP® Synchrony™; Puritan Bennett KnightStar 330® and KnightStar 320®; ResMed VPAP® II ST; and Breas PV102.

Volume ventilators deliver a pre-set volume of air. These machines can deliver much more air than bilevel devices, and thus enable deeper breaths for improved coughing and air stacking. They may be necessary for people with poor lung elasticity, such as those with pulmonary fibrosis, and stiff chest walls, as with kyphoscoliosis, when bilevel is not enough. Volume ventilators, though larger and heavier and more expensive than bilevel units, are quieter, have more alarm features, overcome airway secretions and resistance, have an internal battery, work from battery power easier, can be used for 24 hours, and are well-suited for tracheostomy use.

Examples of volume ventilators include the LP6 Plus, LP10, and Achieva® from Puritan Bennett, PLV®-100 and PLV®-102 from Respiroics, TBird® Legacy from Thermo Respiratory Alternate Care, and PV501 from Breas.

A new generation of ventilator technology has produced the LTV™ series from Pulmonetic Systems, Inc. These new ventilators are compressorless and run by turbines. They are very small – about the size of a laptop computer – and lightweight, about 13 lbs., but more expensive. They also have the capability to offer both volume and pressure support.

Who decides which equipment to use? How?

The answers to these questions focus on whether there is breathing muscle weakness or whether there are reasonably normal breathing muscles but obstructive sleep apnea (OSA).

If there is night-time breathing abnormality due to muscle weakness, it is best treated with a machine that assists ventilation, such as the aforementioned bilevel pressure device or volume ventilator.

If the upper airway tends to close off during sleep, OSA occurs. This is often successfully treated by continuous positive airway pressure

(CPAP* which delivers a constant flow of air to keep the airway open. It is certainly possible to have weakness in the throat/pharyngeal area that produces OSA, without weakness of the breathing muscles. If this is the case, CPAP is the appropriate treatment.

Whether to use a portable volume ventilator or bilevel pressure device is an important decision. Sometimes the choice reflects the experience and training of the pulmonologist or respiratory therapist. Often cost is a factor. In Europe, the costs of the bilevel pressure devices and the volume ventilators are not as disproportionate as they are in the United States.

The ventilator which is most comfortable for the user and fits his or her individual ventilatory needs best should be the overriding choice. The physician, respiratory therapist, and ventilator user should collaborate on determining the best system, although ventilator users are not often given the opportunity to try different ventilators and systems.

Where is the best location to start noninvasive positive pressure ventilation (NPPV)?

Generally, NPPV is started in the home by a respiratory therapist from the home health care agency or durable medical equipment (DME) provider, as ordered by the physician (who is not present). However, home health respiratory therapists have limited time, and the home health care agency does not receive reimbursement for the time needed. The therapist usually cannot demonstrate the whole range of equipment and interface options available. Follow-up is needed repeatedly in the first months to ensure that the equipment and interfaces are comfortable and working properly to achieve optimal benefit.

The use of NPPV can also be initiated as part of hospital discharge, where there should be more time to do it properly. However, many pulmonary critical care physicians are highly ICU-focused, and they and the respiratory therapy staff may not have the experience and interest needed to get optimal results.

When possible, the best approach may be for the individual to visit the home MV unit of a medical center for daytime assessment and for teaching the use of NPPV. The person can try various equipment and interfaces to see which would work best under the guidance of an experienced physician and respiratory therapist. The day visits can be repeated as

needed for setup and followup. This is in addition to the home health care/DME company's home visits after the system is selected and ordered.

What does a respiratory therapist do?

Respiratory therapists work under the direction of a physician, usually in hospital settings where they perform intensive care, critical care, and neonatal procedures. Polio survivors usually interact with a respiratory therapist in their physicians' offices and/or in their homes during visits from a therapist hired by a home health agency or a home medical equipment supply company (Apria, Lincare, etc.).

Respiratory therapists perform procedures that are both diagnostic and therapeutic. Some of these activities include: taking arterial blood gas (ABG) specimens and analyzing them to determine levels of oxygen, carbon dioxide, and other gases; measuring the capacity of the lungs to determine if there is impaired function; and studying disruptive sleep patterns. Respiratory therapists help set up and maintain the various equipment (CPAP and bilevel devices, ventilators) to assist breathing, adjust the settings, adjust the mask or other interface, instruct in their use, and monitor compliance.

What is an interface?

An interface connects the tubing from the volume ventilator, bilevel device, or CPAP to the person using it. Examples include nasal or facial masks, nasal pillows, lipseal, mouthpiece, or tracheostomy. Often the individual is handed only one mask to try by a respiratory therapist from a home health care company, but several different masks may need to be tried in order to find one that fits properly. Many people do best when they can choose at least two (nasal) interfaces that are comfortable and rotate between them. Individuals can use a mouthpiece if they have nasal congestion due to a cold.

Adapting to and making adjustments to an interface is critical and often requires patience and determination. Many users creatively adapt their masks to achieve the best fit.

What is a tracheostomy and when is it necessary?

A tracheostomy is an artificial airway created during a surgical operation called a tracheotomy. A tracheostomy may be necessary for polio survivors who cannot tolerate noninvasive ventilation, for those who can no longer be adequately ventilated

noninvasively, and for those who need ventilation more than 20 hours per day. Other considerations include a severely impaired cough and inability to clear secretions, and significant swallowing problems. Some polio survivors who need 24-hour ventilation may prefer to use noninvasive ventilation.

The decision to undergo a tracheotomy is a serious one and should be made by a fully informed individual along with caregivers in consultation with the physician.

How can a polio survivor improve cough?

Retained secretions in people who have impaired coughing ability can turn a common cold into pneumonia. To improve cough, there are two forms of assisted coughing.

Manually assisted coughing involves another person administering a thrust to the chest and abdomen of the individual with neuromuscular disease immediately after that individual takes a big breath.

Mechanically assisted coughing can be performed with the CoughAssist™ by J.H. Emerson Company. The CoughAssist applies positive pressure to provide a deep breath in, then shifts rapidly to negative pressure to create a high flow out, as with a normal cough.

What is cor pulmonale?

Cor pulmonale (right-sided heart failure) can occur in post-polio and in other diagnoses, such as COPD. In both, the low oxygen level causes pulmonary hypertension, liver enlargement, and swollen feet. Cor pulmonale is detected by a careful physician examination, keeping respiratory muscle weakness in mind.

What about oxygen?

Tony Oppenheimer, MD, retired physician in pulmonary and critical care medicine from Southern California Permanente Medical Group, cautions, "Administering oxygen does not provide assistance to the weakening respiratory muscles, but gives both the patient and the doctor the false impression that appropriate treatment is being provided. Underventilation is mistaken for an oxygen transfer problem. Indeed, administering oxygen can mask the problem.

"Also there is a danger of causing respiratory depression by giving oxygen. It will improve the oxygen saturation, but not the underventilation. It may increase the danger of dying of sudden respiratory failure.

“Some situations may require administering oxygen, such as cor pulmonale or pneumonia due to infection or aspiration. If this occurs in people with respiratory muscle weakness and hypoventilation, then it is important to provide both assisted ventilation and supplemental oxygen, and use ABGs to monitor them.”

A useful analogy from Lisa S. Krivickas, MD, Spaulding Rehabilitation Hospital, Boston, in regard to people with respiratory failure from neuromuscular disease is that the lungs are like deflated balloons that are not strong enough to inflate.

To inflate the balloon, mechanical assistance to force air into the balloon is needed. Blowing oxygen across the mouth of the balloon (the equivalent of using supplementary oxygen delivered by nasal cannula) will do nothing to inflate the balloon.

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**Thoughts from Peter C. Gay, MD
Associate Professor,
Critical Care and Sleep Medicine,
Mayo Graduate School of Medicine,
Rochester, Minnesota
USA (507-284-5398)**

Presented at GINI's Eighth
International Post-Polio
& Independent Living Conference, June 2000

On weakness ... “The vernacular defining post-polio syndrome includes non-specific weakness. Many physicians overlook the fact that polio survivors are describing respiratory problems.”

On symptoms ... “The important thing to recognize is that the vast number of polio survivors do not necessarily have lung disease, per se. The problem usually is the inadequate way they move air in and out of their lungs.

“It is important to determine which symptoms are related to breathing, which are related to the heart, and which are related to deconditioning. Even Olympic athletes can become deconditioned.”

On abdominal paradox ... “Many polio survivors have difficulty with breathing while lying. Physicians can assess this by observing the abdominal paradox which occurs when the abdomen inappropriately collapses inward as the chest expands during inhalation.

“Normally when one lies down and takes a deep breath, the diaphragm pushes down and the abdomen pushes outward. If the diaphragm is very weak and the chest muscles are doing most of the work, then the abdomen is going to paradoxically collapse. This is a very specific sign that a physician can recognize by placing a hand on the abdomen and asking the patient to take a deep breath. If the abdomen collapses during inspiration, it is a sign of a weak diaphragm. During sleep, this is critical to understand.”

On deterioration of quality of sleep ... “The sleeper that people get, the more they want to sleep, and the more they are tortured by the need to wake up to breathe.”

On sleep apnea ... “The ‘I won’t breathe’ form is central sleep apnea. The controller, during REM sleep particularly, stops firing impulses adequate to make one breathe. It is important to demonstrate the difference between these because different equipment is needed for each form.

“The ‘I can’t breathe because the upper airway is blocked’ form is obstructive sleep apnea. It is most common in males and is due to being overweight and to the size of the neck and structure of the upper airway. In post-polio patients, the weakness of the muscles of the mouth can be such that, when lying on one’s back, the muscles can block off and cause snoring.”

On night-time assisted ventilation ... “Breathing at night is like driving. You need power steering. You still want to drive, but it feels like you are driving a big Mack truck. You need a device that allows you to turn that steering wheel more easily.”

On using oxygen ... “In normal sleep, sensitivity to CO₂ is reduced so that we all shallow breathe during REM sleep. Elevated CO₂ during REM sleep lets people stop breathing or slow breathe until the oxygen saturation levels get so low that the brain alarms to say, ‘Wake up!’ From that standpoint, supplemental oxygen tends to be a poison to people with this problem who are not also getting ventilation at the same time, because they lose the low O₂ wakeup alarm.”

Polio Network News Editor’s Comments

With special thanks to Judith Raymond Fischer, volunteer editor of IVUN News, this issue of Polio Network News features the breathing problems of polio survivors.

Why dedicate a whole issue to this subject?

#1 – A common misconception about home mechanical ventilation is that it is the same as being in an ICU – unconscious, intubated, and connected to a large hospital ventilator – as depicted on popular medical TV shows. Using a ventilator at home is very different, as described by polio survivors Jean Davis and Marion Gray, who sent photographs of their satisfied and well-ventilated selves.

#2 – It is the one aspect of the late effects of

polio, besides swallowing, that could be potentially life-threatening. And, in my travels, I continue to hear stories from polio survivors who have breathing difficulties.

#3 – I know many polio survivors who now use night-time ventilation and feel so much better, but their pathway to this relief was through the emergency room. I believe our Network is obligated to provide knowledge to prevent this from happening to others.

#4 – This issue is a good way to educate polio survivors who, in turn, can educate their doctors. I have heard the comment, “I am not having breathing problems. The physician checked my lungs and they are fine.” Or, “The physician checked my breathing and said it isn’t bad enough yet and he didn’t think I would want to use a ventilator this young.”

#5 – The decision about the type of ventilation to use and when it will begin should be made in collaboration with your doctor and your family. The purpose of this Polio Network News is to ensure that the decision is an informed one.

My appreciation to Tony Oppenheimer, MD (eaopp@ucla.edu), and to ventilator user Linda L. Bieniek for their insightful reviews.

We all struggled with what to include and how to explain a complex topic briefly and simply – one that really may apply to you.

– **Joan L. Headley, MS,
Executive Director, GINI**

My Journey to a Good Night’s Sleep Marian Gray, Oakland, California

When I was 5 years old, I contracted polio. The family doctor, summoned to my home, carried me out the front door. I have not retained much of the following weeks and months except that my parents were kept away from me, and, at some point, I felt that I was suffocating. I was placed in an iron lung, but do not remember how long. Rather than being sent to a rehabilitation facility, I returned home and had visits from a physical therapist. I had leg braces, a strange arm brace that held my right arm straight out from my shoulder and bent at the elbow, and a little wheelchair.

I did not attend school until third grade, and by that time I had tossed the braces and wheelchair. Breathing did not seem to be an issue then. At age 8, I had a spinal fusion and was out of school for fourth grade. Back in school for fifth grade, I used a wheelchair for

trips to the playground where the other children used me as a battering ram.

Around this time, I remember having difficulty coughing up secretions when I had respiratory infections. I remember being embarrassed in class while trying to cough, terrified that I would choke to death. Years later, I figured out that shoving myself on my abdomen could help while trying to cough. I still use that same method.

In the early '80s, I attended a GINI conference in Saint Louis. There was a lot of talk about breathing problems and respiratory infections. I remember Augusta Alba, MD, mentioning the possibility of "drowning in your secretions" and the necessity of dealing with this aspect of the late effects of polio. One of the vendors had a chest shell breathing device that I tried. Someone nearby said, "You should have seen the look on your face when you tried that thing." So that is what it felt like to breathe!

Back home in California, I tried to track down information about breathing devices and how to deal with respiratory infections – without much luck. One pulmonary doctor told me that, because I had not died during the initial attack of polio and no longer used the iron lung, I could not have breathing problems related to polio. I did not believe him, but did not feel in serious trouble except when I caught a cold.

Then came nightmares of drowning or suffocating, waking up choking, morning headaches, and, worst of all, getting up and down many times during the night to use the bathroom. I eventually went to another pulmonologist who sent me home with a pulse oximeter. I was also referred for a pulmonary function test that was only done in a sitting position, not repeated while lying on my back (supine). Based on the results of these tests, I was provided with a bilevel positive airway pressure device and a mask. I tried it for a few nights, but it was awful.

About five years ago, a respiratory therapist friend encouraged and helped me to get an appointment with a doctor at Kaiser's regional rehabilitation facility in Vallejo, California. I had pulmonary function tests and was referred to the overnight sleep lab. After two hours, the lab technician came into my room and said, "You're not breathing enough." She gave me nasal pillows to use with a bilevel device. For a few minutes I thought I would surely suffocate and die, but the technician was very comforting and managed to calm me down. Eventually, I fell asleep.

My new doctor prescribed a Bi-PAP®. Since my insurance policy does not cover durable medical equipment, I paid for these items myself. I was sold nasal pillows, headgear, and tubing to attach to the machine that I rented for a month. There was no mention of other brands or models that might exist. When I began using the new equipment, I hated it. The machine was noisy, I heard the air coming in with every breath, and I felt the air as it shot each breath at me. The nasal pillows leaked and my nostrils were sore in the morning.

I tried to educate myself about the whole situation and found a polio chat room where breathing issues were rarely discussed, except once when someone mentioned a breathing machine that was quieter than others. So, there were choices out there. I would not have to settle for the first machine I tried.

Over the next couple of months, I rented about five different machines and tried a variety of masks (interfaces). My husband, Roger, assembled files of information and phoned vendors and manufacturers to learn what was available and what each might cost. Roger and I get similarly possessed when we are in the market for a new washing machine or a new variety of tomato for the garden. But in a serious medical situation, should it have to be do-it-yourself? There is no equivalent to Consumer Reports to provide a thorough, unbiased comparison of ventilatory equipment.

When it came time to quit testing machines and buy one, I settled on the Quantum® Pressure Support (no longer being manufactured). It was the biggest, heaviest, most expensive one I had tried. But the adjustable rise time sold me. Each inspiratory breath is delivered gradually. This is essential for my comfort. I also liked the controls on the Quantum. They are located on the front and are easily adjustable when necessary. There are no secret adjustment codes available only to "professionals." The Quantum can also be set with a backup rate for timed breaths, a feature I use. With some of the machines I rented, my spontaneous inhalations were apparently not always strong enough to trigger the machines to give me a breath.

Next, I wanted a smaller, lighter-weight unit for backup and for travelling, and found the Sullivan VPAP® II ST which has adjustable rise times and can be set to my specifications. I now use the VPAP exclusively and keep the hulking Quantum as backup.

At journey's end, I now go to sleep within a few minutes of going to bed. I have no more

morning headaches. I have not drowned nor suffocated in a nightmare. Best of all, I no longer need to get up to go to the bathroom during the night. (According to Colin Sullivan, BSc Med, MB, BS, PhD, FRACP, FAA, from Australia, who helped develop the VPAP, there is a biochemical chain reaction that may result in nocturnal urination when people are underventilating during sleep.)

While waiting to discover the ideal mask, I use a ResMed Mirage® and Ultra Mirage®, liking different features of each. I also use a heated, homemade humidifier and so far have resisted spending hundreds of dollars on a “real” one. Use of a humidifier was not mentioned when I bought either of my machines, and I found that dry air being blown into the nose and throat could be uncomfortable.

I located mail-order companies selling equipment and supplies on the Internet. The prices are often better than buying through a local respiratory equipment dealer. For repeat orders of supplies that I know will work, this can be a saving.

My Search for the Solution Jean B. Davis, Albany, Georgia

After five days as an inpatient at Vanderbilt Stallworth Rehabilitation Hospital in Nashville, Tennessee, under the care of Brenda Jo Butka, MD, and her staff of respiratory therapists, I am able for the first time in months to breathe adequately at night, to sleep, and to function at optimum capacity during the day.

I contracted polio in 1953. It left me quadriplegic and dependent on the iron lung for five months. I left Vanderbilt University Hospital two months after being weaned from the iron lung and was able to breathe without any respiratory assistance. My almost total quadriplegia continued, however, and that condition worsened over the years as I experienced the late effects of polio.

The late effects of polio also caused my breathing capacity to deteriorate over the years, and about 12 years after I left Vanderbilt, I began to need help with my breathing during the night. I started using negative pressure ventilation with a cuirass and the Monaghan 170C ventilator. Then, with the passage of 15 more years, I began to require assistance during the daytime, using an early PVV ventilator with mouthpiece and then a PLV®-100 volume ventilator with mouthpiece during my waking hours. I continued to rely upon the Monaghan and cuirass during the night.

About two years ago, I began to have problems sleeping. I did not seem to be getting enough breath to allow me to relax and go to sleep. My equipment provider substituted a NEV®-100 for the Monaghan to drive my cuirass, and my breathing problems at night noticeably worsened. Because the exacerbation of my breathing problems coincided with the use of the NEV®-100, I erroneously attributed them to the equipment.

I was unable to find anyone in this area – southwest Georgia – who could offer any solution to my breathing problems, (although a therapist suggested that I might need to use the iron lung again), until one day in 1998 when I was discussing the problem with the manager (a registered respiratory therapist) of my equipment provider in Atlanta. She gave me the name of Brenda Jo Butka, MD, Medical Director of Pulmonary Services at Vanderbilt Stallworth Rehabilitation Hospital since 1995. I contacted Dr. Butka and was in the process of arranging an appointment when my van was rear-ended by a truck, and I sustained a broken left hip. That interrupted my plan to travel to Nashville to see her.

My breathing problems at night continued to worsen, however, and I began trying to supplement the NEV®-100 and cuirass with the use of my old PVV positive pressure ventilator and mouthpiece. This did not work, and early in 2000, I again contacted Dr. Butka and arranged to enter Vanderbilt for evaluation and treatment.

Although I dreaded the trip – nine hours by automobile from my home – it was apparent from the first that Dr. Butka and her staff were eminently experienced and competent in the kind of breathing problems I was having. That in itself was encouraging and reassuring.

When I went to Nashville, I was apprehensive that the solution to my problem would be to return to the iron lung. This would have meant a substantial diminishment in my quality of life, and I dreaded the prospect. Dr. Butka put those fears to rest immediately. She made it clear that the solution to my problem was yet to be determined, but the solution was not the use of the iron lung or negative pressure ventilation in any form.

During the ensuing five days of my stay at Stallworth, Dr. Butka confirmed that using negative pressure ventilation equipment during the night was inadequate for me. My oxygen saturation levels were substantially below normal, which accounted for my feelings of breathlessness, inability to sleep, and the

general feeling of malaise during the day.

It was decided that the use of a positive pressure volume ventilator (I use the PLV®-100) with nasal mask at night was the appropriate solution. I had been told about this option at home, but I was not convinced that this was the proper solution to my problems. There appeared to be no one at home who could guide me in the use of these options, and I had not really given the masks a fair trial. They felt uncomfortable and intolerable, and I did not know how to use them correctly.

At Stallworth, I was shown a variety of masks, how to properly use them, and how to deal with the problems of skin irritation and discomfort. I also became convinced that use of the mask would solve my breathing difficulties.

The first night with the nasal mask I slept six hours and my oxygen saturation levels went up to 98% and 99%. The next night I slept eight hours, and thereafter I had eight and nine hours of uninterrupted sleep. My oxygen saturation levels continued in the range of 98% and 99%. Since I have returned home, I am sleeping as I have not slept for months and my oxygen levels remain at the 98% level.

I now use Mallinckrodt's Breeze™ SleepGear™ (which contains ADAM nasal pillows with tubing going up over the nose and forehead, held in place at the back of the head) and find it the most comfortable for me.

Brenda Jo Butka, MD (615-963-4032)

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Networking Institute (GINI)
International Polio Network (IPN)
coordinated by:
Gazette International Networking Institute (GINI)
4207 Lindell Boulevard, #110
Saint Louis, MO (Missouri) 63108-2915 USA
VOICE: 314-534-0475 FAX: 314-534-5070
Relay MO: 800-735-2966 (TDD), 2466(V)
gini_intl@msn.com
www.post-polio.org

[Editors comment. We fully appreciate this is all American information. However we hope that this will help you discuss your problems with your specialiaists. We welcome some more British stories of how you are coping on any subject but particularly this one.

At present we cannot advise on UK makes of equipment, you will need to discuss this with your specialists.]

Letters to the Editor,

Merseyside - I was diagnosed with PPS nearly five years ago, but on looking back realised that I had been deteriorating for a lot longer than that. I was lucky enough to be included in one of the four rehabilitation research groups at St Thomas' Hospital in 1999/2000. I was part of a group of ten, and apart from an aunt who contracted polio at the same time as myself, this was the first time I had met other people who had suffered with polio. Imagine my amazement therefore when earlier this year I found another PPS sufferer who lived down the same road as myself! Since then I have been put in touch with two other people within a 15 mile radius and we have decided that it would be helpful for us to form our own support group. We shall meet up a few times a year and pool ideas, resources, moans and generally have a good time! I was wondering whether there were any other PPS readers of LincPin in the Merseyside area who might like to join us.

If so please contact me :
Di Brennand on 0151 924 4680
or email: d.brennand@liv.ac.uk

Cornwall - There is a new informal pps support group based at the Rehabilitation Unit in Hayle. If you would like information please contact Chris Salter
linpolioweb@loncps.demon.co.uk
or Mary Frost,
Physiotherapy Department.
Marie Therése House
St. Michael's Hospital, Hayle, Cornwall.
(01736) 758875

Hampshire - Dear Friends, I was delighted to read that you intend to publish a long article on respiratory problems as I have many questions?

Hoarseness - the more tired I am the worse it is, talking becomes a real problem.

Dry Coughs/Choking - Perfumes, sprays etc, set it off and I cannot be anywhere near them now.

Warm Building/Crowds - I cannot sit in any enclosed area if there is no or little ventilation.

Gulps of Air - often my chest grasps for enormous bouts of air and it really shakes my ribs and chest. There is no pain attached, but it happens suddenly and is over quickly. Its not yawning but the process is similar.

Fast Breathing - I often wake in the night gasping for air and it takes a while to get my breathing back to MY normal. Windows are open and I am not hot.

Chest pains - I regularly have pain under my left chest, down my side and around to the lest side of my spine. I do have scoliosis.

I have been a Lane Fox Patient for four years and go again at the end of August. If you have similar

problems it would be nice to share them and help me not feel so alone. If you do not have email then write to me via the office address.

Clare Colfer - Hampshire -
<clare.colfer@cwctv.net>

EATING WELL EASILY PART 1 **by member Virginia Holland**

Much as we enjoy eating, don't you sometimes wish we didn't have to eat? I find it can take up so much time and energy, going shopping, thinking about what to have for lunch/dinner etc., and then actually preparing the food. It's eaten in a flash and then there's all the clearing up to do.

For the last three months we've been using the Sainsbury's to You delivery service and can thoroughly recommend it. I order over the phone rather than the Internet, although you can do either. As we already shopped at Sainsbury's we were sent a list of everything we'd purchased over the previous few months, with all the necessary reference numbers (very clever, this modern technology). If anything I've ordered is unavailable at the time the shopper goes round picking out my order, a sensible substitute is included. Substitutes are pointed out at the time of delivery and don't have to be accepted. There is a £5 delivery charge, but as we are three in family I find this well worthwhile in the time and energy it saves both my husband and me. Even for someone living alone with a limited budget, it might still be a useful service, perhaps once a month, to deliver the heavy non-perishable items, along with the perishable items for that week.

But to get back to the challenge of providing three meals a day, plus a couple of snacks..... Even if we enjoy cooking, there are times when we all need easy meals, times as well when we suddenly realise we're hungry and need to eat but don't have much energy to prepare anything. I can't promise any fantastic recipes here, because as a family we eat very simply, but just a few ideas for quick, easy snacks and meals, with reasonably healthy eating in mind.

We've discussed before that it's important to have balanced meals with some protein, carbohydrate and a little fat at each meal. During hot weather, it's quite common not to feel all that hungry sometimes, yet it can be a mistake to go too long without a proper meal, just relying on snacks that are not balanced. It's especially important not to miss breakfast, making this a substantial meal, if you can. (You may have heard of the expression "Eat breakfast like a king, lunch like a prince and supper like a pauper".) Bacon, eggs and sausage are not the only protein food to have at breakfast. Baked beans and/or mushrooms on toast, kippers or kedgeree would make a great start to the day. Muesli,

with nuts or seeds such as sunflower or pumpkin make a change, along with milk or yoghurt. Also you might try wheatgerm or soya milk to give variety. Some shy away from nuts, thinking them too fattening, but a few unsalted nuts along with some fruit make a great snack to keep you going, and the fat they contain is good fat that you need.

Apart from some protein, it would be good to include some fruit, vegetables or salad at each meal. These foods are largely carbohydrate (starches and sugars) so, used along with the protein they form a light, balanced meal, without the need of too much bread or potatoes, especially if you find it hard to keep your weight down. Most protein foods contain some fat so there isn't any need for a lot of extra fat - a little butter, olive oil in a dressing and nuts and seeds would supply all your needs. Fruit, vegetables and salad contain valuable vitamins and minerals and it would be good to include something from this group at each meal, i.e. fruit with breakfast, salad at lunch and vegetables in the evening. That way you easily get your recommended five portions a day.

If you need to rely on frozen or tinned fruit and vegetables, don't worry too much, although it would be a good idea to look for tinned fruit in fruit juice rather than syrup, and vegetables tinned without added salt, if possible. Frozen vegetables would be preferable to tinned, as we're told that frozen vegetables have been frozen so quickly after harvesting that they often contain more nutrients than supposedly fresh produce. I personally prefer to use fresh fruit and vegetables where I can, but am often guilty of buying far too much food at any one time, and then finding myself using up week-old broccoli, etc. that is definitely past its best. If you find it convenient to prepare vegetables ahead of time, it would be a good idea to put them in a plastic bag in the fridge till needed rather than leave them standing in water, as a lot of the nutrients will leach out.

On warm days what I find very useful are cold dishes that can be stored in the fridge for a few days that I can dip into, just adding a salad to make a light satisfying meal. As a family, we don't eat a lot of meat but do like fish of all kinds, especially the oily ones like salmon and mackerel. I find it so quick and easy to cook, usually just baking it in the oven and, along with two or three veggies cooked in the one saucepan, it makes a good meal. If I cook more than we need, cold fish is quite useful in various dishes. I also make good use of tinned fish - again, all kinds of fish - sardines, tuna, mackerel, salmon. Tuna is quite nice flaked

and mixed with a tin of red kidney beans and sweetcorn. Add some dressing or mayonnaise for flavour and moisture. It is quite filling and goes well with salad of any kind. Once made up in the fridge, it will keep for a couple of days and can be dipped into for a quick snack.

Rice salads are very useful too. I particularly like to use brown basmati rice. Once cool, I add anything, really. Bits of chicken, flaked fish, prawns, raw red onion, spring onions, cashew nuts, celery, radish, peppers, courgette - absolutely anything I have to hand. Broccoli is very good, just cut up into small florets and cooked very briefly so that it is still firm. Anything like this can be added to any salad. Once again, a dressing of olive oil and lemon juice or cider vinegar and maybe garlic, herbs or mustard will add flavour. Another idea along these lines is to transfer a tub of plain cottage cheese to a larger container and add any of the above ingredients. Once again, this should keep well in the fridge for a couple of days. Use your imagination and you might discover your own favourite recipe that you can share with us!

When you read about the need for having a small amount of protein at each meal, you might automatically think only of meat, fish, eggs and cheese, but there are a lot of dishes we can prepare using vegetable protein. I make quite a few meals with beans and lentils. Lentils cook quickly and don't need to be soaked beforehand. I so often forget to pre-soak beans though, that I do keep some tins in, especially black eye beans, borlotti beans, flageolet and cannellini, also chick peas - all available in the supermarket. They are all slightly different in flavour and, mixed together with a dressing and anything else you like to add, they look attractive and are filling and nourishing. A chick pea dip called houmous is a great standby to have in the fridge. A couple of rye crackers and sticks of carrot and celery to dip into the houmous makes a light lunch or snack any time.

A lot of people like the idea of eating more vegetarian food but they can only think of eggs and cheese and are unsure about using vegetable protein. The thing to remember about vegetable protein like beans and lentils is that to make a complete protein, you need to add something like bread or rice, in other words, a grain of some kind. This isn't hard to remember if you think of our old standby "beans on toast". Combining the beans with the toast gives you a complete protein. Similarly, rice and beans, a staple of much of the world, also combines to make a complete protein. There are other combinations that it is helpful to know about, but I'd like to explore that further next

time when we'll be thinking more about warming food as the days draw in.

If you're conscious of improving your diet, it's important to take things slowly and take time to develop new tastes. It can be very stressful if you get too anxious about following suggestions too strictly. The main point to keep in mind is to have plenty of variety and allow time to enjoy your meals - after all, food is one of life's pleasures that most of us can participate in!

Vivien Holland -
32 Green Lane, St. Albans AL3 6EZ.
<vivienholland@hotmail.com>

ONLY A FEW LEFT OF THE NEW BOOK

POST-POLIO SYNDROME

A Guide for Polio Survivors and Their Families
by Julie K. Silver, M.D.

The retail cost of the book is £19.95. plus £2.00 p&p.

We have obtained a discount and **cost to members is £13.95 plus £2.00 p&p**. Please will you send request and remittance to the Secretary, 12 Larch Ave, Allington Gardens, Allington, Grantham, NG32 2DR. Please allow 14 days for delivery.

ELDERLY

While working for an organization that delivers lunches to elderly shut-ins, I used to take my four-year-old daughter on my afternoon rounds. She was unfailingly intrigued by the various appliances of old age, particularly the canes, walkers and wheelchairs. One day I found her staring at a pair of false teeth soaking in a glass. As I braced myself for the inevitable barrage of questions, she merely turned and whispered,

"The tooth fairy will never believe this!"

A Medical Alphabet

A's for arthritis

B's for bad back

C's for the chest pains.

Corned beef? Cardiac?

D is for dental decay and decline

E is for eyesight--can't read that top line

F is for fissures and fluid retention

G is for gas (which I'd rather not mention) and other gastrointestinal glitches

H is high blood pressure

I is for itches

J is for joints that are failing to flex

L for libido--what happened to sex?

Wait! I forgot about **K** for bad knees (I've got a few gaps in my **M**-memory)

N's for nerve (pinched) and neck (stiff) and neurosis

O is for osteo-

P's for porosis

Q is for queasiness. Fatal? Just flu?

R is for reflux--one meal becomes two
S is for sleepless nights counting my fears

T is for tinnitus--bells in my ears

U is for difficulties urinary

V is for vertigo

W is worry

About what the **X**--as in X ray--will find
But though the word "terminal" rushes to mind,

I'm proud, as each **Y** - year - goes by, to reveal

A reservoir of undiminished

Z - zeal---

For checking the symptoms
my body's deployed,

And keeping
my twenty-six doctors employed.

from Marsha in Texas,
marsha@ccms.net

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

Membership and Requests for Information Packs, Leaflets, copies of articles to
Hon. Sec. Wendy Grimmitt <CWGrimmitt@aol.com>
12 Larch Ave, Allington Gardens, Allington, Grantham, NG32 2DR

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 Lincs PPN. c/o 4212 Blanding Blvd, Jacksonville FL 32210, USA)
Other Countries please contact for details.

All other correspondence and enquiries - items for newsletters - to
Lincolnshire Post-Polio Network, 69 Woodvale Avenue, Lincoln, LN6 3RD, UK
Tel: +44(0)1522 888601 Fax +44(0)870 1600840

Next LincPIN Newsletter - August 2001
Articles for publication by September 20th - Publication date 5.10.2001

Founder & Chair - Hilary Hallam <linpolio@legend.co.uk>

Vice Chair - Janice Eary <janiceeary@hotmail.com>

Vice Chairman/WebSite Administration, Chris Salter - <linpolioweb@loncps.demon.co.uk>

Honorary Secretary - Wendy Grimmitt - <CWGrimmitt@aol.com>

Honorary Treasurer, Frank Grimmitt - <CWGrimmitt@aol.com>

Committee Members - Phil Bilton, John Eary, Ted Hutchinson, Jennifer McGowan.

Survey Results from Janice Eary, Vice Chair.

I would like to thank the 68 of you who returned completed questionnaires and to the very constructive comments many of you made.

The results of this survey will help us to go forward in the direction that you as members want. The committee will take very careful note of all the comments and suggestions you have made and where possible act on them.

If you have any other ideas or would like to make any comments on the results of this survey or on anything else for that matter please write or email.

Thank you all again for taking the time to complete this questionnaire. Further comments from Hilary and Chris at the end of the results.

Section 1. Information Pack.

(8 of the respondents had not received an Information Pack, so they have not been included in the totals for this section)

Q1. Did you find the Information Pack as a whole:-
a) very helpful 61%, b) helpful 30%, c) not very helpful, 4%, d) of no use to me 2%.

Q2. Is the amount of information given on Polio and its late effects:-
a) too much 2%, b) too little 4%,
c) enough for my needs 92%.

Q3. Is the type of information given:-
a) very helpful 52%, b) helpful 42%,
c) not very helpful 3%,
d) of no use to me 3%.

Q4. Is the information easy to understand?
Yes 71%, No 23% (6% said some parts were not very easy to understand)

Q5. How useful have the personal profile chart been to you?
a) very useful 16%, b) useful 40%,
c) not very useful 26%,
d) of no use to me 18%.

Q6. Have you used the diary and activity planning sheets?
Yes 30%, No 70%.

Q7. If yes were they:-
a) very useful, 30%, b) useful 66%,
c) not very useful 0%,
d) of no use to me 4%.

Q8. If no can you say why?

1. I seem to use my energy seeing to my daily needs, then don't get down to the diary.

2. I know my illness is worsening, but at the moment with pacing I complete a fairly normal day (at a much slower rate of course) and I don't feel the need to plan my time in such detail.
3. I take my activities day to day and plan accordingly.
4. Sorry I haven't got round to it, new member.
5. Too lazy to do it.
6. I keep intending to use them but I am a bit lazy about putting things down on paper on a regular basis, I have to be in the mood.
7. Already worked out activity/expenditure regime.
8. I don't/want/need to see a Doctor. Therefore had no need to gather evidence.
9. Because I tend to go with the flow and see how I feel from day to day.
10. My energy levels are very low, so I am used to planning very carefully my small number of activities.
11. Probably not appropriate at present.

Comments.

1. Very informative useful packs.
2. All I can say is 'thank you' and keep up the good work.
3. A good idea which helps to formulate evidence.
4. I am ashamed to say that although I received the pack I have never read it or put any of its suggestions into practice. Perhaps I wouldn't be in my present state if I had!
5. Great idea for new members.
6. I found the leaflet on medications particularly interesting.
7. Excellent.
8. It may help if we had professionals in the UK to assess us. Even Lane Fox do not issue us with guidelines. Knowing my own body has helped me to assess my own needs and work around them.

Section 2. Newsletter.

Q1. Do you enjoy reading the newsletter.
Yes 90%, No. 8%.

Q2. Do you find the content as a whole:-
a) very useful 50%, b) useful 36%,
c) not very useful 8%, d) of no use to me 6%.

Q3. Can you say which parts of the newsletter you find particularly helpful (you may tick more than one)
a) editorial 52%, b) personal stories 58%,
c) 'hints and tips' 62%,
d) articles on polio and post polio 82%
e) 'entertainment features' 25%.

Q4. We realise that a number of medical articles are difficult for the lay reader to understand, however do you find these articles generally:-

<p>a) very helpful 22%, b) helpful 58%, c) not very helpful 16% d) of no help to me 4%.</p> <p>Q5. Have you ever given your Doctor or other medical professional, a copy of article from the newsletter? Yes 52%, No. 48%.</p> <p>Q6. Does your partner or other close family member read the newsletter? Yes 44%, No. 48%</p> <p>Q7. If yes do they find the content:- a) very helpful 20%, b) helpful 60%, c) not very helpful 16%, d) of no help at all 4%.</p> <p>Q8. If no, or they find the content of no help can you say why?</p> <ol style="list-style-type: none"> 1. Just leave it to me and our Doctor as they have lived with my problems long enough. 2. I tell them anything new. 3. I have no family. 4. I have a mentally handicapped wife. 5. Son and Daughter in Law, very busy, and don't have time. But would read a single article if relevant to me and I asked them to. 6. No partners. 7. Too busy to read it at the moment. 8. I think my husband relies on me to tell him anything I think may interest him. <p>Comments.</p> <ol style="list-style-type: none"> 1. I think it is a first class publication, very well written and of significant scientific value. 2. Occasional articles on diet? High protein? Excluding dairy products etc. would be useful. 3. Some art work 'lighter articles' on coping with post polio. Copy could be broken up a bit, some colour added. It can be a bit hard to read. 4. Keep up your excellent work. 5. Perhaps look at the overall design, there are large areas of solid text that could possible be broken up in different ways; sub heads/computer graphics 6. Seems very good. Maybe a section for contacting similar suffers in my own area? 7. On the whole I find it brilliant, far more helpful than the BPF one. My only quibble is that as Secular Humanist I find the quasi religious bits (usually American) slightly off-putting. 8. It is varied, informative and interesting. 9. I am grateful to the American medical profession for their research into PPS, but could we have less emphasis on America as a country. What about Australia and the rest of Europe. Chidden in the developing world are still contracting polio. Is there any awareness there that energy conservation and not exercise is the way to avoid future problems. 10. Less American info and more UK. Less negative 	<p>and more positive outlook info and encouragement after all most of us have lived longer than anticipated.</p> <p>11. To biased towards the USA.</p> <p>12. To many articles advising on diagnosis. As there is nobody in the UK that can help us, I find these articles maddening. Most articles are on helping/advising on use of our polio affected limbs, but none on respiratory/scoliosis difficulties. These two areas affect me more than weak polio limbs, yet I don't see any articles on them.</p> <p>13. Perhaps publish contacts for anyone just needing someone to swap moans and groans with, and suggestions. Although I wouldn't complain about the content at all. People have obviously worked very hard on the newsletter and praise is more than due.</p> <p>14. I think you do a wonderful job, I am more grateful than I can say.</p> <p>15. I think you do a wonderful job, it's a lifeline.</p> <p>16. The newsletter has too much American information.</p> <p>Section 3 WebSite.</p> <p>Q1. Do you have daily access to the Internet? Yes 50%, No 50%.</p> <p>Q2. Have you ever used the WebSite? Yes 56%, No 44%.</p> <p>Q3. If yes, how often do you use it? a) more than once a week 11% b) weekly 15%, c) more than once a month 27% d) monthly 17%.</p> <p>Q4. Do you find the website:- a) very helpful 57%, b) helpful 35%, c) not very helpful 6%, d) of no help to me 2%</p> <p>Q5. Does anyone use the WebSite on your behalf? Yes 16%, No. 84%.</p> <p>Q6. Have you any comments or suggestions you would like to make about the website?</p> <ol style="list-style-type: none"> 1. No I am just sorry that more people dont have access. 2. Voice Therapist found it very interesting and enlightening. 3. I have downloaded some very useful information and articles. 4. Good design. Keep up with web technology as budget permits. 5. One of my main reasons for wanting to get 'on-line' at home is to connect to this site. 6. The competence and skill of your organisation has led you to become a world site - plan accordingly. This may be a role you do not want however. 7. This is very important! I would not have found you otherwise.
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8. An excellent WebSite. Well presented and accessible. One minor comment it was difficult to find special articles, e.g. on Bulbar Polio.
9. To me it is very good.
10. I find the website interesting and easy to use.
11. First class website.
12. I think there should be a part of the site for members only. There is no point in having a newsletter for members if everyone is able to read it on the web.
13. Set up site to permit members to download and store/print complete newsletter, or mail a floppy of CD for overseas members. Thus keeping your overseas mail costs down, give overseas members the option.

General Comments and Suggestions.

1. Essential reading - the only source of correct information on PPS, which is clearly explained and scientifically validated in the UK, it should be distributed and published more widely. Hillary's articles are excellent. I have learnt a lot from the newsletter and other articles sent to me.
2. Keep up the good work and thanks.
3. Do not think I wish to make the expenditure to be on the web as I do not have enough hours in the day now to do all I would like to. I think you provide a very good publication.
4. No, but thank you for the group and thanks for asking.
5. Personally, I think you all have done a quite magnificent job, alerting polio survivors and medical people to problems and the best way forward, especially regarding pain and time management. Congratulations to Hilary and all supporters.
6. There are many of us living on our own, please remember this as many articles refer to partner/ family help.
7. More about UK email groups please.
8. Thank you for battling on our behalf and feeding us with all you obtain. Knowing things is better than feeling alone and out in the dark.
9. Keep it up.
10. No, other than please keep on doing what you do! I find the medical stuff really useful. I can get articles on knitting a three piece suite somewhere else!
11. Keep up the good work. Congratulations to you all.
12. Really good work everyone!
13. Thank you for your excellent efforts.
14. Lincs PP Network was my first contact with other 'old polios'. I have since joined the BPF, and am now an outpatient at Lane Fox, who are keeping an eye on me, together with my GP. She is most grateful for copies of articles etc which I pass on to her and together we are learning about PPS and what to do about it.

Combined reply from Hilary and Chris.

To put it in simple terms, one of our goals is to hasten

the day when your GP will tell you about PPS not the other way around.

Remember we have members or are in touch with many people using day and or night time ventilation, and have tracheotomies, in fact Dr. Henry Holland has had one for over 30 years. We would be more than happy to put you in touch with others so that you can discuss how beneficial these have been to their lives.

The medical articles etc that we do have access to have come about through attendance at Post Polio Conferences, receiving other groups newsletters and taking part in the polio support forums on the Internet. In fact without the Internet we would not be typing this today and possibly still be searching for a diagnosis.

Our biggest restriction to change is finance. Our biggest problem is energy levels to do all the work that we would like to do. Fund Raising is an urgent need but we have restricted time and energy to allot to this. Remember that all the work including the WebSite is done voluntarily and much of the expenses to do what we do do comes from our own or our families pockets. We are not looking for hundred thousands - five thousand would make a huge difference to improving our service to you and the medical profession. If you have any contacts or ideas to help us raise funds then do please get in touch. Every penny helps.

The Information Pack is under constant review and at present undergoing a complete draft change of how the information is presented. We are discussing the splitting of this into sections with fees attached to some parts. People enquiring for information will then be given a choice of some free material and some at the cost of printing that material.

The Newsletter. The LincPIN. This as mentioned in the Editorial is intended to provide Information on post polio issues. Together as a whole all 30 issues contain a wealth of information and articles on many polio and post polio related subjects. If anyone not on the Internet would like a copy of the contents of previous issues then please contact us.

I agree that sometimes there is a lot of information from America, but most conferences, research, pps support groups are in America. We have printed articles from Canada, Australia, Ireland, Germany, UK etc., We can only put in information that we have access to. There is a language issue with European Newsletters which we do not have the funds to have translated and therefore we do not now request them. I have a wonderful copy of the Finish Polio Newsletter but the word Polio is the only one I can understand!

Again I ask why not write to us with your stories, hints and tips, questions, ideas for future issues etc. Vivien Holland joined and has sent articles for each newsletter. Sylvia Dymond has written to us a few times. Old and new members we need your input. Only today I was asked would Christine write some more articles for us as she wrote some really great stories that were so vivid

you could almost see it happening. I agree, over to you Christine to please write more stories for us.

We fully appreciate that we do not all want the same amount of information and it is very difficult to pick and choose good articles to answer the questions posed to us. Sometimes these - as this issue on breathing - will contain much that some just do not want to read. However, there are others who not only want to read this, but have symptoms that are not being addressed due to lack of knowledge by the health professionals seeing them. It is therefore important that we do provide articles of a more medical nature that will be read - and most importantly - the information taken on board.

We are looking at providing a change in format and later when funding permits some colour.

The WebSite. One of the intentions of the web site is to provide an information resource for medical professionals. Since our web site first appeared the use of the Internet by medical professionals has increased dramatically and continues to do so. We do receive emails and phone calls from health professionals in the UK and from abroad who have found us on the internet looking for more information.

While we emphasise that we are not an Internet support group, rather a support group making we hope effective use of the Internet, it is difficult to imagine what progress and contacts we could have made without the communication facilities provided by the Internet.

While our online library is probably one of the largest in the world it only contains a small percentage of post-polio related medical articles published over the years. We are dependent on authors or publishers giving us permission to effectively republish articles.

You can search the site or just the Library using words like bulbar using the Search engine available. (Please do not use the word polio or post polio, as the number of instances that is used is tremendous)

We intend to expand the "Library Assistant" section of our web site in order to offer more guidance on how to locate and obtain copies of medical journal articles. However, it can be quite expensive. For example, a copy of one particular 1988 article from a US journal ordered via the British Library comes to £18, over £10 of that being the publishers copyright fee. Note that is just for one copy and doesn't include any publication rights.

If you have any queries about our Site and how to find information then email <linpolio@legend.co.uk> I will be more than happy to point you in the right direction. I was new to the Internet myself six years ago and still have much much more to learn.

Thankyou from Chris and myself for the supportive comments.

I / We Membership No.

Address

Phone Number Email Address

will be / are unable to attend the AGM Day of Events

I / We have booked / have not booked rooms at the IBIS Hotel

and will be arriving at on

If you are coming by Train then please let us know so that if possible we will meet you at Lincoln Station.

I enclose the sum of £ for lunches @ £3.50.

I would like to Nominate / Offer to Stand

.....

For the Post of

.....

Workshops.

I would like to discuss the following subjects if possible.

.....

.....

Question in Editorial - If you have had to give up work early because of PPS
please can you tell us in a few words
why, what job you had and how much a percentage drop in income that has meant for you.

.....

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.....

.....

.....

Questions for AGM which will be answered then or in the following issue of the newsletter overleaf please.

Please return as soon as possible to

Hon. Sec. 12 Larch Ave, Allington Gdns, Allington, Grantham, NG32 2DR

**For fast acting relief,
try slowing down.**

-Lilly Tomlin

comedian in rowan arnd martins laughin in Questions for AGM.

Woman's Quote of the Day:

"Men are like fine wine. They all start out like grapes, and it's our job to stomp on them and keep them in the dark until they mature into something with which you'd like to have dinner with."

Men's Counter-Quote of the Day:

"Women are like fine wine. They all start out fresh, fruity and intoxicating to the mind and then turn full-bodied with age until they go all sour and vinegary and give you a headache."
millie.....