

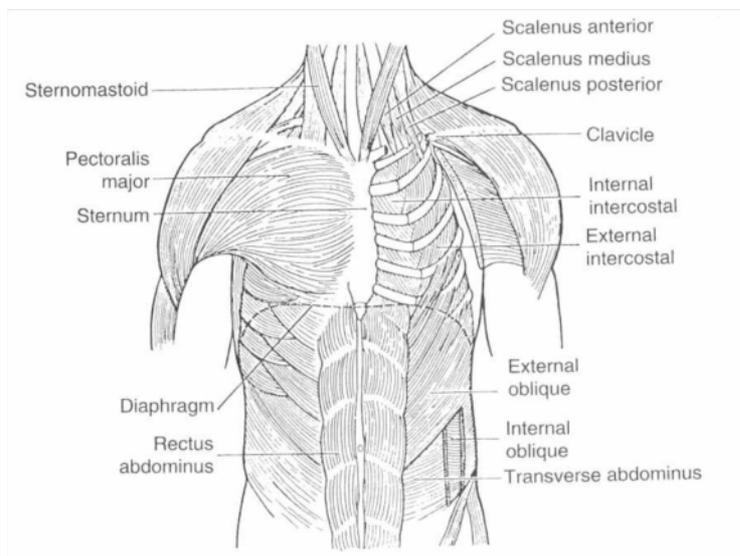


The LincPIN

The **Lincolnshire Post-Polio Information Newsletter**
Volume 5 - Issue 9 — June 2006

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

TO BREATHE we use Lungs, Diaphragm, Intercostals and Accessory Muscles.



Scanlan, CL, et al. (1989). Egan's Fundamentals of Respiratory Therapy.

Diagram shows Diaphragm and Accessory Muscles

**Do you have weakness
or stiffness
in any of these muscles?**

**Do you stop breathing to
concentrate on
achieving an action?**

**If you do, is this because
you are using
accessory breathing muscles
to assist your weak muscles
to achieve that task?**

Changes happen slowly and become our new norm - we must report the changes.

- Do you run out of breath now before finishing a sentence?
- When you cough do you have to do this softly as it hurts your rib muscles to cough loudly? Ask to have your chest expansion measured on repeated breaths.
- Do you have to pause for a few seconds between mouthfuls of food or drink?
- Did you turn over in your sleep but now do you have to wake to a higher level of consciousness to physically turn over, and how often do you do this each night?
- In bed - have you noticed you sleep in one position far better than any other?

AGM - September 9th 2006

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This publication is provided as a service to those seeking such information. The opinions expressed in this publication are those of the individual authors and do not necessarily constitute endorsement or approval by the Lincolnshire Post-Polio Network. ALWAYS consult your doctor before trying anything recommended in this or any other publication.

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John R Bach, Margaret Tilton—NeuroRehabilitation 8 (1997) 139 - 153
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Donations: Jim & Jenny Rayner, Sylvia Fortune, John Doohan, Sue Pownall. Eunice Stone, Kay Preece, Diana Nash, Yvonne Webb, Ann Stone, Norman Jones, David Shaw, M. Horton, Pamela Minnitt, Roy Prentice, Judy Barter, Barry and Olivia Branston. Di Brennand, Pauline and Robin Butler, Denise Carlyle, Sheila Dunnett, Margaret Edmonds, Hilary Boone, Pat Hollingworth, Mary Kinane, Mary McCreadie, Di Newman, Chris Salter; and from USA, Robert Price, Jean Hill, Beverly Buccellato, Lena Jennings and Susan Sonski.

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Please make cheques payable to 'Lincolnshire Post-Polio Network'

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Next LincPIN Newsletter - September 2006

Articles for publication 4th August by post or - newsletter@lincolnshirepostpolio.org.uk

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Message from the Chair

Dear Readers,

This is an important time for the organisation, and for our members in the UK, some of whom are also members of the British Polio Fellowship. Many of you will have followed recent developments in the debate about PPS and how services can and must improve so that more polio survivors can benefit from further research. At the time of going to press, we have been invited to collaborate with the BPF in the context of an Expert Panel on PPS. It is our considered belief that most of our members would welcome a more formal collaboration with the BPF at this time, so we will be keeping you posted on this issue.

Numbers attending the AGM have been decreasing. We wondered if this is in part due to the time of year, late October. Many of us find travelling in the colder months difficult. With this in mind, we have changed our financial year to run from April to March. This means the Annual report and accounts can be finalised earlier in the year and we can hold future AGMs in the warmer months. We did not get confirmation from the Charity Commission in time to send out information for a June meeting so this year we have fixed the date for September 9th. This year's accounts will therefore encompass the shorter period August 2005 to March 2006. Thanks go to Denise who has been working hard behind the scenes to complete the accounts and find an external examiner.

We are grateful, as always to Sheila in Lincoln who helps us keep in touch with local contacts, especially when Hilary is in the US, and are pleased to confirm that Sheila has secured the Memorial Hall in North Hykeham as a venue. Our main speaker for the afternoon, Helen Kent, will be here to address current issues in respiratory assistance.

Members of the Operations team continue to do trojan work behind the scenes, bringing up topics suitable for debate, and keeping the Subscriber's List active around a variety of topics. If you have recently acquired a computer this is a good time to subscribe to our lively members email list. All contact details appear on the inside front cover, in case you wish to subscribe.

Best wishes,
Mary Kinane, Chair.
Contact mary.kinane@lincolnshirepostpolio.co.uk

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Editorial by Hilary Boone.

Yes folks, Richard and I got married on the 25th March 2006 in a wonderful native American ceremony in the 'Plaza' of the Portavant Temple Mound, Emerson Point Preserve, Florida, near where we spend our winter months [except its hotter than the UK summer]. We chose a native American ceremony because of our love of re-enactments and it was performed by a very dear friend and fellow Florida Frontiersmen of ours, Pat Walking Owl Murphy a Reverend of the Métis tribe. As we married during the Manatee County Heritage days members of the public were coming into the clearing to see the time line of re-enactors. From early Ameri Indians, through the times of the De Soto Spanish Landings, Pioneer times of the early 1800's [the time we do], and Civil War Re-enactors of the 1860's. When you read the piece below from our Wedding Invite you will see why this place is so special. We married near the shore of the River between the Temple Mound and a huge cross on the opposite shore line.

Taken from our Wedding Invite and excerpted from *Naturalist Karen Fraley, 'Around the Bend Nature Tours'* <http://www.aroundbend.com/>

Our haunting walk through the woods ends abruptly at a clearing. To our right is the Manatee River and to our left is the largest known temple mound on Tampa Bay. The trail takes us through this 1,000-year-old Indian village. Interpretive signage helps us imagine what life was like then: "The heavy growth of trees you now see would not have covered everything: The shell mounds would have gleamed white in the sun, topped and surrounded by thatched houses. Smoke from cooking fires drifted skyward as people worked at their daily tasks and children played. Canoes of hunting parties landed along the shore to unload the day's catch, while the air filled with an irregular rhythm of conch shell hammers tapping open shellfish."

We look up and imagine the chief and shaman leading a ceremony for the villagers below. For reasons unknown, the ritual buildings on top of the temple mound would be burned down regularly. The people would cover the mound with another layer of earth and shell and erect new buildings. In this way, the temple mound grew over the years in size and elevation. The native people started building this mound around 800 A.D. and abandoned it about 1500 A.D. A recent rain has turned the resurrection fern a lush and verdant green, carpeting the branches of the giant live oaks that protect this ancient temple. We are reminded that, as visitors here, we are guardians of both the past and future. We try to identify with the spiritual importance and natural order that the passage of time has given to this special place.

We got a big surprise when the Press turned up and we made the next days issue of the Sarasota Herald. We camped out that night on a loaned feather bed in our tent to the sounds of the night... including one of the Civil War horses getting his hoof caught in his lead and panicking and kicking a large plastic bucket to pieces. The next day we demonstrated items that we use in our re-enactments to the public that visited. At about 4p.m. with help from the other re-enactors we packed our belongings drove home and guess what... crashed out and spent the next two days catching up on energy levels. Honeymoon will come later when we have saved up enough energy.....☺

This issue, Number 57, of the LincPIN I have devoted mostly to Respiratory Issues. I know that some of you may not want to read all the information but it is important that we continue to highlight the issues that more polio survivors are asking us for help on. These issues are being discussed on other polio lists, highlighted in others newsletters, so its not just us, it's a worldwide problem. How long are we prepared to be told there is nothing wrong with us when there is, because the form of testing used did not pick it up?

When we eventually take the plunge and report symptoms to our health professionals stating that we think we might have breathing and/or sleep/swallowing issues and get told that 'if you did not have bulbar polio then you won't have problems', 'the figures are all within the normal range', etc. you begin to wonder if you are losing your mind. After all it's taken months if not years to admit the problems/symptoms to yourself, let alone a medical professional, and now you are told you don't have them.

I reported on my sleep study and respiratory lab testing in the December issue. In February's issue added an article from Post Polio Health International, Ventilator Users Network. When Richard started having more problems we asked to be referred to a pps knowledgeable physician. Richard was told 'not expected to have any problems if you were not in an iron lung, and from seated testing only his diaphragm was strong. Luckily the health system works more quickly in the USA and because of abnormal oximetry testing at home [25% of the night under ventilated] and 'apnoeas per wife' [doesn't that conjure up a marvellous picture] he managed to get a cancellation sleep study. The Doctor rang next day to say 'you are right he does have severe problems and I have ordered a bi-level machine for him'.

We are so lucky to have internet contacts across the world and were able to call on many friends for help. Gladys Swensrud from San Diego, and Larry Kohout from Minnesota stepped in with information and full explanations of all the terms. We had to go through a very fast learning curve. Gladys put me in touch with Helen Kent, the Owner of Progressive Medical in San Diego. This led to the first machine being changed for a better one, and the settings adjusted from the downloaded information. Result, Richard is sleeping better, he has more stamina during the day, and less muscle cramping pain. [*NOTE, just got email regarding knee replacement for a non polio, statement by therapist - that holding your breath while doing stretches or exercises can give you cramps in whatever you are stretching or exercising.* Do you hold your breath to concentrate on an action?]

Helen Kent founded Progressive Medical in 1983. Their goal is to 'wake up America' to the benefits of better sleep while eliminating the dangers of sleep disorders. They work with patients, physicians and other providers to make them aware of the serious risk of sleep disorders, sleep apnoea and disease-related breathing problems. Their speciality is Neuromuscular Ventilation. They work closely with organisations supporting people with ALS, MS, MD and PPS. As you will see from the back page, Helen is going to speak at our Annual General Meeting and offer all attendees that wish it some simple respiratory tests that will show if you need to take the matter further. Some days life is hard, but the day I got Helen's email offering to come and help us in the UK was a real boost.

Because of the steep learning curve we had to go through to understand all this I decided to put it all together in this issue. The main article I have put together from the slides and notes of Dr. Oppenheimer's presentation in San Francisco in 2003. I have added explanatory boxes, definitions of words and phrases, and information from others sources. If you need more help in digesting this, [maybe we should print on rice paper] then please get in touch.

You may not need this information now, but you could need it later on. Please do not rely on being told that you are fine, if you think your symptoms match what you read here. Prepare yourself well for your appointments. Ask for copies of your tests and the reports. If you find yourself in the position of NOT having your symptoms corroborated by the tests and/or assessment, then its time to look at all your notes, pick the most important issue and go and see your GP asking for his last appointment. Demonstrate this issue if at all possible and point out anything on the report, test results that you think might have been misinterpreted. Your GP is the best person to case manage you on your journey to better management of your condition.

Do you have any 'dropping off to sleep' issues?

Epworth Sleepiness Scale

The Epworth Sleepiness Scale is used to determine the level of daytime sleepiness. A score of 10 or more is considered sleepy. A score of 18 or more is very sleepy. If you score 10 or more on this test, you should consider whether you are obtaining adequate sleep, need to improve your sleep hygiene and/or need to see a sleep specialist. These issues should be discussed with your personal physician.

- 0 = would *never* doze or sleep.
1 = *slight* chance of dozing or sleeping
2 = *moderate* chance of dozing or sleeping
3 = *high* chance of dozing or sleeping

Situation	Chance of Dozing or Sleeping
Sitting and reading	_____
Watching TV	_____
Sitting inactive in a public place	_____
Being a passenger in a motor vehicle for an hour or more	_____
Lying down in the afternoon	_____
Sitting and talking to someone	_____
Sitting quietly after lunch (no alcohol)	_____
Stopped for a few minutes in traffic while driving	_____
Total score (add the scores up)	_____
(This is your Epworth score)	_____

I want to highlight a problem for Polio Survivors with this Questionnaire. How you answer these questions could affect how you are perceived to be having problems. If you have PPS and are using aids and assistive devices, pacing and resting and managing your energy levels well then you would be factoring in rests and nap times. Are you working on ten energy tokens a day, seventy a week and planning your life? So if you answer, like we did, for a normal ten energy token day [after all that is most of our days] with very low numbers you get a total low number.

There are events that we want or need to do and we know that they will take up more than 10 energy tokens a day. What do we do, we plan the week ahead. This weekend we can see both days will be 16 token energy days. So we know that the day/s before we need to use less tokens and store a little energy, and we know that come Monday we are going to be more fatigued, have more pain, etc. We ensure the fridge has easy to reheat food in it, we get up later. We sit around and read and watch TV and don't mind dropping off to sleep. We might go and rest in the bedroom instead of chair in the afternoon. What we can be missing is that this is important information and if you answer the questions after a day like this how high is your score now?

We have just asked a Pulmonologist about this and he says he always tells his patients 'to answer as if it was your worst day' e.g. when you have overdone.

Do you need respiratory testing?

If, as you read on, you think that you are experiencing any of these symptoms, then think about how you are going to word this to a health professional. When do they occur; time of day; after doing a certain action - bending over putting your shoes on -do you have more scoliosis leaning further forward as you walk/do an action of daily living, after using up more than normal energy tokens. Do you hold your breath when concentrating on an action. For instance, when you have to climb a few stairs; when you are walking and carrying an item; when you are bending up and down to get items from the dryer and folding the washing; etc.

What we are asking you to look at is which muscles are you using to do an action. Are you using others instead of paralysed or very weak ones and/or are you asking other muscles to assist weak muscles to continue to achieve that action? Are you using accessory breathing muscles to assist? Are you now causing conflict for your muscles?

'Ok' your Muscle Team Leader says, 'she is walking but she has leg muscle weakness, so come on trunk muscles numbers 3 to 7 will you please assist'. Now you stop and pick up the washing and your Muscle Team Leader says 'oh!, weak arm muscles need more help, trunk muscles 5 to 10 your help is needed'. A minute later Trunk Muscles 5, 6 and 7 call out 'we need more assistance here, we are struggling she is walking and carrying Grandma's crockery.' The Muscle Team Leader does not get the information in time and rather than let her drop the crockery trunk muscles 5, 6 and 7 go to help the arms and that leaves the legs without the extra needed help and they fold and she finds herself on the floor, wondering how on earth she got there.

Factor into this that some trunk muscles are also accessory muscles of breathing and may have their own weakness and we can have major problems.

The following are excerpts from polio survivors own experiences.

Hilary and Richard. Lying next to someone and listening to them breathe and then stop and then breathe again is tough. Richard had told me that I snored very badly and that I stopped breathing at times. The way my tests were reported did not corroborate my symptoms, but I now have more information I will be taking this up again when we return to the UK. I did not realise how worrying it was for Richard to watch me and wonder if he fell asleep would I carry on breathing, till I started doing this for him. Recently I have watched him lying on his back, breathe five times and then nothing—one recorded time was 42 seconds!. In the past when I heard no breath I would just nudge him, not realising the seriousness of the situation. He now has a bi-level VPAPIII S/T machine - this machine keeps his airways open and instigates breathing if he stops - his breathing at night has improved considerably. He has much more stamina during the day and has noticed considerably less cramping pain in his muscles. [See added note on page 5]

Larry Kohout - [Excerpts From the Fine Art of Breathing, published in full in an earlier LincPIN] Forty-two years passed..... In the early to mid '80s, however, I started suffering from overwhelming fatigue, increasing muscle pain. Because of these symptoms, and the evidence of denervation seen by the EMG, my doctors diagnosed PPS. But breathing or swallowing problems were still miles away in my mind. About 1995 I began to realize that I became short of breath after consuming an alcoholic beverage. The realization came slowly, and when I did make the connection the solution was simple: I quit drinking. It was hardly a sacrifice since Cathy, my wife, is allergic to alcohol: the two of us rarely drank. And remember, I didn't have any breathing problems.

In the late fall of 1999 I became aware, again slowly, that when I was talking I'd often run out of breath before I came to the end of a sentence. Other things began to filter into my consciousness. When I'd exert myself in the slightest, I'd start to pant. I'd feel breathless when I'd read aloud. I was breathless after meals. At the same time I was aware that I was waking up at night on an almost hourly basis. When I did wake I'd often have to go to the bathroom, and so I became concerned about a possible prostate problem, but I didn't connect this to a breathing problem.....

When I went in to see my PCP [*Primary Care Physician*] to discuss the outcome of the tests, he told me that the tests were entirely consistent with neuromuscular disease, and there was nothing to be done for it. He did say if things got bad enough, he would put me on oxygen. That's when the bells went off in my head. I had read an article that talked about the fact that oxygen was a no-no (well - only in very special cases) for people with neuromuscular problems. I went home and dug out the article *Oxygen is NOT for Hypoventilation in Neuromuscular Disease* by E.A. Oppenheimer, MD, FCCP. Here it said quite clearly that "Patients with neuromuscular diseases who are developing progressive respiratory failure due to respiratory muscle weakness will die unless mechanical ventilation is used." Opps! Did he say die? Yes, that is exactly what he said. I'd best do some more looking.

Before I get too far, I want to point out an important issue. My PCP had told me that there was nothing to be done for this. That is exactly what he believed. He is not dumb, under-educated, or out-of-touch. He is just like so many other people who work in a particular field; he doesn't know everything. I later came back to him and told him the results of my search. He nodded quietly and said, "And again, I've learned something new." This is precisely why I believe I must take responsibility for my care, and why I spend so much time reading all I can regarding my condition.....

[Larry has asked me to add a note here - I found a pulmonologist familiar with neuromuscular breathing problems. As it is the transitions are harsh and confusing. It was the pulmonologist who prescribed the BiPAP for me.]

The doctor also prescribed a machine called a bipap for me. A BIPAP is a Bilevel Positive Airway Pressure ventilator. The machine is small and quiet and, in the machine I got, ran on either 110 volt house power or a 12 volt battery. It connects to a mask that fits over your nose and supplies a volume of air that is forced in at a prescribed pressure for the inspiration cycle. It then drops the pressure but still blows air into your nose during the exhalation cycle. The reason for the constant flow of positive pressure is to make sure your nasal passages do not close down, obstructing your breathing.

The very first night I used the machine I only woke up once. My waking problems were not caused by a need to go to the bathroom but by my breathing problems. The doctor had recognized my wakefulness as a symptom of the breathing problem. From that night on I slept through the night with only one or two waking episodes. But I had a sleep study scheduled and I had to discontinue use of the bipap for 48 hours prior to my sleep study. Apparently, use of the bipap (or any other mechanical ventilator) throws off the data that is gathered in the sleep study.

This article is ended here. The full article was printed in LincPIN.

Larry Kohout,

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Post Polio Syndrome – Fourth Year Lessons
By Gladys Swensrud - February 2004 to February 2005
Excerpted paragraphs with permission.

I made a visit to my Pulmonary Care doctor, Dr. Murray. We discussed the importance of correctly assessing and maintaining my neuromuscular breathing difficulties. We reviewed how I was first assessed by an overnight-at home, night oximetry, sleep study in November of 2001, and for 2 ½ years I used a Continuous Positive Air Pressure (CPAP) machine, to attempt to meet my breathing needs, for what was thought to be very mild, Obstructive Sleep Apnea (OSA). In spite of using a CPAP faithfully during that time, I was still experiencing many daytime problems, which could be night breathing related. After extensive reading and research on pulmonary issues specifically related to Post Polio, I requested further testing to be sure that Continuous Positive Air Pressure was in my best interest with my muscle challenged situation.

Dr. Murray was extremely helpful in doing every test possible within my HMO's ability to get to the core of my problem. All the tests he ran came back nearly "within the normal range" (one of my HMO's favorite statements!). Although he had done what he could, current medical understanding of what I was experiencing is puzzling to most health professionals. Throughout the weeks in which this was unfolding...*I remained tenacious!* Even if my HMO's testing process did not indicate a change in the present therapy, I knew something was definitely still wrong, and at any cost, I needed to find out how to fix it. It was the intervention of Progressive Medical, coupled with Dr. Murray's assistance, which finally set me on the right course.

Because of my concerns that I shouldn't leave any stone unturned where my breathing problems were related, I next went outside of my HMO to Progressive Medical for a breathing evaluation. They determined with a simple pre-test that I had a breathing deficit, which would require a change from my CPAP to a bi-level machine. And they felt I should be further studied; their *in-home* test would be advisable. Based on the Progressive pre-test information, and trusting my judgment that Progressive Medical might have a solution to my predicament, Dr. Murray, doing everything he could to help me, approved the trial of a bi-level machine to be paid for by my insurer to replace my CPAP. And he ordered an *overnight, hospital sleep study* within my HMO to determine the values at which my bi-level would be set. To complete my investigative cycle, I, at basically the same time that my HMO hospital sleep study would be done, agreed to the Progressive *in-home* extensive sleep test. This would complete my groundwork and give me input from two directions that could be essential in solving my breathing puzzle.

Once the HMO, overnight sleep study was performed, the personnel in charge of evaluating/reading the computerized print out determined (in their opinion), 2 ½ years later, I *now* had moderate Obstructive Sleep Apnea with **no** signs of Central Sleep Apnea. They felt my bi-level values should be set at 16/12. That was a far cry from my HMO's original testing value determination of a CPAP setting at 10cm of continuous pressure, which I had lived with for the last 2 ½ years. And to complicate this even more, I would have continued to live with a CPAP of 10cm for the **foreseeable** future because *I was the one initiating this inquiry*, not my HMO.

With my overnight, hospital sleep study in hand [which if I had not requested a copy, I never would have received one], and as an informed, modern patient, I went directly to the Internet to find out how to correctly read my results. There is a plethora of information available, but one site was particularly useful to me. It analyzed the results step by step and walked me through the meaning of each result. What a magnificent treasure trove of information! http://www.suite101.com/article.cfm/sleep_apnea/57133

And after absorbing the data, I was left wondering how my HMO could just assign a diagnosis to me without first explaining how they reached their conclusion? I think medical professionals no longer have the time to participate in that portion of the diagnostic process.

After examining my results, I had questions galore about my sleep study. For instance: Why did I never get to stages 3 and 4 of the five sleep cycles? Why had my oxygen level fallen to below 60% at one point and close to that at other times? Why could I not stay in the few REM cycles that I did finally reach? It was like I would go into and out of them in a flash. Why was I constantly in stages 1 and 2 of sleep, and what exactly did that mean? What did it mean that I instantly fell asleep, almost the second I laid down? Even with electrodes stuck to me, literally from head to toe, to record my every move, in a cold, foreign, hospital room with a hard bed and strange noises coming from a CPAP machine that wasn't mine, it took me only 1½ minutes to fall asleep. Wasn't that unusual?

The next step was to take my sleep study results to Progressive Medical to be thoroughly reviewed, at which time they sent me *home* for a 4-night sleep test using a ResMed VPAP III (S/T) with Res-Link machine. It used a smart card, which evaluated my breathing along with other vital statistics of my sleep habits within that period (from total hours of sleep to Minute/Median Minute/Maximum Minute Ventilation to Mask Leak timing to Tidal Volume to AHI to Time in Apnea to % of Spontaneous Breaths per night with EPAP settings of 4.0 and IPAP settings of 12.0 to Pulse Rate, to Rise Rate, etc.). The results were very specific to my particular situation, and they discovered with bi-level (S/T) values of 12/4 and a back up rate of 8 Beats Per Minute (BPM), I was having **no** nighttime apnea episodes. Another important component of their testing equipment was they were able to determine, within the 4-night test, I relied upon my back up rate to initiate breaths 30% to 50% of each night. This would be supportive of the fact that my breathing issues also have a Central Sleep Apnea component that was not read by the HMO testing method.

I must recognize at this point my 1½ years and growing friendship with Rick Van der Linden, the PPS Manager himself! Rick has been the sounding board for most of my zany thoughts in year four. His analytical mind keeps me on track when I waver from my Post Polio objectives. I can bounce ideas off of Rick, and, unlike my dear, overloaded husband, Keith, Rick's eyes don't begin to glaze over and roll around after I inundate him with a ton of data. What I see in my own situation, and in that of many other polio survivors experiencing PPS, is a desire to protect from overdosing our spouses and loved ones. **We** must live with Post Polio Syndrome every minute of the day, but why should they? They are the glue of our lives, and TMI (Too Much Information) causes them to hear, "Blah, blah, blah, blah, blah," instead of what is most important for them to hear. So I have found gathering with other polio survivors in support groups and sharing friendships via snail mail and email with those also experiencing my issues is extremely helpful.

Gladys Swensrud—swensrud@pacbell.net

***“To breathe or not to breathe
To sleep perchance to dream
To wake refreshed
From this sea of troubles we devoutly wish
To promote more awareness of neuro muscular issues
And end the heartaches and thousand times frustration
Of non-corroboration of our reported respiratory symptoms.”***

With thanks and apologies to William Shakespeare.

This article has been compiled by Hilary Boone, Founder, Secretary and Newsletter Editor of the Lincolnshire Post-Polio Network, from the majority of the text and notes on the slides of the following presentation and other sources as reported. I have resequenced some of the information presented but retained the Slide Numbers for reference.

**The Evaluation and Management of Respiratory Disorders
Edward Anthony Oppenheimer, M.D.
Los Angeles, California
San Francisco Bay Area PPS Group / Kaiser Permanente Conference
Aging with Disability – The Late Effects of Polio
Sept. 19, 2003**

During the Conference Dr. Oppenheimer gave me permission to use his presentation and handouts to promote the respiratory needs of polio survivors. It is only in the last six months, since personally experiencing the testing, and more importantly the last three weeks when my husband has gone through the same procedure, that I have come to understand the problems being experienced, the terminology of testing and machines and realised the full importance of this work. I have expanded on initials and added dictionary definitions of many of the terms used for better understanding. It is with regret that I have to report that Dr. Oppenheimer is no longer with us. His expertise in this field was invaluable to polio survivors and those with neuromuscular disorders. We must continue his work.

The knowledge and experience of physicians (even specialists in neurology or pulmonary medicine) is often limited regarding PPS (*Post Polio Syndrome*) and care of people with Neuromuscular diseases. Often this is linked with lack of enthusiasm, lack of encouragement. Many physicians today are so busy that they do not find time to dig deeper when an unfamiliar problem presents itself, when a polio survivor comes in for an office appointment. Ideally a physician would be delighted, and would study the issues, and consult with available colleagues who are specially experienced – and then provide good care and progress in his/her abilities as a physician. Many polio survivors have difficulty finding such a physician. Other speakers on the program at this conference discuss this and how to prepare for a visit with your physician. The more prepared a person is, with good information and discussions with other polio survivors, the better.

[Note from last slide]

[Slide 2] The very slow progression of motor neuron impairment in PPS may result in early symptoms being over-looked both by the individual and the physician.

“Respiratory muscle weakness frequently goes undetected in patients with neuromuscular disease until ventilatory failure is precipitated by aspiration pneumonia or cor pulmonale (*Heart disease that results from abnormally high resistance to the passage of blood through the lungs; it often leads to right heart failure*). Diagnosis is delayed because limb muscle weakness prevents patients from exceeding their limited ventilatory capacity. A few patients develop severe respiratory muscle weakness despite little or no peripheral muscle weakness.”

– Laghi and Tobin (2003)

[1] Breathing Problems in Polio Survivors [Slide 6]

- Respiratory muscle weakness
- Bulbar impairment [*affecting nerve cells in the base of the brain, controls breathing*]
- Chest wall stiff and inelastic [*Try taking chest expansion measurements per breath*]
- Scoliosis [*When standing are you now leaning over and squashing diaphragm?*]
- Sleep disordered breathing
- Other additional conditions such as COPD (*Chronic Obstructive Pulmonary Disease*)
- Aging

[2] Who is at high risk for respiratory problems? [Slide 7]

42% of patients with post-polio syndrome

88% of who needed ventilator during acute phase

High spinal polio resulting in upper body weakness and/or diaphragm weakness; or bulbar polio during acute phase

Scoliosis

Polio survivors who also have COPD, asthma, obesity, or cardiovascular disease

[3] Symptoms of PPS respiratory problems. [Slide 8]

- Excess fatigue, low energy, anxiety, cognitive impairment
- Poor sleep, frequent awakening, orthopnea (*The inability to breathe easily unless one is sitting up straight or standing erect.*), daytime sleepiness, restless legs, morning headache
- Shortness of breath, orthopnea, DOE [*could not find explanation*]
- Weak cough, difficulty clearing secretions
- Ankle swelling
- Aspiration [*the sucking of food particles or fluids into the lungs*]

[4] PPS Muscle weakness: Respiratory impact. [Slide 9]

- **Inspiratory muscles** – inflate the lung – Prescribe: assisted ventilation: NPPV (*NPVV, noninvasive positive pressure ventilation, commonly said as Nippy*)
- **Expiratory muscles** – effective cough – Prescribe: use assisted cough methods if PCF < 270 lpm (*Peak Cough Flow, litres per minute*)
- **Bulbar** – upper airway function – Prescribe: both of the above, plus PEG and if severe TPPV (*PEG, feeding tube insertion - TPPV, tracheotomy positive pressure ventilation*)

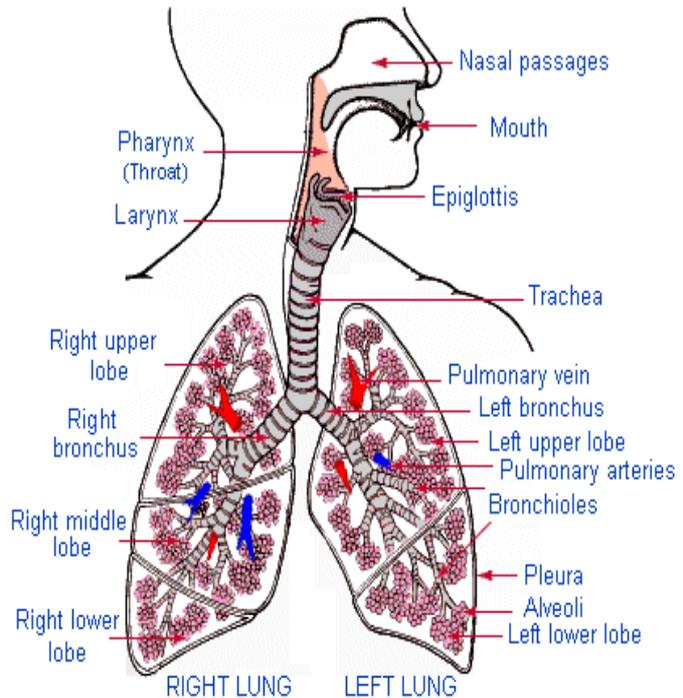
Continues on page 14.

How do lungs work?

Every time you breathe in (inspiration), air travels from the nose or mouth, through the voice box (larynx), and down the windpipe (trachea), which then branches into the main bronchial tubes with one going into each of the two lungs.

The bronchial tubes keep dividing, becoming narrower and narrower in the process. At the end of the smallest airways are the alveoli, tiny air sacs that look like clusters of grapes. There are 300 million alveoli in the lungs – if you laid them side by side, they would cover a tennis court.

The alveoli are the "work horses" of the lungs since it's here that the oxygen from the air is soaked up by blood, at the same time that the blood dumps carbon dioxide, which the body cannot use, back into the alveoli. The blood then distributes the oxygen throughout the body so it can produce energy, and the carbon dioxide is breathed out (expiration).



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Diagnosing respiratory muscle weakness: from www.mndcentre.org.uk

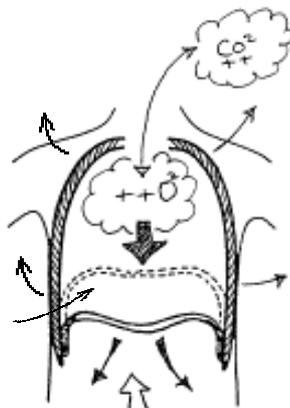
During metabolism the body consumes oxygen and produces carbon dioxide. Oxygen is supplied and carbon dioxide is removed by the lungs. This can only occur if an adequate volume of air is exchanged in the lungs and this is achieved by increasing, then decreasing, the air pressure in the lungs. The co-ordinated action of the diaphragm, accessory and abdominal muscles expand and contract the rib cage creating the differences in pressure which are responsible for the flow of air. The diagnosis and treatment of ventilatory compromise therefore requires some understanding of the action and anatomy of respiratory muscles.

To breathe in, the upper thoracic accessory muscles contract and the ribcage moves out and up and at the same time the diaphragm contracts and moves down. This expands the lungs, reducing air pressure in the lungs and so drawing air in through the airway.

Normal Respiratory Function

Accessory muscles move the rib cage out and up

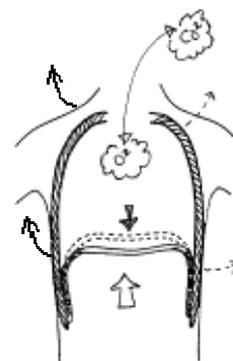
And the diaphragm contracts, pushing down abdominal contents.



Abdominal Pressure

Weak Respiratory Function

Accessory muscles are unable to move the rib cage outwards and the diaphragm can be too weak to contract and push down abdominal contents.



Abdominal Pressure

[5] Inspiratory muscles: [Slide 12]

Diaphragm *
Internal Intercostals – parasternal *
Scalenes *
Sternocleidomastoid
Trapezius
Levator Scapulae
Rhomboids
Serratus Anterior
Pectoralis Major
External Intercostals

* **Active during normal inspiration.** Others are accessory respiratory muscles.

Expiratory muscles:[Slide 15]

Pectoralis Major (upper)
Latissimus Dorsi
Internal Intercostals - interosseous
Transverse Thoracis
Internal Oblique
Rectus Abdominis
Transverse Abdominis
External Oblique

[Slide 13 note] Most polio survivors with respiratory muscles weakness have a weak diaphragm. They are more short of breath when lying down, and have a Vital Capacity lying down (supine) >10% lower than when sitting up. However this depends on which respiratory muscles are impaired – thus there are some polio survivors who breathe best lying down (Dr. Arnold Beiser was an example of this).

[6] Bulbar muscles: [Slide 16]

- Responsible for pharyngeal and glottic upper airway function, swallowing, speech, cough
- Pharynx – a collapsible floppy airway stabilized by contraction of pharyngeal muscles. Muscle weakness → unstable airway with obstructive events
- Epiglottis (*The flap that covers the trachea during swallowing so that food does not enter the lungs.*) closes automatically upon swallowing – incomplete or uncoordinated closure ⇒ cough, choking, gagging, aspiration, infection...

[7] Sleep and the weak diaphragm [Slide 14]

- **Mechanical aspect:** Postural disadvantage occurs when lying down
- **Neurological aspect:** During deep sleep, particularly REM (*rapid eye movement*) sleep, intercostals (*Muscle tissue between two ribs. This muscle is a type called skeletal muscle.*) and accessory muscles (*see later in article*) become flaccid and are not available to assist the weak diaphragm.

Dreams occur during REM sleep. We typically have 3 to 5 periods of REM sleep per night. They occur at intervals of 1-2 hours and are quite variable in length. An episode of REM sleep may last 5 minutes or over an hour. About 20% of sleep is REM sleep. If you sleep 7-8 hours a night, perhaps an hour and half of that time, 90 minutes, is REM sleep.

REM sleep is characterized by a number of other features including rapid, low-voltage brain waves detectable on the electroencephalographic (EEG) recording, irregular breathing and heart rate and involuntary muscle jerks.

By contrast, NREM (non-REM) sleep is dreamless sleep. During NREM, the brain waves on the EEG are typically slow and of high voltage, the breathing and heart rate are slow and regular, the blood pressure is low, and the sleeper is relatively still. NREM sleep is divided into 4 stages of increasing depth of sleep leading to REM sleep. About 80% of sleep is NREM sleep. If you sleep 7-8 hours a night, all but maybe an hour and a half is spent in dreamless NREM sleep.

[8] PPS Respiratory pathophysiology [Slide 17]

- Gradual loss of muscle strength: inspiratory, expiratory ± bulbar
- Scoliosis
- Decreased chest wall compliance
- Deep stages of sleep worsen Respiratory Failure
- Sleep disordered breathing (SDB) due to bulbar impairment ± central CNS (*Central Nervous System*) changes:
OSA (*Obstructive Sleep Apnoea*),
CSA (*Central Sleep Apnoea*), hypopneas,

[9] Sleep disorders are frequent in PPS [Sl.18]

- Hypopneas and hypoventilation
- Sleep disordered breathing without hypoventilation
- Obstructive Sleep Apnoea
- Central Sleep Apnoea
- Mixed sleep apnea

[10] Sleep always worsens respiratory failure [Slide 19]

This slide's title is quoted from Dr. Colin Sullivan, Sydney, Australia (Margaret Pfrommer honor lecture at ACCP's CHEST 2000 – a version of this presentation is included on ResMed's CD ROM – order #10712)

- Intercostal and accessory muscles are flaccid during REM sleep + weak diaphragm with postural disadvantage
 - Hypoventilation:
↓O₂ ↑CO₂
- Initially arousals which ⇒ sleep fragmentation
- Cascade of events follow, including:
 - Blunted arousal response, reduced REM (*Rapid eye movement*) sleep
 - Depressed chemoreceptors ⇒ progression of Respiratory Failure
 - Cardiovascular and neurohormonal changes
 - Cognitive impairment

Continued on page 16

The central nervous system is that part of the nervous system that consists of the brain and spinal cord. The central nervous system (CNS) is one of the two major divisions of the nervous system. The other is the peripheral nervous system (PNS) which is outside the brain and spinal cord.

The peripheral nervous system (PNS) connects the central nervous system (CNS) to sensory organs (such as the eye and ear), other organs of the body, muscles, blood vessels and glands. The peripheral nerves include the 12 cranial nerves, the spinal nerves and roots, and what are called the autonomic nerves that are concerned specifically with the regulation of the heart muscle, the muscles in blood vessel walls, and glands.

(Hypopnea: Literally, under breathing. Breathing that is shallower or slower than normal. Hypopnea is distinct from Apnea in which there is no breathing.)

(Hypoventilation: The state in which a reduced amount of air enters the alveoli in the lungs, resulting in decreased levels of oxygen and increased levels of carbon dioxide in the blood. Hypoventilation can be due to breathing that is too shallow (hypopnea) or too slow (bradypnea) or to diminished lung function.)

Cardiovascular: The circulatory system comprising the heart and blood vessels which carries nutrients and oxygen to the tissues of the body and removes carbon dioxide and other wastes from them.

Pulmonary hypertension: High blood pressure in the pulmonary artery that conveys blood from the right ventricle (chamber of heart) to the lungs. The pressure in the pulmonary artery is normally low compared to that in the aorta (artery that leaves the heart) Pulmonary hypertension can irrevocably damage the lungs and cause failure of the right ventricle.

Cerebrovascular: Pertaining to the blood vessels and, especially, the arteries that supply the brain.

Dr. Colin Sullivan – Oct. 2000 – Pfrommer lecture - ACCP

[Slide 19 note] At onset of sleep ventilation falls lowest in REM sleep. Arousal is the 1st and most important mechanism to protect you but it causes sleep fragmentation. Cardiovascular changes: Pulmonary hypertension, cor pulmonale (with ankle edema—*swelling*), Arterial hypertension, other cardiovascular complications (coronary vascular and cerebrovascular events). Increased sympathetic output, Hyperexcitable state. When bulbar muscles are significantly impaired upper airway obstructive events can occur during sleep. This may also explain the tendency for deaths to occur at night.

-- References:

Sullivan, C. E., F. G. Issa, et al. (1981). "Reversal of obstructive sleep apnoea by continuous positive airway pressure applied through the nares." *Lancet* 1(8225): 862-5.

Sullivan, C. E. and E. R. Ellis (1987). "Nocturnal positive pressure ventilation via a nasal mask." *Am Rev Respir Dis* 136(3): 791-2.

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Continued on page 18

Respiratory Muscle Testing. The respiratory muscles elevate and lower the ribs, in a cyclic manner, resulting in inspiration and expiration to maintain arterial blood gases within a normal physiologic range under varying conditions from rest to extreme exertion. Due to a large cardiopulmonary reserve, homeostasis is usually maintained in spite of severe lung disease or respiratory muscle weakness. Respiratory insufficiency or failure, which results in abnormal blood gas tensions, occurs after the work of breathing exceeds this reserve. **Without careful assessment of respiratory muscle function, significant weakness may go undetected.**

In restrictive pattern disorders there is a mechanical or bellows dysfunction resulting in impaired ventilation. Examples include post poliomyelitis syndrome.

The diaphragm is the primary muscles of inspiration. Vital capacity (FVC) and maximal inspiratory pressure (PiMax/MIP/NIP) are good indicators of inspiratory muscle strength. Vital capacity is measured with a spirometer. The patient is instructed to inspire maximally then exhale as much air as possible; slow maximal exhale measures VC, and rapid maximal exhale measure forced vital capacity (FVC). PiMax also known as negative inspiratory pressure (NIP), is measured after maximal expiration at residual volume.

Pitfalls.

1. Failure to measure lung volumes in both supine and seated positions in persons with neuromuscular disorders or spinal cord injury.

2. Poor effort due to cognitive status, pain, or anxiety during pulmonary function testing.

CLINICAL PEARLS.

1. The most sensitive indicator of respiratory muscles weakness is reduction in maximal static inspiratory pressures. (PiMax or MIP)

2. In persons with neuromuscular disorders or spinal cord injury, **spirometry should be performed in both supine and seated positions.** In persons with neuromuscular disorder who have diaphragmatic weakness, lung volumes are lower in the supine position due to increased work of breathing required to move the diaphragm against the abdominal contents and overcome gravity.

©Handbook of Manual Muscle Testing by Nancy C Cutter and C. George Kevorkian
McGraw-Hill, Health Professions Division. ISBN 0-07-033150-2

Excerpted from chapter by Sally Ann Holmes, MD,

Assistant Professor, Department of Physical Medicine and Rehabilitation, Baylor College of Medicine.

Pulmonary Function Studies.

FVC - Forced Vital Capacity.	The amount of air moved when lungs are forcefully expanded after maximal expiration.
TV - Tidal Volume.	The amount of air moved in normal inspiratory effort.
TLC - Tidal Lung Capacity	The amount of air contained within the lungs at the end of maximal inspiration.
FRC - Forced Residual Capacity.	The amount of air in the lungs at the end of normal expiration.
RV - Residual Volume	The amount of air in the lungs at the end of maximal expiration.
FEV1 - Forced Expiratory Volume	Forced expiratory volume in one second.
Minute Volume	Tidal volume times rate of breathing per minute
PiMAX or MIP - Maximal Static Inspiratory Pressure	Static pressure measured near RC after maximal expiration
PeMAX or MEP - Maximal Static Expiratory Pressure	Static pressure measured near TLC after maximal inspiration.
MVV - Maximal Voluntary Ventilation	Total volume of air expired during 12 second period of patient breathing as fast and as hard as possible: expressed in L/min
PCF - Peak Cough Flow	The amount of air flow during maximal cough expressed in L/second.

©From Handbook of Manual Muscle Testing by Cutter and Kevorkian—ISBN 0-07-033150-2

TESTING PATIENTS WITH NEUROMUSCULAR CONDITIONS.

Testing Polio Survivors. Not an easy task. No two the same, no set pattern. If we have arrived in your office/hospital for an appointment then it is because we have had symptoms for some time. Where we are now is the last place we want to be. Ask us when we notice these symptoms; what actions are we doing, have done earlier in the day, the day before. Ask us how we do the actions and if possible observe them.

Repeat test three times to same level if possible. If you are asking patients with neuro muscular weakness to do this and are telling them to rest as long as they need between tests because of their fatigue then PLEASE record their resting times. You have allowed their weakened muscles to recover between each test - the figure recorded only relates to how they achieved this test. It may not relate to their ability in real life. What result would you get if you asked them to repeat to standard resting time?

Using other muscles to achieve breathing tests. Polio Survivors are canny folks and for all their lives have used trick movements, asked other muscles to take over tasks and/or assist in actions. To hold their breath for ten seconds might require additional muscle use. For instance, are they tightening leg muscles and pushing both feet hard against the floor to hold their breath for ten seconds; are they raising their head to bring in more muscles to assist in the supine test? Has this skewed the figure recorded?

Observing us doing some of the actions might show that:-

- we stop breathing to concentrate on achieving an action;
- that we could be using our accessory breathing muscles to help us achieve another task taking away their ability to assist in breathing
- that we lean further over as we walk/walk and carry reducing the ability of our diaphragm;
- we are upper chest breathing for long periods, etc.

If you are testing in a hospital environment where the patient is not doing their normal daily tasks - using up their normal energy tokens - have they got more energy available to achieve what you are asking? If your sleep testing is done in a multi bed ward, is your patient sleeping as deeply as they do at home?

Are the tests you do and the way you record the results giving you an accurate picture of how neuromuscular patients breathe as they go about their daily lives?

© Hilary Boone, Founder, Secretary and Newsletter Editor, Lincolnshire Post Polio Network—May 2006.

[11] Clinical evaluation [Slide 22]

- Listen to the person's story, goals and preferences
- Physical examination
- Tests that may be helpful:
 - Spirometry; supine VC, MVV
 - Peak cough flow (PCF)
 - Echocardiogram
 - Sleep study if no hypoventilation is present
 - MIF and MEF
 - Pulse oximetry, ABG
 - Overnight home oximetry

Follow-up monitoring

- Physical examination: check speech and voice volume, cough, scoliosis, ability to breathe lying down, abdominal movement during inspiration, etc .night home oximetry only if other tests listed above it are relatively normal and there is a reasonable question regarding respiratory/bulbar muscle weakness.
- Sleep study (polysomnography) is advised for selected polio survivors who have sleep related symptoms, when there is a question of Sleep Disordered Breathing, and the other tests find no evidence of significant respiratory muscle weakness with hypoventilation.

[12] Monitor respiratory status [Slide 23]

- Clinical physiological monitoring allows patient to choose MV (*mechanical ventilation*) or palliative care, before acute respiratory failure occurs
- Vital Capacity sitting and supine
- MIP and MEP (*Maximum Inspiratory and Expiratory Pressure*)
- Peak cough flow rate (PCF)
- Spot oximetry, and nocturnal oximetry

[13] Home respiratory monitoring by patient [Slide 24]

- Peak cough flow (PCF) Unassisted and assisted PCF
- Peak flow rate
- Incentive spirometer (e.g.: Tri-flow type)
- Oximetry spot tests (e.g.: Nonin Onyx 9500)
by RT, (*Resp Therapist*) PHN (*Pulmonary Health Nurse*) or by patient

Deciding to use assisted ventilation requires careful consideration to achieve optimal decision-making. Ideally the Polio survivor and family member or friend should participate in a specially designed educational program for about two hours (with experienced staff available, Respiratory Therapist ± Respiratory Nurse ± Pulmonary MD) this can often be coordinated and presented by an experienced RT. This should include:

- Easily understood information
- Possibly a video showing the home ventilator and interface options
- Some hands-on opportunity to try different available ventilators and interfaces
- Peer networking
- A group discussion period
- An opportunity to discuss issues on individual follow-up visits

[14]Major options if Mechanical Ventilation is needed [Slide 27]

- Iron Lung, porta-lung, cuirass
- Rocking bed, pneumo-suit
- **NPPV – Noninvasive positive pressure ventilation**
- **In-Exsufflator: CoughAssist**

**Always start with
NPPV unless
this is not tolerated.**

- Pneumobelt (IAPV)
 - Tracheotomy ventilation (TPPV)
- Pneumobelt is useful for daytime assistance – It is under-utilized. IAPV = intermittent abdominal pressure ventilator.
- Tracheotomy is useful for selected VAIs when NPPV is no longer satisfactory.

[15] Reasons to start NPPV early [Slide 28]

- To improve: symptoms, Quality Of Life, sleep, and daytime function
 - Provide the experience and skills needed in case acute respiratory infection occurs
 - Hands-on NPPV experience helps with ventilator decision-making
 - Equipment may improve cough
- There should certainly be symptoms related to respiratory muscle weakness and some evidence on pulmonary function testing that support this conclusion. The available guidelines need to be kept in mind, however each person needs individual consideration in view of their situation with the advice of their pulmonary physician.

[16] USA Consensus Conference NPPV Guidelines Criteria to qualify for NPPV:[Sl.29]

Diagnosis of PPS with respiratory symptoms attributed to hypoventilation, *and*

At least one physiological abnormality:

- FVC < 50%, or
- MIP < 60 cm H₂O, or
- PaCO₂ ≥ 45 mm Hg, or
- Sleep oximetry SpO₂ < 88% for at least five continuous minutes

CHEST (1999) 116:521-534

American College of Chest Physicians (1999): Clinical indications for noninvasive positive pressure ventilation in chronic respiratory failure due to restrictive lung disease, COPD, and nocturnal hypoventilation--a consensus conference report. Chest (1999) 166:521-534

[17] HCFA Respiratory Assist Device (RAD) Policy [Slide 30]

Requirements for a Bilevel Respiratory Aid Device (NPPV) device with or without back-up rate for Neuro Muscular diseases:

Documentation of NM disease (without significant COPD)* and...

1. PaCO₂ ≥ 45 mm Hg while awake; or
2. Sleep oximetry SpO₂ < 88% for at least five continuous minutes; or
MIP < 60 cm H₂O, or
FVC < 50%

* By MD with experience & training in non-invasive respiratory assistance -Oct 1999

Medicare Guidelines are similar to those recommended by the Consensus Conference (Chest 1999) – previous slide.

HCFA is now CMS (Centers for Medicare and Medicaid Services).

FDA has regulatory authority to approve a product as a ventilator (not CMS). The FDA approved bilevel equipment with back-up rate capability as ventilators. A ventilators, by law, require on-going Medicare reimbursement as long as the beneficiary uses it. The level of reimbursement is higher because a “ventilator” requires “frequent and substantial servicing” by the home medical equipment company. CMS proposes to change reimbursement for these bilevel ventilators (K0533) to ‘capped’ reimbursement which is a lower monthly payment for only 13-15 months...

[18] Most Post-Polio VAIs use night-time Mechanical Ventilation [Slide 31]

- This improves: Survival, Quality Of Life, and daytime function, Abnormal Blood Gases and sleep quality
- Daytime function improvement is due to:
 - Resting muscles for 6-10 hours at night
 - Ventilatory support at night prevents sleep related progression of respiratory failure

The two explanations for the benefit from nighttime Mechanical Ventilation are:

1. Resting muscles for 6-10 hours at night
2. Ventilatory support at night prevents sleep related progression of respiratory

failure

Both statements are probably true. Traditionally it was felt that muscle rest was the reason. Today it seems clear that treating the sleep related problems, that result in progression of Respiratory Failure, is very important.

Home Ventilator Guide is IVUN's latest resource compiled by Judith R. Fischer. The comprehensive resource displays technical information about the world's home ventilators in charts that are easy to read and makes comparing home ventilators more convenient. It features bilevel positive airway pressure ventilators, volume-cycled ventilators, pressure support ventilators, and combination or multi-mode ventilators.

<http://www.post-polio.org/ivun/HomeVentGuide05S.pdf>

Bilevel Positive Airway Pressure Ventilator. - Bilevel ventilators developed by modifying CPAP to also produce inspiratory positive airway pressure [IPAP] to assist inspiration (breathing in). IPAP and expiratory positive airway pressure [EPAP] setting are adjusted separately. People with neuromuscular disease and weak diaphragmatic muscles often may have difficulty breathing in and need IPAP set higher than EPAP, e.g. an IPAP of 14 and an EPAP of 3. The difference between IPAP and EPAP is called the span, and in these cases should be at least 10. [From Home Ventilator Guide page 3]

[19] Interfaces [Slide 32 and notes]

Nasal mask or pillow- Mouthpiece - Full face mask - Custom made interfaces

I usually advise my patients to have three comfortable interfaces: a nasal mask and a nasal pillows; and a mouthpiece. Most people need to work with an experienced Respiratory Therapist and try at least 6 - 7 different nasal masks and pillows to find two that fit correctly and are comfortable. If a mouthpiece is used with a bilevel S/T ventilator, a small hole needs to be drilled into it or it needs to be attached to a whisper valve to work properly with bilevel's EPAP.

Ideally a person come to an experienced medical center for day visits, or stays overnight, to be properly started on NPPV. This requires time for the staff to work with the patient, provide a "no rush" situation to try different equipment and interfaces and time to get used to the experience. Louie Boitano, MS, RR (Northwest Assistive Breathing Center, Pulmonary Clinic, University of Washington, Seattle) describes his approach in an article in Ventilator-Assisted Living: "Getting Used to Noninvasive Bilevel Pressure Ventilation" - Ventilator-Assisted Living (Summer 2003) Vol. 17, No. 2

Post Polio Health International Ventilator Users Network [IVUN] www.post-polio.org/ivun/index.html

[20] Bi-level Spontaneous “S” Mode - (set to switch between prescribed pressures.) [Sl.39]

- Delivers an expiratory pressure (EPAP) and a higher inspiratory pressure (IPAP)
- Goal to normalize ventilation (blood CO₂ level) OR relieve airway obstruction
- Responds to spontaneous effort only
- Useful for selected COPD and Sleep Disordered Breathing

[21] Bi-level Spontaneous / Timed “S/T” Mode - (set to spontaneous mode but switches to a timed mode [referred to as the back up rate] when breaths are not initiated by the individual.) [40]

- Same as “S” mode with the addition of:
 - Back-up rate setting for periods of apnea, hypoventilation, or to decrease work of breathing
- Most appropriate patient types:
 - Neuromuscular disease ⇐ **Post Polio Syndrome**
 - Central apnea
 - Nocturnal Hypoventilation

[22] IPAP – inspiratory positive airway pressure [Slide 41]

- Pressure support delivered to the patient when the machine is triggered into the inspiratory phase
- Increasing IPAP and IPAP-EPAP difference will increase tidal volume
 - Improves alveolar ventilation - Rx for hypoventilation
 - Decreases CO₂ levels and/or increases O₂ levels
 - Reduces accessory muscle use

[23] EPAP – expiratory positive airway pressure [Slide 42]

- Amount of pressure remaining in the circuit during the patient’s expiratory phase
- Increasing EPAP will:
 - Eliminate obstructive apneas and hypopneas
 - Increase Forced Residual Capacity

[24] Factors Affecting the Level of Ventilatory Support [Slide 43]

- Difference between the IPAP and EPAP levels set: DP should be > 10 cm H₂O
- Inspiratory time
- Impedance of the patient’s chest wall / lungs

[25] Bilevel S/T (Spontaneous/Timed) ventilator usual initial set-up: [Slide 38]

EPAP: 3 - 4 cm H₂O

IPAP: 8 - 10 cm H₂O

IPAP is gradually increased, as needed, to 14 to 20 cm H₂O

ΔP (IPAP – EPAP) should be ≥ than 10

High-span bilevel ventilation is advised. The ΔP (IPAP – EPAP) should be greater than 10 cm H₂O to achieve satisfactory alveolar ventilation.

[26] Back-up rate in S/T mode [Slide 44]

In the Spontaneous / Timed mode, the rate is set as a “back-up”

- To decrease work of breathing (WOB)
- If patient has exhibited central apnea
- In case of abnormal slowing in the patient’s spontaneous respiratory rate

Suggested initial settings:

- Daytime: 4-6 bpm below the patient’s resting respiratory rate (RR)
- Nighttime: set at patient’s resting rate

The suggested initial back-up rate settings reflect my usual approach. This needs to be adjusted to the needs of each individual ventilator assisted person (there is no one approach that is correct for everyone). My goal is to provide as much muscle rest at night as possible, and thus to eliminate the need to use respiratory muscle effort to trigger breaths while sleeping at night by adjusting the back-up rate to the person's resting rate while sleeping. It requires an experienced RT to adjust the NPPV ventilator to achieve the best synchrony between the patient and the bilevel ventilator [this is discussed by Dr. Colin Sullivan in his talk "Sleep – It's Role in NPPV given at Chest 2000 – the Margaret Pfrommer honor lecture)

[27] Setting-up NPPV requires [Slide 49]

- Experience: MD, RT, RN + Patient – and team work
- Equipment and interface options [*look at a variety of masks and try more than one*]
- Time to work with patient

[28] Initial goals of NPPV [Slide 46]

- Relieve symptoms
- Normalize sleep
- Provide experience with NPPV, as the number of hours needed daily gradually increases
- Prepare patient's ability to survive an acute respiratory infection
- Maintain oxygen saturation at $\geq 95\%$ – use NPPV without added oxygen

[29] Follow-up of NPPV [Slide 47]

- Regular visits to check patient and adjust equipment
- Initial IPAP: usually is 8 to 10, then increase gradually to 14-20 cm water
- Initial EPAP: 3 to 4 cm – usually not changed
- Patient comfort and skin care
- Several interfaces – include a mouthpiece
- Safety issues

[30] Effective cough is critical [Slide 56]

- Practice repeated huff cough
- Breath stacking techniques – increases MIC
- Check peak cough flow rate
- Manual cough assist methods – increases PCF
- Train to use a device to improve cough and clearance of secretions; e.g. – CoughAssist
- NPPV often fails if secretions cannot be cleared

[31] Nutrition and Respiratory muscle strength [Slide 51]

- Malnourished people become weaker, immune function becomes impaired
- Respiratory muscle strength is further impaired if person is malnourished

OXYGEN SHOULD NOT be used to treat hypoventilation [Slide 43]

Indications for oxygen for a polio survivor

- COPD, cor pulmonale,
other lung disease causing a low PaO₂ - without hypoventilation
- Pneumonia Air travel Palliative care

[32] Respiratory muscle performance **Well nourished.** **Poorly nourished*** [52]

MIP {-cm H ₂ O}	95	35
MEP {cm H ₂ O}	151	59
VC {% predicted}	101	63
MVV {% predicted}	80	41

*71% of ideal body weight.

Arora & Rochester (1982) Amer Rev Resp Dis 126:5-8

[33] Safety drills are very important [Slide 50]

- Make a list of all possible problems & emergencies ...with action needed
- Ventilator Assisted Individuals and caregivers should be trained; and practice at least once a month the actions needed for each possible problem
- Basic emergency equipment should be available, including an Ambu bag

[34] Respiratory tips to staying healthy - Basics [Slide 20]

- no smoking;
- avoid second-hand smoke and environmental hazards;
- get both pneumovax and influenza immunizations;
- avoid people with viral respiratory infection;
- good posture; treatment of scoliosis if needed;
- good nutrition, avoid obesity.

[35] Respiratory tips to staying healthy - Additional Steps if needed:- [Slide 21]

These are additional steps to consider particularly if there appears to be evidence of some slowly progressing respiratory or bulbar muscle weakness.

- Consider home monitoring using simple equipment: Peak Flow meter, and an incentive spirometer (used at hospitals for post-op care) – using these once every week or month allows you to be sure you are staying the same or detect a pattern of worsening and keep a written log
- Glossopharyngeal breathing; learn and practice it daily. [*GPB or Frog breathing uses the muscles of the tongue (the glossa) and the throat (pharyngeal muscles) to force air into the trachea and lungs through a repetitious process. This process involves using the tongue and throat muscles as a pumping mechanism to force air into the lungs*]
- Chest expansion exercises - Use GPB, Ambu resuscitator bag, or volume ventilator to maintain lung and chest wall compliance:
- Learn assisted cough techniques when peak cough flow (PCF) becomes abnormal < 270 lpm

[UK information. See next page, paragraphs relating to this subject taken from UK article by Dr. Robin Howard and Dr. Craig Davidson from the Lane Fox Respiratory Unit.

Long Term Ventilation in neurogenic respiratory failure]

[CPAP - CONTINUOUS POSITIVE AIRWAY PRESSURE [Slide 49]

CPAP should NOT be used for a polio survivor

with respiratory muscle weakness and hypoventilation.

CPAP is useful for polio survivors without hypoventilation
(with good respiratory muscle strength) – who have sleep apnea.

Long Term Ventilation in neurogenic respiratory failure.

Robin S Howard and Craig Davidson. J. Neurol. Neurosurg. Psychiatry 2003;74,24-30.
The Lane-Fox Respiratory Unit and Department of Neurology, Guy's & St. Thomas' Hospital,
London,

Excerpted paragraphs from UK perspective.

1. Respiratory failure often develops insidiously and symptoms may not be pronounced or complained about. Breathlessness is particularly unreliable in the context of a patient with limited mobility. Nocturnal hypoventilation and/or recurrent upper airway obstruction with sleep disruption may initially cause no symptoms. Eventually patient or carers notice insomnia, daytime hypersomnolence and lethargy, morning headaches, reduced mental concentration, and depression, anxiety or irritability. In addition there may be a complaint of abnormal sleep movements, nocturnal confusion, or vivid or distressing dreams.

2. When upright, active abdominal muscle contraction during expiration may mistakenly suggest preserved diaphragmatic function as the diaphragm passively descends at the beginning of inspiration. It is an important, and often missed, sign of profound respiratory muscle weakness.

3. Adequate ventilation is dependent on respiratory muscle pump, the ventilatory load placed upon it, and the central drive. In patients with neuromuscular disease, more than one factor is often present. A reduction in central drive occurs in sleep, even in health, when respiration is dependent on diaphragm function, especially during REM sleep when the accessory muscles become inactive. At this time, airway resistance also increases, particularly of the upper airways. These factors may thus combine to cause hypoventilation. Sleep is a critical period for respiratory compromise.

4. During acute poliomyelitis respiratory insufficiency occurs as a result of respiratory muscle weakness or involvement of the central respiratory control mechanisms. Respiratory insufficiency may develop many years after poliomyelitis, even in the absence of any obvious respiratory involvement during the acute illness of convalescent phase. [19]

[19 - Howard RS, Wiles CM, Spencer GT. The late sequelae of poliomyelitis. QJM 1988;251:219-232 Forced vital capacities of the 40 patients who did not receive respiratory support during their acute illness but came to need it after a mean latent period of 33.7 years ranged from 0.8 to 1.81 whilst FVC of the 48 patients who received support during the acute illness, but have not required it subsequently, ranged from 1.3 to 2.31. Additional note. Most of the people in the study were severely affected originally, 58.2% needed respiratory support during the acute illness.]

5. Symptom scores, such as the Epworth sleepiness score, are of less use in neuromuscular disease than in conventional non-neurological OSA [Obstructive Sleep Apnoea]. This is partly because of acclimatisation to symptoms, partly the expectation of deterioration in the more progressive disease, and also because OSA is associated with more sleep arousals leading to sleep deprivation. OSA occurs more frequently in neuromuscular disease than in the normal population. For instance, we found that >40% of polio survivors referred with fatigue and other symptoms of the post-polio syndrome have OSA caused by occult or mild bulbar weakness. OSA is also more common in other neurological diseases, especially with bulbar involvement.

6. Continuous positive airway pressure (CPAP) is effective in treating OSA. It stents open the upper airway and, by reducing arousals, provides relief of daytime fatigue. CPAP therapy does not correct alveolar hypoventilation and in progressive neuromuscular disease we would initiate NIV [non invasive ventilation, same as NPPV] in the absence of symptoms if significant nocturnal hypoventilation is revealed by oximetry or the daytime Pco₂ is >7.5kPa. Risk factors for respiratory failure include clinical evidence of diaphragmatic weakness, such as paradox or orthopnea, a vital capacity >50% predicted, or SNIP < 30cm H₂O. As the vital capacity falls progressively, in many conditions, serial measurements can guide both discussion of NIV and its initiation.

N.B. We recommend reading the full articles to ensure full understanding of the excerpted items

Pulmonary dysfunction and its management in post-polio patients.
John R Bach, Margaret Tilton—NeuroRehabilitation 8 (1997) 139 - 153
Excerpted items - Lincolnshire Post Polio Library article.

1. Abstract

Respiratory dysfunction is extremely common and entails considerable risk of morbidity and mortality for individuals with past poliomyelitis. Although it is usually primarily due to respiratory muscle weakness, post-poliomyelitis individuals also have a high incidence of scoliosis, obesity, sleep disordered breathing, and bulbar muscle dysfunction. Although these factors can result in chronic alveolar hypoventilation (CAH) and frequent pulmonary complications and hospitalizations, CAH is usually not recognized until acute respiratory failure complicates an otherwise benign upper respiratory tract infection. The use of non-invasive inspiratory and expiratory muscle aids, however, can decrease the risk of acute respiratory failure, hospitalizations for respiratory complications, and need to resort to tracheal intubation. Timely introduction of non-invasive intermittent positive pressure ventilation (IPPV), manually assisted coughing, and mechanical insufflation-exsufflation (MI-E) and non-invasive blood gas monitoring which can most often be performed in the home setting, are the principle interventions for avoiding complications and maintaining optimal quality of life. © 1997 Elsevier Science Ireland Ltd.

2. Respiratory muscles weaken with age, fatigue, and ultimately with the death or dysfunction of over-worked anterior horn cells which had survived the acute poliomyelitis. This is manifested by a decrease in pulmonary volumes, maximum inspiratory and expiratory pressures, and peak airflows.

3. Patient evaluation - [a] Full batteries of pulmonary function studies and arterial blood gas sampling are rarely useful for outpatients with any primarily restrictive pulmonary conditions unless concomitant intrinsic lung disease is suspected. A careful history, simple spirometer, and a peak flow meter are most useful for routine patient evaluation and an oximeter and capnograph are useful for more affected patients.

[b] The VC should be measured with the patient sitting, supine, side lying, and when wearing thoracolumbar orthoses when applicable. A properly fitting orthosis can increase VC whereas a poorly fitting one that restricts chest movement will decrease it. The VC is often most reduced when the post-poliomyelitis individual is supine because of inordinant diaphragm weakness. The presence of CAH may not be suspected unless the VC is obtained in this position. Evaluation of FEV1 should be done whenever COPD is suspected.

[c] Although patients with CAH can have many transient and often severe oxyhemoglobin desaturations, a 'sawtooth' pattern with more than 10 transient 4% or greater desaturations per hour in a symptomatic patient with normal supine VC and mean SaO₂ may signal uncomplicated sleep disordered breathing. For symptomatic patients oximetry studies alone are highly sensitive in screening for this condition. Outpatient polysomnography can assist in the evaluation of patients who are symptomatic despite having inconclusive nocturnal oximetry and carbon dioxide studies and relatively normal VCs . Some patients' symptoms are the result of a combination of inspiratory muscle weakness and sleep disordered breathing. Patients should be re-evaluated yearly or whenever there is a change in symptoms. should be done whenever COPD is suspected.

4. The management of post-poliomyelitis respiratory sequelae - Patient counselling includes cautioning to avoid dehydration, heavy meals, extremes of temperature, humidity, excessive fatigue, exposure to respiratory tract pathogens, obesity, sedatives, and narcotic use. The need for appropriate flu and bacterial vaccinations and early attention to maintaining alveolar ventilation and eliminating airway secretions during respiratory tract infections are important to decrease the risk of pneumonia. Therapeutic exercise programs, extremity bracing, energy conservation, assistive equipment needs, and day to day functioning should also be addressed. The key therapeutic goals are to maintain normal alveolar ventilation around the clock, to provide 'range of motion' to the lungs and chest wall, and to provide sufficient PCF to effectively clear airway secretions. Therapeutic options for accomplishing these goals should be presented and the patient ultimately trained and equipped. [End items]

E-Mail Forum by Mary McCreadie.

The Forum became decidedly lively following the March issue of the British Polio Fellowship's bi-monthly magazine, The Bulletin. "In a profile of three newly-appointed BPF Trustees,. One stated that *'She became frustrated with the direction of the Fellowship and decided to become a Trustee. She felt it was going more towards supporting people with post polio syndrome rather than all the members. "Not everyone thinks there is such a thing, it could just be old age," she says.'* Our members responded...

"I thought the BPF had come out of denial about PPS and to read that one of the Trustees puts this forward as her main reason for taking on the position has, frankly, annoyed and upset me."

"If a Trustee of a body, representing those with this condition openly doubts the existence of the condition then what hope have any of us, whether BPF or LPPN members, have of convincing our GP's etc that it is genuine."

"...I expect something better from an organisation which supposedly exists to represent and support people like me. If this lady thinks PPS is 'just old age' can she explain why my symptoms first appeared in my mid-forties?"

The latest issue of The Bulletin contained a well-written letter from one of our members Diana Foweraker, which voiced the feelings of most pps sufferers beautifully. The BPF now states that the trustee's remarks had been 'taken out of context'; that the profile wasn't complete. The BPF have published a Policy Statement defining PPS in outline, and confirming their belief that it is a genuine condition. Whilst the whole affair caused a lot of upset and outrage, **something good has come out of it** – which proves that it is much better to speak up than suffer in silence! We must point out that they have mentioned PPS in a considerable amount of past literature.

Loos [UK light hearted term for Toilet] featured once again – this time we discussed access to disabled loos, and some good advice was given:

"As far as pubs are concerned, if visiting a new one, it is worth ringing up beforehand to find out if they have an accessible loo."

"Ring your local authority, tell them you are disabled and would like a 'Radar' key, [Radar keys open all toilets with Radar locks, and we have found Radar padlocks on gates in nature preserve as public access is a 'kissing gate'] and they should then tell you that you can have one by calling at the office and producing £6."

"Alternatively, go to: <http://www.radar.org.uk/radarwebsite/> Select "National Key Scheme" from the left hand navigation column and that will provide background information. Note that as previously covered on this list, you should be able obtain the key 'VAT free!'"

There were also tributes to the longest iron-lung survivor, **John Prestwich**. "Sadly, John who had been in hospital since January 12th passed away on February 27th. http://www.action.org.uk/news_media/john_prestwich.php

We've discussed itching, thin and cracked skin – which has produced some useful advice:

"I have found taking Vitamin C and zinc very good. I take 1000mg of low-acid Vitamin C every day. This advice came from one of our Australian sources - Tessa Jupp, who is a nurse and nutritionist. When things get out of hand with a skin infection, it's homeopathic remedies every time and they work for me like antibiotics never have."

“**I use a** product with Urea in it for my feet called CCS Skin Care Foot Care Cream. It helps with cracked heels, and it has had an interesting unexpected effect: for years I suffered with verrucas on my feet, and found them impossible to eradicate – if I got rid of one, another would appear. After using this product for a few weeks, all the verrucas disappeared, and have not returned! It's available in branches of Boots and Lloyds chemists. ”

A discussion about the best kind of wheelchair cushions taught me a lot! The advice given enabled me to tell Wheelchair Services what I needed. In a very short time I was provided (free) with a superb gel-cushion which has done a lot to alleviate the soreness which comes from sitting in one position for any length of time.

As we're short of space this issue, I shall just mention a few more of the other topics, in the hope that they will inspire more of you to come and join in! The more voices we have on our list, the more information can be passed on. As you can see, we talk about anything and everything that affects our lives as polio survivors.

Other subjects ranged from helping-hand dogs, experiences with neurologists, attitudes of medical professionals, and the television film on Sister Kenny.

If you would like to join the list and are a paid-up member of the LincsPPN, send an e-mail to join-pnl@lincolnshirepostpolio.org.uk including your full name.

Email request - **Dear Lincolnshire Post Polio Network Members,**

I am a novelist working on a book that revolves around London during WWII. One of my characters, a woman, contracts polio in late 1942, perhaps early 1943. She would be around 23, living in Middlesex and working for the Women's Auxiliary Air Force. She's born in Dagenham, where her parents and younger siblings still reside during the course of the story. I'm having the dardnest time finding any information on treatment of polio during this time. I am aware there was the Iron Lung, but was this the only course? If anyone has any memories of this time and would feel comfortable sharing them, please feel free to contact me either by email or letter. Being as specific as possible about your personal experiences or memories of others' experiences would be incredibly helpful. What might seem like a boring detail to you, could be a gold mine to me!! Thank you deeply in advance. Best Wishes.

Jane Ratcliffe, 2588 Marcy Court, Bloomfield Hills MI 48302 USA

janeratcliffe@mac.com

Email about Shiny Braces - Barbara Snow from the San Andreas PPS Group in California posted the following on a Post Polio List about her braces.. She was more than happy to share this when I asked if I could publish and said she would love to hear from some more UK PPS folks.

In high school I wore two long leg braces. I remember getting a new pair and they were all shiny, stuck out like a sore thumb I thought. I got a metal file and sat there for hours in my room trying to make them dull. Of course if they weren't shiny no one would see them! On a visit to my Orthotist he questioned me about how this happened, I told him the whole story. He was furious as he said he worked hard making those braces look nice. I got my last brace from him 11 yrs ago and he still remembered..... P.S. I never could walk and hold hands or an umbrella because I used crutches. Now that I am in a power chair I can do both.

Barbara Snow <basilbabs@GOLDRUSH.COM>

AGM - September 9th 2006

Speaker Helen A. Kent, BS, RRT

Annual General Meeting
Saturday 9th September 2006
Memorial Hall, North Hykeham, Lincoln, Lincolnshire
Doors open 10.00 a.m. AGM starts at 10.30 a.m.
Buffet Lunch at 12.00 followed by

MAIN SPEAKER

Helen A. Kent, BS, RRT,
Owner of Progressive Medical,
Carlsbad, California, U.S.A. 92010

www.progressivemed.org

Helen will be speaking about the problems experienced by people who have neuromuscular conditions:-

1. What tests should be done and the information they provide
2. Mechanical ventilation equipment being used today
3. Support that patients should expect.

Helen is very passionate about her work, helping neuromuscular support groups in California and patients with various types of neuromuscular problems all over the world.

Her holiday plans bring her to the UK in September and she offered to fly in a few days earlier to speak to our members. She is offering all attendees some tests which will show if they need/ do not need to see a Respiratory/Sleep Consultant.

Tea, Raffle and Questions & Answers.
Please submit questions, even if you cannot attend.

Doors close at 5.00 p.m.
N.B. There will be Friday and Saturday Evening Get-togethers.

All members attending who would like to be tested please
return the enclosed slip as soon as possible
so that we can assist Helen in planning her day.