

POST POLIO MATTERS



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**FEBRUARY
2018**

Issue 101

**Polio Survivors
Network
AGM**

**Will be on
SATURDAY
28TH APRIL
2018
In Lincoln**

**NEC
BIRMINGHAM**

**NAIDEX
25th - 26th
APRIL
Naidex.co.uk**

**MOTABILITY
BIG EVENT
6th - 7th
JULY 2018**

**---
Motability.co.uk**

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Post Polio
Library**



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Post Polio Support Group Ireland - ppsg.ie
New Name and Logo - www.polio.ie

Living in an Iron Lung:
'It was a long, airtight coffin-
shaped box with my head
sticking out at one end'

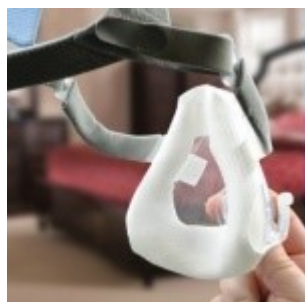
Read Jim Costello story
Pages 6 to 8



How I pace and rest all my muscles that help me breathe



This is my latest prescribed Bi-level machine - a ResMed S9 [there are other makes]. The part on the left is where a variety of settings are made by the Respiratory Physiologist to fit my needs. The open lidded part to the right is the humidifier, filled to a line on the yellow piece with water to provide moist air which really helps. The hose connects to a mask.



**Some examples of
different masks**

**and liners that can
minimise mask leaks
and facial marks**

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New Members and Donations received from October 2017

**New Members - Gerard de Zeuw, Jim Underhay,
John Britt and Maria Scarlett,
Welcome back Norma Head.**

**Polio Survivors Network would like to thank
the Family and Friends of Simon Parritt who donated £1048.75
in memory of Peta Parritt, Simon's Mum - Page 13**

Zoe Standerline who donated £120 in memory of her mother

**Once again we thank Val Scrivener for donating
£20 from the sale of her cards [see back page] and
£35 for a talk she gave to her church on her polio experiences.**

Annual General Meeting - Saturday 28th April 2018 - Lincoln

Venue confirmation not available at time of printing.
Further information will be emailed or posted to you shortly.

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

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Editorial by Hilary Boone

The weeks have flown past since the last newsletter. There are two issues I have decided to write about that have added to managing our lives. I have had to do a lot more paperwork than normal completing forms and requests for financial and annual review information from the NHS, Social Services. This takes more and more time to complete each year. We are eternally grateful for the funds that make a huge difference to managing our lives. However the stress that it causes drains energy from the depleted amount we now have from our neurological condition/s lives.

On top of this Richard was under 65 on April 8th 1948 so we have also had to complete his application to change to PIP [Personal Independence Payment] from DLA [Disability Living Allowance]. More info on page 13 from Benefits and Work. First you get a letter asking you to ring if you wish to apply. Then we were sent the application form [delayed 10 days by Xmas Post] leaving us only 3 weeks instead of 4 to return it with corroborating evidence that we wanted to submit. We found this very time consuming as Richard could only manage to read, understand and give me his reply for about three questions [of 15] a day. I completed a first draft and searched his medical files for what I thought would be useful reports/letters to send in. We then sent this to a couple of people for advice as to 'were we on the right track for what was needed?' We were advised to make some changes and completed a second draft. I rang our Surgery to ask how did we go about getting a letter from them and was told to submit copy of the form which I did. Got a bit of a shock when a few days later got a call to say "No letter, if the DWP want information they will write to us"

We not only completed the form but provided a typed copy to ensure that there was no difficulty in reading my handwriting as I now have to really concentrate to write clearly and pace and rest every few lines. We added a covering letter with details of the copies of additional information. Photocopied everything and posted this Recorded Delivery. Received a text the next day that it had been received and that he may need to attend a face to face consultation before they make a decision. No further response at date of sending to Printers. We then took a desperately needed four day break at Centre Parcs but within four hours of arriving home I received a phone call from a new to us Reviewing Social Worker wanting to reassess Richard. Here we go again.

My second issue was that I have had a couple of falls, one badly sprained ankle Dec 1st because my legs collapsed after I stepped into a pothole in the carpark at the Kinema in the Woods after watching the fantastic film BREATHE. I have great difficulty getting up from the floor normally but thankfully Wayne and Vicki were able to lift me [wet butt from puddle in the pothole] into the car. When we got home Wayne brought our shower wheelchair to the car and I used that for the first few days. Saw our Chiropractor two days later and with treatment was able to walk on it carefully using a walking frame or rollator. There is no room for my scooter in our small home.

Then six weeks later I passed between the sideboard and Richards electric chair and fell [no idea why] onto Richards Recliner Chair with my ribs landing on the wooden arm end. Boy did that hurt. First problem again was 'How do I get up from the floor?' I had to wait till PA arrived and then found that the previous way of backing up on my hands and knees to my recliner chair, wriggling my butt onto the seat, leaning back and with arms on the arms of the chair wiggle myself further back onto the seat was no longer possible. I could not push myself high enough to get on the seat so had to use the little folding stool to do the height in two stages. Then I had for the first time to use the full raise on my recliner chair to be able to get my body over my knees to stand up. Where was I going? To the toilet and now I realised that I am going to hurt myself if I use the edge of the bath and sink to lower myself. Managed to modify that and then thought oh heck I am going to have to modify how I get up as well and loads of other actions. How do I get in and out of bed, roll over. I could not sleep on my normal left side so had to sleep in reclining position on back with foot end of bed raised. Today on Facebook polio list there is another person reporting similar 'I cant get up from the floor the same way' and the responses of the different ways that polio survivors have now had to work out are amazing. One in the USA has to ring 911 and say "I am not ill but stuck on the floor and need help to get up again" How do you do it?

OUR AGM will be held on Saturday 28th April 2018, Venue in Lincoln. Registration from 10.30am and start at 11.00 am followed by buffet lunch. More information will be emailed/posted shortly.

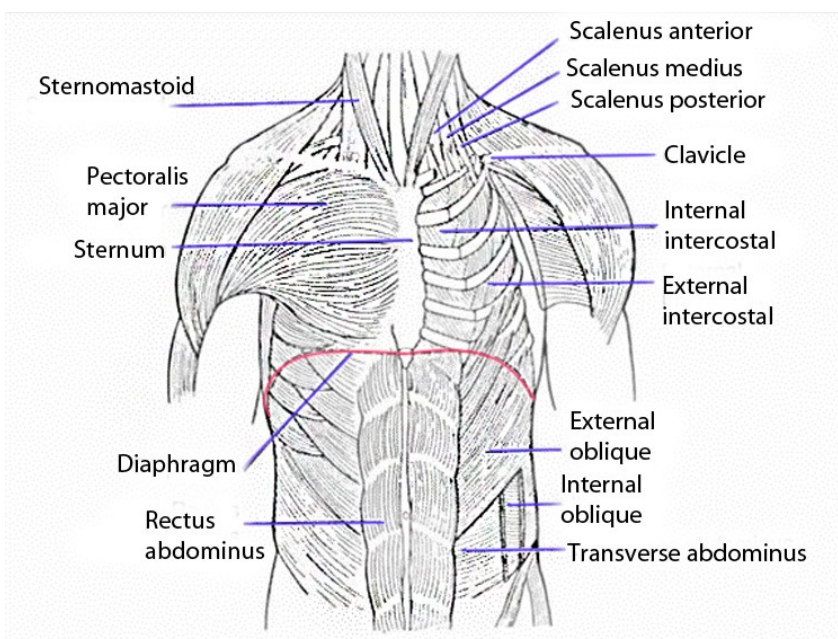
MESSAGE FROM OUR CHAIR - *You, Breathing and Polio*

Many of us who had polio years ago might, or at least should, know by now that we need to keep an eye on things, not just the 'parts' that we know were initially paralysed or affected but as polio had the potential to damage **ALL** muscles even those that seemed unaffected at the time of your initial infection.

So, when it comes to breathing those, like myself who spent around 4 months in an iron lung are at greatest risk of developing breathing problems later in life, but the rest of you can also begin to experience poor breathing, especially when sleeping. Whilst awake you may be compensating more and more with some of your breathing muscles which are weakening and so you begin to experience problems when asleep as you rely more on involuntary breathing muscles (see below) which cannot cope alone any longer. As a result there is a build-up of carbon dioxide which will cause you to have a range of problems you might not associate with your breathing. These include sleepiness in the day, anxiety, shortness of breath, depression, high blood pressure, waking feeling unrefreshed or tired still. Of course these symptoms are common to many conditions and excluding other things is important, but you may be experiencing a multi factor problem.

There are many muscles involved in breathing

It is important to realise that there are many muscles involved in breathing not just your chest and diaphragm but also what are called accessory respiratory muscles groups. Take a look at the diagram below. The muscles involved in breathing are many and include neck, pecs and various areas that are illustrated below. So, it might be that if you experience weakness or pain in any of these areas your breathing may also be affected.



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

Don't let it creep up on you

Breathing problems can be insidious and creep up on you as you age and many of the symptoms can be similar to lung and

COPD

Chronic obstructive pulmonary disease. An umbrella term for a group of usually progressive lung disorders with overlapping signs and symptoms, including asthma, bronchiectasis, chronic bronchitis, and emphysema;

OSA

Obstructive sleep apnea occurs when part of the airway is closed off (usually at the back of the throat) while a person is trying to inhale during sleep

CSA

In Central sleep apnea, the airway remains open, but the nerve signals controlling the respiratory muscles are not regulated properly. This causes wide fluctuations in the level of carbon dioxide (CO₂) in the blood.

Mixed Sleep Apnoea

Both OSA and CSA

CPAP

Continuous positive airway pressure. A method of positive pressure ventilation used with patients who are breathing spontaneously, done to keep the alveoli open at the end of exhalation and thus increase oxygenation and reduce the work of breathing.

Bi-Level / BiPAP

Bilevel positive airway pressure. A method of respiratory therapy in which the level of air pressure delivered to the respiratory system increases during inspiration and decreases during expiration

pulmonary disease but they do not necessarily require the same treatment. As problems might begin by only impacting when you are asleep or lying down it is easy to ignore or miss what is happening until it is critical especially if you are being treated for something else. Depending on your medical history you may also have other issues such as COPD and pulmonary and heart disease, which complicates the assessment and treatment and your physicians should therefore know about your polio in order to treat all your issues and not ignore your previous polio.

Every cloud has a silver lining

Oddly, we have benefitted from the explosion of obesity in the population as the related obstructive sleep apnoea or OSA as it is called affects a much larger patient group and has attracted more public health funding. This has boosted the technology to treat this obese group and has led to a commercial market for development of small portable positive pressure machines. They are referred to as NIV or non-invasive ventilation, unlike the old large and bulky iron lungs which used negative pressure.

It is important however to understand that as a polio survivor who is experiencing breathing insufficiency and or sleep apnoea your requirements may be different from patients with obstructive breathing whilst asleep due to obesity and also different from patients with lung disease who may also be using oxygen.

What is CPAP

Essentially, the first option for patients with OSA is usually a CPAP or continuous positive airway pressure where a constant pressure flow of air is applied via a nasal or full-face mask. Essentially this is designed to keep a patient's airway open as there is a tendency with some overweight people and others for their airway to block and pushing a continuous flow of air in all the time this keeps their airway open. This is almost always not appropriate for someone who had/has weak breathing muscles due to polio (or some other neurological problems). Your respiratory physician should of course know this but it is worth noting in case they are unaware of your polio or how to treat it, as you probably require what is called a Bi Level Machine or BiPap.

Why BiPAP

The usual best option for polio survivors is a BiPAP or bi level positive airway pressure, in which air is delivered via a mask or nasal pillows. As you breath in the machine detects your breath attempt and air is pushed into your lungs at either a set pressure or a set volume but as you breath out there is a lower, or sometimes, no pressure. Setting the pressures and or volume as well as various triggers to detect your particular respiratory needs is the job of your respiratory team working with you to achieve what is comfortable and effective. This may take time and patience on both sides and can change over time.

Masks and Interfaces

There are vast numbers and types of masks and nasal pillows and it is often problematic to find one that suits you. Unfortunately, the NHS services may not have access or contracts to offer or even mention the huge range and so you may find yourself thinking you have to put up with (or worse discard using) one from those on offer. You don't. Once again due to the number of people in the UK who now are having sleep disordered breathing and OSA due to weight issues there has been a growth in web sites and support for them. You can benefit from accessing these and view all the type of masks and equipment that is on the market that your physician is not aware of, or is not able to offer in their service. They are not cheap so buying and trying it and it not working can be an expensive game.

Challenges and trouble of BiPAP

The truth is that coming to terms with having to wear a mask on your face every night for the rest of your life can be daunting both from a comfort and psychological point of view. In addition, everyone is different and finding the correct mask or Interface, as it is called, can take a lot of time and effort. Some of the common issues people face are feeling claustrophobic, the mask hurts their face, their nose or skin becomes sore. The masks can also often leak air around the

edges making a lot of noise and or even blowing air in your eyes. A problem which often isn't addressed is the fact that if you sleep with someone, it can disturb them and might be a barrier to sexual intimacy. Indeed, if you are dating someone new and want to stay the night, bringing along a machine and mask is, as you can imagine, not an easy hurdle to negotiate.

Finding the correct mask or interface

As mentioned above there are many websites offering many different types of masks and nasal pillows, some of these websites are local to the UK and also in the USA, however you may not be able to get these on the NHS always, but it is worth arguing your case.

Comfort and leakage.

As a lot of the masks are used by people who may have more flesh and fat on their face the seal between the face and the mask is often better than those who have a slimmer facial structure. The best solution to this is of course customised masks that are moulded to your individual face shape but at present this is not easily available. The other solution is to use what are called mask liners which you put between your face and the mask to soften the pressure and improve the seal often reducing to almost nothing any leaks. There are two kinds of liners on the market currently and as far as I know the NHS currently will not fund these. They are however a life saver for many of us. [Editors note:- Richard has used Remzzz mask liners, featured in earlier issues.]

Chin Straps and mouth breathing

Some people find when they sleep their mouth may drop open a little or they actually breath through their mouth. This can be made worse as the air pumped into your nose via a mask or nasal pillows blows straight out of your mouth and not into your lungs sufficiently. The higher the pressures you require the greater this problem becomes. The standard solution to this is for you to use a chin strap. Again, there are many types and once again the web is the place to go as the ones on offer at most clinics are very basic.

Claustrophobia

For some this is a very big problem and if this is something you struggle with it would be good to try nasal pillows before a mask, but if that's isn't possible because you need high pressure or they are uncomfortable you should seek help from a psychologist who may be able to work with you to overcome this problem. It can often be combination of psychological and the actual fitting or type of mask.

Pulse-ox equipment.

There are quite a few different types available on the internet. See sites mentioned below. [Editors note:- Richard has used one for many years and the best we have found is one like a watch with a finger attachment that we tape on with micropore and set to record. In the morning we can download and print off the information.]

Finally

If you feel any of the above applies to you, or might do consider it and bring it up with your physicians. Getting help may be very complex as few give the full time and multidisciplinary effort and skills needed to achieve the maximum. Often, due to limited time, skills or contracts the options offered are not all that they might be and an average best fit approach is adopted. If you need support or information around this before or after you have spoken to your health care professional do please get in touch with us and we will aim to help you as much as we can.

Useful sites

www.hope2sleep.co.uk

Hope2Sleep is a Registered Charity run by Sleep Apnoea Sufferers, CPAP & Non-Invasive Ventilator Users and Sleep Professionals and has a range of products including a mask liner for most mask types.

www.eu-pap.co.uk commercial suppliers of all everything to do with BiPAP and CPAP including Remzzz mask liners.

TO BREATHE

**we use Lungs, Diaphragm, Intercostals [muscles between the ribs]
and Secondary Accessory Muscles. [See diagram on page 4]**

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 secondary accessory breathing muscles
to assist your weak muscles to achieve that task?**

Hilary's experience. In October 1988 I had a fall that started seven years of functional decline with NO medical corroboration that there was anything wrong with me. During these seven years on an increasing basis I would suddenly found myself on the ground and each time once I had got up again I could find nothing that I could have tripped over. November 1995 and I mentioned my prior polio and at last it was in the equation. The issue that I thought about the most during this time was why did I keep falling over?

Now my prior polio was in the equation and I knew PPS existed was there something I was missing? I believe there was and wonder what you think? For five years I ran six disabled craft classes in village halls and carried boxes containing all the different tools, instruction books and materials that might be needed in my car boot. Many of the times I had found myself suddenly sitting on the ground BUT when I was carrying the boxes back to my car at the end of the day. My thoughts decided that I was using my upper body and trunk muscles to carry the boxes, help my weaker legs walk and breathe and after a short distance could not sustain all three actions. I believe my brain decided that I had better continue breathing and if I dropped the box something might break so sorry legs we can't help you walk any further and my legs just gave way. Do you think I was right? Have you or do you experience anything similar?

Polio Survivors Network research and presentations since 2000 have promoted the most important factors to obtaining medical help **is to be honest with yourself and tell it like it really is**. Explain that you have had to change the way you do ANY action of daily living from x to y and over say six/twelve months. Ask health professionals what has happened to your body that you have had to do this.

Think about all your actions of daily living. It is important to consider the length of time you are doing an action and if there is a change then when does that happen. If you are fine in the morning but start to have issues later in the day when does this start and is there any difference depending on what you have done that day, the day before, etc [Use page 10 of My Polio Life as an aide to recording short comments].

1. Do you run out of breath now before finishing a sentence?
2. Is your voice lower and/or hoarser than it used to be?
3. When you cough do you have to do this softly as it hurts your rib muscles to cough loudly? Do you do this all day or does it only come on later in the day?
4. Do you have to pause for a few seconds between mouthfuls of food or drink?
5. Did you turn over in your sleep fairly easily but now do you have to wake to a higher level of consciousness to physically turn over, holding sides of the bed, mattress handles, adjacent cupboard, rails, etc. and do you know how often you do this each night?
6. In bed - have you noticed you sleep in one position far better than any other and is this different from how you used to sleep a few years ago?
7. If you can climb a few stairs do you stop to rest half way, or more than once?

Remember time constraints at medical appointments can mean your muscles might only be tested once and if normal [Grade 5] the tester will move on to the next muscle/muscle group. If you are unable to sustain or repeat the test for very long then this will not be picked up. Remember when you are in hospital you are probably not using the same amount of energy you would at home. If test results seem better than you expect/have achieved before at home or as an outpatient then it is a good idea to mention you are not doing as much as you do at home.

1. Ask to have your chest expansion measured on repeated breaths. Does the figure decrease?
2. Ask to have your Maximum Inspiratory Pressure measured and repeated a few times. Ask for all the results so that you can discuss this with all your health professionals. Many polio survivors have been told 'you are fine' to find out later that their results were not normal at around -80 but -52, -46, but not below -30 where treatment would be prescribed.

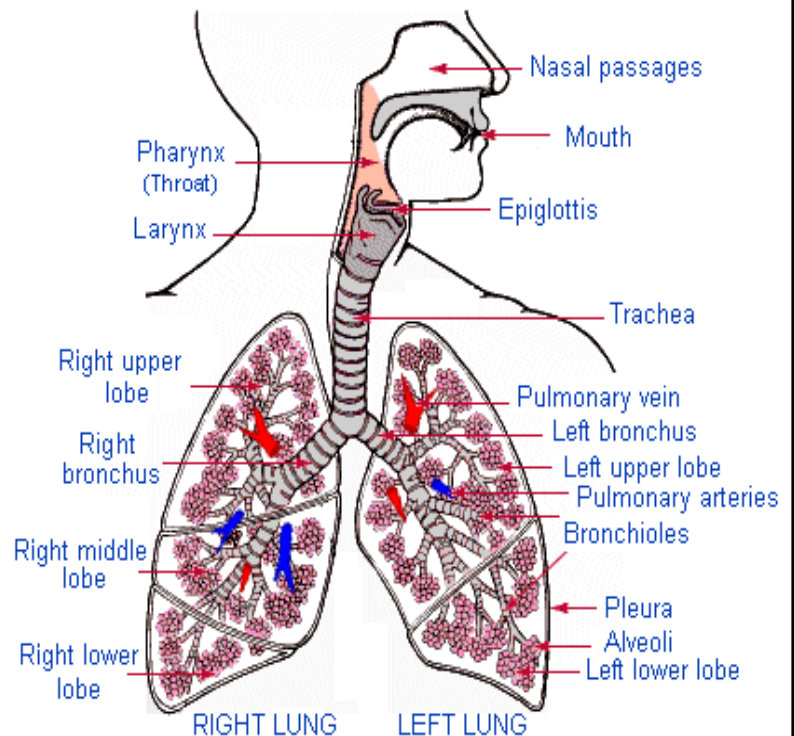
How do lungs work?

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)

© ONTARIO LUNG ASSOCIATION



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

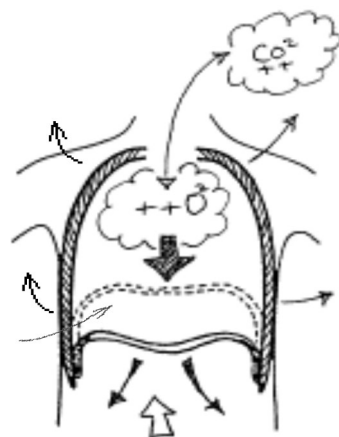
During metabolism the body consumes oxygen and produces carbon dioxide. Oxygen is supplied and carbon dioxide is removed by the lungs. This can only occur if an adequate volume of air is exchanged in the lungs and this is achieved by increasing, then decreasing, the air pressure in the lungs. The co-ordinated 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.

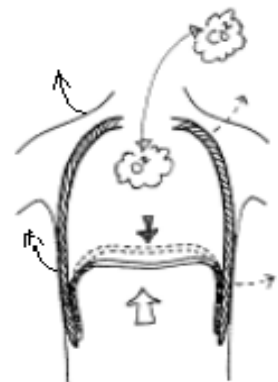
And the diaphragm contracts, pushing down abdominal



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

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.

EDITORS NOTE:- Personal experience of myself and my husband at a variety of different medical establishments in the UK and USA, and discussing many other polio survivors experiences over the years at length leads me to add the following:-

Health Professionals it is important to understand that Polio Survivors will prepare to attend appointments where any tests [inc. lung function] are to be carried out, usually getting someone else to drive and load/unload wheels, arrive early and often research what tests include and usually push to do their very best to achieve putting their whole body energy into it. To add to this In-patients will not be doing their normal daily activities and so will have more of their daily energy tokens available.

Most of us have been asked to repeat each of the lung function tests three times to the same level and because we experience fatigue we are to rest all the time we need to between each repeat. However it is usual that the Test Result sheet that is sent to the Consultant contains only the BEST result of each 3 and no mention of how long the patient rested between each repeat. We, and others in UK, report that no supine testing has been done at all but one hospital.

QUESTION? Does this practice give the Respiratory Consultant enough/accurate information to understand how the polio survivor patient managed during their testing and is managing their respiratory function at home?

???????

Living in an Iron Lung:

'It was a long, airtight coffin-shaped box with my head sticking out at one end'

Paralysed by polio at the age of 15, Jim Costello wants those who oppose vaccination to look at him and reconsider their views.

DECEMBER 11TH 2016

thejournal.ie/readme/what-is-life-like-for-a-polio-survivor-3128107-Dec2016/



I AM NOW 73 and my polio journey began when I was admitted to Cherry Orchard Hospital in Dublin, in 1958 with suspected meningitis. I was 15. Within days I was transferred to the polio ward and put into an “iron lung ventilator”. I was diagnosed with acute respiratory poliomyelitis – my upper body was paralysed.

It was thought I might have contracted polio when I went up to Dublin from Clongowes Wood College by bus, to an international rugby match between Scotland and Ireland. It was learned afterwards that there had been a small outbreak of polio in Scotland, and I may have picked up the virus from a carrier in the crowd.

Living inside an iron lung

In Cherry Orchard, the iron lung helped me to breathe. It was a long, airtight, coffin-shaped box with my head sticking out at one end, supported on a small ledge by a pillow.

I lay there listening to the motor pumping a large bellows which changed the air pressure inside. It created a partial vacuum to lift my ribcage to draw air into my lungs and then a positive pressure to partially compress my lungs so I could breathe out.

I wasn't scared going into this box. I was too ill and in too much pain to care. What really frightened me was when a nurse or a doctor wanted to open the iron lung. In the beginning I couldn't breathe at all once it was open and this terrified the life out of me.

I had severe pain throughout my whole body, especially in my arms and legs. Yet even severe pain can be coped with to some extent, but your next breath is very personal and something you cannot do without.

Changing my pyjamas or the sheets was carried out by a team of nurses, who had everything prepared beforehand. They would work very quickly to do what was necessary, monitoring me carefully. It would often take a number of sessions of opening the lung and pulling my stretcher bed in and out to get the task done. It was a nightmare.

A physiotherapist began working with me to try to get me breathing on my own. She had a stopwatch and got me to stay out of the lung a few seconds longer each day. This was quite terrifying in the beginning as I had great difficulty breathing. When I began to recover my breathing eventually, the physio would do exercises and stretch my arms and legs, which was extremely painful. It usually ended up in a crying and shouting session.

'My lungs are 75% paralysed'

Polio had paralysed my upper body. I have a triple curvature of the spine, and I wear a spinal brace, an adaption of a Milwaukee brace. I have no use of my arms, and my lungs are around 75% paralysed. Yet I can't ever remember thinking to myself – I am paralysed.

The severity of my breathing difficulties completely blocked out any other concerns. The two most important things in life are your next breath and your next heartbeat, without them you have no life.

After a year and a half in Cherry Orchard Hospital, with financial assistance from my generous aunts, I was transferred to England, for another year and a half to the Nuffield Orthopaedic Centre in Oxford. I began using a “Cuirass” ventilator, which was like a tortoiseshell on my chest, working similarly to the iron lung.

Working life and polio activism

When I returned to Ireland, with my Cuirass, I attended the Central Remedial Clinic, firstly on a daily basis, gradually reduced over a few years. I joined the family clothing business where I spent the following 10 years, after which we decided to wind it up. I ventured into a number of businesses, until retirement in the early 1990s due to ongoing respiratory ill-health.

In 1993 I was involved with 6 other polio survivors in setting up a charity to help people who had polio or who have 'Post Polio Syndrome' - the Post Polio Support Group {PPSG} I worked with the group voluntarily for over 22 years, as chairperson, then as a director and I'm still involved in an advisory capacity. We realised at the time that polio survivors were not being adequately looked after by the various Health Boards around Ireland.

Very little was known in Ireland of Post Polio Syndrome (PPS), a condition that can severely affect polio survivors some 20-40 years after their initial infection. The effects of PPS include great difficulty undertaking the most basic functions of daily life, including bathing, dressing and making a cup of tea.

Ireland's polio survivors still suffer

It causes pain, fatigue, severe intolerance to cold, breathing and swallowing difficulties and often problems related to sleep. It may also reduce a polio survivors' ability to walk. Having originally being hit by a severely disabling condition, they now find themselves in their later years coping with a second disabling condition.

Three are thought to be approximately 7,000 polio survivors living in Ireland. PPSG presently has a membership of over 900 survivors. The majority of survivors mainly contracted their original polio infection in the 1940's to 1960's.

An ongoing need for our work is expected over the coming years as polio survivors in Ireland experience problems with PPS and old-age. PPSG's main mission is to ensure that polio survivors can live with dignity. We are founder members of the European Polio Union, which brings together polio support groups throughout Europe, where there are estimated to be 760,000 polio survivors.

'I'm lucky to be alive'

Around two years ago walking any distance became difficult due to my respiratory paralysis and I had to begin using a powered wheelchair, which also carries my ventilator. At weekends, I live at home in Sandymount in Dublin, where I am looked after by my beloved partner of over 30 years, Delia.

Without Delia I would be totally hospitalised for life. The rest of the week, I live in the Elm Disability Unit in Cherry Orchard Hospital. I am extremely well looked after by doctors, nurses and carers, and while I mainly use an NIV ventilator (non-invasive ventilation) through a nasal fitting, or full face mask, I still use the "Alligator" iron lung ventilator when necessary.

I am lucky to be alive - in a medical sense I owe my survival to the exceptional care and support from many people over the years, in Ireland and also in England. Most importantly, I couldn't have done without the support of my tremendous lovable partner, Delia, my family, notably my sister Muriel and her family and friends, particularly my lifelong friend Philip and his family.

The personal caring dimension that people in places like Cherry Orchard Hospital bring to their work, makes all the difference and sustains people like me far more than the treatment or pills.

I was recently thrilled and honoured to receive the Louis Pasteur Polio Hero medal in Paris, presented to me by Sanofi Pasteur a vaccine leader against polio, working with the Global Polio Eradication Initiative. They also honoured four Pakistani vaccine administrators who risk their lives to do their work.

I ask, if the people who attach vaccination teams could see me and people like me, is that the really how they could like their own children to live their lives?

Also I appeal to the WHO and Rotary International and the other organisations working with them to eradicate polio. When their job is done, which I know will be soon, and congratulations for the great work, please consider this: turn their valuable work towards the millions of polio survivors, particularly in underdeveloped countries, who now face post polio syndrome.

For more information on polio, post polio syndrome or to find out about the support provided by Post Polio Support Group to polio survivors, call 01 889 89 20, or see www.ppsg.ie.



This NEW name reflects the way polio survivors refer to themselves and indeed, has been used by us frequently in media and social media as a way of reminding the public: 'We're still here'. While 'Post Polio Support Group' will remain our official name, we believe that this simpler and clearer brand name can have a positive impact on our fundraising and promotional activities, giving us a clear, focused title, as a national polio organisation.

We have worked on creating a new logo to suit this new name and we are delighted to reveal it on the cover of 'The Survivor' magazine and on our homepage of our website, now called **www.polio.ie**.

The new logo and identity has been created by Geraldine Martin who worked on the production of our 'How We Survived and Surprised' book. The new look is inspired by a short story within that book, 'Louis Heels' by Anne Shanahan.

The footprints are leading away from polio and can suggest a long journey taken as survivors. They can also indicate how, despite their difficulties, Polio Survivors have made their mark, such as within their local community or society as a whole. One shoe is smaller than the other, a common experience for many children with polio. There are numerous interpretations. No doubt you as the polio survivor, will have your own.

Editors Note:-

I answered our charity phone line one evening to Jim Costello with some information for me about my attendance at their forthcoming Conference. "Polio in the 21st Century" Medical Conference: The Late Effects of Polio and Post Polio Syndrome. 12th and 13th March 1999. Jim explained that he was ringing me from his iron lung to explain the whoosh noise. This was a real eye opener, especially to someone who has so few memories of her early polio life age 5.

LincPIN Volume 2, issue 4 - <http://www.poliosurvivorsnetwork.org.uk/lincpin2-4.pdf>

FROM FRONT PAGE

Quote from Irelands First PPS Conference March 1999 in Dublin.

Negative Advice [that produced a very positive response] from
Dr. Lønnberg, PTU Denmark, Danish Society of Polio and Accident Victims.

"HOW TO GET THE LATE EFFECTS OF POLIO"

"Push yourself to the limit and a bit more.

Do the same activity again and again.

Don't take any breaks.

Pay no attention to pain and fatigue.

Eat, drink and smoke more than ever.

Avoid assistive devices.

Don't listen to doctors"

Thanks to Youngstown State University Digital Maag you can listen to the Sharon General Hospital polio interview January 23rd 1952 where WPIC radio personality Mr. Caldwell interviews several families with children who suffered from polio. The recording also includes the sound of the iron lung respirator.

Peta Parritt 1919-2017

My mother, Peta, was a remarkable woman. Of course many children say that of their parent or parents but so many would say this of my mother. Peta was the name she chose for herself as she didn't like her given name which maybe sets the tone for her life in many ways.

Born the year following the end of First World War in 1919 and dying on Armistice day in 2017, 98 years later. She was someone who lived through a huge change in the world and society. She was born into a London working class family going back some 250 years. Her father was a waiter as was his father and other members worked on the river. She married my father a farmer's son from Lincolnshire in the War and had my brother in 1943 living in an attic flat in Wimbledon. When I came along in 1950, the NHS was only a couple of years old and antibiotics and modern medicine as we know it now was in its infancy. Whilst my life was to change irrevocably in January 1956, this was also true for my parents. Like many at that time my mother had a terror of her children catching the feared polio. She had asked my father, who travelled to the USA on business, to try and get the vaccine which was available more freely in the USA, whilst still only on trial in the UK. The fact that I then contracted polio, ending up in Fulham Fever Hospital in an iron lung (or my spaceship as I called it) and totally paralysed was a devastating blow which I believe she never really fully recovered from, despite going on to have 2 more children, 12 grandchildren and 2 great grandchildren.



However, my mother was a fighter. One of the first battles was against hospital authorities and doctors following my transfer from Fulham to Queen Mary's Hospital for Children, Carshalton. After only a couple of months she had to rescue me from a hospital ward and nursing regime that was rooted in 19th century where children were hit and there was a regime of emotional abuse. She sat outside the office of the lead consultant at the RNOH London for days until he finally agreed to see her and then agreed to take me. The only condition was that my consultant at Queen Mary's Carshalton would agree to write a 'release' letter to the RNOH. After having to threaten them with the press the consultant reluctantly and angrily agreed to a transfer. I recall as a 5 year old, being told on the ward that I would never walk again if my parents moved me.

In The Royal National Orthopaedic Hospital in Stanmore I travelled what seemed a million years into the hands of a caring and supportive staff and wonderful environment for the next 18 months until returning home at aged 7 still unable to walk, dress or feed myself. Yet again my mother worked tirelessly to look after me and get the best treatment. When the consultant wanted to stop physiotherapy as it was no longer effective or required, my parents argued and my mother bullied him until reluctantly they allowed me to continue despite saying I had reached the best I could. My mother took me on the train from Putney to St Thomas Hospital for my physio several times a week for the next year. I eventually learned to walk, dress and with manage with minimum support.

These are just a couple of many examples of my mother's strong and determined personality. My siblings and her grandchildren and many other people can attest to the impact she had on their lives. Both my parent's disregard for professional and organisational pride and arrogance and never feeling less important than another human being, be they a medic or professional has enabled me to live my life as best I could. They say that polio people are difficult and type A personalities, but in my case maybe that has been fuelled by the example of a feisty, lively and committed person who was my mother who would never take something lying down and was never overwhelmed or impressed by anyone's position or status.

I am so grateful to all those who have given so generously to PSN in her memory and this does reflect I am convinced what she meant to so many of all ages, not just our immediate family. Until a few months ago my mother was always interested and engaged, enjoying the theatre, parties, eating out even driving her micro, heaven help us! She remained mentally active and interested in politics, art, music, writing to everyone from the Prime Minister to her local MP. She also wrote fiction most of her life even learning to use a computer and publishing one of her books in her 90s. It is naturally sad that she is no longer with me but I am immensely lucky to have had her in my daily life for so many years.

Simon Parritt, Chair.

PROVEN ENERGY BOOSTS - Presentation by Betsy Thomason RRT

Post-Polio Health 11th International Conference 2014

First featured in Post Polio Matters, June 2014, Vol 8, issue 4.

Betsy Thomason, BA RRT, graduated from American University with a teaching degree. Subsequently, she attended Bergen Community College, receiving an associate's degree in respiratory therapy. Betsy credits her love for the outdoors with expanding her knowledge of the outdoors that she loves to share with others.

I [Hilary, Richard and his PA Wayne] attended her presentation and was a bit taken aback by the information. I wondered how many other Polio Survivors reading this will have, like me, held their breath to perform an action. I thought it gave me more stability and oomph to do things, like get up out of a chair.

Betsy Thomason told us that what we should be doing is to gently blow as if we were blowing a child's pinwheel. This takes little effort and when you finish the in-breath is automatic and for me (and I expect all of us) larger than normal. Betsy told us that instead of holding our breath to perform an action try blowing out gently and amazingly it is easier. As a swimming teacher teaching I knew that performing breaststroke arms is a good example of this. As your arms go forward together you blow out ["blow your hands away" I used to tell the children] then as you circle your arms out and round and this opens up your rib cage further and the in-breath is automatic.

A personal word of caution. On land I found that whilst I could do this that repeating it more than a couple of times, because it increases the depth of breathing, made me a little dizzy. So as normal I have started slow using one slow breath out to get up out of chairs, and doing two BODs a few times a day, stretching intercostal muscles.

Adding today.... I have just received a copy of Betsy Thomason book [JUST BREATHE OUT see back page] purchased through Amazon and was surprised how many BODs I had incorporated into our daily exercises in our hot tub. Using basic swimming strokes and stretching actions I have built up a series of exercises that we could do. How many sets and number of repeats will depend on what we have done the day before and that morning, and in fact what else we have to do that day. Every exercise I had based on a breathing out counting system. Example lying on back with arms supported on the rests in the captains seat area kicking legs almost like a cycling action, Legs, right left, right left. Blowing out on counts 1,2,3, and allowing the automatic in breath on four. Repeats counted as 1,2,3,4, 2,2,3,4, 3,2,3,4, 4,2,3,4 etc. I have now built up to 30 repeats on a good day. Being in warm water up to your neck relaxes tight muscles and is making a difference to managing our health.

The book contains others experiences, and lots of ideas when to breathe out as you turn over, sit and stand from a bed. How about the Crab Walk, you want to be seated with your shoes off and knees bent so that your feet are under your knees. Pretend that your toes are crabs. Curl your toes, lifting your arch off the floor. Then repeat the curl, letting your whole foot move forward an inch or two. Repeat with that foot, other foot, and if you can both together.

BreatheOutDynamic system - BODs Basic Two-Step.

OUTBREATH - BODs Step 1

Simultaneously squeeze your belly muscles - close the bellows - and blow out gently through pursed lips. These actions push air out of your lungs and slow down the flow of air out of your mouth.

INBREATH - BODs Step 2

Now simultaneously release your belly muscles - open the bellows - and stop blowing out, allowing the universe to refill your lungs. Your only task is to let your belly muscles relax. You have just started learning the BreatheOutDynamic system.

SEE BACK PAGE

HSE battles new wave of polio issues 30 years after last recorded case | The Irish Times.

[Mon, Feb 12, 2018, 01:00]

*An iron lung helps a young boy with polio breath during the 1950s.
Photograph: Jonathan Kirn/Corbis via Getty Images*

Sarah Burns writes:

More than 30 years after the last Irish case of polio was recorded, the health service is treating a new wave of patients struggling with the complications of the disease.

Up to three new patients a month are presenting with post-polio syndrome at Beaumont Hospital, most of them drawn from among the “new Irish” communities.

Consultant neurologist Prof Orla Hardiman says about 70 per cent of the new patients at her post-polio clinic were born outside Ireland.

“The polio epidemic finished in the 1950s, and there were a few people in the 1960s who had polio. But we’re seeing a new wave of people now, a lot of Nigerians, Indians, people from Asia who would have had polio in childhood, are here now and they need some support.”

Polio: ‘At one stage I thought I was having a stroke’

Family Fortunes: Polio took me from my friends in 1950s Cork

Polio and record crowds: hurling draw throws up historic ties

Initial recovery.

The last case of polio in Ireland was recorded in 1984, but post-polio syndrome affects survivors many years after their initial recovery. Late-occurring effects include muscle and joint pain, lack of strength and increased muscle weakness, fatigue, breathing and swallowing problems, and severe intolerance to cold weather. There are an estimated 7,000 survivors of polio in Ireland today.

In the winter, they may need to turn the heat on even during the night, because their intolerance to cold is severe

Prof Hardiman said over the past 23 years around 800 patients have presented to her post-polio clinic.

The Post Polio Support Group (PPS) was founded in 1993 to provide support and services to polio survivors. It currently has 930 members with 22 social support groups throughout the country.

Emma Clarke Conway, PPS development officer said: “Somebody who may have had polio as a child may go on to recover and to live fairly normal lives. Then later on, if PPS kicks in, they may find themselves needing callipers, walking sticks or even wheelchairs.

Heating grant.

“We would provide them sometimes with physiotherapy or occupational therapy. We also provide a heating grant to some who are financially vulnerable because their heating bills can be extremely high. In the winter, they may need to turn the heat on even during the night, because their intolerance to cold is severe.”

PPS also runs support groups for polio survivors in Dublin, Naas, Wexford, Sligo and Cork.

Polio no longer exists naturally in Ireland largely due to immunisation. Children are vaccinated against the disease as part of the six-in-one vaccine at two, four and six months of age. Booster doses are given at four to five years of age.. Source article. <https://www.irishtimes.com/news/health/hse-battles-new-wave-of-polio-issues-30-years-after-last-recorded-case-1.3388634>

How to avoid being scammed online from Steve Ives.

Scamming is when you are tricked into giving money or information.

There are many websites that can offer advice on avoiding being scammed. Most banks and financial organisations have simple, easy to read and understand literature.

Do not be frightened by these warnings or you may end up doing nothing ever again.

So... If you are rushed into making a decision then somebody is trying fluster you into making an quick and possibly unwise decision. If you are told that you must act immediately then DON'T act at all. If it is really an emergency then they will act at their end or get back to you.

If you are a Facebook addict do not post that you are at a concert or on holiday somewhere until well after the event. It is as good as saying to a thief that your house is empty and ready to be burgled.

Do not put personal details on social media such as Facebook.

Never give out bank details or personal details.

Do not reveal account details to somebody you do not trust.

Do not reveal passwords to anybody.

Do not just throw out documents containing personal details, rip them up before throwing them out. Spread the rubbish about so that jigsaw addicts cannot easily piece them together.

If in doubt ask a trusted adult. If you are unsure what you are doing ask your trusted adult to watch what you are doing you and advise. Do not let them lean over and do it for you. Do it yourself.

As a teacher I was always told that if somebody does something for you you will remember 10% of what happened. If you do it yourself you might remember 90% so insist on filling in forms and using the computer yourself. It will seem difficult at first but that is how you learn. Imagine how young children feel at school in a strange lesson.

If you get an email look at it with a critical eye. If it contains spelling mistakes ignore it. [www.amzon.co.uk - did you notice there was no second a in amazon?] Trusted UK banks and building societies will not make spelling mistakes.

If a deal looks too good to be true then it probably is too good to be true.

Never send cash or cheques to an unknown account.

If you are buying goods or services on line then the URL (the website name) will start with https://

If it is just http:// do not buy as it is not a secure website. Secure websites will also have a padlock sign in the URL.

Do not open unsolicited emails; doing so could infect your computer.

If you ignore a strange letter or email then a legitimate sender may try again.

Pension scams. Most if not all company pensions give a good value. Moving your pension to a private provider is unlikely to give you a better return. Remember they have shareholders and agents who want a cut of your cash.

If you get an email from say Facebook or PayPal saying that your details might have been compromised and asking you to log on and confirm the details they have for you then STOP and delete the email. It is likely to be a fake.

If in doubt STOP AND THINK!

For example: An unsolicited email to hilary.boone@poliosurvivorsnetwork.org.uk was recently received by PSN stating that it was doing a 'fraudulent verification survey' and you must verify your account and "if verification is not gotten from you within the next 48 hours we will consider you a fraudulent user and shut down your account". This may make you think that it is legitimate. It may well be, but then you notice it has come from a steels company and why would they contact us? Did you notice if verification is not **gotten** from you?

If it appears doubtful then delete it.

The Continuing Sagas of *Deluged Dot

I was perusing last year's saga entry for February 2017. I was then Decamping Dot as we were busily sorting and packing for our imminent departure to the 'middle' of the country. We have been here in South Staffs albeit with a Walsall postcode for almost a year and whilst I do miss 'living on the edge'; I do not miss those biting North East winds battering our front door across the North Sea straight from the North Pole!



Although in fairness to my erstwhile geographical location we do appear to have moved to a more soggy, damp, grey and dreeky area of the country that is also prone to more snow and ice than I am used to. I have never known it to rain so much and I am originally from Lancashire memorable for its dark satanic mills, cotton and bucket-loads of the damp stuff!

Readers who are familiar with my meanderings (or have a good memory) may be surprised to learn that I am in rude health (for me) and have not had any serious injuries or breakages for over a year now. (Apart from a couple of mugs that missed the kitchen cupboard shelf I chucked them on.....oh, and a few scrapes and bumps on the car..... How boring is that?)

Being where I live now also means that I am nearer to my 'big' sister who we visited in Shropshire fairly recently. We had a curious conversation as she has no recollection of me ever having had poliomyelitis when I was a baby and still denies that I did. When I asked her how was it that I was hospitalised, didn't walk until I was over two years old and had one leg shorter than the other' she said that she hadn't really thought about it! Also..... my limping, frequent falls and weekly trips to the community clinic for therapy and physio was because I was a prem baby! (To be fair, she was a new bride with a baby on the way when this all happened). Now I know that my polio was not severe and 'not obvious' as I was a baby who was hospitalised with suspected meningitis and sent home as this was not the case. The retrospective diagnosis of mild poliomyelitis only forthcoming a few years later. My 'bad leg' and right tendon was operated on when I was 8 years old – by this time, even the family goldfish knew what caused it! Families eh!

On another but related note, the striking thing about moving house has been moving GP practices as well. My GP or should I say GPs have not been on my roller coaster medical journey and it is not easy starting again. Which of my ailments from my list do I take for my 10 minute consultation with an unknown doctor who has not read my medical notes on the screen? Will they think I am time wasting? A hypochondriac? A wimp who cannot manage pain? A junkie hooked on prescription drugs? Whilst the latter is probably true how enthusiastic should I look when asked if I have considered swimming.... or attended the pain clinic to manage pain better or what I have sounds like fibromyalgia.... (they haven't heard of PPS of course nor read the newsletter that I left previously for them). Maybe I do have fibromyalgia (I can add it to my list)! To be fair the Practice has recently amalgamated with the one in the same building and now has over 25 GPs and over 25,000 patients. Wonder if I can re-register with my previous Practice it is only a 322 mile round trip..... It all adds to a feeling of being 'mis-placed' or out of sync.... Maybe I am deluged in more ways than one or maybe they can't understand my northern accent and flat vowels!

***deluge** - 'delju:dʒ/ verb

past tense: **deluged**; past participle: **deluged**

overwhelm with a flood. "caravans were deluged by the heavy rains"

synonyms: flood, inundate, engulf, submerge, swamp, drown

"caravans were deluged by the heavy rains"

inundate with a great quantity of something. "he has been **deluged with** offers of work"

In the Bible it said it rained for 40 days and they called it a disaster. In Britain we call it Summer.

You know your British when you eat your Picnic in the car because it is raining.

What do you call it when it rains chickens and ducks? Foul weather.

Why is Britain the wettest country. Because royalty has reigned there for years.

POST POLIO SYNDROME EXISTS

WHO ICD Code 10- G14 - UK Read Code Version 2, F29y1 and Version 3, X0002p

N.B. UK READ CODES CHANGE TO SNOMED APRIL 2018

Colleges of Medicine please add more facts to your lectures on the Polio Virus and the effects that it could have had on our bodies. Ensure health professionals understand how varied our nerve damage, our recovery and stable years have been. The majority of us recovered that well that externally we do not look like those photos in the old medical books. That there is a massive overlap of symptoms with other neuromuscular conditions. Tell them about **Post Polio Syndrome** and give them links to where they can find more information. Thankyou.

The most accepted articles PSN have found by NHS professionals are:-

PatientPlus article POST-POLIO SYNDROME

Written by U.K. Doctors for Doctors

<http://patient.info/doctor/post-polio-syndrome> [2016 VERSION by Dr. Colin Tidy]

**And in case you need an anaesthetic
an excellent leaflet translated into English
now used by many PPS Groups around the world.**

POLIO PATIENTS AND SURGERY.

Information for health staff.

Lise Kay, MD, Surgeon PTU – Danish Society of Polio and Accident Victims

**[http://www.ptu.dk/fileadmin/FILER/PDF/ISSUU_PDF/BROCHURER/
Polio_operation_ENG.pdf](http://www.ptu.dk/fileadmin/FILER/PDF/ISSUU_PDF/BROCHURER/Polio_operation_ENG.pdf)**

Text copies of both have been sent to members and are available on our Website link on front page

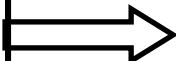
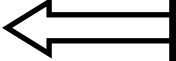
REMINDER FOR MEMBERS

Have you changed your home, email address or phone number recently?

Did you let us know? Do your relatives know you are a member?

POST POLIO MATTERS needs your stories, articles, tips, etc

**MEMBERS, any POLIO SURVIVOR, CARER or HEALTH PROFESSIONAL
PLEASE SUBMIT ITEMS FOR FUTURE ISSUES**

 **DEADLINE FOR NEXT ISSUE IS APRIL 10th 2018** 

How about a recipe that tastes great on the lips but not on the hips.

CARERS, FAMILY, FRIENDS, GP's - would you like to write and tell us how we might help our Carers, Family, Friends and GP's understand what you go through helping us manage our lives. 

Management Committee [Trustees] and Operations Team

Management Committee [Trustees]

Chair - Simon Parritt - simon.parritt@poliosurvivorsnetwork.org.uk

Secretary, Membership & Email enquiries - Dorothy [Dot] Ives - dot.ives@poliosurvivorsnetwork.org.uk

Treasurer - Margaret Marris - margaret.marris@poliosurvivorsnetwork.org.uk

Newsletter Editor - Hilary Boone - hilary.boone@poliosurvivorsnetwork.org.uk

Operations Team

Phone Enquiries - 01522 888601 [Hilary Boone]0

Email general enquiries - info@poliosurvivorsnetwork.org.uk [Dot Ives]

Printing and Website - Elpeeko Ltd, Lincoln.

Please contact us if you would like to help with our work

Membership

Full membership includes voting rights and is available to polio survivors, their partners, families and friends.

Associate membership, no voting rights, is available to patient organisations, health and social care professionals working in the interests of polio survivors £10.00 per year

Membership Fees

UK Individual - £ 12.50 per year [Renew on 1st July or 1st January after date joined.]

Associate Membership - £ 10.00 per year

Yearly fees can be paid by Standing Order.

Life membership - £ 150.00 or pay by Standing Order £ 5.00 x 30 mo.

We welcome members living in other countries and details will be sent upon request.

Please note the majority of information will be sent via the Internet.

Email:- membership@poliosurvivorsnetwork.org.uk



All Forms are available on our Website,
by phoning our helpline or writing to us.
<http://www.poliosurvivorsnetwork.org.uk/>

giftaid it

Donations

Donations, small or large, towards our work will always be gratefully received.

SEE BACK PAGE - Val Scrivener is making and selling brilliant photo greetings cards

- Some members send us a few postage stamps
- Some members take their newsletter via the internet saving us printing and posting costs.
- Others add a donation amount to their yearly cheque, or Standing Order amount.
- Some members send us a donation with some specifying, e.g. for AGM, for Conference Fund
 - UK Taxpayers can Gift Aid their subscription and donated amounts.

NEW CONFERENCE & MEETING FUND

To support attendance at National Meetings and PPS Conferences

The Gift Aid scheme. Charities can reclaim an extra 25% in tax on every eligible donation by a UK taxpayer. This 'transitional relief' does not affect your personal tax position. You must pay tax at least equal to the amount reclaimed on your donations in the current tax year.

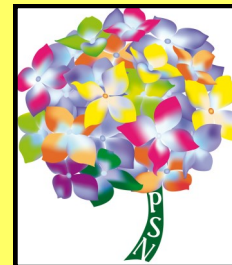
If you pay tax at the higher rate, you can reclaim tax relief on your gross donation at 20% (i.e. the difference between the higher rate of tax at 40% and the basic rate at 20%).

Polio Survivors Network

Lincolnshire Post Polio Network - Registered Charity No. 1064177

Website - www.poliosurvivorsnetwork.org.uk

Email - info@poliosurvivorsnetwork.org.uk



POST POLIO MATTERS

because **WE'RE STILL HERE!**

© www.post-polio.org

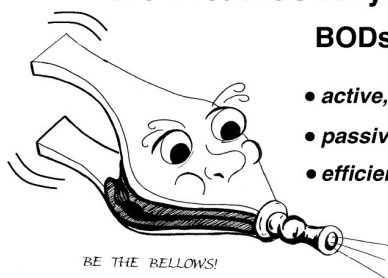
BREATHING TRAINING: DEVELOPING A USER - FRIENDLY BODY

Featuring

the BreatheOutDynamic system

BODs

- active, spine-stretching outbreath
- passive, relaxed inbreath
- efficiency for energy and relaxation



- Purse lips / pull in belly
- Focus on exhalation
- Relax for inbreath
- Use images / imagination
- Exhale on exertion
- Think Positive: I CAN DO THIS
- Be patient - You are changing habit patterns. Muscles are slow learners.
- Use BODs every day
- When in DOUBT, blow OUT!



Betsy Thomason, BA, RRT
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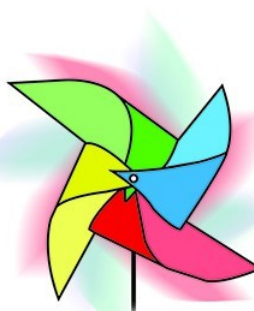
BT Breathing Training, LLC offers individual and group BODs instruction for people who want to improve—even maximize—their physical ability, experience increased energy, and manage stress. For more information, visit the website www.btbreathingtraining.com.

From Post Polio Matters - Volume 8, Issue 4, June 2014

Speaker at Post-Polio Health International 11th Conference

Foreword by Mike Ramsay, MD

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