

SUPPORTING
PHI'S CAMPAIGN

**WE'RE
STILL
HERE!**

October 10-16, 2010
www.post-polio.org

OCTOBER 2010



**2010
WORLD
HEALTH
ORGANISATION**

Codes

**POST
POLIO
SYNDROME**

G 14

**POLIO
CANADA**

ANNOUNCES

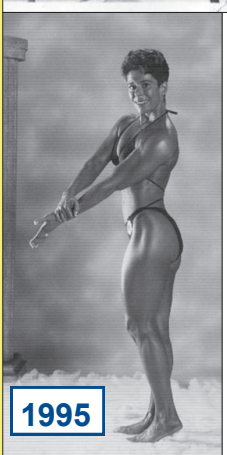
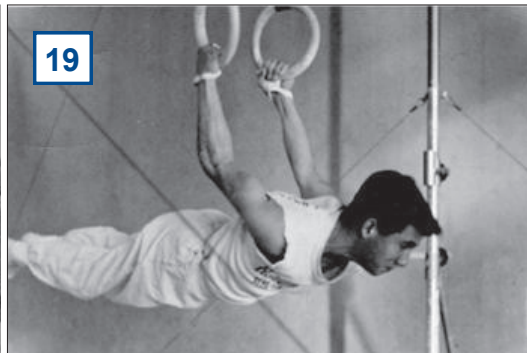
**FERDINAND
from
GERMANY
wins**

**POLIO
WORLD**

**PHOTO
POSTER
COMPETITION**

POST POLIO MATTERS

The Polio Survivors Network Newsletter - Volume 7, Issue 2
n.b. Volumes 1 to 6 published under the name LincPIN.
www.poliosurvivorsnetwork.org.uk



**WE BOTH CAUGHT POLIO
AS CHILDREN AND WORE CALLIPERS**

ARE YOU SURPRISED?

**HOW WELL SOME OF US RECOVERED
HOW MUCH WE HAVE ALL ACHIEVED**

**HOW WE LIVE OUR LIVES NOW
WE HAVE POST POLIO SYNDROME**



www.ferdinand-schiessl.com

Walking on Wheels

50 Wheel-friendly Trails in Scotland
www.walkingonwheels.org

A former Occupational Therapist, Eva McCracken was a keen walker before multiple sclerosis resulted in the use of a wheelchair. In 2000 she discovered the joys of rambling in the Scottish countryside on her electric wheels and kept the information on accessible trails which formed the basis of the book. Eva provides a practical guide to the difficulties, sights and attractions the wheelchair/scooter users might encounter. From 2 to 12 miles, maps, photos and details on the nearest wheelchair accessible toilet. Cualann Press ISBN 0-9544416-8-0 Price £10.99



URGENT

**UK Polio
Survivors
please
help
research
into PPS**

**RESULT
STUDY
NOW
EXTENDED
TO XMAS**

See Editorial

**NAIDEX NEC
BIRMINGHAM
April 5, 6, 7
2011.**

**Disability
Equipment.**
www.naidex.co.uk

**MOBILITY
ROADSHOW
June 30th to
July 2nd 2011
East of
England
Showground,
Peterborough**
www.mobilityroadshow.co.uk

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New Members and Donations received.

**We welcome new members Walter Goodwin, Richard Barry,
Verité Reilly Collins, Elizabeth Tilbury and Sue Freeman**

Thank you to the following for donations given towards our work.

Nicholas Harvey, Stuart Tanfield, Val Scrivener, A. Johnson,
Ann Telford, Walter Goodwin, Sandy Yarrow, Ros Sinclair,
Mrs. Staniforth, Joy Witheridge, Pauline Dunham, Vic Gabriel,
Maureen Devine, Sue Freeman. Richard Barry, Bob Price, Sherrye Parr.

In memory of Polio Survivor Audrey Maddock

The Helen Jean Cope Charity & Hydrate for Health

Total since last newsletter is **£1,609.50**

We have no paid employees. We would like to recognise and thank the following for so generously donating their time. The Trustees, Dave Eate, Chris Salter, Di Brennand, Margaret Edmonds, Judy Barter, Barry and Olivia Branston, Bob Price and Anne Bennett.

Donations & offers of time towards our work are always welcome.

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

Sharing information with other PPS Groups has been the best source of information for this charity so Richard and I joined the Scottish Post Polio Network and went to their AGM in Glasgow on 2nd October 2010. We stayed 4 nights, travelled in glorious weather and fitted in a couple of Museums. SPPN have been working really hard to ensure more health professionals are aware of PPS by distributing the SPPN issue of 'The Late Effects of Polio. Information for Consultants and General Practitioners first published by Queensland Health Australia in March 2001. [52 pages] 2 Speakers Mary Guild and Eva McCracken in this newsletter. More next issue.

Phone Team. HUGE THANKS to the Polio Survivor ladies of the Phone Team, Di, Margaret and Judy who have done sterling work for many years. Family commitments must take precedence so they will be hanging up their receivers at the end of November. Any member who would like to join the rota of taking calls and forwarding information to the Committee please contact us.

Membership. Your membership status is on the envelope label, either Life Member or Renewal Date as a way of saving on printing and postage costs. If you have an email address or enclose an sae we will notify you of receipt of monies. Other than that we ask that you check the date on the label has changed. Life Members your last newsletter [by post or by email] included a Contact Information Update Sheet, This was to check that you had not moved, changed email address, or your status for Gift Aid changed. Only 3 were returned. Return the one included with this issue and ensure our records are up to date. Maybe you might like to purchase a few of Val Scrivener's Photo Cards to help support the work we do at the same time.

Review of Epidemiology and Service Use in Rare Long Term Neurological Conditions (RESULT) Update - Response deadline extended to Christmas.

Out of the 206 responses to this survey for the 7 conditions 35 were from Polio Survivors. Considering the BPF and PSN notified our members we are surprised how few have responded so far. The deadline has been extended and we would be thrilled if we could report a huge increase in responses from Polio Survivors in the next newsletter. This is a marvellous opportunity for Polio Survivors to provide information that when collated could influence improvements in services. Ring Sonal Shah on **0121 414 8585** or go to www.haps.bham.ac.uk/primarycare/ccd/neuro/result.shtml

The Rough Guide to Accessible Britain is free to holders of a Blue Badge or a Disabled Person's Railcard. You can order by telephone 08000 953 7070 or online www.accessibleguide.co.uk/ Braille and large print versions also available. If you do not have a Blue Badge or Disabled Person's Railcard you can purchase a copy at a cost of £6.99 (inc. P&p)

The Hydrant. We have four, two 1L and two 75cl. Now we do not have to lift the bottles we are drinking far more each day. Great in bed, recliner chair, car, on wheelchair, just clip the tube where it is easily reached. Before you ask, trips to the loo are settling back to same number of trips as our bladders adjust.

Polio Survivors Network - Trustees' Meetings - 2010 - 2011

The Trustees meetings will be held on the following dates
via Skype teleconferencing facility which is free to Skype users

Wednesday, 18th August, 2010	11h.00 am -13h.00 pm
Wednesday, 20th October, 2010	11h.00 am - 13h.00 pm
Wednesday, 15th December, 2010	11h.00 am - 13h.00 pm
Wednesday, 16th February, 2011	11h.00 am - 13h.00 pm
Wednesday, 20th April, 2011	11h.00 am - 13h.00 pm

Saturday, 19th June, 2011 (provisional) Annual General Meeting

If you have any matters for our attention at our meetings please get in touch via
info@poliosurvivorsnetwork.org.uk

or Tel: 01522 888601 or write to us at Polio Survivors Network PO Box 954, Lincoln LN5 5ER

**The Helen
Jean
Cope
Charity
donates
£1,000
towards
our work.**



**WATCH OUT
FOR OUR
NOVEMBER
QUESTIONNAIRE**



**“don’t
count
time
make
time
count”**

Message from the Chair

Dear Members and Friends,

Since our last newsletter we have received a donation of £1000 from The Helen Jean Cope Charity which has been gratefully received and is donated for our general funds to continue the work of our Polio Survivors Network. Also many thanks to Glenna and her husband for the hard slog they put in sending out the many letters to funders. Well done Glenna and Roland, your hard work paid off!

Unfortunately and disappointingly, Barbara Taverner, our newest Trustee has had to resign due to other commitments. We do need more Trustees and if anyone is interested and would like to have a chat about what the role involves please do get in touch - my contact details are given below.

In our Annual Report we reported on page 3, Future Plans:

“to collect our members experiences of the difficulties they face both before and after diagnosis of Post Polio Syndrome”

One of the methods we can use to enable the Trustees to both understand and represent your experiences of Post Polio Syndrome is a questionnaire. We will be writing to our UK members in November about this and, ideally, would like all of you to complete and return the questionnaire. By doing so, it will help us raise awareness better, help Glenna represent your interests on the British Polio Fellowship’s Expert Panel and the Royal College of Physicians Guideline Development Group for PPS. It will also help us to raise funds. So, look out for the brown envelope in November with a letter from me asking you to fill out a questionnaire!

Well it’s Autumn and the leaves are turning golden and falling. That time of year when the momentum gathers and hurtles us towards the Festive Season and the end of yet another year. For me Autumn is a reflective time and wherever my reflections take me I come back to something my grandma use to say, “don’t count time make time count”. Please make your time count as a Polio Survivor by completing our questionnaire - your life and times are important because you are still here!

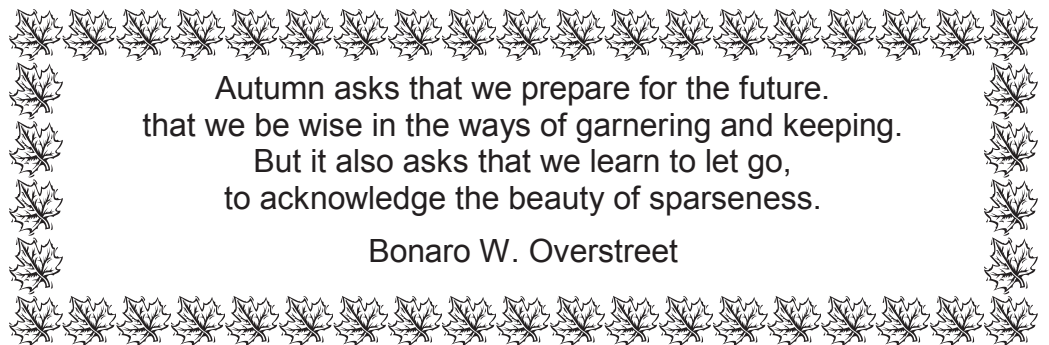
Don’t forget I am happy to hear from you at any time and my contact details are below. With all my best wishes to you and your families

Sandra

sandra.paget@poliosurvivorsnetwork.org.uk

Tel: 01494 729373

Mob: 0777 294 0905



Autumn asks that we prepare for the future.
that we be wise in the ways of garnering and keeping.
But it also asks that we learn to let go,
to acknowledge the beauty of sparseness.

Bonaro W. Overstreet

Doing Life Differently: RADAR, the Disability Network has a series of free publications written by people living with ill-health, injury or disability for disabled people. There are 3 titles in the series so far: "Doing Work Differently", "Doing Money Differently" and "Doing IT Differently".

You can obtain these from RADAR's website as free downloads using this link www.radar.org.uk/doinglifedifferently/ **OR** by writing to RADAR, at 12 City Forum, 250 City Road, London, EC1V 8AF, enclosing £1 to cover postage.

NHS White Paper: Equity and Excellence : Liberating the NHS

In the Foreword to the White Paper it states that the Coalition Government will make the NHS more accountable to patients, free staff from excessive bureaucracy and top-down control. Spending on the health service will be increased in every year of this Parliament.

First, patients will be at the heart of everything we do with more choice and control, helped by easy access to information about GPs and hospitals.

Second, there will be a relentless focus on clinical outcomes, success will be measured against results that really matter to patients, e.g. improving cancer and stroke survival.

Third, we will empower health professionals. Doctors and nurses will be given more control. Healthcare will be run from the bottom-up, ownership and decision-making in the hands of professionals and patients.

The final sentence in the Foreword ... Only by putting patients first and trusting professionals will we drive up standards, deliver better value for money and create a healthier nation.

As part of the above we will see the formation of GP consortia - GP practices in a particular area will work collectively and be responsible for commissioning (buying in) the services their patients need. £80 billion plus will be allocated to GPs to commission services. This will be a major change in the way your health services are delivered.

The consultation period for the White Paper has closed but you can obtain full details by using this link www.dh.gov.uk/en/Publication/Publications/PublicationsPolicyAndGuidance/DH_117353

OR you can order a copy of the White Paper, which is free, by writing to
TSO Publications Centre PO Box 29 Norwich NR3 1GN
You can order copy(s) by Telephone: 0870 600 55 22 or Fax: 0870 600 55 33

GLOBAL POLIO ERADICATION INITIATIVE

A few facts from - www.polioeradication.org

Total cases	Year to date 2010	Year to date 2009
Globally	717	1165
- in endemic countries:	143	898
- in non-endemic countries:	574	267

September 2010 - Onset of the most recent cases	
26th September	Pakistan
18th September	Russian Federation
16th September	India
4th September	Afghanistan
2nd September	Democratic Republic of the Congo.

What Your Voice is Saying About You: Vocal Changes and the Late Effects of Polio

Mary Spremulli, MA, CCC-SLP, Punta Gorda, Florida, info@voiceaerobicsdvd.com

A speech-language pathologist in private practice, a clinical consultant with Passy-Muir, Inc, and a national seminar leader on medical topics, Mary Spremulli addresses how voice changes may relate to polio survivors, a topic raised frequently by PHI [Post-Polio Health International] readers.

Why does my voice sound this way?

Over the last few years, a number of individuals with a history of polio 40 or 50 years ago have been referred to my speech pathology practice complaining of changes in their vocal function. They were often young children at the onset of their polio, so some of them are unsure if their original diagnosis was bulbar or spinal.

Now, many of them in their 60's and 70's report voice problems or changes, such as: "my voice is weaker," "my voice is scratchy and hoarse." Not infrequently, these changes in voice are accompanied by changes in swallowing function with associated complaints of increased "choking" when eating or drinking.

Is this related to having had polio?

In many of these instances, the change in voice can represent further weakening of the respiratory and phonatory (voice production) system. In particular, if individuals had initial bulbar polio symptoms, they have likely already spent a lifetime using some compensatory respiratory and oral-pharyngeal muscle function. This muscle function may now be further weakened due to further muscle degeneration, age-related changes, muscle disease atrophy or vocal misuse. Separating out the causes and contributors to current voice problems can be challenging for the voice therapist or otolaryngologist.

Why should I see an Ear, Nose and Throat Doctor (ENT)?

Any sudden changes in voice function, or any change, such as hoarseness, that persists for more than a few weeks warrants an examination by an ENT. The ENT will conduct a direct visualisation of your vocal folds and larynx (voice box) by passing a small scope with a camera through your nose and making sure there are no growths, such as nodules (calluses that form from misuse) or polyps (a usually benign, fluid filled outgrowth of tissue that also may be from misuse) or tissue changes suggesting a more serious diagnosis.

A direct visualization can also confirm the contribution of acid reflux, in particular stomach acid that escapes from the top muscle of the esophagus (food pipe). This type of reflux, is also referred to as laryngopharyngeal reflux or 'silent reflux' and it is often a factor causing hoarseness or other voice changes.

Patients are often surprised when the ENT prescribes anti-acid medication for their voice changes, not realising that our anatomic design places the opening of the esophagus and the opening to the windpipe dangerously close, and the vocal folds often receive the insult of acid which may escape from the top muscle of the esophagus.

What is a voice evaluation?

Following an ENT examination, patients are typically referred to a speech language pathologist (voice therapist), who may conduct further instrumental examination using videostroboscopy. In videostroboscopy, a rigid scope with a camera attachment is placed through the mouth to visualize the larynx and evaluate the dynamic movement of the vocal folds.

The voice therapist will also perform a clinical evaluation of vocal function. This exam involves

taking a thorough history that includes questions about how you use your voice throughout the day, medication use that may be affecting your voice - particularly inhalers and steroids - as well as any surgery you may have had on your throat or any tubes placed down your throat during surgery in an emergency to maintain ventilation. Measurement of pitch, vocal intensity and voice duration are obtained, as well as observations of your respiratory patterns.

In addition to this history and perceptual data, the voice therapist will observe how you use your breath support and voice during conversational speech. Behaviours that can harm the vocal folds, such as frequent throat cleaning or coughing, will also be noted as these common habits over time can injure the vocal folds. You will likely also be asked about hearing, since a decline in hearing may cause difficulty in your ability to accurately judge vocal intensity in your own voice or others.

Although not directly related to voice production, the vocal folds position at the opening of the windpipe also makes them gate keepers against foreign bodies entering into the upper airway. Therefore, you will be asked about any problems you may be having with choking or coughing when eating or drinking. These symptoms may also be an indication that the sensation of the larynx or function of the vocal folds have declined in some way, permitting food or liquid to now enter your upper airway. A separate swallowing evaluation maybe recommended.

Can voice therapy help?

Once an accurate diagnosis of your voice problem is made, treatment will likely be a combination of medical and therapeutic management. Problems requiring further medical treatment will be handled by the ENT. These may include medications to treat acid reflux, thick/thick mucus/ secretions or to reduce post-nasal drainage. More serious problems, such as polyps, may require surgery.

The voice therapist will focus on vocal hygiene, which includes modification of environmental factors that may be serving as irritants to the larynx and vocal folds, instruction in the methods to eliminate throat clearing and other abusive habits, and encouraging improved hydration through water intake and/or steam.

Then, much like a music teacher, the remainder of voice treatment will focus on improving functional use of your voice instrument. In the case of someone with poor diaphragmatic breathing and respiratory muscle use due to polio and post-polio symptoms, a modified respiratory muscle training program may be recommended.

Relaxation techniques and methods to reduce muscle straining in the neck muscles and larynx may be demonstrated. Use of optimal pitch and posture and techniques for improving loudness without straining will all be emphasized. Voice treatment may be offered for six to eight visits, with development of a home exercise program to encourage strengthening of the system, preservation of muscle function and maintenance of any improvement achieved. For individuals with voice changes from PPS, conservation techniques, including use of personal voice amplification devices may also be beneficial.

Our larynx is a rather amazing organ. Our ability to use its shared functions of breathing, digestion and voice production make it clearly one of our uniquely human gifts. Throughout our lives, our voice mirrors physical growth and other body changes. It conveys our physical and emotional health, and at times, it inspires poetry.

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[Editors Note: Remember to write/email/ring us at any time if you have issues you would like more information on. You will also be able to tell us more if you complete the Questionnaire coming in November, and we would appreciate a high response to this.]

National Institute of Disorders and Stroke, USA.
**News Item. - Post-Polio Patients Have Swallowing Abnormalities
that Increase the Risk of Choking**

For release: Sunday, April 21, 1991 [Date last modified Thursday May 6th 2010]

Many post-polio patients have swallowing abnormalities that increase the risk of choking but are unaware of their condition, according to a study directed by a scientist at the National Institute of Neurological Disorders and Stroke (NINDS) and published in the April 25 issue of the *New England Journal of Medicine* . * .

Of the 500,000 Americans who survived acute polio, more than 125,000 now have post-polio syndrome, in which progressive muscle weakness develops 25 to 30 years after the initial disease.

Previous reports have demonstrated that post-polio syndrome weakens the muscles of the arms and legs — causing patients difficulty when walking, lifting, or reaching. The recent study shows that this progressive weakness also affects the bulbar muscles of the tongue, mouth and throat and triggers swallowing problems — called dysphagia — in most patients.

"These findings should prompt physicians to check their post-polio patients closely for abnormal swallowing," said Marinos C. Dalakas, M.D., the NINDS scientist who directed the study. "Unlike new weakness in the arm or legs, which causes obvious problems with movement, deterioration in swallowing is easily overlooked — even with standard neurological exams," Dr. Dalakas stressed. "If dysphagia is not specifically tested, problems may remain hidden until the patient suddenly becomes aware of choking."

During the study, scientists examined swallowing among 32 patients randomly chosen from a larger group of post-polio patients. Using specialized imaging techniques, including videofluoroscopy and ultrasonography, they detected dysphagia in 31 patients — but only 14 were aware of this problem.

Typical signs of dysphagia included excessive tongue movements, a delay in the swallowing reflex and constriction of throat muscles, and uncontrolled flow of food from the mouth into the throat. These problems were often more severe on one side of the mouth and throat.

Dr. Dalakas and his colleague Barbara Sonies, Ph.D., of the National Institutes of Health also detected dysphagia using an index that assesses oral motor function based on 10 tests of muscle strength and motion, such as strength of tongue and lips, voice quality, and swallowing ability. "As the index score rises, the patient's risk of choking also goes up," Dr. Dalakas said. "Using this index, physicians can predict which patients are likely to choke."

Dr. Dalakas suggested that patients with post-polio syndrome visit their physician for a check of dysphagia and, in some cases, change eating routines to reduce choking risk. For example, patients with significant dysphagia should chew food on the less affected side, consume softer foods, use smaller bites when eating, and eat more slowly. He also recommended that family members or companions of such patients learn the Heimlich maneuver.

The exact cause of post-polio syndrome is unknown. During the first, acute polio infection, the virus destroys nerve cells that control limb and bulbar muscles. This causes symptoms that range from weakness to paralysis, depending on the number of nerve cells destroyed and how well the remaining, healthy neurons can compensate.

In post-polio syndrome, however, the compensating neurons become overworked and are no longer able to control muscles as effectively, Dr. Dalakas said. Post-polio syndrome may also be aggravated by the aging process, in which all individuals lose some neurons. In most individuals, half of the nerve cells controlling a muscle must die for weakness to result. Since the number of neurons is already abnormally low in post-polio patients, small additional losses can easily trigger

muscle weakness.

"Studies of post-polio syndrome are rapidly advancing our knowledge of how motor neurons survive and endure and what causes them to dysfunction," said Murray Goldstein, D.O., M.P.H., NINDS director. "Thus, this research could have implications for other diseases that affect motor neurons — such as amyotrophic lateral sclerosis, or Lou Gehrig's disease, and the neuropathies. It may also help scientists to understand how aging affects the nervous system. "

The National Institute of Neurological Disorders and Stroke, one of the 13 National Institutes of Health in Bethesda, MD, is the primary supporter of brain and nervous system research in the United States.

* "Dysphagia in Patients with the Post-Polio Syndrome." Barbara C. Sonies, Ph.D., and Marions C. Dalakas, M.D. New England Journal of Medicine; April 25, 1991; pp. 82-91.

No Crust Quiche

about 1 cup leftover or frozen veggies
about 1 cup grated cheese
4 eggs
1 can evaporated milk
1/2 cup flour, optional
Bits of meat or seafood, optional

Spray vegetable oil in a large pie pan or 9" square pan. Put in vegetables and cheese. Beat eggs, add milk, and flour (optional) in a bowl. Pour over veggies. Add some salt and pepper but lightly.

Bake at 325 degrees for 50 to 60 minutes or until a knife inserted into the center comes out clean. Cool, and serve warm.

- Is also good cold, or warmed in the microwave for breakfast or any meal.

- Freezes well (I cut the leftovers into single servings and freeze).
- I always make it without flour, and there are fewer calories (and no extra carbs).
- Can use any of your favourite veggies and/or leftover bits that you have kept in your freezer.
- Save bits of cheese in a freezer bag to use in recipes like this.
- Can use an equivalent amount of egg whites or "egg beaters."
- Can use skimmed evaporated milk for less fat and calories.
- Get someone else to beat the eggs, and grate the cheese!
- Meat or seafood can be added for extra protein, if desired.

Some UK = Metric = USA measures.

- | | | |
|---|-------------------------------------|--------------------------|
| • 1 ounce flour | 25g | = quarter cup |
| • 4 ounces flour | 125g | = One cup |
| • 4 ounces butter and other fats, including cheese | 125g | = One stick |
| • 8 ounces butter and other fats, including grated cheese | 250g | = One cup |
| • 7 ounces caster/granulated sugar | 200g | = One cup |
| • One ounce (1oz) | One rounded tablespoon | |
| • One tablespoon of liquid | 3 teaspoons | |
| • One teaspoon liquid | 5ml | |
| • One British teaspoon | is the same as an American teaspoon | |
| • One British tablespoon liquid | 17.7ml | |
| • One US tablespoon liquid | 14.2ml | |
| • 8 tablespoons which is 4 fluid ounces | 125ml | Half cup |
| • 8 fluid ounces | 250ml | One cup (Half a US pint) |
| • One British pint/20 fluid ounces | 600ml | Two and a half cups |

Breathing and Sleep Problems in Polio Survivors

Prepared by International Ventilator Users Network (IVUN) www.ventusers.org

Reviewed by Nicholas S Hill, MD, Tufts-New England Medical Center, Boston, Massachusetts.

It is critically important that polio survivors, especially those diagnosed with post-polio syndrome, obtain proper testing, diagnosis, and management of breathing and sleep problems. The problems may result from weak breathing muscles in the chest and abdomen (diaphragm and intercostals).

Pulmonary function tests (mostly non-invasive) can measure the strength of respiratory muscles and usually include a test for forced vital capacity (FVC) - the maximum amount of air that can be exhaled. This test is typically administered when a person is sitting in the upright position, but also should be administered when a person is lying down (supine position). People who may not experience breathing problems sitting up may find themselves struggling for breath when lying down. This problem is known as orthopnea, and a marked decrease in FVC whilst lying down indicates that the diaphragm is weak.

The late E. A. Oppenheimer, MD, a pulmonologist with years of experience of treating polio survivors, described it, "As one ages with the late effects of polio, respiratory muscle strength may decrease. This may be particularly evident when you lie down, because in this position, the diaphragm has to work harder both to pull air in and also to push the intestines and other abdominal organs which are out of the way when one is upright due to gravity."

Polio survivors also may have obstructive sleep apnea (OSA), central sleep apnoea (CSA), a combination of OSA and CSA, and/or hypoventilation (an imbalance in the gas exchange in the lungs due to too little breathing - carbon dioxide builds up and oxygen drops). In obstructive sleep apnea, the upper airway collapses and blocks the flow of air so the person stops breathing periodically. These cessations of breathing are known as apneas and hypopneas. An overnight sleep study may be helpful to confirm the presence of OSA if it is suspected, based on snoring and daytime sleepiness.

Most sleep laboratories are set up to detect obstructive sleep apnea, for which the appropriate treatment is continuous positive airway pressure or CPAP, but not to measure carbon dioxide levels directly, which would be the best way to detect hypoventilation, for which the appropriate treatment is bi-level or positive pressure ventilation. The test for high carbon dioxide level would be to measure arterial blood gases (requiring blood to be drawn via needle from an artery—usually in the wrist) or to monitor end-tidal or transcutaneous CO₂, which is usually not done. However, sleep labs look for sustained drops in oxygen saturation during sleep that would be indicative of hypoventilation and then can proceed to additional testing to confirm hypoventilation, if needed.

When a bi-level device, a form of positive pressure ventilation, is prescribed, it will provide two levels of pressure; inspiratory (IPAP) to help blow air into the lungs, and expiratory (EPAP) to help keep the airways open and to blow off CO₂. These pressures can be set and adjusted separately. IPAP settings are higher than EPAP settings, with a span of at least 8 to 10 advised for adequate breathing assistance, e.g. (IPAP of 14, EPAP of 4, Bi-level units with a back up rate are recommended for people who may not be able to initiate a breath on their own, particularly at night. The bi-level device can provide timed backup breaths.

It is important for individuals to understand that polio survivors do not "forget to breathe" when they become overly fatigued. What happens is that the muscles become too weak to move sufficient air, especially during sleep. Post-polio syndrome can also sometimes cause central sleep apnea which causes the brain to temporarily "forget" to signal breathing muscles to take a breath. This is evident during a sleep study when there is no chest wall movement for at least 10 seconds, indicating that the individual is not breathing and is apneic. Bi-level ventilation

administered using a nasal or face mask can help with either problem.

Although a polio survivor may not have breathing or sleep problems when initially diagnosed with post polio syndrome, periodic testing is important because such problems may develop overtime or a change of breathing machine and/or settings may be warranted.

Tests for Breathing Problems If You Have a Neuromuscular Condition.

Prepared by International Ventilator Users Network (IVUN) www.ventusers.org

Reviewed by Nicholas S. Hill, MD, Tufts-New England Medical Center, Boston, Massachusetts.

If you have a neuromuscular condition such as post-polio syndrome, ALS [MND], or Duchenne muscular dystrophy, you may not realise that your breathing muscles are weak and can become weaker. You may have difficulty breathing deeply enough to fully expand your lungs or coughing strongly enough to clear mucus from your lungs.

It is essential to have periodic measurement of your respiratory muscle function and strength, and your oxygen and carbon dioxide levels to determine whether you may need to use a breathing machine (bi-level device or ventilator) during the night and/or need help with coughing. If you are a polio survivor, measurements of forced vital capacity (the maximum amount of air one can exhale) should be taken BOTH when you are sitting upright and lying down (in the supine position).

Even after you begin using assisted ventilation (a bi-level device or ventilator) it is critical that you periodically have your breathing monitored to prevent respiratory complications in the future and to improve your quality of life and survival. The recommendations below were written for individuals with Duchenne muscular dystrophy, but they are also appropriate for people with ALS and post-polio syndrome.

Routine Evaluation of Respiratory Function.

Objective evaluation at each clinic visit should include: oxyhemoglobin saturation by pulse oximetry, spirometric measurements of FVC, FEV1, and maximal mid-expiratory flow rate, maximum inspiratory and expiratory pressures, and peak cough flow.

Awake carbon dioxide tension should be evaluated at least annually in conjunction with spirometry. Where available, end-tidal capnography can serve the purpose of monitoring your CO2 levels. The need for arterial blood gas analysis will depend on your doctor's recommendation. If capnography is not available, then a venous or capillary blood sample can be obtained to assess for the presence of alveolar hypoventilation (too little breathing causing CO2 increase).

Additional measures of pulmonary function and gas exchange may be useful, including lung volumes and assisted peak cough flow.

Careful evaluation of patients for evidence of other respiratory disorders, such as obstructive sleep apnea, oropharyngeal aspiration, gastroesophageal reflux, and asthma.

Annual laboratory studies in patients requiring a wheelchair for ambulation should include a complete blood count, serum bicarbonate concentration and a chest radiograph.

Finder JD, Birnkrant D, Carl J, et al. Respiratory care of the patient with Duchenne muscular dystrophy, *Am J Respir Crit Care Med.* 2004;170:456-65. Official Journal of the American Thoracic Society. ©American Thoracic Society. Reprinted with permission.

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Continued from previous page.

Medical Articles: Breathing and Sleep Problems in Neuromuscular Conditions.

Compiled by International Ventilator Users Network (IVUN) www.ventusers.org

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Editors comments

Members have reported problems for many years now with breathing, sleeping, swallowing and the forms of assessment, e.g. Lung Function Studies, Sleep Tests in hospital and at home, and swallowing testing. We have been and are still researching all these issues and requesting discussions with appropriate health professionals. Up to now we have had little success but are hopeful of a good reply to our latest request.

Remember it is essential that you give as much pertinent information as you can at appointments. It is the change in how you do actions of daily living now compared with how you did them prior to your current issues that gives the health professional the best information to help you. For most of us it is a **loss of endurance**, both repeating and sustaining actions.

From the front page of our 28 page Respiratory Newsletter, LincPIN, Vol 5, Issue 9, June 2006. [<http://www.poliosurvivorsnetwork.org.uk/images/lincpin/lincpin5-9.pdf>] Members who do not have a copy of this issue and are unable to download it from the Internet [at home or have it downloaded for you at your local library or internet cafe] please write for a copy. A book of first class stamps would be appreciated to help with postage costs

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

- Do you stop breathing to concentrate on achieving an action?
 - 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?”
2. We know some other members have bi-levels but maybe not all. If you are interested in being put in touch with one another then please email/write/phone.
 3. If you have been prescribed a CPAP and not a bi-level ventilator we advise you to discuss this with your GP/Respiratory Consultant to ensure that you are on the right machine.

Dancing on Wheels - [Speaker Mary Guild, Scottish Post Polio Network AGM]

This is a short story told at our recent Scottish Post Polio Network on 2nd October 2010:-

My name is Mary Guild and I contracted polio at the age of 6 months. I led a fairly normal life and with the aid of callipers had no major mobility problems until Post Polio Syndrome set in during my early 50's and that's when I became dependant on a wheelchair.

My brief talk today is about mobility and liberation – two words which you wouldn't normally find in your average word tin !!!

No one wants to be in a wheelchair but I'm a great believer in making the most of what we have and instead of feeling a sense of "why me" turn that negative into a positive by realising that this chair opens so many doors – doors that, pre wheelchair days, were the barriers to social inclusion. You may be declining activities that involved walking. You sit back and reluctantly stay at home, declining social invitations from friends, unable to do some of the activities you once enjoyed due to increased weakness, pain, fatigue, fear of falling and lack of endurance.

For me my wheelchair is my pass to freedom - gives me free rein to explore the great outdoors, breathe in the fresh air, smell the pine trees and feel the rain on my face. My chair allows me to travel freely whether it be by plane, train, boat and more recently by bus – the latter quite a new and exciting experience for me, not to mention the free bus pass!! Think about your carbon footprint - for those who have cars - leave it at home occasionally - save a fortune on ever increasing fuel prices. Organisations before us have campaigned tirelessly for access to public transport - use it or else we lose it. I touched on the outdoors earlier and my passion is rambling and my chair has given me access to so many country parks, National Trust gardens and sunny coastal paths. The Wheelchair Centre in Edinburgh are constantly having to renew my batteries !!!!

My chair emancipates me from my laborious, energy-sapping polio gait. In fact, it lets me roll in grace and elegance! I think that often people resist the wheelchair because, after all, it is the universal symbol for disability; and they fear that the social stigma attached to that will brand them anew as: 'different' 'other', 'less than' or that horrible phrase "wheelchair bound"!! I wish we could change that and let it be the universal symbol for freedom and independence. Chances are, if you need a wheelchair and are resisting, your disability isn't all that hidden anyway. A wheelchair can smooth out a compromised gait, it can free your arms from crutches and walking frames and in a lot of ways, it gives you back much of your mobility and independence.

So, use your wheelchair with pride and confidence. If you embrace it, those around you will follow suit, and before you know it you'll be helping to change those outdated social stigmas.

Another speaker was Eva McCracken, author of Walking on Wheels - see front page.

Two excerpts from PSN's copy of Walking on Wheels.... 'The paths through the Local Authority parks are on the whole easier, either because they are better surfaced or because parking and toilets are more likely to be available. For the more adventurous I have sought out longer, usually linear, paths which I have accessed in my electric wheelchair or scooter and which offer a good day out in more open countryside. My grading system is subjective but I hope as you try out the trails you will get to know it and find it useful.'

'Toilet abbreviations W/C wheelchair accessible. (R) and (L) indicate space for wheelchair on that side when facing toilet seat.' [Editors note - If only all guides could include this information]



POLIO SURVIVORS NETWORK PHONE TEAM
Seeks Members to Join the Rota to take Calls
and forward information to the Committee



Shoes – The Big Dilemma!

It seems to me that almost every woman I come across today has more shoes in her wardrobe than Imelda Marcos had in her hey-day! Even my eight year old granddaughter is already starting to show signs of this feminine obsession! This summer she never seemed to have quite the right flip-flop for her chosen outfit – despite both her mother and I feeling that if she had any more pairs their whole family would have to start looking for a larger house!

To my great sadness I have never really been able to indulge in this harmless passion. I was born towards the end of 1951 and contracted polio a week before my fourth birthday. From the days of my first steps the doctors had decided that I was 'knock kneed' and, from the age of two had equipped me with sturdy 'over the ankle' leather lace up boots – I am still not clear what they were supposed to do for me! All in all, it seems that I was doomed to wear ugly footwear from my earliest days! My poor mother must have despaired of making her little dark haired, blue eyed daughter look pretty in the beautiful clothes she lovingly made for me in those rather more frugal times, while she was wearing big, clumpy brown leather boots! In the summer before I was four it all got too much for her and she rebelliously bought me a pretty little pair of colourful, strappy sandals! All my life I have remembered those little shoes – **the only pretty pair of shoes I have ever worn!**

My experience of contracting polio was much the same as everyone else's. Fever hospitals, lumbar punctures, inhuman visiting hours, long months in hospital and a range of medical experiences (some obviously good, but others most definitely not). Looking back I can see how difficult all of this must have been for such a small child to process. Eventually, when I finally came out of hospital, it was with a full-length calliper on my left leg. At that time, in the mid 1950's, there was no such thing as a calliper with a bending knee for a child of barely five, and it also seemed certain to everyone that I was doomed to a life of leather lace-up shoes! By the time I reached my early teens I did finally progress to a calliper that bent at the knee (try going into any public ladies' loo with a calliper that doesn't bend at the knee, and shutting the cubicle door!). However – there was still the matter of the 'sensible' leather lace-up shoes!

Both my mother and my maternal grand-mother were inherently stylish women. During my formative years I had spent hours watching, and helping, my mother dress for elegant evenings out with my dad, and looking at photographs of my grand-mother, who had been a very successful hair-dresser in her time, wearing a range of wonderful iconic fashions, from Fortuny dresses in the 1920's to Chanel suits and Dior's 'New Look' in the 1940's and early '50s. I am sure that we all remember what happened to fashion in the mid 1960's? I was turning into a young woman who wanted to be able to wear all the lovely, colourful fashions that were very specifically aimed at my age group. There was, obviously, no real problem with me wearing the clothes – the problem came with the footwear! I did not feel that clumpy, brown leather lace-ups really set off a jazzy coloured Biba mini dress! I could almost hide them under the odd maxi-dress but I started to feel that a huge part of what would have been my life in other circumstances, was being taken away from me.

Maybe it is that Type A personality that has driven most of us polio survivors all of our lives, but I was not going let this defeat me! Eventually it came to me that there was no real reason why I had to wear the same sort of shoe on my right leg that I was doomed to wear on my left! There was no medical reason now for me to do so and although the shoe that I wore on my right foot would always have to have pretty well the same heel height as the one on my left, that, in reality, was my only constraint! It seemed to me that people stared at me in any event – they might as well stare at a me who was feeling and looking pretty, as one who was looking clumpy and old-fashioned and feeling depressed! Looking back, I think that the key, for me, was mentally 'disconnecting' the rest of my body from my paralysed left leg. I felt that just because my left leg was viewed as disabled the rest of me didn't have to be! It wasn't long before this idea had transformed my life! As with most of these things I think that it is a state of mind. If you think that

you **can** do something it seems to me that you mostly can! If you are sitting there believing that you are defeated by some circumstance or situation it is even harder to for you to win out in the end. Suffice it to say that, in the 1980's, when there was a craze for colourful leggings topped with big sweaters, I was out there, with bright pink ribbons wound round my right leg and tied to the metal sides of my calliper, topped with a big chunky sweater that came to about 8" above my knees! Over the years I have worn colourful sandals, one single wellington boot, black leather thigh boots – you name it – if it was at all possible for me to manage in it, and I felt that it looked good - I wore it! I felt great and **no-one**, over all those years, has ever made a single comment to me about it!

As I am now in my late 50's PPS raised its ugly head about 15 or so years ago and things have changed a little. I still wear 'odd' shoes – but I have to be a bit more careful about heel height and the amount of support the shoe gives me. I don't walk quite as much as I used to, and certainly barely at all outside of the house. I have accepted the assistance of a wheelchair, both an electric one in the house and a push one for the car. But, even though I am getting a little older, I still feel the need to be colourfully and fashionably dressed! It really doesn't matter to me whether I am out and about, or just having a quiet day at home. As I am writing this I am wearing grey combat trousers and a pleated and embroidered white linen top, and wearing a black sandal on my right foot. The only person I am expecting to see today will probably be my daughter, but what I wear is more about making me feel good about myself than it is for anyone else! I am now a grandmother of three delightful little individuals, aged from three to eleven. I am a very involved grandmother and I try hard to go to all of their school functions. I am really proud that my three grand-children tell me that I am the most glamorous granny they know - even in my wheelchair – and I don't think that they have ever noticed my 'odd' shoes either!!

Member Gaby Martin <gabymartin@btconnect.com>

Laughter IS the Best Medicine.

For those of you who watch what you eat, here's the final word on nutrition and health. It's a relief to hear the truth after all those conflicting medical studies.

1. The Japanese eat very little fat, lots of carbs, consume a lot of liquors, and suffer fewer heart attacks than Americans.
2. The Mexicans eat a lot of fat, eat a lot of carbs, drink lots of alcohol, and suffer fewer heart attacks than Americans.
3. The Chinese drink very little red wine, eat lots of protein & carbs, and suffer fewer heart attacks than Americans.
4. The Italians drink excessive amounts of red wine, tons of carbs, and suffer fewer heart attacks than Americans.
5. The Germans drink a lot of beer, eat lots of sausages and fats with carbs on every dish, and suffer fewer heart attacks than Americans.

CONCLUSION:

Eat and drink what you like. Speaking English is apparently what kills you.

This woman rushes to see her doctor looking very much worried and all strung out. She rattles off, "Doctor, take a look at me. When I woke up this morning I looked at myself in the mirror and saw my hair all wiry and frazzled up, my skin was all wrinkled and pasty my eyes were bloodshot and bugging out and I had this corpse-like look on my face, What's wrong with me, Doctor?"

The doctor looks her over for a couple of minutes then calmly says.....
"Well, I can tell you that there is nothing wrong with your eyesight "

JULY/AUGUST 2010

Psychological Resilience and Depressive Symptoms in Older Adults Diagnosed with Post-Polio Syndrome Diana Pierini, BSN RN • Alexa K. Stuijbergen, PhD RN FAAN

Rehabilitation Nursing, 35, (4), pp 167-175.

“Depression is a serious co-morbidity in persons with disability, yet few studies have focused on depressive symptoms in persons aging with post-polio syndrome (PPS).”

This research of polio survivors over 65 with PPS utilizes a large sample size and a variety of scales of psychological resilience [a combination of positive traits and coping responses or behaviours that facilitate the successful management of unexpected changes or formidable stressors in one's life.] The following are excerpted comments to give you a flavor of the research project.

“PPS may strike 10 to 50 years after the initial polio infection and presents the polio survivor with the disappointment of an unexpected surge in physical deterioration.... Depending on the severity, these new symptoms are viewed by some as an unwanted hassle, and for others, an overwhelming stressor leading to fear, frustration, anger and depression. For many the onset of PPS demands a regrouping of coping skills for individuals who thought they had overcome their biggest polio related hurdles.....

Discussion. Returning to our conceptual framework of psychological resilience in the context of aging persons with diagnosed PPS, we proposed that resilience is a broad construct comprised of a combination of various resilience factors: character traits (e.g. acceptance, curiosity, flexibility) and coping responses or behaviors) e.g. talking to family or friends about PPS, problem-solving) that facilitate the successful management of unexpected changes (i.e. diagnosis of post-polio syndrome) or formidable stressors (unexpected increase in functional limitations) in one's life. We hypothesized that as use of resilience factors increased, the level of depressive symptoms would decrease. Psychological resilience was suggested by the results; 53% of the sample rated their health as good or excellent despite the following findings that a) they were polio survivors currently experiencing post-polio symptoms; b) there was a high level of self-reported depressive symptoms [M=8.69, SD=5.2), and c) 40% scored at or above 10 on the CES-D 10, indicating the presence of moderate to severe depressive symptoms.

These findings reveal a paradox. How could depressive symptoms be quite pervasive, yet more than half the sample report good or excellent self-rated health? Studies of persons who have survived severe crises or illnesses such as polio have shown that depression may be a lingering and chronic problem throughout the remainder of life (Bruno, 1999, Hollingsworth, Didelot & Levington 2002) however, resilience traits and coping responses may counter depressive symptoms by fostering feelings of hope, self-reliance, and optimism. Further study may unravel the relationship between high levels of Self Reported Health and concomitant high levels of depressive symptoms in the context of aging with a disability such as in PPS.....

Rehabilitation nurses can utilize these findings by first recognizing and encouraging resilient attributes in their patients such as realistic acceptance of PPS, a future-orientation, optimistic self-rated health, and willingness to maintain social ties with at least one confidant or friend. Establishing a trusting collaborative relationship is the vehicle through which these patients' strengths are discovered. Most importantly, it is essential to assess persons aging with PPS for depressive symptoms as a routine practice at each point of care. Diana Pierini
dianapierini@mail.utexas.edu

Members Hints, Tips and Bits

I am not medically qualified but as a Health writer and Polio Survivor have researched many items that might help others. Remember to discuss any treatment or over the counter items with your medical professionals before use.

Side Effects of Drugs.

I have devoted almost a whole website into how to handle side effects - www.after-cancer.com

[Excerpt. Cancer treatment in hospital does come to an end! As a patient, I suddenly found there is light at the end of the tunnel. When daily visits to hospital finished, I could start planning fun things again. However, I discovered that hormonal drugs (the little pills they tell you to take every day for five years) can have nasty side effects: 95% of us will get these.

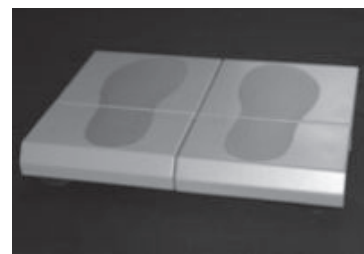
But – for every ‘nasty’ that comes up, there is probably a gorgeous treatment or super product that helps with side effects – these make life easier and more fun. I call these Having Fun After Cancer.

We know medical staff are overworked. Cancer patients often feel they can't bother busy staff to find solutions. Others can't stand side effects and make the decision to stop taking the drugs that cause the problem.

So I set up this website to give some fun ideas for zapping side effects, and to readers that yes, some of the problems caused by side effects can be with us for some time – but there are fun and comforting ways of coping – in other words HAVING FUN AFTER CANCER. Hope some of them might work for you.]

Pedana Stabilometrica. Last month in Italy I was introduced to a machine called a Pedana Stabilometrica. I went on this, and it measured my stability - and told me that out of my 70 kilo weight I carried 44 kilos on the left side and 26 kilos on my right side.

Might this be of any use to other Polio Survivors having to convince medics they have a problem? I will report more on this and my trip to Italy in the next issue.



[Editors note - **The Posture Scale Analyser** was developed as a response to requests from chiropractors from the US and Europe looking for a bilateral scale to indicate the lateral weight distribution of their patients.] http://en.cojeda.com/Posture+Scale+Analyzer_2_0_219.aspx

Dry Eyes - My French Ophthalmologist told me we get 'dry eyes' and to try 'Systane' which you can get over the counter.

[Editors Note - Systane Lubricating Eye Drops moisturizes the surface of the eye for fast and long lasting relief of the feeling of dryness, Irritation, burning, stinging, grittiness or foreign body sensation caused by environmental factor. Personally after reading this we spoke to our Pharmacist who suggested a choice of items on the shelf. We picked the Optrex Actimist Eye Spray and both of us have noticed a considerable reduction in the dry burning sensations. This is just to inform you of our experiences of dry eyes and Polio Survivors Network does not endorse this product. ALWAYS consult your doctor/pharmacist/health professionals before trying anything recommended in this or any other publication.]

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Member Chartered Inst. Journalists; Sports' Journalists' Assn. Assoc. Guild Health Writers

Polio Biology XIII by Professor Eddie Bollenbach.

Is it more feasible to use stem cell therapy on victims of polio infection, and that this would be more realistic than protecting children from polio in the first place?

First of all, there are a few outbreaks here and there and locals have bought into anti-UN US propaganda that the vaccine will hurt kids or give them AIDs. But there are only a few cases in the underdeveloped world and although the Rotary missed it's goal of eradicating polio by 2000, there is no reason to believe that this is an impossible goal. It is not the tenacity of the 3000 yr old virus (it is much much older than that in primates and humans), but the ignorance of human beings which has prevented the eradication which I believe will come.

On the other side of the coin I would be wary of treating children with stem cells as they often turn cancerous and that is something you do not want to create in the Central Nervous System. Before this type of treatment would be approved and recommended as safe and efficacious there would have to be large trials, including animal trials to eliminate the possibility of cancer. Also, other technologies would have to be developed to "scaffold" the growing nerve cells to muscles. We might even need to produce new muscles for the nerves to connect to. I think this can be accomplished in the foreseeable future and several researchers are working on it. There is an old Chinese saying which is apropos here: "The superior physician treats the disease before the symptoms manifest. The inferior physician can only treat the symptoms of the disease he failed to prevent." I'd go with renewed effort to vaccinate children in areas of the world where polio, once epidemic, is now endemic. And I see no reason why this cannot be accomplished before stem cell technology will be a safe and efficacious choice in polio remediation.

Member Professor Eddie Bollenbach <eddie.bollenbach@poliosurvivorsnetwork.org.uk

Hilary write...Do any other members now experience not hearing the first half of a sentence said to them when they are concentrating on another task?

This problem started for me a few years ago but it is getting worse. I am only 63 and I have had my hearing tested and been told that it is down a bit on both sides, normal for age, and nothing to worry about. If I am watching tv, working on the computer, reading a book, in other words concentrating on something and someone in the room speaks to me I do not realise that they are talking to me till they are halfway through the sentence. I can also be in another room in easy hearing distance but where there is some low noise in the room I am in, microwave going, water running. I am getting very frustrated by this and so is Richard. OK there are times when he does not have the energy/air to speak very loudly but this is happening all day long and even when he is sitting in the chair next to me! I have tried two ways of dealing with this. Telling him I have not heard him and pretending that I have heard all he said and making what I hope is the correct 'mm' noise. Neither are really working for us.

I think back to a first class upgrade flight from America about 6 years ago where after the meal I started to feel awful, a panic attack looming fast, and there were five more hours to go! The only way I was able to deal with this was to constantly say in my head the words of nursery rhymes, count backwards from 1000, etc. It was exhausting. I decided that I overloaded on sugar with the delicious desserts, chocolates and 2 free drinks. I never touched another sweet item or alcoholic drink on a flight after that and it did not happen again. I have also noted that if I eat sweet things in the evening that I wake more often with 'brain racing'. I was diagnosed with Type II Diabetes 18 months ago but went on a low glycemic load diet and test results are now normal. So 99% of the time I do not eat high glycemic foods anymore... Oh heck, I have to admit to eating some chocolate last evening so now I realise why I have been up since 5.10 am unable to sleep. Duh!

However, it is the concentrating on one thing to block out another that intrigues me. Is what I am experiencing caused by PPS fatigue issues/another getting old factor/another reason/a combination... Richard just said... I think it is just a female thing! ☺

Management Committee [Trustees] and Operations Team

Management Committee [Trustees]

Chair - Sandra Paget - sandra.paget@poliosurvivorsnetwork.org.uk
Vice Chair - James [Jim] Pullin - jim.pullin@poliosurvivorsnetwork.org.uk
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[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

Friend/Supporter. If you would like to support the Polio Survivors Network you can do so by making a yearly donation of your choice.

You will receive a yearly update of our activities and be invited to our AGM.

Membership Fees

Individual - £ 12.50 per year
Life membership - £ 150.00 or pay by Standing Order £ 5.00 x 30 mo.
Associate Membership - £ 10.00 per year
Yearly fees can be paid by Standing Order.

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.

Donations

giftaid it

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

NEW →

Val Scrivener is supporting us by making photo greetings cards for you to purchase

- 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.
 - UK Taxpayers can Gift Aid their subscription and donated amounts.

The Gift Aid scheme. Charities can reclaim an extra 25% in tax on every eligible donation by a UK taxpayer. Between 6 April 2008 and 5 April 2011, the government will also give UK charities an extra 3% of all eligible donations. 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%).

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<http://www.hydrateforhealth.co.uk/the-hydrant.html>



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