

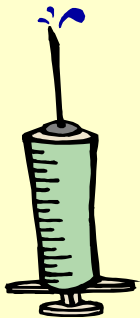
POST POLIO MATTERS

The Polio Survivors Network Newsletter - Volume 7, Issue 10
n.b. Volumes 1 to 6 published under the name LincPIN.
www.poliosurvivorsnetwork.org.uk

**November
2012**

Vol 7, Issue 10

**DON'T
FORGET
YOUR
FLU JAB**



**International Day of Persons with Disabilities,
3 December 2012**

**Theme: Removing barriers to create
an inclusive and accessible society for all**

**POLIO
SURVIVORS
NETWORK
IS A MEMBER
OF**



Published

**Intelligent
Outcomes:**

Applying the health
and social care
reforms to improve
outcomes for
people with
neurological
conditions.

August 2012

www.neural.org.uk



REMINDER

If you are having problems living with Polio, Post Polio Syndrome, including trying to obtain/retain any type of benefit please let us know to add to our knowledge base

NAIDEX NEC BIRMINGHAM

30 Apr - 2 May 2013

Visitor enquiries

Tel: 0844 588 8076

www.naidex.co.uk

MOTABILTY ROADSHOW

27 to 29 June 2013

Telford International
Centre TF3 4JH

Tel: 0845 241 0390

www.motabilityroad
show.co.uk



If you read an article that could interest other members please send it to us.

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New Members and Donations received.

Welcome to New Members

Rita Unger, John Carrass, Susan Kirwan.

Thank you to all members who have recently renewed.

Thank you to the following for donations given towards our work
Dorothy Ives, Jean Simm, Susan Kirwan, Ann Telford,
Joy Witheridge, John Finley, Susan Freeman, Joanne Curtis,
Janet Dobbie, Rosemary Staniforth, Zsuzsanna Snarey,
Victor Gabriel and Water Goodwin.

A total of £ 155.00 since last newsletter.

Total of £749.00 so far this year.

Val Scriveners Card Sales total £ 40.00 this year.

Help our funds by ordering - info on back page.

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

I cannot believe the date, this year has whizzed by. Ellen in Florida has just told us that at last she has been able to turn the air conditioning off and open the windows; we have just put the central heating on; my daughter in Canada showed us photos of their snow and our grandson's new snowsuit and boots ok up to 30 degrees below!!

The Newsletter this time has some information on benefits and the proposed new systems. Wouldn't it be great if they could finalise how things are going to work and keep it like that so we did not have to start all over again ever few years with all the stress it entails.

I had uploaded everything for the front page but for the space where we now have the Crippen cartoon. Chris sent me a link to the cartoon and it really fitted with this issue so I uploaded it. I then had to smile when I read the International Day of Persons with Disabilities theme beneath it.

Crippen - Disabled Cartoonist. See www.crippencartoons.co.uk. We have made a donation to Disabled People Against Cuts [DPAC] for the use of this. This is the third one we have used and the last one he did specially for us.

Also there are ideas from members, things that are making their lives easier. Maybe you have some aids or ways of doing things now you are coping with pps that you could tell us about. It might be something as small as a pen that is easier to hold, or a piece of equipment, or just a way of doing an action. The views are those of the authors and not necessarily PSN's but we hope that you might read something that could help you.

For instance, if you are on the Internet have a look at Knork www.knork.net. We bought a set of four at Naidex a couple of years ago. They are made of good quality stainless steel in one piece. The basic item is a fork with a sharpened tine that you can use as a knife. Great if you need or like just using one item to eat with. They now have a huge selection of items and can be bought from Amazon and Disability shops.

An action that I use to help me sit up to get out of bed. I turn on my side and bending my fingers on both hands link them together in an S shape and then holding my elbows out I can then pivot on my left elbow to sit up.

The back page includes information on another Polio Survivors book. Wendy Wolf who lives in Tucson, Arizona. I learned about this from Micki Minner, Polio Epic.

Why not buy a pack of Val Scriveners photo cards to help us raise funds. I have changed the five pictures on the back page for different ones but there are many more examples to choose from. If you want more information drop her a line or give her a call.

The next newsletter will be printed at the end of January. I have a temporary file that I add anything I find or sent to me. Please help me by sending me items to choose from.

A month before time to compile the newsletter I block off days and hours in my Diary [see pages 17 for a sample plan] and allow two weeks to finalise it. Preferably send info at any time but the deadline for the next issue will be January 15th 2013.

The Trustees have decided to write to you separately with this issue and we have printed it on yellow paper so that you notice it when you open the envelope.

Quality of Life is most important. Hope the ideas in this newsletter will help.

Polio Survivors Network - Meetings

If you have any matters you would like us to discuss 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

Cherish your arms, by Member Anne Wood - 2012

Having been on the slippery slope of PPS for over 20 years, I have figured out various short cuts and tips to cut down on arm usage. I've been jotting things down as I think of them, but so many ways have become second nature to me by now that it takes a bit of head-scratching to think of them all and wonder if everyone does things my way or if I have developed strategic methods peculiar to me.

Losing leg strength is one thing, overcome to a reasonable extent by using a wheelchair and other adaptive equipment, but arms are so precious. Homes can possibly be altered to cope with wheels, but there is no device to take the place of arms and life is incredibly difficult when their use is diminished. I am conscious of my arms at all times, I never over-tax them either with movement or weight.

One of the worst stresses arms undergo is lifting and carrying, and I look back ruefully at the years I spent pushing myself up from chairs and beds as my legs began to weaken. Currently I have 2 perching stools, one in the kitchen and one in the shower, indoor and outdoor power chairs, all set at just the right height for me to get up with minimum use of my arms, and a rare recliner armchair which raises me vertically without tipping me forward. www.chessco.net Contact them at chairs@theliftchaircompany.co.uk

I also have a powered cushion-lift, www.mangar.co.uk/products/cushion tel: 0800 2800 485, which again raises me straight up and I can take this with me when travelling.

My bed, likewise, raises me the same way, as well as having a reclining mode - email tbs@thebedshop.co.uk tel: 0800 9757473.

I don't go *anywhere* if I can't take one of my wheelchairs as, apart from sitting at the right height to get up, I need the armrests and an air cushion in a cheap cotton tote bag at my back to accommodate my scoliosis. The air cushions cost a few pounds in a camping shop or on the internet and I tuck one, half filled, into the tote bag, or other lightweight bag with straps, to keep at my back, supported by the wheelchair handles. The tote bags are also invaluable to carry shopping and I can hook any number on my chair.

Also hanging off the arm of my chair is a tubular pencil case into which I put my small bottle of water, and I keep a Whiz urinal www.whizaway.com in my capacious bag on the back of my chair, used in conjunction with my own one pint plastic screw-top milk bottle with handle. I believe the Whiz can be prescribed by your GP.

I sometimes order bulk groceries from my local superstore via the internet, and I ask the driver to put the bags straight on to the kitchen table. I generally arrange for a friend to help me put them away, but if I'm on my own I put the goods on my kitchen trolley to move them nearer the fridge, cupboards, etc.

I slide heavy pots and pans across the worktops which are in a continuous run along the kitchen walls in an L-shape. I rest the edge of saucepans of cooked vegetables on the sink and slide the contents into a colander. My kettle sits in a tilting stand and I fill it using a plastic jug. I eat in the kitchen and my perching stool is just the right height at the table - I either drag it or "walk" it to the right spot, and I can perch on it to work at the sink with the cupboard underneath open. If a table isn't convenient for a wheelchair or perching stool, try fitting a tray into an open drawer to make a little table for one.

I have a washing "basket" on wheels to carry my laundry and a peg bag on a hanger to hook over the line.

A grabber is invaluable for picking up dropped items and the little magnet on the end is useful. A little piece of double-sided sticky tape on the end is great for picking up small items. It can also reach up to shelves, though things I use on a regular basis I keep lower down. I have a long-

handled dustpan and brush. I rarely iron, but I bought a little travel iron very cheaply and it is extremely lightweight for the odd item needing a press.

I am right-handed and because my left shoulder is paralysed I've greatly over-used my right arm, so I try to use my left arm instead when carrying anything small such as a book or hot water bottle. I tuck it right up into my armpit so the dead weight of the arm keeps it there.

Holding a phone to my ear is impossible for more than a few seconds and I wouldn't manage without my earpiece, or headset, which I keep plugged into my cordless model. I have two so that one is charging while the other is kept in my pocket or clipped on to my waistband. I keep my mobile phone in another pocket. At night I keep the phone and mobile on my bedside table.

Also inseparable from me is my Community Alarm button worn round my neck, which I can press for help in the event of a fall, and which I wear 24 hours a day, even in the shower. My local council supplies this for a small monthly charge.

In the dark evenings I have more than one light on so that when a bulb blows I'm not in total darkness; I have a battery light or torch in most rooms for the odd occasion when there is a power cut.

It took me a long time to work out a comfortable way of using my desktop computer – even the occupational and IT therapists weren't very helpful. I park my indoor wheelchair as near to the desk as the control will allow, then I rest a beanbag tray on the arms of the chair and the desk, put the cordless keyboard on the tray and I use the cordless mouse on the tray in front of the keyboard. The beanbag tray is useful for many activities when one might sit at a table.

I am in love with my Kindle e-reader, as I can lay on my side in bed and hold it with just one hand, turning the pages with minimum movement of my thumb.

All these ideas help make my life a little easier, and I hope some of them will be helpful to you now or in the future.

Editors Note. Computer. Sitting at a desk with weaker arms and painful lumbar region was not working. In the States some years ago I saw the benefits of a recliner chair and having computer on a trolley next to this and a keyboard on a bean bag tray. I am now in my recliner chair with laptop on a laptop tray on my lap. My neck is supported by a neck cushion. My elbows are on the arms of the chair. My left palm is resting on the front of the laptop [it is a wide laptop because I have big hands and need the wider keyboard] and only my fingers move. My right arm swivels from my elbow and does the bits the other hand can't reach. Ipad is great too for night-time reading. Use it same as Anne kindle. No more amitryptaline to reset my time clock when I cant sleep. Few pages and I can drop off again. Plus its great for taking short notes at a meeting.

A CONVENIENCE FOR THE LADIES - Member Anne Wood.

For those ladies who are unable to rise from a public toilet if it is too low, the Whiz Freedom may be the answer to your problems when you are away from home.



It is a female urinal which can either be used to enable you to stand over a toilet and point it at the porcelain, like men do it, or you can turn it round the other way and direct the urine into a pint plastic milk bottle. The bottle can then be emptied and rinsed, or you can put the screw lid on and take it away with you for disposal.

I believe they are available on prescription, or you can order one online at www.amazon.co.uk/ and type in Freedom Purple who make this version, or order one from a chemist. [4 versions shown maximum £12.00]

Editors note:- Stuck in a traffic jam!! this is not the time to try this for the first time. Practice the different body positions you might need to use this in in the shower is really helpful.

Falls - Some information that might help you in the future.

By Hilary Boone.

Richard and I had enjoyed 17 and 7 years respectively re-enacting the early 1800 pioneer times in America. In 2008 we decided to live permanently in the UK and as we couldn't find a UK group sold our tent and fire. Our clothes and the rest of accessories we shipped back to the UK hoping that we might be able to wear them at an event or two.

Earlier this year we found the British Westerners Association who meet for three days three times a year in Lincolnshire. We contacted them and they said 'everyone is welcome so come to our next camp', it's behind a motel where you can stay if you want. We arrived and booked into the motel and got our gear on and were soon wheeling our way towards their camp. We had a brilliant time and went to the Saturday night event including a country/rock and roll group. However pacing and resting meant back to the motel room each time and missing out a lot on the life we had enjoyed for years. Motel and restaurant food costs would restrict the number of days.

We decided to join and wished we could camp again and so stay for four days instead of two. When we told Richards PA about the weekend he said 'If you want to camp I would be happy to work the hours necessary.' Our eyes lit up could we increase our social life and have more great memories like our earlier years? We contacted the BWA and found there was an electric hook up in the Re-enactors area to charge our wheels and run Richards ventilator. We could cope if we had proper beds and we found a company that could make us some bed frames that took apart like they used to use in those times. We then found a company that sold off the tents that they used for films/events when they were nearly coming up to being replaced to re-enactors.

We decided the social outings and memories would far outweigh the 'managing camping' and we wouldn't mind having a few days once home doing nothing much to catch up on energy. You only live once and we are only in our early 60's and this would be great medicine for us both.

We bought a second hand white wall tent in time for Americana International [a 4 day event in Newark in July] where we had a brilliant time with great music on five stages. Loads of American cars, trucks, food, and re-enactors. <http://www.americana-international.co.uk/>

Two months later we set off for the BWA Autumn weekend. We had a brilliant time being with folks who loved depicting the American West from 1750 to present day. Because we only had to ride 75 yards we had the energy to go out at night to both Friday and Saturday night events. Great music and loads of laughter. At last we were having a social life again.

Sunday. Time to pack up and go back home. Our PA soon had the beds apart and stuff outside the tent to load into the trailer. Because I still find it hard to do nothing - despite being told to rest he was happy to do it all - I loaded a few bits, resting in the car for a few minutes each trip. Stupidly I decided to demonstrate how to fold the tent from one side which meant I was on my legs, using my arms and breathing. I realised I had to sit again but only managed four steps before my legs gave way and down I went. Having done Judo in my earlier life I tried a judo roll hit my left shoulder on the ground with my legs going right over the top. My shoulder hurt so much I thought I had broken or dislocated it. I sat holding my arm close to me till I felt ready, with a lot of help, to get up off the grass and into the car. We were soon on our way to A&E but I am sad to say that the health professionals knowledge of polio and pps was minimal; there was no understanding of the difficulties I would have coping with one arm out of action. I have been advised that formal complaints have to be recorded and I might get better results from doing this.

Where part of the body cannot be used as normal, PSN advise polio survivors to practice with that part out of action for as long as possible prior to the operation. Having such a hard time over the last eight weeks I believe it is imperative that we do this NOW because it is much harder to work it out when in pain. I had to modify getting in and out of recliner chair/electric bed/car and up and down off the loo etc. Not only did I have the pain of the 'partial' dislocation of my

acromioclavicular joint to cope with but also the pain caused by the strain of having to use muscles in my right arm and side of my body in a different way. On top of this the only way I can sleep is on my left side and the pain in my left shoulder meant sleeping sitting up for 3 weeks.

I saw our Chiropractor who treated me and also strapped my shoulder with balance tape to support it. I took the tape off to have a bath the day before seeing him next time and could see how much the taping was helping me. I have been four times and it has been a great help. Here is the information on the tape from the Chiropractors website.

Newland Chiropractic Clinic, Lincoln. - www.newlandchiropractic.co.uk

BALANCE AND KINESIO TAPE.

Balance tape unlike conventional taping methods has an elastic quality to it. It is increasingly used in the field of sports medicine/ injuries, and more athletes, footballers, tennis players, cyclists can be seen on TV wearing it while competing.

What does it help?

Research is at an early stage, it is only in the last 2-3 years that any controlled trials have emerged and currently these are not robust enough to claim Taping as an effective sole treatment for any conditions.

How does it work?

It can be applied in various ways which can serve to:

- Take pressure off painful areas, this reduces the tension through weak or inflamed muscles and tendons reducing the pain and further damage caused if the patient has to continue to use the joints, for work, day to day activities etc.
- Relax muscles, depending how it is applied the tape is thought to activate stretch receptors in the skin which feed back to influence the control of the muscle tension under the skin or activate muscle spindles within the muscle which would increase the activity and endurance of the muscle.
- Promote blood and lymphatic. When applied to the skin with stretch the elastic tape naturally wants to recoil, lift skin and fascia to allow blood and lymph flow to increase which is thought to speed up the healing process.

While wearing the tape movement of the joint/region is not restricted and therefore allows the wearer to continue to use the affected joint during the recovery period.

We use this tape on both amateur and professional sports men and women, on adolescents with poor posture, various postural pain syndromes and to protect inflamed muscles and tendons.

Research

1. Thelen et.al. The clinical efficacy of kinesio tape for shoulder pain: A randomised, double-blinded, clinical trial. *Journal of orthopaedic and sports physical therapy* 2008, Vol 38, No. 7.
2. Hsu et.al. The effects of taping on scapular kinematics and muscle performance in baseball players with shoulder impingement syndrome.. *Journal of electromyography and kinesiology.* 2009 Dec, 19 (6) 1092-9
3. Aspegren et.al. (2007) Conservative treatment of a female collegiate volleyball player with costochondritis. *Journal of manipulative and physiological therapeutics,* 2007 May;30(4), 321-5
4. Chen et.al. Effects of kinesio taping on the timing and ratio of vastus medialis obliquus and vastus lateralis muscle for person with patellofemoral pain, Department of Sports Medicine, China Medical University.
5. Tsai et.al. (2009) Could kinesio tape replace the bandage in decongestive lymphatic therapy for breast-cancer-related lymphedema? A pilot study. *Support Care Cancer,* 2009 Nov;17(11),1353-60

More information on how the tape has been helping Richard and I overleaf.

Balance Tape on my back along my lower ribs. [From previous page]

About three months ago our Chiropractor started trying some balance tape on my back on my lower ribs to see if it would help my hypoventilation [shallow breathing] issues. The tape is cut to about six inches in length and the corners rounded off. The tape is then stuck next to my spine and stretched and angled down along my lower ribs and stuck down. [see info at bottom of page]



So how is this helping me? Two mornings later I got up and walked from bedroom to lounge and was a bit stunned because I could see the paintings on the wall. I realised that my body position was much straighter than normal. Instead of mostly breathing shallowly at the top of my lungs [physio reported mostly upper chest breathes in 2004] I was able to breathe lower down and deeper when sitting.

Following my fall in 1988 and the start of my new problems I had quite a few falls. Later when I learned more about PPS I remembered that every time I could find nothing that I could have tripped over.. but realised that I had been carrying boxes. Was my brain telling my leg muscles sorry cant help you walk any more I only have energy to help her arms so she does not drop the boxes? My legs were just giving way. Since then I have repeatedly raised with health professionals that because my muscles are now weaker that 'they' cannot sustain actions for as long. Trying to do more than one action at once drains them even more. Have you held your breath to complete an action, e.g. To climb a few stairs, lift something for longer than normal?

I noticed after about ten steps my body position started to bend forward again and if I started to use my arms this increased and if I pushed myself was soon back to as bent as before. Resting and return to being straighter again. Bent forward your chest area to breathe is reduced. Sadly so far the only person to take this on board had been my Chiropractor till a few months ago when our new Respiratory Physiologist referred me to the Consultant to discuss further.

Most surprising to me was when at home, where I only wear thick socks and no AFO for my dropped foot, that I was not having to lift my right leg as high. My gait had improved and whilst I cant heel and toe I can almost put my foot down flat. The chiropractor explained that this was most probably due to the better body position. He has now written to my health professionals to ask that further testing takes place so that the changes I am reporting can be assessed and reported on by them as well. In case the information might help your health professionals help you now he has given permission for me to print part of the text of his letter below.

To help our skin breathe we have found using two positions, one above the other, four days on, a day off and then four days on the alternate position works best for me.

Excerpt from Chiropractors letter to Hilary's health professionals.

I have applied the tape over Richard and Hilary's ribs and intercostals muscles. I was attempting to promote inhalation and decided to apply it from erector spinea adjacent to L1, diagonally laterally and superiorly, perpendicular to the ribs up to about 7th rib with tape under tension. It seems to have had a greater effect on Hilary. She has been more upright since having the tape applied and I assume this is because the tape is facilitating the internal intercostals muscles, aiding expiration but also facilitating thoraco-lumbar extension to enhance the lordosis during inspiration, aiding the diaphragmatic drop and enhancing lung capacity.

The available research can be found here:-
www.kinesiotaping.com/global/association/research/

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Member Zsuzsanna Snarey writes...

I would like to share with you a good idea that my daughter had. She noticed that I use a stool in the kitchen to prepare food and wash up but when I used the same stool to sit at the kitchen table it was the wrong height. So for my birthday my daughters bought me a hairdresser's stool from www.the-salon.net. It is a backless gas lift stool that adjusts from 41 to 58 cm high and is on castors so that I can scoot from cooker to sink to fridge or table to serve food.

It costs £42.95 free delivery and it arrived in two days. it is a bit like a computer chair but with stylish chrome legs and rolls very smoothly. I have to be careful that I don't miss it when I sit down and have to use the worktop to stand up. I find it a great help and it is very easy to lift me up from 41 to 58 cm.



Hilary writes... I use a computer chair in the kitchen if there is no help to put the shopping away. Having ended up on the floor because the chair shoot backwards and hit the fridge 8 years ago. I now always back the chair to the wall or work surface so that it cannot shoot backwards as I push myself up on my arms to stand.

POLIO SURVIVORS NETWORK

'WHAT YOU NEED TO KNOW ABOUT MY CONDITION'

We have included a copy with this Newsletter and advise how helpful this has been when we have had an accident to hand over to ambulance men/ A&E, other health professionals. You need to update this if your medicines or abilities change. We also have a copy with us when we see new health professionals and offer this. Some take it some don't. Available online.

Would you like to be put in touch with other members/carers/family/friends who have similar issues and/or hobbies to yourself?

- We have members who have PPS and Parkinsons or Cancer.
- We have at least six members who use a bi-level ventilator at night.
- We have at least four members who live in a Residential Home.
- We have at least eight members who have a Personal Budget from Social services to help them employ personal assistants and purchase equipment that is not available from the NHS to help them manage their lives.
- Maybe you are a Carer, Sibling or Child of a Polio Survivor?
- If you have a computer and have or can download Skype [which is free and free to hold video phone calls with other people on skype around the world] Would you like to meet others for a chat or if new to this have another member show you online how to use it?

If you are interested in telling others about your hobbies or specific issues that you would like to share information with other members then please drop us a line, email or ring.

An older gentleman was on the operating table awaiting surgery and he insisted that his son, a renowned surgeon, perform the operation. As he was about to get the anaesthesia, he asked to speak to his son.

"Yes, Dad, what is it?"

"Don't be nervous son; do your best, and just remember, if it doesn't go well, if something happens to me, your mother is going to come and live with you and your wife....."

All You Need Is A Web Browser To Read POST POLIO NEWS [ppn]

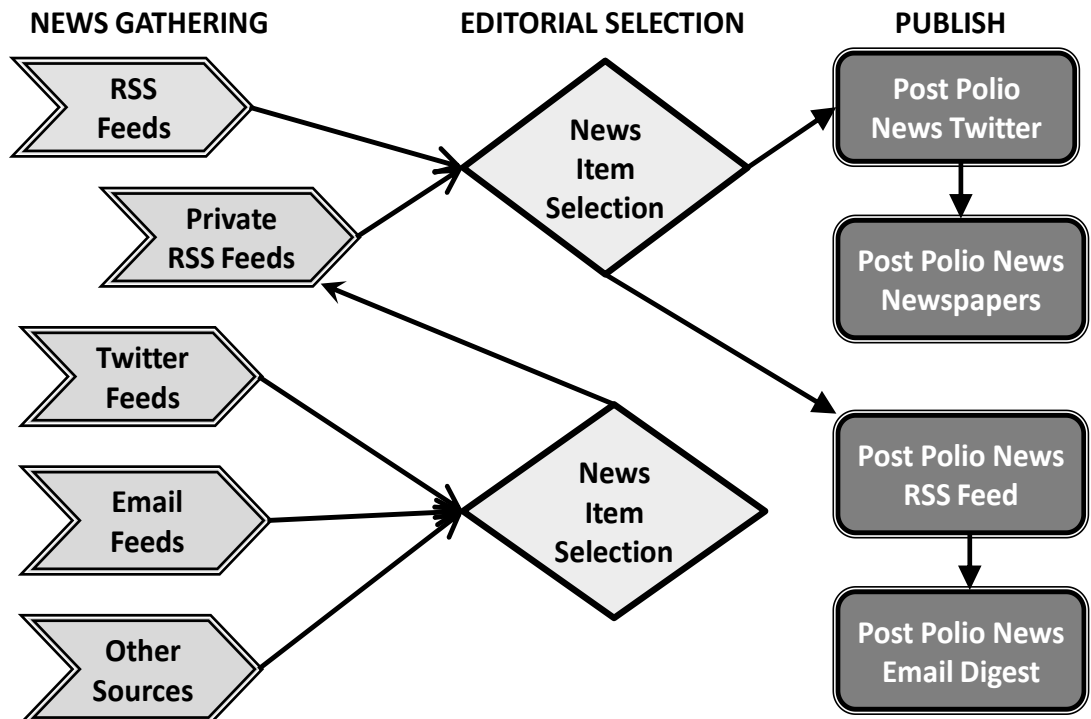
Twitter, Newspaper and RSS feed can all be browsed without requiring extra tools or subscriptions.

Go to www.post-polio.org.uk/ and check out the "Tips".

POST POLIO NEWS

An online news cutting service that specialises in news relating to polio and post polio issues

POST-POLIO NEWS INFORMATION FLOW



My Speech at October 20th 2012 Rally 'A Future that Works' by Sue Marsh.

Originally published in "Diary of a Benefit Scrounger", 21 Oct 2012

<http://diaryofabenefitscrounger.blogspot.co.uk/2012/10/my-speech-at-oct20-rally.html>

As most of you will know, I spoke at the October 20th Rally in Hyde Park yesterday.

I've been ridiculously ill and am waiting to go back into hospital for yet more surgery. For weeks, all I've really done is stay in bed being sick and writhing about, or attend bizarrely important stuff. I don't know if I can sum up how very odd that is.

My amazing GP allows me the meds I need to get through it all and I get unsteadily to my feet, pull on a frock, paint my puffy, tired face with an inch of make up and somehow transform into confident, insistent campaigner.

Yesterday, my twitter account was never quiet as hundreds of you thanked me, but it's an enormous privilege. It really is.

The life that so often seeps away from me has so much purpose. Every single time one of you tells me it gives you hope, it gives ME hope. The talents that sat dusty in my mind can be used for a great good and that is a truly amazing thing. I'm privileged that you let me be your voice and that others have been so generous in facilitating that.

To that end, a HUGE thank you to Brendan Barber for asking me to speak and to the TUC generally for supporting our campaign at many events and conferences now.

So, here's the video of my speech yesterday, and a transcript.

Another HUGE thank you to James Albury (@alburyj) for recording it and to Steve Sumpter (@latentexistence) for posting it to youtube for us.

<http://www.youtube.com/watch?v=eN-u-zeMlZE&feature=youtube>

Begin Transcript.

Friends, every last one of you that marched today believe in one thing above any other. Justice. You couldn't sit at home while injustice and exploitation are closing in on us wherever we look.

You are the faces, here, today, of so many millions more who are shocked and frightened by the careless way this coalition of clowns are ripping our communities apart.

But there is a casual cruelty taking place that is so inhumane, so calculating, right now, here, in the UK in 2012, that it shames us all.

When you get home tonight, home to every corner of our nation, tired but exhilarated, weary but filled with pride – When you see the vast, defiant crowd, speaking with one voice, I beg you, to remember this :

For every one of you who marched today, a seriously ill or disabled person will lose the Disability Living Allowance they rely on to live with dignity and a little security.

This parliament of fools use numbers lightly. They count their losses in billions, their debt, in trillions, those thrown on the scrapheap of their incompetent policies in millions.

But THIS - this here, today - is what half a million people look like.

But there's more :

A million more - TWICE as many as you marching here today - will be "reassessed" by the French IT company, Atos as fit for work. Their only income ripped away on the hunch of a few millionaires. Every single "report" or "committee" or "enquiry" into Work Capability Assessments have found them "Unfit for purpose".

Coroner's are reporting this "reform terror" as cause of deaths. Doctors demand WCAs are withdrawn immediately. Appeal tribunals warn that they are swamped to crisis point and beyond.

Hundreds of thousands of profoundly disabled children will see their support cut by an impossible 50% while Osborne's "Bullingdon Budget" gave millionaires £40,000 extra. Each.

The Independent Living Fund – Scrapped.

Severe Disability Premiums – Scrapped.

Social Care packages - slashed.

They are not numbers Mr Cameron, they are LIVES!

They are *our* mothers; *our* brothers; *our* daughters and sons.

Disease or Disability can strike any *one*, at any *time*.

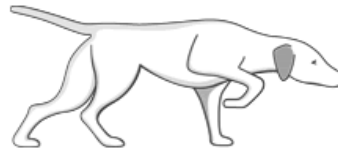
We are the sick and disabled people of the UK, so under threat are urgently crying for help against the wind, like a drowning man.

And so, I'd like to leave you with the words of Edmund Burke :

**"Justice will NOT be served until those who are unaffected
are as outraged as those who are."**

PLEASE, STAND WITH US, SPEAK OUT WITH US, WE NEED YOU.

**PLEASE get outraged, because sick and disabled people in the UK
need you as never before.**



The benefits of subscribing to **BENEFITS AND WORK.**

Have you had enough of struggling to get what you're entitled to from an impossibly complex, confusing and unfair benefits system? Of not knowing what lies behind all those questions, forms and medical examinations?

Subscribe to Benefits and Work and you'll instantly put an end to the misery of not knowing: not knowing what you need to write in the hundreds of boxes in that claim pack; not knowing what's going to happen at your medical; not knowing how best to prepare for an appeal.

Subscribe right now and you'll instantly get a full year's unlimited access to all our renowned guides to:

- **Disability Living Allowance**
- **Employment and Support Allowance**

and more and to all the DWP materials we've obtained using the Freedom of Information Act.

You also get unlimited access to all our members only news stories and the chance to share worries, get support and make friends in our members only forum.

What are the limits on what I can use?

You can visit and download everything you need as often as you need for a full year.

All we ask is that you only use the resources for yourself or the person you're providing care for. If you want to use the guides in the course of your work then please join as a professional.

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Register online:- <http://www.benefitsandwork.co.uk/component/juser/register>

Email: - office@benefitsandwork.co.uk [NB Initial contact by email or letter, address below]]

If you are not on the Internet the guides are available for purchase.

ESA Guides Pack. £ 9.95

A set of 4 detailed guides to take you all the way through the Employment and Support Allowance (ESA) claims, medicals and appeals process.

DLA Guides Pack £ 9.95

A set of 4 detailed guides to take you all the way through the Disability Living Allowance (DLA) claims, medicals and appeals process.

Write enclosing a cheque or postal order to:-

Benefits & Work Publishing Ltd, PO Box 4352, WARMINSTER, BA12 2AF

Members please let us know what you think about the Guardian item overleaf:-

If you don't have internet access or have internet access but only use a little of the services that are available and would have difficulty applying for benefits etc online because of financial cost and/or too stressful trying to learn all that is necessary and trying would be detrimental to your health/or other reason..

Just 19 doctors for over a million PIP assessments

Benefits and Work can reveal that Atos will use just 19 doctors to carry out personal independence payment (PIP) medical assessments in most of England and all of Scotland from April next year, according to bid documents lodged in the House of Commons library. The doctors will be outnumbered fifty to one by, mostly private sector, physiotherapists.

We can also disclose that campaigning charity Disability Rights UK is to be one of the subcontractors helping Capita to carry out the PIP assessments that will spell the end of working age DLA and a severe loss of income for around half a million disabled claimants.

Plus, we give you the first glimpse of how different your medical will be depending on where you live in the UK.

PHYSIOS OUTNUMBER DOCTORS 50 TO 1

It is believed that Atos will have to assess well over a million claimants for PIP – some on paper only - of whom at least a quarter are likely to have mental health conditions or learning difficulties. Yet the majority of the health professionals involved will be private sector physiotherapists with limited knowledge or experience of dealing with these conditions.

Figures in the bid documents reveal that Atos will use 433 physiotherapists, 173 nurses, 35 occupational therapists and 9 doctors in London and Southern England. Just 19% of the service will be provided by NHS staff, whilst private sector company Premex will provide 30% and The Injury Care Clinics will provide 15%.

In Scotland and Northern England, Atos plan to use 500 physiotherapists, 200 nurses, 40 occupational therapists and 10 doctors. The NHS will provide 36% of the service.

Atos say that this mix of health professionals was based on a number of considerations, including the “cost differentials between the types of HPs [health professionals]” and “the desire for this work” amongst different types of health professionals. There is no mention of how many, if any, of the nurses will be specialist mental health nurses.

From The Guardian Social Care Network - Tuesday 16th October 2012.

Why digital exclusion is a social care issue

As our society becomes increasingly digitalised, figures reveal a large proportion of those not online have a disability or are elderly

Next year the welfare system will undergo an overhaul as universal credit is introduced. The benefit, replacing six others, includes a new requirement to apply for benefits online. With millions of people having never used the internet, however, it raises the question of how those not online will manage.

Universal credit is just one example of how, as our society becomes increasingly digitalised, those who are not online are at risk of becoming excluded. And it's not just a case of people opting not to be online.

This year there were 3.91 million disabled adults who had never used the internet, according to figures from the Office for National Statistics. This is just under half of the 7.82 million adults who had never used the internet. Ian Lyons, from the Shaw Trust, which supports disabled and disadvantaged people live more independently, says many websites are not accessible for people with a disability.

<http://www.guardian.co.uk/social-care-network/2012/oct/16/digital-exclusion-social-care>

See note in block on previous page.

The Respite Association was born on May 16th 2001 by a group of people all with first hand experience of the stress put on carers.



When you are caring for someone the task can be overwhelming. You can be on 'duty' 24 hours a day for seven days a week with no breaks or holidays. This is too much to ask of anyone.

We provide short term assistance in funding of appropriately qualified respite care for disabled, sick, elderly or terminally ill persons in order that their regular carer, whose income is limited, can be allowed to take a much needed break.

Whilst providing suitably qualified carers in the home or funding a temporary place in a residential care centre can be expensive, the benefits to a carer are beyond measure. The cost and level of support varies dramatically from a few pounds to several hundred with an average around £400.

NEW 'FREE HOLIDAY' SCHEME LAUNCHED.

We are delighted to announce the launch of our 'FREE HOLIDAY' scheme for Carers.

Thanks to the help of the staff of Messrs. T-Systems Ltd, Bakkavor Ltd., and a donation from the Drapers Foundation we have been able to purchase a super static caravan sited at the Richmond Holiday Centre in Skegness on the Lincolnshire coast.

The caravan will be offered to suitable Carers 'FREE OF CHARGE' for breaks of a week (or long weekend) and the holiday will include access to the excellent facilities and entertainment programme of the Holiday Centre, all Carers will need to pay for is their food.

Examples (not a comprehensive list) of Carers who may qualify for a 'FREE HOLIDAY' will include:-

Parents with a disabled child who is going to a summer camp leaving the parents with a chance to have a holiday on their own or perhaps with another (non disabled) child so he/she can have some quality time with mum and dad.

Adult carers who look after a spouse or elderly parent who can be cared for elsewhere whilst the usual Carer(s) have a break.

In very special cases we may allow an adult Carer to go with the adult they care for.

The caravan is equipped with a TV/DVD player, microwave, cooker, fridge/freezer, crockery/utensils/pans/glasses, hair dryer, vac, iron & ironing board, heater, books, DVD's table and chairs for veranda.

Sleeping accommodation is one double and two single beds. Please note this accommodation is for Carers so is **NOT DISABLED ADAPTED.**

Application forms can be downloaded from our website www.respiteassociation.org

HOW YOU CAN HELP US TO HELP CARERS.

It is a terrific challenge for our two staff to raise all the funds needed to continue to run the Charity and without some help from others we will struggle to meet the demands being made on us. Asking local organisations to make us a beneficiary of an event, holding a coffee morning, donating funds, etc. At this time it looks as if our income for 2012 may be around 20% down on last year.

The Respite Association, 102 High Road, Moulton, Nr Spalding, Lincs, PE12 6PD

Telephone: (01406) 373163

E-Mail: help@respiteassociation.org

PLACES TO VISIT that offer good access and information.

The Eden Project in Cornwall Ten top reasons to visit.

1. the world's largest rainforest in captivity with steamy jungles and waterfalls
2. cutting-edge architecture and buildings
3. stunning garden displays all year round
4. world-class sculpture and art
5. evening gigs, concerts and an ice rink in the winter
6. educational centre and demonstrations to inspire all ages
7. brilliant local, fairly traded food in the restaurants and cafes
8. a rainforest lookout that takes you above the treetops
9. living example of regeneration and sustainable living
10. free land train pulled by a tractor.

From the Access Guide. www.edenproject.com/access-guide

Volunteers. The Eden Project offers a scheme for people who experience mobility or sensory impairments. They have an excellent team of volunteers to assist visitors around the project. There is no charge for this service. In order to ensure that there is a volunteer available please book by telephone on (01726) 818895 before your visit. When on site a member of staff is always close at hand to offer you all/any assistance required.

Assistance dogs are welcome at Eden and water is available for them around the site. We do not allow other dogs into the Eden Project.

Carers - if you have a carer to help you there is no admission charge for them.

Mobility vehicles. We welcome all types of mobility vehicles and we also have a number of manual wheelchairs (approx 40) which are free of charge and available to borrow on a first come first served basis *booking isn't necessary for the manual chairs* These chairs are stored in the disabled parking areas Apple 1 & 2.

We have a very small number of powered chairs which are available to book in advance (we recommend one months notice to avoid disappointment). If you would like to book a powered chair please call 01726 818895 during office hours (Mon-Fri 9-5.30, Sat & Sun 10-6)

Eden Project, Bodelva, St Austell, Cornwall, PL24 2SG, UK.

Book online save 15%.

No access to the internet, ring 01726 811911.

MEMBERS PLEASE TELL US ABOUT GOOD PLACES YOU HAVE BEEN TO.

Important changes to Employment Law The National Minimum Wage October 2012

	NEW RATE	NO CHANGE
Apprentices	£ 2.65 per hour	
16 to 17 year olds		£ 3.68 per hour
18 to 20 year olds		£ 4.98 per hour
21 and over.	£ 6.19 per hour	

ENERGY TOKENS and PACING & RESTING by Hilary Boone.

Each polio survivor has 10 energy tokens per day, 70 per week. Change tokens into money and you have £70.00 to spend on energy for the week ahead. Unfortunately the only person who can work out how much of each activity you can do for each coin is you. Take an average day for you and write down the activities for that day. You have 10p's, 20p's, 50p's and £1.00 coins. It will take a bit of juggling around to work out how you spend your £10.00 but it is worth it.

You can now start to plan ahead. Make up a chart on the lines of the example opposite. N.B. This does not contain enough information it is just to give you the basic idea, I have shown how some days you might need to spend more than £10 so this will leave less for the days either side.

First fill in what you have to do. Getting up and going to bed, dressing and undressing, washing, whatever you need to do to eat, these all have to go in first. Then add in the important things for this week, i.e. medical appointment, bank visit, family event. Now add in resting time. You will then see what time is left for other things, things that you would love to do. Not enough energy to do all you want to do? Now you see this laid out you might find like many of us have that you could have saved some coins if you had used an aid/piece of equipment/asked someone to do something for you. Saving energy to use it doing something you would prefer to do far outweighs how you feel about using an aid that you have fought not to use or asking someone for help. What is important is your quality of life.

If you have said 'I am not there yet' then I will tell you that nearly every polio survivor reading this will have said the same at some time, me included. Within 18 months of finding PPS existed and starting all the research I was at a Rehabilitation appointment when the Registrar told me I should be doing some of this and I said this. He said 'How can you possibly tell others that this is what they should do if you don't accept that you are there now and have been for some time?' Also ask yourself have you tried some new equipment and wished you had started using it months earlier. Most of us have, and being honest I still do the 'not yet' at times and later wonder why.

Taking the appointment which includes tests and seeing a Consultant. Find out how long the appointment is likely to take. How far from the car park. Get out your prescriptions/bottle ready for urine sample/aids/etc out the day before. Extract some information out of your file on you for this appt and write it up on one sheet of paper. Basic info on you, answers to questions you might be asked, questions you want to ask. [Your file - 'My Polio Life' copies of letters, test results, pictures during your polio life showing ability] Copy for health professional could be offered but don't be offended if they refuse it. A member told us the doctor threw her medical article in the bin but when she asked the nurse to get it back for her it was no longer in the bin. N.B. If the health professional you are seeing has been taught only a few facts about polio, maybe nothing about PPS then it could be difficult for them when they realise you may know more than they do.

Think about the tests/examination and what would be the best clothes to wear. If any of this is difficult take someone with you to help so you don't get overtired. Now normally we would have had a bath on the day but this is energy sapping so have the bath the night before and only wash the bits they are going to look at the next morning. ☺

If you would normally drive and get your own wheels in and out the car why not get someone to do this for you. It will save energy and most probably less sweat and frustration. Ensure that you arrive in plenty of time to find or your driver to find that elusive disabled car parking space, get to the appointment, via the toilet if necessary, and give you a few minutes to relax in the waiting room to collect your thoughts.

Having someone with you that you have already discussed how you want them to be involved, remind you by prior agreement if you have forgotten anything, provide confirmation of what was said, is helpful. I did not take anyone at a recent hospital appointment in the Fracture Clinic and so do not have confirmation that the Doctor said 'I see you had polio, which leg did you get it in?' [Colleges of Medicine please teach just a few more facts about polio and pps]

Time	Thu	Fri	SAT	SUN
7 to 9	Up wash	Up wash	Up wash	Late morn
9 to 11	Items for hosp appt.	Rest	Lazy morning	Dressed and rest.
11 to 1	Lazy day	Driven to hosp appt.	Local shop	Driven to
1 to 3		Hosp -tests	Rest	Family lunch
3 to 5		Consultant Driven home	Items for Sunday	Rest
5 to 7		Rest	Rest	Family tea
7 to 9	Bath	Rest	Rest	Driven home
9 to 11	Bed at 10	Bed at 10	Bed at 9	Bed at 9
Token Total	£ 7.00	£ 15.00	£ 8.00	£ 14.00

ACTIVITY BEFORE AND AFTER CHANGE	Total time.	Time Doing	Time Resting	Pain Level	Fatigue Level
Getting up, showering and dressing	8.00 - 10.00	30 mins	90 mins	3	5
Changed to showering Underwear and calipers Top Clothes <i>Time resting SAVED Pain and fatigue DOWN</i>	8.00 - 9.00	15 10 5 30 mins	10 10 10 30 mins 1 HOUR SAVED	2 ↓	3 ↓
Doing the Town Centre using electric scooter, walking only where necessary, bags carried on scooter.	11.00 - 2.30	3 hours 30 mins		2	4
Walking round using cane. One shop rest, another shop and lunch one more shop, Taxi as exhausted <i>Time doing REDUCED Time resting INCREASED Pain and fatigue UP</i>	11.00 - 2.30	10 10 10 30 mins	15 60 105 3 Hours	4 ↑	7 ↑

Now for something completely different.

A letter home from a Redneck Recruit in the US Marine Corps.

USMC Training Camp,
Parris Island, South Carolina.

Dear Ma and Pa,

I am well, hope you are. Tell Brother Walt and Brother Elmer the Marine Corps beats working for old man Minch by a mile. Tell them to join up quick before all of the places are filled.

I was restless at first because you get to stay in bed till nearly 6. a.m. But I am getting so I like to sleep late. Tell Walt and Elmer all you do before breakfast is smooth your cot, and shine some things. No hogs to slop, feed to pitch, mash to mix, wood to split, fire to lay..., practically nothing.

Men got to shave but it is not so bad, there's hot water.

Breakfast is strong on trimmings like fruit juice, cereal, eggs bacon, etc., but kind of weak on chops, potatoes, ham, steak, fried eggplant, pie and other regular food, but tell Walt and Elmer you can always sit by the two city boys that live on coffee. Their food, plus yours, holds you until noon when you get fed again. It's no wonder these city boys can't walk as much.

We go on 'route marches' which the Platoon Sergeant says are long walks to harden us. If he thinks so, it's not my place to tell him different. A 'route march' is about as far as to our mailbox at home. Then the city boys get sore feet and we all ride back in trucks.

The sergeant is like a school teacher. He nags a lot. The Captain is like the school board. Majors and Colonels just ride around and frown. They don't bother you none.

This next will kill Walt and Elmer with laughing. I keep getting medals for shooting. I don't know why. The bulls-eye is near as big as a chipmunk head and don't move, and it ain't shooting at you like the Higgett boys at home. All you got to do is lie there all comfortable and hit it. You don't even load your own cartridges, they come in boxes.

Then we have what they call hand-to-hand combat training. You get to wrestle with them city boys. I have to be real careful though, they break real easy. It ain't like fighting with that ole bull at home. I'm about the best they got in this except for that Tug Jordan from over in Silver Lake. I only beat him once. He joined up at the same time as me, but I'm only 5'6" and 130 pounds and he is 6'8" and near 300 pounds dry.

Be sure to tell Walt and Elmer to hurry and join before other fellers get into this set up and come stampeding in.

Your loving daughter,

Alice.

Your Newsletter needs your stories, hints, tips and bits to make us laugh..

A way of doing something, or aid, that helps you might help someone else. Tell us.

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

CARERS - Are you a Carer and would like to write and tell us how we might help Carers understand what you go through helping us manage our lives.

Articles and items for Post Polio Matters
are always welcome, by post, by email and by phone if writing is not easy for you.

Deadline date for next issue is January 15th 2013

Management Committee [Trustees] and Operations Team

Management Committee [Trustees]

Chair - Position Vacant

Secretary - Hilary Boone - hilary.boone@poliosurvivorsnetwork.org.uk

Treasurer - Gillian Bryan - gillian.bryan@poliosurvivorsnetwork.org.uk

Trustee - Chris Salter - chris.salter@post-polio.org.uk

Operations Team

Membership Secretary - Gillian Bryan - membership@poliosurvivorsnetwork.org.uk

Phone and Email Enquiries - Hilary Boone - info@poliosurvivorsnetwork.org.uk -

Administrative Support - Gillian Bryan - gillian.bryan@poliosurvivorsnetwork.org.uk

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

Membership Fees

UK Individual - £ 12.50 per year

Yearly fees can be paid by Standing Order.

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

Associate Membership - £ 10.00 per year

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.

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.
 - 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. 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

Registered Charity No. 1064177

Website - www.poliosurvivorsnetwork.org.uk

Email - info@poliosurvivorsnetwork.org.uk

P.O. Box 954, Lincoln, LN5 5ER, U.K.

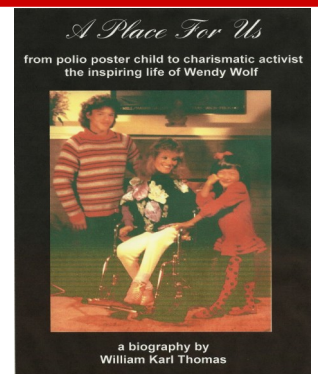


☎ 01522 888601

POST POLIO MATTERS because **WE'RE STILL HERE!**

"A Place For Us" by Polio Epic's own Wendy Wolf - Tucson, Arizona.

From polio poster child to charismatic activist, read about the inspiring life of Wendy Wolf. This is an inspiring story of interest to every person with a disability, their family, their caregivers, and their friends, and in plenty of time to inspire gift giving during the holidays. Media Maestro - Book Division is proud to release this hardcover biography of Wendy Wolf. The book is available through any bookstore by its ISBN number and from Amazon.com and BarnesAndNoble.com very soon.



Wendy Wolf entered an iron lung at the age of four and emerged a polio survivor whose life illustrates the challenges of opportunity and acceptance people with disabilities face and the triumphs and successes this extraordinary woman achieved. Though she came close to death, she survived the iron lung and 7 subsequent surgeries, ultimately suffering almost total loss of use of all four limbs. She went on to earn 3 degrees, improve the lives of hundreds of children through her services as a Speech Therapist in New York and Mexico and Arizona, founded the first Independent Living Center in Arizona, found a unique introductory service for people with disabilities, raised two foreign born special needs children largely as a single parent, advocated for many issues to improve the lives of people with disabilities, and become Ms. Wheelchair Arizona 2006 and, at the Ms. Wheelchair America 2007 Pageant, won the Nicki Arde award for her lifelong history of advocacy.

To learn more about Wendy Wolf, visit her LIFE website: www.LovelsForEveryone.com

Read an excerpt from this book. This book may be ordered from any bookseller by its ISBN #978-0-9799477-2-8, or from the publisher, MediaMaestro.net.



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