



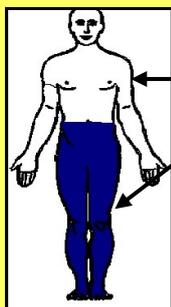
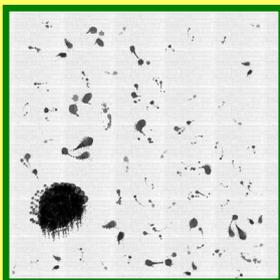
POST POLIO MATTERS

The Polio Survivors Network Newsletter - Volume 7, Issue 11
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www.poliosurvivorsnetwork.org.uk

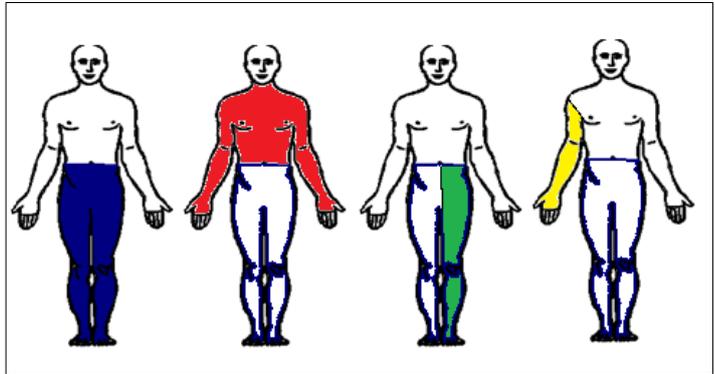
February
2013
Vol 7, Issue 11

COLLEGES
of
MEDICINE

PLEASE
teach
students
more facts
about
POLIO/PPS
Thank you



NOT
ONLY
BUT
ALSO



“I was paralysed waist down”
“I am an upside down polio survivor”
“I only had polio in my left leg”
“Only my right arm was paralysed”

In 1875 - Four case histories were reported in French literature by Carriere, Raymond, Cornhill and Lepine.

These patients, all young men, had paralytic polio in infancy and developed new weakness

NOT ONLY in previously affected muscles
BUT ALSO in muscles believed to be uninvolved

All had physically demanding jobs and performed repetitive activities.
Post-Polio Syndrome : Pathophysiology and Clinical Management, A.C. Gawne & L.S. Halstead.
Critical Reviews in Physical & Rehabilitation Medicine, 7(2): 147-188 (1995)

At Post-Polio Health International 9th International Conference on Post-Polio in St. Louis, Missouri, USA June 2005. Dr. Esquenazi told the audience..
POLIO is not a focal disease **but a systemic disease which affects the whole body and had a larger effect in the areas where clinical paralysis and weakness was seen at the time of polio.** He described Polio as throwing a large bucket of black paint at a white wall ending up with one large blob and lots of little blotches everywhere else. The wind changes every time you do this so the pattern for each polio survivor is different. **That's POLIO!**

Major issue for Polio Survivors.

Polio Diagnosis - BLUE area Paralytic Polio - WHITE area No Diagnosis
Polio Survivors can and members report new symptoms in our white areas
Good recovery does not mean we had a mild case

DIAGNOSIS is by EXCLUSION of other conditions but
we can have every other condition instead of or as well as PPS.

Many Polio Survivors have been diagnosed with other conditions as well, including MS, Parkinsons, Diabetes, Cancer, Sleep Apnoea, ME/CFS, cardiovascular, blood pressure, etc.,

**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

**EXTRA!
EXTRA!**

**19th - 20th
OCTOBER
2013**

**EUROPEAN
POLIO UNION
AGM AND
CONFERENCE
Republic of
Ireland.**

europeanpolio.eu

**31st May to
June 3rd
2014**

**Post-Polio
Health
International
PPS Conference
"Promoting
Healthy Ideas"**

**St. Louis
Missouri, USA**

post-polio.org

Contents

Page 2	Contents, New members and Donations
Page 3	Editorial
Page 4	Message from the Trustees
Page 4/6	Memories or No Memories
Page 7	Managing my PPS Life
Page 7	Diagnostic Name [front page info refers]
Page 8	Appointments
Page 9	Brown envelopes dropping on the doormat
Page 10	Symptoms
Page 11	Aids and Equipment
Page 12	Other items
Page 13	High fructose corn syrup and glycemic index
Page 14	Post Polio News inc. medical article abstract re statins.
Page 15	Various items.
Page 16/17	Update from the Neurological Alliance.
Page 18	Diary of a Benefit Scrounger - David 1, Goliath 0
Page 19	Contact & Membership Details.
Page 20	Aspects of Post-Polio Syndrome - English version 2012. By Dr. Peter Brauer, a Polio Survivor. Published by POLIO Selbsthilfe e.V, Beilefeld, Germany
Page 20	Support PSN - buy Val Scrivener's Photo Cards.

New Members and Donations received.

Welcome to New Members - info sent to 4 people

Thank you to all members who have recently renewed.

Thank you to the following for donations given towards our work

Vivien Holland, Margaret Edmunds, Pam Bamford, Barbara Smith,
Barry Branston, Olivia Branston, Christine Darlington, Walter West,
Susan Freeman, John Ward, Helene McLean, Margaret Lamb
Diana Nash, Anne Wood, Wendy Grimmit, Stuart Barnett
Dinah King, Yvonne Grosse, Diana Nash, D Rose, Lynn Hobday

A total of £ 187.00 since last newsletter.

Val Scriveners Card Sales adds another £ 20.00

Help our funds by ordering - info on back page.

We have no paid employees.

**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

Snow and more snow and its 'washing powder snowing' at the moment. That was two days ago and now its really sunny and quite warm.

Trustees - good news see next page.

Health professionals are still not being taught enough facts about how the polio virus affects our bodies by Colleges of Medicine. This year I have already had six phone calls from people who had found us on the internet. All asking for help and all sadly reporting similar issues that I had from 1988 to 1995 when I found PPS existed and my polio was at last in the equation. Issues that most of you have also experienced.

The main issues raised were years of reporting symptoms that had not been corroborated by the forms of assessment used and therefore for a considerable time either no diagnosis, a generic back or limb pain diagnosis, right through to 'its all in your mind'. One person was given a diagnosis of PPS but no further support, another definitely not PPS after a 20 minute appointment with minimal physical assessment, yet the symptoms and issue with daily living they are reporting match pps. Two without diagnosis still employed and struggling to maintain that without the available help they could be offered once a correct diagnosis given. The other two had been told it was probably arthritis.

One member reports - "a locum called today - looked in her late 20's - did not have a clue about my polio and had never heard of PPS. Give her her due she did ask lots of questions but I can't see the NHS giving me any remuneration for enlightening her!"

How you answer questions at appointments. Remember it is important if you are asked "Can you do x?" that you think and report 'How you do the action, how you have changed the way you do this in the last x number of years to ensure the picture you paint is the same in your mind as theirs. Similarly, if asked about other symptoms, e.g. Constipation, it is important to qualify how this affects you because it could be only go once a week, or daily but stools are hard and it takes ages and this difference would alter treatment options.

The theme of this newsletter covers all sorts of information from other members of problems and extra information: all sorts of things that are helping make managing daily life easier.

JOHN warns.... Since October, I have had 3, yes three catalytic converters stolen from my Mobility Van. Can anyone beat this?

Naidex or Mobility Roadshow - Intend to go and want to meet others, let us know what date.

Do we have your latest home and email address? It would really help if everyone with an email address could email membership@poliosurvivorsnetwork.org.uk and let us know if you are already subscribed or would like to be subscribed to our EMAIL Discussion List or just wish us to use this to contact you with information between newsletters, etc. If you are not on the internet then please drop us a line. We are always pleased to hear from members.

EXTRA! EXTRA! Dates just announced as going to press. European Polio Union, [EPU] AGM and Conference in Republic of Ireland, 19th to 20th October 2013 and Post-Polio Health International [PHI] Conference May 31st to June 3rd 2014 in St. Louis, Missouri, USA. If you might be able to attend either conference and would like more information as it becomes available then please email/write to PSN. Hilary & Richard planning to attend both. We are now re-scheduling trip to Canada to see daughter & family then USA to see Richard's family who live 70 miles from St. Louis to May 2014.

Polio Survivors Network - Meetings

If you have any matters you would like us to discuss at our meetings please get in touch via
hilary.boone@poliosurvivorsnetwork.org.uk
or Tel: 01522 888601 or write to us at Polio Survivors Network PO Box 954, Lincoln LN5 5ER

MESSAGE FROM THE TRUSTEES

Hilary, Gill and Chris are very grateful to Dot and Simon and Barbara for offering themselves as Trustees to share the management of the Charity.

We have had our first meeting where we discussed a variety of issues. We have now decided to concentrate our efforts on one major project that should provide the best outcomes for all polio survivors. Over the next couple of weeks we will be collating as many points as we can come up with to formulate a more detailed agenda for our next meeting, mid March. At this meeting we will finalise the terms of the project, who is going to do what, and we look forward to telling you more about this in our next newsletter in May.

Please note that Barbara does not have internet access but will be receiving communications by post, and can be joined to Internet Skype calls via her home phone. She missed our first meeting due to medical reasons. If anyone else would like to join the Trustees or offer a few hours a month to do some online or local research then please get in touch with Hilary. .

Best wishes Hilary Boone, Gill Bryan, Chris Salter, Dot Ives, Simon Parritt, Barbara Tavener.

MEMORIES OR NO MEMORIES OF MY EARLY POLIO YEARS

Firstly, we need to think about what level of language and understanding we had at the age we had polio. This can make a huge difference to what and how we remember. Those who were very young without enough language to express their questions, feelings or understand what was said can still have emotional memories triggered by nurses uniforms, hospital smells, etc.

Secondly some of us remember everything and some, like me, almost nothing at all. It has been suggested that if you have a traumatic experience your brain can decide that it does not want to remember some things and 'locks' that file.

Members with computers can subscribe to our email discussion list and a recent thread was memories of our earlier polio life triggered by The Mary Berry Story - on BBC TWO on January 29th and 5th February 2013. Mary Berry reveals how contracting polio influenced a career which has spanned 50+ years. Here is a selection of the comments.

Zsuzsanna - I also had to have my left arm tied to the top of the bedstead. I had forgotten. Luckily my left arm recovered but my legs didn't. Still I don't envy Mary Berry who can walk in high heels and without the aid of a stick. I'd rather be me! I also had specially made shoes lace up ankle boots. How I longed for fashionable shoes! I had an operation on my left foot to stop it hanging and I was hoping to be able to wear ballet shoes afterwards but no. It didn't happen!

Pat - quite extraordinary seeing her hand, neck, arm and how when walking down the steps she did it, dot-and-carry-one exactly how I used to do it. Very similar to my own condition except mine is on the right side including leg weakness. I was 23 when I had polio, Certainly brought back memories.

Di and Norman - wondered if Mary has any 'late effects' as she appears very active for her age.

Bridget - Mary Berry was in the bed next to me at the Bath and Wessex Orthopaedic. I have several photos and newspaper cuttings from that time and I have spoken to her since, her memory is somewhat different from mine. We had nobody in the ward on an iron lung, but one girl Deidre X who came from Portland had been in one. Barbara X did not die and eventually went home to London she had really bad junior arthritis. After seeing the programme I made a list of every single girl in the ward all 15 of them, thank goodness PPS has not affected my memory. [X Last names withheld]

Hilary - I was nearly 5 when my mum and baby brother travelled to Benghazi on warship HMS Delwara to join my father, seconded to the army to work on the phone system. Shortly after arrival my brother and I got whooping cough, then I caught polio and went into isolation. I have no memories of my time in hospital and things are very sketchy for decades. I do have odd flashbacks from reading others stories so I suspect it is all there but in 'hidden files'.

John - Found it fascinating reading memories, brought back some of the things I used to do. Standing on a telephone directory and curling my toes over the edge, and especially wearing leather shoes with leather soles and heels. How my mother and father paid for them during the war I will never know.

Michael - I think we should all record our memories as polio effects each person differently. I have a photo of myself with calipers at 6 years old in 1950. I believe having walked, run and played as a child before 3½ the shock shut out my mind to any memories of my past life before polio and my time in hospital. Whether the shock is true or not I don't know. Maybe, it was the polio. I don't remember my year and half in Exeter Isolation hospital.

Pat - In 1957 I shared a small ward with a lady called Elizabeth X who was expecting. She came from the Bedford/Luton area and was very encouraging to me. There were also two men from that area, one was so tall that they had to extend his bed by putting a cot mattress across one end. When they were able to walk they used to come to see me. Now my memory is triggered maybe I'll remember their names. Maurice comes to mind. Also in Neasden were two small boys both called Peter. I became friends with Doreen Buckner, later Buckner-Hicks, who died several years ago. Another lady was pregnant, Joan. We all went onto RNOH Stanmore.

Val - I contracted polio at 16/17 years old. It started as flu and as I 'appeared' to be losing the flu symptoms my mother said that it was time to stop 'pretending' and to get myself up and about. I got myself downstairs but when it came to going back up I was unable to do it, at which stage I was told to stop acting and to get on with it. My father realised that I wasn't in fact acting and the doctor was called. He immediately became alerted to the problem and I was taken to the Spittlesea Isolation Hospital in Luton (now under Luton Airport). There were just two cases in Bedford at the time, me and a young married woman who lived not very far from my home and whose arm was paralysed. I remember arriving at the hospital in the early evening and being (it seemed at the time) surrounded by faces, being asked to raise one leg then the other and having my right leg raised only for it to be dropped back onto the bed, unable to control it myself. I was in one of the glass-sided side wards and when the curtains were pulled back I was aware that this was one of a row of similar 'compartments' along a corridor. After some days a ward was opened up in the old part of the hospital and I was wheeled on a trolley, with the snow falling, across a courtyard and into a cold, bare ward where, two days later I was joined by Barbara. The nurse in charge of us was an ogre but I often look back now and wonder how much of what I hated her for at the time was responsible for getting me back on my feet. She made me exercise until my body had no life left in it and then one day, as I sat in the middle of the ward and needed the toilet rather urgently, she decided to ignore my calls. In my anger I thought 'I'll show her' and I struggled out of the chair and took I don't know how long to haul myself to the end of the ward with the aid of the chair. Having been told previously by the doctor that I may not walk again and if I did it would be with callipers I now knew that I could manage it and from that point onwards I determined to stay on my feet. I admit that I was so much luckier than most but I often wish that I had returned to thank that nurse who I only saw at the time as being so hard-hearted and uncaring. I think she was just what I needed to get me to where I am today.

Gill - Yes, I remember being pushed outside for fresh air while at Winford. I remember sitting on a made bed and not being allowed to get back into it to keep warm. It had to stay neat and uncreased all day. I am sure I was bored. We had nothing to read or to do. I loved books and must have missed them. I can't recall talking to the other children. This is one of five or six memories I have about my original polio experience. I can remember going in to hospital and arriving home after many months but only the few 'snapshots' in my mind about the rest of it. I've always thought it strange that I have absolutely no recollection of learning to walk again. I like reading the experiences of people who can remember so much more.

Di—My friends are fighting fit and don't understand about pacing and resting. They are enjoying hectic retirements! C'est la vie!!!

Members are encouraged to send bits for our next issues.

WALKING, CARRYING, BREATHING, and FATIGUE.

I have fallen three times in the last six months with damage whilst not too serious has caused long term recovering issues and pain. Last fall at Xmas has added to my prior knowledge and I wonder.....

Let me explain. I had my first PPS symptoms in 1988 following a fall. For the next seven years when my prior POLIO was NOT in the equation I had quite a few occasions where I found myself on the floor. I assumed that I had tripped over and would check to see what but never found anything. It was not till some years into PPS research that I had a 'bulb flash moment' every time I had fallen I had been carrying boxes. My body was getting weaker and now knowing that muscles can help others to do tasks that they would not normally do [our trick movements] wondered if my weakening trunk muscles were the problem.

Later with Polio Respiratory knowledge I thought "my trunk muscles, some of which are secondary accessory muscles of breathing, were helping me breathe, my weaker legs walk and my weaker arms carry the boxes. After a certain distance did my Brain say "Muscles you can't keep up all three of these tasks something has to go. Breathing is essential, if dropping the boxes means something will break then Legs sorry but cant help you any longer" I was not tripping over my legs were just collapsing.

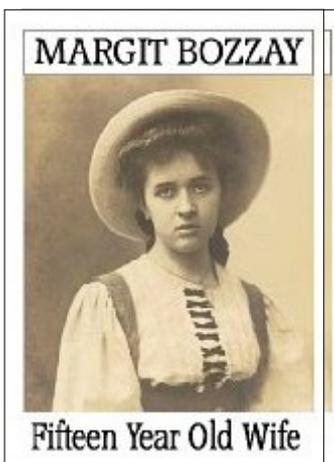
When I fell in September I had just said I must sit down before I fall. Three steps later down I went, I had pushed myself just that bit too far and I was wearing shoes/AFO. Just after Christmas a relief PA was arriving any minute and we decided she could go with Richard in his wheelchair to a local store and I would go into town. I put on my shoes and AFO and she arrived. Richard then said, "I don't think I will go today". Now I had to find some tasks for her to do whilst I was out. I walked to the bedroom and collected a few items to iron, back to the kitchen for a few more, turned and two steps later I found myself on the floor on my back with my legs from my knees back bent under me. It seemed as if my legs just stopped but my body kept going and I landed heavily on my knees. A tendon on the inside of my left knee has been playing up ever since. When out I use my scooter or if walking a short distance a cane or rollator. I do not wear my trainers and AFO in the house. I have to take them off as soon as I return home because they feel heavy [like wearing lead boots] and just wear socks. The bungalow is small so walls and cupboards are handy to hold onto. I had once again pushed my muscles too far without pausing to allow them to recover. The extra weight from shoes/AFO had shortened the distance I normally walk at home. If I can see a problem I now say, 'left, right, left, right' as I walk and this has helped.

Do any other members experience this and/or are there times when you are doing an action and you stop breathing for a few seconds to concentrate on using legs [climb stairs - did this for years when lived in house], arms [lifting items, carrying shopping few feet from car to kitchen]?

I have reported respiratory issues for seven years but 'you are fine [meaning you do have issues but they do not reach our criteria for advice/treatment] see you next year". I have to sleep on my left side [my worst allowing my best side uppermost] to breathe at night. If I fall on back it is not long before I wake to turn back again. I think the form of assessments being used are not specific enough to corroborate/understand the issues we are reporting. That some of our fatigue could be under diagnosed/ hypoventilation [shallow breathing], when doing actions of daily living. Look forward to hearing from members. Hilary.

Member Zsuzsannah Snarey tell us about 'Fifteen Year Old Wife' Kindle edition.

www.amazon.co.uk/FIFTEEN-YEAR-OLD-WIFE-ebook/dp/B006YQOL90



Margit Bozzay, my grandmother, was a celebrated author and journalist in Hungary in the 1930s. She wrote several novels which were reprinted many times, but during communism her books were banned for their slightly religious and upper class content. She was responsible for a women's column in the daily paper and wrote articles for several magazines. In this, Fifteen Year Old Wife, the first of her autobiographical novels, she described her unfortunate early marriage and the reasons for its break up. She had two sons, my father being the eldest. I did not know her because she died at the young age of 49 from ovarian cancer, when I was six months old and by translating her books [inc. Labour of Love and 'The Lesson Ends'] I found out what a strong determined person she was. I also wanted my children and grandchildren, who do not speak Hungarian, to know about her and their heritage.

Currently £2.37 in UK. USA change co.uk to .com and its \$3.68.

Get Kindle on Ipad [both Richard and I have this and its good] and Computers.

Zsuzsanna just let me know its available in print as well now £7.19 pence.

Managing my PPS Life

N.B. The information on the next 8 pages of this newsletter is taken from Polio Survivors personal experiences to help increase your base knowledge of ideas/equipment that have worked for others to discuss with your health professionals.

Remember we all had different levels of polio damage, recovery, what we did in our stable years and issues we have now. No two of us are exactly the same, a nightmare for those assessing and treating us.

DIAGNOSTIC NAME ? [Front page refers]

What diagnosis were your parents, or you if you were older, given:- infantile paralysis, paralytic polio, non paralytic polio, spinal polio, bulbar polio, spinal bulbar polio, abortive polio?

After best recovery and during your stable years of functioning if you referred to your polio how did you phrase this? Did you say have polio or am a polio survivor or had polio or ?

We all had different levels of damage and recovered to different levels. Some were left with obvious polio limbs, wore callipers, special shoes and walking aids, or used wheels. Those health professionals who have knowledge and experience of polio will recognised this. However, many of us recovered outwardly that well that we showed until we started with PPS/show no easily recognisable sign of having had polio. How many of us who did recover well have been told that 'you must have had a mild case' but now demonstrate a moderate to high level of changes in the way we do actions of daily living. After the success of the vaccine, as the decades passed the number of facts taught by Colleges of Medicine reduce and reduce. Leaving many health professionals without enough facts to recognise our 'polio and pps'.

Symptoms - There are a huge number of symptoms experienced by the general public.

Symptoms of Post-Polio Syndrome

- ◆ **Fatigue** often overwhelming, both physical and mental.
- ◆ **Loss of muscle strength** and/or use also in muscles below the line of clinically evident weakness at the time of the original infection
- ◆ **Pain** in muscles and joints.
- ◆ **Trouble breathing and/or swallowing.**
- ◆ **Problems sleeping**
- ◆ **Intolerance of cold**, causing muscle weakness and sometimes burning pain and/or discolouration in limbs.

Diagnosis is by exclusion of other conditions. We can have every other condition as well as PPS. Many polio survivors have also been diagnosed with MS, Parkinsons, ME/CFS, Fibromyalgia, etc. How many other neurological conditions have the same symptoms as the bolded words?

Other members have also been diagnosed with diabetes, arthritis, cancer, blood pressure, cardiovascular issues, gastrointestinal problems, obesity [and if we have difficulties exercising is there any wonder this is a major issue for some of us], stroke, etc..

Looking at the information on the front page.

Note that as early as 1875 it was recorded that all four men who had had paralytic polio in infancy had developed new weakness **NOT ONLY** in previously affected muscles **BUT ALSO** in muscles believed to be uninvolved. {The white area of the body pictures}

Dr. Esquenazi reminded the International PPS Conference that "Polio is NOT a focal disease but a **systemic disease** that affects **the whole body** and had a larger effect in the areas where clinical paralysis and weakness was seen at the time of polio."

Looking at the body pictures on the front page, pick the nearest to you, or draw your own. Do you have symptoms or problems in **WHITE** areas on your diagram. PSN therefore recommends that you inform all health professionals (including all alternative and complimentary therapists) that you are a polio survivor and that the symptoms you are reporting could be compromised by the damage to your body from polio.

APPOINTMENTS

- A. If possible ring and find out how long has been allocated.
- B. For medical appointments have any tests/x-rays etc been pre-planned, or you could be asked to undergo. Make sure that the clothes you wear on that day are easy to get on and off and rather than struggle and ask staff for help or take someone with you.
- C. Conserve your energy. Save it for the major reason for the appointment. How are you going to get there, drive or be driven, where is the car park and route to the department and how long is this going to take. Remember leave yourself time to go the loo and recover from the journey. If the appointment is at your home, tidying up more than normal, getting out the silver and best china and baking cookies to make a good impression can wear you out. Everything should be as an average day for you.
- D. Seriously consider taking/having someone with you who can take notes and with your agreement remind you of anything you have forgotten.
- E. Think about the reasons you are asking for/being given an appointment and list the top 3.
- F. Pretend you are the health/social service/benefits professional you are going to see and what information would you want you to provide to get the best outcome. How long is the appointment, how many facts can you realistically discuss, so start with the most important.
- G. After the appointment review what happened. If things did not go as well as you hoped do not leave it, talk to your family/friends/GP/support group and decide on the next step.

Make up a sheet taking into account [an idea of information that could be helpful]

- 1. Appointment with, date and time and venue.
- 2. Your contact details.
- 3. Medical appointment
 - 3.1 Your current medications and any vitamins etc you take regularly.
 - 3.2 Allergies and Intolerances.
 - 3.3 Relevant to this appointment
 - i) Equipment you use / would like to discuss
 - ii) Symptoms
 - iii) The three top points that demonstrate your issues. If you have a couple of photos then and now that demonstrate the change in your ability that could be helpful and save time.
 - iv) Questions you want to ask.
 - 3.4 List other issues for your benefit that you still need to discuss at a later appointment with this professional or with another department.
- 4. Appointment with Social Services or Benefits Office.
 - 4.1 Reason for appointment.
 - 4.2 New issue - contact support group, obtain leaflets, search online for information and advice about the process that you will be going through.
 - 4.3 Forms that need completing, get copy beforehand and go through it ahead of time with family member/friend/support group.
 - 4.4 Relevant to this appointment.
 - i) In order of priority what facts can you give to support your request.
 - ii) Have copies of documents that might need to be seen. If you have a couple of photographs, and now maybe short video clips [on your mobile] that demonstrate the changes in your ability could be helpful and save time.
 - iii) Questions you want to ask.

Yes we are proud of what we can achieve but we must tell it like it really is.

BROWN ENVELOPES dropping on the doormat....

Now you have new medical issues do you cringe when a brown envelope arrives on your doormat, immediately dreading what you are going to have to read or fill in?

The following points have been raised:-

- Endless forms with questions that are not clear enough to know exactly what information they are seeking.
- Some questions need the same answers and you wonder if they are trying to catch you out.
- Having to give personal information on finances that is hard now you see in 'black and white' how much less you are now getting compared to when you were earning.
- Repeatedly being asked for the same financial information by different departments.

Suggestions that have helped some members.

Don't open the envelope in the lounge or bedroom so the contents if they are going to cause stress do not upset the aura in that room. Try opening them in the toilet and if you don't like what you read pretend to 'flush it down the loo', put it back in the envelope and leave it in there till later. You still have to deal with it but this can take the edge off when you smile at the thought.

Get someone else to open these letters first and tell you if its ok or got 'mostly the same questions yet again'. Sometimes it can be an eye-opener seeing someone else get as frustrated as you were by some of the questions. 16 years ago my daughter came in, saw I had been crying, picked up the Disabled Facilities Grant form and said 'Social Services have told me I am your official carer {news to me} so I will fill this in for you'. She started to read out loud and on page 2 read 'Is your home a benefice of an ecclesiastical estate?' and exclaimed 'what on earth is that?' and some pages later 'Do you have an invalid carriage [pronounced not valid], what on earth is an invalid carriage?' When I pronounced it correctly she exasperatedly sighed 'How many decades have they been using this form that term is as old as the dodo?' I have to admit by now I was struggling not to laugh, and it was really helpful seeing how I had felt. [At this very moment a brown envelope dropped on my doormat - thankfully the Carers Team Newsletter]

Start filling the form in in pencil or use another sheet of paper so that you can get someone else - family member/friend/support group - to check your answers to ensure what you have written conveys your current situation as it really is.

Keep copies of any forms that you submit so that when you have to do this again you can refer to your previous answers. If you forget to do this then ring and ask for a copy to be sent to you.

Keep paperwork or copies of paperwork that you might have to refer to again in a box file or start a list of the information requested and where you have it filed, e.g. Bank statements [blue file], Receipts [envelope for each year in red box file].

If you have to tick a choice of box answers and there is no box for the answer you need to give then add another box and explanation.

Maybe you can do food shopping [with help and aids] and you do bathe and wash your hair [with help and aids] and you can make a meal [by using prepared ingredients because you cant cut them up] etc, then you must add the [extra info] and if you can only do one or two of say five every day then you need to state this on every section linking it to the other responses.

Question. Can you pick up a two pence piece? - is asking about your finger dexterity.

Answering Ticking the "Yes" box without qualifying that you have developed trick movements, e.g. You are in an electric wheelchair and your arms are weak but you have a stick so that you can slide the coin towards the edge of the table and then with one hand push it into the other. I know we are proud we can, but tell it like it is.

SYMPTOMS/AIDS and what has worked for me

The following is a selection of symptoms that members have raised with comments from others, 'what works for me'. PSN cannot recommend any of the suggestions. However, we know that sharing this information has enabled polio survivors to raise points with their health professionals that has helped with diagnosis, advice, management, etc.

Eyes - Hilary raised issue with disturbed vision in the early 90's, two years before she found PPS existed. Four years at two hospitals with nothing found. Some years later when reporting this on a Polio email discussion list three other polio survivors came back with similar issues. One man in Australia with a best friend Optician read all the emails and was tested further. The resulting information - the muscles that moved his eyes were weaker on one side than the other so Hilary took this information to her Optician. He tested her as normal with nothing found, read the report and did more tests and confirmed that the muscles on the left side of her face were weaker. Also the moving from light to dark/dark to light was because the movement of the pupil was also delayed and it took longer for her eyes to adjust than in earlier years. [technical term Accommodation]. You can try moving your eyes left and right and then moving your head instead to see if there is any difference. [NB Hilary is body one - BUT ALSO in her white area]

Ellen "over the past year I have noticed that whenever I try to look over my left shoulder with just my eyes I have double vision. Just recently over the right also. I am an upside down polio and know the left side of my face was affected. I will take this information to my eye doc"

Polio Quebec in 1997 advised me 'when tired during the day/driving/at meetings try shutting your eyes and turn off all sound for 20 minutes. This lets your face muscles pace and rest.

Ellen added "when watching TV I find after awhile I will see double on just the TV. When this happens I play simple card games on my Ipad and listen to the TV. It doesn't happen with my Ipad or notebook. But will with a real book. Will start taking eye breaks/rest now.

Pat reported a few years ago that her weak eye problem was corrected with a prism in the left lens. [Hilary rang opticians and found she has prism in left lens too]

Swallowing - Member says "I have to ensure food is chewed very thoroughly and swallowed in very small amounts. Have problems choking when eating. The testing only identified when scanned drinking that I have irregularities, end of story.

Slackness at the back of my throat that allows liquid to go down ahead of me actually swallowing. Barium swallow but nothing showed up, however I realised afterwards that this is because the liquid was of a smooth, slightly thickened consistency and swallowing that caused me no problem. I simply swallowed in a steady manner. If I am eating something that requires chewing, say an apple, that releases liquid ahead of the solid matter being swallowed and this is where I have to be careful. I make sure that my chin is down.

Second member reported having the same issues with the fluid from apples.

Third member same problems with anything juicy, especially grapes, and try to remember to chew on one side so that the juice is less likely to go down the throat.

Hilary - "Years of problems with sometimes not being able to swallow, choking on some foods and when I burst out laughing. Eventually confirmed at third appt which took ten years. This was after I gave them information from a chiropractic assessment that pointed out that watching me say 'Ah' and repeating it showed weakness of the palatal [throat] muscles evident left side on third swallow and right side on 5th swallow. This triggered extra tests at 3rd appt and at last was told "yes you were right you do not complete all swallows and you have a pocket that is catching some small bits of food/pills. Nothing we can do". Earlier research from Peter Ellis, Nepean, Ottawa had told me that I should sigh so shoulders relax and keep chin down and head slightly to one side, relax and try swallowing again. Now I saw that my fear was raising my shoulders making swallowing impossible. Managing much better for 7 years now. I do still have issues but now take care and sit properly to eat. [NB I am body one so this is BUT ALSO in my white area]

Swollen Legs - Discussion started with taking Ramipril 10mg and Amlodopine 5mg but my left leg has started to swell.

'I was prescribed Amlodopine which did turn my legs pink instead of their cold blue but my legs started to swell and the skin broke down. I was taken off the Amlodopine and put on low dose Ramipril.

M&S support tights comfortable and helped keep swelling down but my arms are no longer strong enough to put them on.

Travel stocking worked for husband.

Electric rise leg raise chair keeps swelling down reported by quite a few members.

Gastro issues. Reported are 'I have constipation' and 'it is taking me far longer to pass stools now and it wears me out' and 'I eat a good fibre diet and now taking extra medication is helping soften things to a fudge consistency' and "it is taking less time to completely empty my bowels but a lot more effort cleaning myself.'

Dr, Brauer in Aspects of Post Polio Syndrome [info pages 17 * 20] reports on page 99. Symptoms reported in PPS medical articles. [Editors Note % figure used reflects how common the symptom is reported by polio survivors not the mean from each article]

Gastrointestinal disorders up to 80%. Flatulence, obstipation [editors note:- severe and obstinate constipation], constipation, gastrointestinal ulcers, gastritis, reflux of gastric acid, motion impairments [dysmotility] of the esophagus and the intestines as a lack of motion [hypomotility]. Causes are polio damage with an overburdening of the vegetative [autonomic] nervous system.

What has helped me responses are:- higher fibre diet, prune juice [although watch sugar content], Fybogel ok but you have to drink it quickly before it gels up, Benefibre [not available on prescription, sold in Boots, Tesco but dissolves totally in drinks] Macrogol [Movilax] sachets that dissolve in water and retain fluid in your bowels to soften stools, reported one to four sachets a day. Glycerine suppositories.

PSN suggests that asking your GP to refer you to a Bowel Nurse so that you can discuss your specific issues [ensure you qualify what you mean by terms you use, e.g. constipation, one member reports the health professional took this to mean that I did not go for days, when in fact I am expelling hard stools daily but it takes half an hour and wears me out!!!'

Shoulders - Save our Shoulders. A guide for Polio Survivors.

34 page article from Moss Rehab, PA, USA.

www.mossrehab.com/index.php?option=com_docman&task=doc_view&gid=67&Itemid=

Aids and Equipment.

Over the years the best advice and it comes from many PPS groups around the world is

Don't immediately say no when aids, equipment or personal help are suggested to you.

Try different choices before you buy. Over the years many have reported finding out later that what was recommended in stores and occasionally by a non PPS knowledgeable health professional did not work for them, but a different make did.

Pace & Rest and Save energy for things you want to do by asking for help for tough stuff.

Wheel and Walking Aids.

Electric Riser Recliner - adapted now in case of emergency so it will go off once to stand.

Electric Scooter - ensure wheels are large enough for the terrain you need to travel over, the larger the wheel the rougher the ground.

Cane and Crutch handles - arthritic shaped handles less pain in wrists.

Shoes - Velcro fittings and the local cobbler has customised the strap fasteners to the inside rather than outside making it easier for my left hand to fasten them.

Rollators - Using three wheeled one which is more balanced to walk with than one cane or crutch and carries bits in the bag. Cant have one that you sit on because I cant get up.
Four wheel rollators more difficult to fold and get in car than three wheelers but have heard some fallen using three wheelers. Try before you buy.

Travelling

Sat nav mostly with voice off, great knowing how long to get there/home.
Googlemaps - visit the venue and see what entrance/car park look like before leaving.
Uriwell personal toilet - flexible construction fully extended to 750ml.
www.youtube.com/watch?v=UzcjB07KO4

Kitchen

Work surfaces - two different heights for two different tasks.
Sporks - Knife and fork in one, nice weight. amazon.com/sporks
Trolley - move plates, drinks etc from kitchen to where going to eat safely.
Water - Hydrate for health bottles with tube and bite valve that we hook on chair, and by bed, much easier to drink. www.hydrateforhealth.com



Lounge

Electric rise leg raise chairs - less swelling of feet, less jumpy muscles, easier to stand
Electrically operated fans, moving air helps breathe easier.
Curtains/Blinds cord or electrically operated.

Bathroom

Before changing bathroom visit somewhere to try different options, wet rooms work for some, bath and bath lift and soaking muscles works better for others.
Have toilet and sink fixed to wall in small bathrooms, wheelchair footplates go underneath.
Flannels - easier to handle than towel to dry yourself.
Don't waste energy drying, wrap in large towel and rest and drip dry.
Flushable wipes - as a 'nice' addition/alternative to paper.

Bedroom

Electric Beds - try two singles together, or split double, with king size quilt.
Plastic cups/glasses in case dropped so no broken glass.

Diet - Tsp cinnamon in food and cholesterol lowering drink a day, cholesterol results now normal.

Pacing - Break tasks down till you can do a bit, rest a bit that works for you. Then when muscles recovered you can do a bit more and rest/ do and rest till you have completed the task. You can do much more this way than trying to do it in one hit and ending up with more pain and fatigue.

Disability Aid Trust - Everyone deserves a holiday. Help for the disabled to take a break.
www.disabilityaidtrust.org.uk

Disabled Living Foundation - Independent advice, helping people for 40 years. www.dlf.org.uk

Remap - Custom made equipment for people with disabilities. www.remap.org.uk

DisabledGear.com - The place to buy and sell second hand disability equipment online! Guy created the website to be a practical alternative to the expense of new, and address many of the frustrations he has experienced in his years of paralysis.

The FREE ads section is the main reason for this site. It is all about choice, convenience and reduced cost. (We regret that at this stage, the FREE Ads section is for people in the UK and ROI only). [Editors note:- Guy did sell wheelchair trousers and other aids, some of which we have purchased but hot off the press, for a variety of reasons, he is having to wind down the trading arm so check now for stock clearance. We met Guy at Naidex and Mobility Roadshows.]

Editors Note:- Members and Polio Survivors are welcome to contact us by phone/letter/email including sending photos or short film clips on **anything** related to polio, pps that has helped you manage your life to a greater degree.

Eating - corn syrup, glycemic index, and how eating low glycemic foods is better for us.

Member Jann Hartman from Washington State, USA writes:-

According to the Center for Science in the Public Interest: "The heavy concentrations of high-fructose corn syrup in Coca-Cola, Pepsi, and other sugar drinks causes obesity, diabetes, and heart disease."

http://cspinet.org/new/pdf/combined_infographic.pdf

CSPI is a good source of information on food and health. I do subscribe to their newsletter, but a lot of information is right on the internet.

Carbohydrates which are essential part of your diet, along with lean Protein and heart healthy Fats, can cause problems when we eat too many of them or the wrong kinds.

Carbohydrates are ranked on a scale called The Glycemic Index. Foods lower on the index are better. Simple sugars are ranked high on the index, and cause blood sugar to climb quicker than foods ranked lower. Lots of examples, like ripe bananas are higher than unripe ones. That makes sense since they taste sweeter. You can eat them, just eat a smaller amount, and eat with a protein or fat rather than alone. I prefer to use them for sweetening in baked goods or in cereal rather than sugars. But, I rarely eat a banana otherwise. I am very sensitive to sugars (type 2 diabetic) and have to watch my carbs very carefully.

I lost 35 pounds over about 2 years, and glycemic control is much better (nice will likely never be normal). So, it is possible to lose weight even without any real exercise. (I did use a pool for light exercise 3 times a week). You just have to make very good choices on foods, and watch those portions!. Let us know if you have any questions.

Liquid Candy: http://cspinet.org/new/pdf/liquid_candy_final_w_new_supplement.pdf

My Glycemic Index article:- www.post-polio.org/edu/pphnews/pph20-3p8-9.pdf

Jann Hartman - arojann@yahoo.com

Editors Note:- I was diagnosed Type 2 Diabetes 3 years ago [high blood pressure and cholesterol and overweight]. I started using low glycemic load diet reporting this in newsletters. My diabetic, cholesterol and blood pressure results 3 months later were normal. I looked at what I ate and swapped high GL foods for low ones. I have had some relapses but today am still 40lbs lighter and losing again. Xmas to New Year I cheated, gained 12lbs, back on lowGL eating and lost it by 21.1.13. I am unable to exercise.

GLOBAL
HEROES

THE END
OF POLIO

THE
GLOBAL
POVERTY
PROJECT

www.globalpovertyproject.com

www.globalheroes.theendofpolio.com

PSN were contacted yesterday by **The Global Poverty Project**, Oasis Centre, 75 Westminster Bridge Rd, London SE1 7HS. Global Hero's went live on 19th February 2013, and is an innovative, highly personalised and shareable platform in which users create cartoon superhero avatars of themselves on a 'mission' to eradicate polio. The initiative is part of their wider **The End of Polio** campaign, which together with The Gates Foundation and the World Health Organisation looks to see a polio-free future. **Global Heroes** also presents an opportunity to sign a petition to persuade the UK government to commit much needed funding (following the expiration of their polio commitments in 2012) to finally help eradicate the remaining 0.1% of polio cases worldwide.

The Global Poverty Project said it would be fantastic if PSN members and families could join the campaign by visiting their website to share your avatar on Facebook, and tweet support with something along the lines of #GlobalHeroes Assemble! Mission One eradicate polio <http://globalheroes.theendofpolio.com/> In return for adding the info to this newsletter and shortly on our Website we said **it would be fantastic** if the world could know about Post-Polio Syndrome. This includes the estimated 12 to 20 million Polio Survivors alive today and all health professionals. We asked for and were promised further discussions as to how they might take this further.

**An online news cutting service from Chris Salter
that specialises in news relating to polio and post polio issues**

Recent Medical Article.

Statin-Induced Myopathy in a Patient with Previous Poliomyelitis.

Martikainen, Mika H. MD, PhD; Gardberg, Maria MD; Kohonen, Ia MD; Lähdesmäki, Janne MD, PhD.
American Journal of Physical Medicine & Rehabilitation:

POST AUTHOR CORRECTIONS, 30 January 2013

doi: 10.1097/PHM.0b013e318282d17e - Case Report: PDF Only - ePublished Ahead-of-Print.

Abstract:

This report describes a patient with a history of poliomyelitis who developed new, progressive symptoms of muscle fatigue and weakness, suggestive of postpoliomyelitis syndrome. However, comprehensive investigations led to the diagnosis of statin-induced myopathy as the cause of the patient's symptoms. This case highlights the possibility of statin-induced myopathy in patients with a history of poliomyelitis and the differential diagnosis between postpoliomyelitis syndrome and statin-induced myopathy in these patients. The possibility of statin-induced myopathy should be considered when patients with previous poliomyelitis who take statin medication develop symptoms suggestive of postpoliomyelitis syndrome.

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<http://journals.lww.com/ajpmr/Abstract/publishahead/>

[Statin_Induced_Myopathy_in_a_Patient_with_Previous.99462.aspx](http://journals.lww.com/ajpmr/Abstract/publishahead/Statin_Induced_Myopathy_in_a_Patient_with_Previous.99462.aspx)

Or <http://preview.tinyurl.com/aw9rh75>

[Editors Note:- Some Polio Survivors have been reporting new or increased muscle pain after starting Statins for at least seven years and this has returned to before once stopping Statins. Other Polio Survivors have reported no side effects at all and continue to take them. Personally rather than take statins Richard and I asked to try a change of diet first. We were told that we would not be able to reduce it enough but doctor was prepared for us to try. We changed our diet by swapping high glycemic load foods in our diet to low ones and taking one cholesterol reducing drink per day. This worked for us and our current results are now in the normal range]

N.B.

If anyone is interested I maintain a 'private' list of PPS related journal articles on Glassboard. It's not an extensive historical list i.e. it only lists abstracts starting from 258 days ago; when I 'report' a PPS-related journal article on Post-Polio News I also drop the details in "Post-Polio Journal News" on Glassboard.

Glassboard is a private social network for groups. For phone, Android, & now on the web. There is a premium version but I just use the basic free service. <http://www.glassboard.com/>
<http://glassboard.com/support/faqs.php>

**If anyone wants access to "Post-Polio Journal News" email me at
postpolionews@post-polio.org.uk and I will send them a personal invite.**

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.

NEW 'FREE HOLIDAY' SCHEME LAUNCHED.

We are delighted to announce the launch of our 'FREE HOLIDAY' scheme for Carers - a super static caravan sited at the Richmond Holiday Centre in Skegness on the Lincolnshire coast.

Sleeping accommodation is one double and two single beds. Please note this accommodation is for Carers so is **not** disabled adapted. [If they can raise funds for a second caravan it will be]

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.

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 May 1st 2013

A SELECTION OF OTHER PPS GROUPS/NEWSLETTERS WE ARE IN TOUCH WITH

British Polio Fellowship	britishpolio.org
European Polio Union	europeanpolio.eu
Post-Polio Support Group Ireland	ppsg.ie
Post-Polio Health International, St. Louis, USA	post-polio.org
IVUN - International Ventilator Users Network	ventusers.org
Florida East Coast Post Polio Support Group	http://home.iag.net/~bgold
San Francisco Bay Area Polio Survivors	sfbaps.org
Central Virginia Post-Polio Support Group	cvppsg.org
South Arizona Post-Polio Support Group	polioepic.org
Post-Polio Canada	marchofdimes.ca/EN/programs/PolioCanada/
Polio NZ (Inc)	postpolio.org.nz
Post-Polio Network (NSW) Inc, New South Wales	post-polionetwork.org.au
Post-Polio Network WA Inc, Western Australia	http://members.upnaway.com/~poliowa/
The Africa Connection, Post-Polio Network RSA	postpolio.co.za

LATEST NEWS from CEO Arlene Wilkie

Brain awareness week – March 11 – 17 2013

Neurosupport – hosting a Head Matters Tea Party in Liverpool



Wednesday 13th March 2013, 11am to 3pm, alec@neurosupport.org.uk or ring 0151 298 3283

AGM - 26th November 2013, venue London.

Policy and campaigning update

Better Deal campaign achievements - It has been a successful year for neurology. We have secured commitments to three of the five policy calls in the Alliance's 'Better Deal' campaign: development of a neurological dataset, the establishment of a neurological strategic clinical network (SCN) and the appointment of a National Clinical Director for neurology.

Neurology dataset - There is still no confirmation of where responsibility for a neurological database will sit since the Department of Health (DoH) committed to its development. This is despite the Alliance seeking clarification from both the DoH and NHS Commissioning Board (NHS CB). Our next step will be to formally present our concerns in a letter to the Secretary of State for Health.

Strategic clinical network for neurology - Work towards the establishment of the SCN for mental health, dementia and neurological conditions has progressed steadily over the past three months. The NHS CB published the single operating framework for SCNs in November, and recruitment of the Directors and teams is currently underway. Following a SCN simulation event in the autumn, we attended two further meetings in January. A third simulation event will be held on 24 April in the Merseyside and Cheshire area. Please find attached our latest briefing document.

National clinical leadership - The NHS CB confirmed in December that it will appoint 24 National Clinical Directors (NCDs), including a NCD for Chronic Disability and Neurological Conditions, who come into post this April. This represents a huge success for the neurological community. I sat on the interview panel in February and will let you know the outcome of this as soon as we hear anything. In addition, another 15 NCDs will be relevant to the improvement of outcomes for people with neurological conditions.

Meetings with the new Secretary of State for Health - I met with Jeremy Hunt, Secretary of State for Health, recently with the Richmond Group Chief Executives and also with a small number of National Voices representatives. Both meetings presented an opportunity to discuss how to improve outcomes for people with long term conditions and **highlight the dearth of neurological data**, neurological service performance and patient experience.

Long Term Conditions Outcomes Strategy - The DoH confirmed its decision **not** to complete the generic, cross departmental Long Term Conditions Outcomes Strategy in December. This decision was based on the NHS CB's long term conditions responsibilities and Ministers' assessment that proceeding with a Departmentally-led strategy in this area would be inappropriate.

We were actively involved in the strategy development, which has consistently been cited as the reason a neurology specific outcomes strategy is not necessary. The NHS CB have confirmed that this work, together with the NSF for Long Term Conditions, will inform the Domain 2 (long term conditions) vision document currently being developed. We will have an opportunity to comment on this document later in the year.

Consultations - In early December, the NHS CB launched a service specifications and clinical policies for specialised services consultation. We supported members through the development of resources on the new operational model for specialised services and submitted a joint response on the generic neurology specification with the Association of British Neurologists (ABN), alongside our own independent letter (see attached along with a specialised services operational model diagram). We also submitted written evidence to the Health Select Committee inquiry on NICE which focused on the development of its quality standards and the need to prioritise those that are neurologically focused.

Neurology National Leadership Group (NNLG)

At the January meeting, Dr Martin McShane, NHS CB Domain 2 lead, shared his aspirations for the future of care and support delivered by health and related services for people with long term conditions. The Group stressed that it would support his work and that of our new NCD for CD. Members agreed that the NNLG should recruit the new NCD as a Co-Chair.

Dr Chris Clough announced that he will step down as Co-Chair given that his position as DoH Clinical Neurosciences Advisor will conclude upon the new NCD's appointment. The NNLG and the Alliance are very grateful for Chris' commitment and support and we hope to continue to work with him in the future.

Social care and welfare

Having joined the Care and Support Alliance (CSA) in the autumn, we are now also a member of the Disability Benefits Consortium (DBC). This membership will enable us to maintain a good understanding of the key development in social care and welfare policy and input from a pan-neurological perspective where relevant. Our Policy Group has agreed that one Alliance representative should attend each meeting.

Event you might be interested in

Festival of Neuroscience

The British Neuroscience Association are hosting their Festival of Neuroscience at the Barbican Centre 10th -14th April which will enable the public to interact with scientists, carers, charities, funders, policy-makers, celebrities and learn more about the brain and the importance of a multi-disciplinary approach to research

Rare Disease Day

This year, Rare Disease Day falls on 28 February. To help raise awareness, we will be tweeting throughout the day to promote our members representing rare conditions.



This book is written by Dr. Peter Brauer, a Polio Survivor himself who has done extensive research into the medical articles related to Polio and Post Polio Syndrome.

This version 2 with increased chapters has now been translated into English.

It has been published by German PPS support group **POLIO Selbsthilfe e.V., Auf den Hüchten 15 D-33647 Bielefeld Germany**

Hilary has been in touch with Peter Rengis to organise the best way for members, or anyone in the UK, to purchase this book. To order this 228 page paperback please send a cheque for £22.00 to Polio Survivors Network by March 15th 2013. Do not forget to include your name and address. Hilary will then place the order, receive the books from Peter and post them on to each person in the UK. This is easier and cheaper than posting individually from Germany.

There is a fair amount of medical terminology used with some words like 'obstipation' [which turned out to be severe and obstinate constipation], and 'vegetative system' [to be autonomic system]. However, this is written by a Doctor who is a polio survivor himself and who provides a question and answer service to Polio Selbsthilfe members. So he sees the issues from both health professional and polio survivor point of view. We believe that any Polio Survivor seeking help for their issues could find the information helpful when needing to discuss their issues with health professionals.

Hilary has her own copy. PSN has a copy and would be prepared to loan this to anyone in the UK for the cost of postage and packing if you are unable to purchase your own copy. Please contact us if you would like to discuss this.

We will be including some excerpts in the next issue in May 2013. If you have any particular problems drop us a line, email or ring and we will pick sections that match those enquiries.

Whilst on the phone with a member I noted that they referred to themselves as 'we' when I believed them to live alone. Eventually I queried this and was told.. 'Well I am rather large, almost two, so therefore We, not I.' We both laughed lots and agreed that laughter was good medicine. Permission was given to include this.

Diary of a Benefit Scrounger -

A site to share information on Welfare cuts, illness, disability and general, current, political thought.

1st February 2013 - David 1 Goliath 0 - Sue Marsh writes:-

It's been a long road eh?

Remember when we heard about PIP? That DLA would be abolished, despite nothing in the Tory manifesto? Remember how we sat, open mouthed at the disgusting proposals? "Bathing" reclassified as a wipe with a flannel FROM THE WAIST UP? Paraplegics "fully mobile" if they used their wheelchairs TOO WELL? The day we heard 500,000 people would lose out entirely? Half a million of the "most vulnerable" cut adrift?

Remember the enormous thrill as Spartacus Report blazed around the world, the report WE wrote, WE funded, exposing the government as liars and cheats?

Well my friends, a few weeks ago, this stubborn intractable government finally admitted defeat. The fingers I have in various pies started singing an astonishing tune. The government were frightened. They no longer had the stomach for a fight with the very people the public see (rightly or wrongly) as the "real disabled". The private Tory polling was atrocious, the public had been rallying to our cause for longer than the Tories were admitting. Backbenchers were getting twitchy, ministers weren't sure a daily diet of abandoned cancer patients and cruelly cut off Parkinson's grannies were a good idea in the run up to an election.

Crucially, IDS [Ian Duncan Smith] beloved Universal Credit was falling apart. They finally admitted what we'd been telling them all along. Too much reform, too quickly, with too little evidence. Something had to give, and they decided it would be PIP.

Remember our pause clause? When I went to the Lords and asked them to pause PIP till they got it right, then only roll it out in a small pilot followed by an independent enquiry before it was rolled out nationally? They suddenly gave us all that and more. As a cherry on the top the size of Manchester, they announced they wouldn't even make people with lifetime awards go through the transfer until after the next election. Translation? We'll leave this mess for Labour, or we'll take it on when we've won a second term and we can be as foul as we like again.

But campaigners weren't satisfied. We wanted the phrase "reliably, repeatedly, safely and in a timely fashion" added to the legal regulations, meaning people with fluctuating conditions would be as well covered as everyone else. Yesterday, they agreed to that too. I'm having to write my blogs from a hospital bed with nothing but my phone, so can't attach links, but perhaps others will be good enough to post them in the comments section.

Official government figures, say some will still be pushed through the test before 2015 - those who don't have lifetime awards, around 30% of the total. However, the terribly accur [sic] little birdies who got me this far, tell me there may well be just a fizzle. A long pilot, a longer review, a quiet little sigh of defeat.

Now, hard as it is, let's not gloat. We'd hate to goad them back into shafting us, but go get your favourite treat and sit in utter satisfaction revelling in the knowledge that we won. They gave up. We were just too effective, too noisy, too clever, too dangerous.

You did it. You never gave up, you trusted me when I said there was always hope and you won.

Spartacus warriors you are stronger than mountains.

<http://diaryofabenefitscrounger.blogspot.co.uk/2013/02/david-1-goliath-0.html>

or

<http://preview.tinyurl.com/ayefqoh>

Management Committee [Trustees] and Operations Team

Management Committee [Trustees]

Chair - to be decided next meeting

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

New Trustees - Dorothy Ives and Simon Parritt, Barbara Taverner.

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 £10.00 per year

Membership Fees

UK Individual - £ 12.50 per year

Associate Membership - £ 10.00 per year

Yearly fees can be paid by Standing Order.

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

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

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

Email:- membership@poliosurvivorsnetwork.org.uk

All Forms are available on our Website, by phoning our helpline or writing to us.

<http://www.poliosurvivorsnetwork.org.uk/joinus.html>

Donations

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Content

- ◆ Review of the Current Situation and Definition of the Post-Polio Syndrome
- ◆ Characteristics of the Post-Polio Syndrome
- ◆ Problematic PPS Patient or Problematic PPS Physician?
- ◆ Occurrence of the Post-Polio Syndrome
- ◆ Post-Polio Syndrome as an Inheritance of Polio-Encephalomyelitis
- ◆ Risk of the Post-Polio Syndrome
- ◆ Central Nervous System and PPS
- ◆ Problematic Diagnosis of the PPS
- ◆ Symptoms and Signs of the PPS
- ◆ Checklist for the Post-Polio Syndrome?
- ◆ Differential Diagnosis by Exclusion of the Post-Polio Syndrome
- ◆ Classification of the Post-Polio Syndrome as a Chronic Disease
- ◆ Cardiovascular Involvement in Poliomyelitis and Post-Polio Syndrome
- ◆ Fatigue as a Symptom of the PPS.
- ◆ Post-Polio Syndrome and Stress
- ◆ Breathing and Sleeping Disorders in PPS
- ◆ Temperature Sensitivity in PPS
- ◆ Muscle Cramps in Post-Polio Syndrome
- ◆ Burning Muscle Pain in Post-Polio Syndrome
- ◆ Risks in Post-Polio Syndrome
- ◆ Dental Treatment of Polio Survivors
- ◆ False Diagnosis and False Treatment of the Post-Polio Syndrome
- ◆ Post-Polio Syndrome as Causality Hypothesis
- ◆ Poliomyelitis Viruses and Post-Polio Syndrome
- ◆ Medical Assessment of Patients Suffering from Post-Polio Syndrome
- ◆ Post-Polio Syndrome through Vaccination
- ◆ **Acute Post-Polio Syndrome Appendix**
- ◆ I. Poliomyelitis - Striking a Second Time in Life?(Information for patients)
- ◆ II. Post-Polio Syndrome as a Tertiary Consequence of Polio-Encephalomyelitis (Information for physicians)
- ◆ III. Post-Polio Syndrome as a Severe Chronic Disease (Information for funding agencies: health insurances, retirement funds, health and social services)
- ◆ IV. Post-Polio Syndrome as a Physiotherapeutic Problem (Information for physiotherapists)
- ◆ V. Poliomyelitis and Post-Polio Syndrome in numbers
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