



# POST POLIO MATTERS

Polio Survivors Network Newsletter - Volume 8, Issue 3/12  
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[www.poliosurvivorsnetwork.org.uk](http://www.poliosurvivorsnetwork.org.uk)

**February  
2014**

**Vol 8, Issue 3**

Home of the  
Lincolnshire  
Post Polio  
Library



Enter 100+ articles



**END  
POLIO  
NOW**

**POLIO  
TOTALS**

2011 - 650

2012 - 223

2013 - 400

20.2.14 - 15

**Pakistan 13**

**Afghanistan 2**

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



**PSN Annual General Meeting**  
5th April 2014 - 11.30 am - Lincoln

**Meet Us in St. Louis!**

**May 31 - June 3, 2014**

**Hyatt Regency St. Louis at The Arch**

[www.post-polio.org](http://www.post-polio.org)

**P**romoting  
**H**ealthy  
**I**deas   
PHI's 11th International Conference



**POST POLIO SYNDROME**  
**A Condition Without Boundaries**

25th to 27th June 2014  
Amsterdam, The Netherlands

[www.polioconference.com](http://www.polioconference.com)

**NAIDEX NEC  
BIRMINGHAM**  
29 Apr - 1 May 2014  
Visitor enquiries  
Tel: 0844 588 8076  
www.naidex.co.uk

**MOTABILTY  
ROADSHOW**

**NO SHOW  
IN 2014**

www.motabilityroad  
show.co.uk

**PSN  
AGM**  
Saturday  
5th April  
In Lincoln  
More info to  
follow in post



<b>Contents</b>	Crippen Cartoon. [donation sent, crippecartoons.co.uk]
Page 2	Contents, New members and Donations
Page 3	Editorial
Page 4	Message from our Chairman - Simon Parritt.
Page 5	Kathleen Button and Recipe Paleo Alternative to Bread.
Page 6	Polio and after - Over 60 and/or wheelchair user and fit?
Page 7	Loretta my Hero - Inspirational email from Polio Survivor.
Page 8	NHS England, care.data and opting out. Chris Salter
Page 9	Post Polio News. [PPN] Chris Salter
Page 10	PHI 11th International Conference, St. Louis, USA.
Page 11	2nd European Polio Conference, Amsterdam.
Page 12	Hotels, Motels, Public Venues are they all accessible?
Page 13	Recommended Chalet. Memory tips and Vowel oddities.
Page 14/15	Care Bill: a briefing. Partners in Policymaking.
Page 16/17	Benefits and Work Guides you can trust. News update.
Page 18	Val Scrivener Photo Cards plea. PPN Recommended Read. The end of plagues.
Page 19	Contact and membership info.
Page 20	The End of Plagues and more polio themed books.

### **New Members and Donations received.**

**Welcome new member Tony Scrase-Walters [See Page 6]**

**Thank you to all members who have recently renewed.**

Thank you to the following for donations given towards our work  
Special thanks to the family and friends of Dinah Bass now £640.

**2013 DONATIONS GRAND TOTAL - £ 1,984**

**2014 to date - £588.00**

**from**

Barry and Olivia Branston, Ann Stone,  
John Keating, Susan Freeman, Christine Darlington,  
Yvonne Grosse, Shirley Rose, Lynn Hobday, Dinah King  
Dinah Nash - see Editorial.

Family and Friends of Kathleen Button page 5.

**Includes \*New\* Conference and Meeting Fund £ 200.00**

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

**ANNUAL GENERAL MEETING.2014** is being held at 11.30 am. in Lincoln on Saturday April 5th 2014. Full details will be posted to you during early March. Any member who is able to join us is welcome to ring/write or email for more information ahead of the posted information.

**The latest weather** in the world has been horrendous. Difficult for the able bodied but so much harder for anyone with a mobility issue.

USA this month - saw some snow on the ground in 49 out of 50 states on 13.2.2014. Yes, even Hawaii. The only state completely snow free was Florida. 10.23pm on 14th and South Carolina had a 4.1 magnitude earthquake.

UK - Feb 14th news The wettest winter since records began. Heavy rainfall, gale force winds and snow on high ground piling on problems for areas already struggling in the wake of a string of wild winter storms.' Some homes in the Somerset levels are still flooded six weeks later. The Thames has reached its highest level in 60 years.

If anyone has any good tips for coping with adverse weather and mobility issues then please let us know. Remember hints, tips and bits are welcome any time.

**Annual Membership Costs and Funding.** We have kept our Annual Membership Fees to £12.50 per year for many years as we know some of our members are managing their PPS on state and other benefits. Everything with a disabled label is far more expensive so we do understand that some times we have to make the decision either/or. Rather than not re-join please give us a ring. This has only been possible due to the generosity of members who have been able to add a donation with their annual fees. Some members sent funds last year specifically towards the cost of holding the Annual General Meeting, others have sent a book of stamps which is always appreciated. Read Val Scriveners plea on page 18 to help raise funds by ordering a pack or two of her hand made photo cards.

However, to continue with our work and to send representatives to national and international conferences and meetings we have to raise more funds. We now have a dedicated fund raiser on board. It takes some time to send out letters and apply for grants and hear back but we are hopeful that we will have more good news in about six months time.

**Post Polio Conferences 2014.** Post-Polio Health 11th International Conference 'Promoting Healthy Ideas' from May 31st to June 3rd in St. Louis, USA [Speaking at this] followed by the 2nd European Polio Conference 'A Condition Without Boundaries' in central Amsterdam from June 25th to 27th 2014. See pages 10 and 11 for more information including costs.

As you know I attended the European Polio Union AGM and was one of two presenters the next day, in Tullamore Eire last October. This weekend was at our own expense and our only holiday.

**NEW Conference and Meeting Fund.** Last Tuesdays Committee Meeting discussed the costs of registration, hotel bills and travel to attend and speak at national and international conferences and meetings and decided to start a Conference and Meeting Fund and to advertise this in this newsletter. Imagine our surprise when Fridays post contained a letter from Diana Nash with a cheque [gift aided] for £400 towards attending conferences and general costs. We would like to express our thanks and can now start this fund with £200 and the remainder will go towards general expenses. [Abstract sent for European conference waiting to hear if accepted]

If any other members, their family and friends, and readers of this newsletter would like to add to this fund or our general funds we would be more than grateful.

**If you have a few hours now and then and would like to help please get in touch.**

### 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 OUR CHAIRMAN - Simon Parritt

### PSN strength is not about muscle but members

Winter is upon us with all its full and unpleasant force. For those in flood areas it is of course even worse but as we know cold has a huge influence on how we function and feel and I know I am often in shut down mode at this time of year. I hope you are all coping well and hanging on until the warmth arrives.

With this Newsletter I wanted to bring to your attention, as Chair, the importance of networking and growing our support network as we are only as effective as you, our membership. There is no doubt in my mind that we provide something that is not being addressed adequately elsewhere. We are keen to work towards a position where as Polio Survivors we have the best and most up to date information and are provided with a proper assessment and optimum treatment. We want to offer the combined knowledge and expertise that we can bring because we live it and have lived it for years.

The bottom line is that we need more members with their experiences and expertise. PSN is still THE place to collect a body of us who know what the problems are and can pool our collective knowledge to share this with each other and, as importantly, the medical and allied professions. We can aim to educate and inform about post polio and those thousands of us that live with it in this country as well as using the links we have with built up with many other pps support groups throughout the world.

It is a sad fact that less and less people in the medical and allied professions have experience or current knowledge about polio or post polio. As we age and as the incidence of new polio cases decline, in this country at least, the best pool of expertise lies with us, with you. We want you to help us by telling us what you know, what you experience and what is good and what is bad about what is happening to you and your experiences with the support you are getting, or not from the medical professions.

We need you to help us grow by telling those around you with polio to join us. We can only continue to offer more if we have more people involved. In addition by just being members it increases our voice and impact because in today's health and social care environment the onus is on the user, namely you and I, to be active participants in our care and treatment. We are not medical professionals but we are professional polio survivors and often know so much more than we think.

So I am appealing to all of you, to go forth and multiply so to speak, I am sure there are people out there who you know or know of who might benefit from being members. The more we are the more we can ensure we can do what we set out to do. Whilst other organizations work to highlight post polio, we can play an important role in ensuring it is dealt with, with the kind of professionalism and importance it and we deserve as well as supporting each other.

**Simon Parritt, C.Psychol, AFBPsS, MSc, BSc(Hon), BA, CPsSC, MBACP**

Chartered Psychologist

HCPC Registered Counselling Psychologist

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Simon Parritt <[simon.parritt@poliosurvivorsnetwork.org.uk](mailto:simon.parritt@poliosurvivorsnetwork.org.uk)>

#### REMEMBER

No two Polio Survivors are identical - what a nightmare for health professionals we must be!

As Polio Survivors we have developed totally unexpected methods of performing actions often using muscles not normally expected by health professionals to be involved in that action.

## **Kathleen May Button, nee Holmes 14.2.1919 to 3.1.2014**

My mum, Kathleen May was the youngest of seven children, looked after by Gladys after their mother died. On leaving school at fifteen Mum was in service for a while then joined the ATS as the political situation worsened where she met our father, Frederick William Button, a cook in the Lincolnshire Regiment.

She was very young, 20 years, when she and Fred married. He went to war and Mum and Gladys went to keep house for an eccentric academic, Mr. William Lovell. He left the house in Maple Street to my auntie Gladys and when our father came back they all stayed together with us two girls, myself and Pam until the move to Cottage Paddock, in the late 80's.

Mum went from cooking in the army to a dinner lady in school and worked her way up to head cook at Manor Leas in Lincoln. Mum showed great fortitude dealing with the illness of Pam with Polio. After years of operations and treatment, she with Mum's help and determination turned disability into ability. The polio group flourished and Pam has lived a full and active life bringing up two children David and Sara, much of the credit for that she puts at Mum's door.

I believe her years at Cottage Paddock were really happy. She was always tranquil and contented in old age, and a staunch support when my husband died, enjoying her grandchildren and great grandchild Florence and lived alone, with my help, until she fell and broke her hip in August 2013.

After that sadly she faded gently away before our eyes, dying Jan 5th 2014. We miss her dreadfully, particularly her wit and humour. We feel very lucky to have had her for so long.

Mrs. Shirley Bingham.

Polio Survivors Network thank Kathleen's family and friends for their £73.00 donation.

### **RECIPE - PALEO ALTERNATIVE TO BREAD - © Monica McGuinness [goingcavewoman.com](http://goingcavewoman.com)**

HB - If it has been suggested that you could try going gluten free [we are now] and/or lose weight and you would miss Pizza then this is worth trying. It is great on its own, not good enough for sandwiches. Top with pizza toppings [easy on cheese, try few shreds of parmesan] at the time or add to chilled pieces and grill. I did not like cauliflower but love this and still losing weight.

You can make enough for a few meals and keep them in an airtight container in the fridge for up to a week or freeze them for up to 3 months. Once frozen you can reheat them by defrosting, and heating them in a skillet with a smidgen of coconut oil. They get really crispy on the edges if you leave them in for long enough.

- Touch of Coconut Oil – for sauté [HB sold in all good supermarkets in jar]
- 1 Cauliflower [HB I added some broccoli buds, the very top bits fourth time made this]
- 1/2 Onion – Diced
- 1 Cup Spinach – Fresh or frozen [HB I cook mine first now for minute]
- 1/2 Cup Nuts – Ground (optional) [HB Tried cashews and almonds both tasty]
- 2 - 3 Free Range Eggs
- 1 - 2 Cloves Garlic – Crushed [HB used easy garlic from tube]
- Any herb of choice, fresh or dry – Optional
- Freshly Ground Sea Salt and Black Pepper

In a food processor, chop the cauliflower until it resembles breadcrumbs.

In a skillet [frying pan] melt coconut oil and heat the cauliflower, garlic and onion until it browns slightly, about ten minutes.

Beat eggs in a bowl and add cauliflower mix and the remaining ingredients. Stir.

Place parchment paper on a baking tray and spoon mixture into rounds on a tray [for pizza] or spread across tray and cut into slices when cool.

Bake at 350F [180 C, Gas mark 4] for 15 minutes until browned.

## **POLIO AND AFTER**

I am a 71 year old guy who has ended up with PPS after I contracted polio when I was 8 years old in 1950, apparently from the swimming baths in Leeds the city of my birth. It was the first time I was 'blue lighted' into Jimmys [St. James Hospital], and put into an iron lung. When I was eventually transferred into the Children's Ward. It was a great relief, as it was very lonely in the lung and I was the only one in the room. In the Ward there were 32 of us, with quite a lot in wheelchairs, mostly adult ones as there was a shortage of children's chairs.

We would have 'chariot races' down the long corridors, and one day I ran into a nurse that was carrying a tray. She had 120 syringes on it [at that time they were all glass] and I broke the lot. They took my chair off me and confined me to bed. In the Ward there was a toy box, unlike today, so I rolled out of bed and dropped onto the floor. I pulled myself to the toy box with my arms as I had seen a pair of roller skates in the box. With the use of my pyjama cord and those borrowed from other boys, I tied the skates to my knees. This allowed me to drag my useless legs behind me, using my elbows to propel myself. The nurses then relented and gave me back my chair as I was causing sores on my elbows.

In the Ward was a boy called David who was a year older than me, he had a spinal injury so was on his back and saw the Ward through a mirror placed in front of him. He wanted to join us outside, so we put our heads together and came up with a plan. Our pyjama cords came into play again as well as the heavy bandages we had 'borrowed' from the cupboard. About 8 of us tied our 'chairs' to his bed and pulled him through the French windows out onto the lawn (thanks to the Nightingale Wards). Two weeks later David died of his injuries.

We always managed to have a good time (well most of the time). After a long spell in hospital I was sent to a residential rehab centre in St. Anne's-on-Sea run by nuns. Most of us thought them as torturers as they tried to get us walking again. In my case after a year of punishment it worked, although I still had to wear calliper's for about 2 more years.

At one time when we were climbing an apple tree I fell and my calliper stopped me hitting the ground. A branch had gone between the calliper and my leg. Luckily the branch was strong enough to leave me hanging upside down until a ladder was brought to allow one of the nuns to climb up and release me. I was not at that time a popular boy with the nuns.

On another occasion when I was sent for hydro-therapy the pool attendant wanted to put me in the pool whilst still wearing my callipers. You can imagine what would happen if that had happened!!! In the end all the nuns hard work was a success as I later joined the army and went on to be a marathon runner, as well as being the lead cornet player at Kneller Hall, the military school of music [Editors note:- I lived a mile from here and as a teenager used to go to their last Wednesday night of the month concerts]

After I came out of the forces to help look after my father I led an uneventful life until PPS caught up with me and now I use a 'chair' on a permanent basis, but life is still fun. I intend to keep fit and live long.

### **Over 60 and/or a wheelchair user and fit?**

This is a question anyone 60 years old and over should ask themselves, especially if you are a wheelchair user. It is a well known fact that the answer for most people will be 'no' (if they are honest). so why not do something about it? I am over 70 years old and a wheelchair user and have had half of my right lung removed because of cancer. In addition I also suffer from C.O.P.D [Chronic Obstructive Pulmonary Disorder] and PPS (Post Polio Syndrome). Luckily I am quite fit (due to exercise) so recovered very quickly from the cancer operation.

It was while taking part in the Leeds 10K on a hand bike that indicated to me that something was wrong, as I was becoming unusually short of breath. I had to stop three times on the way round. I could not use my racing chair because I was having the same problem. I still raised £350 for Marie Curie Cancer Care. After the un I had an x-ray which showed a nodule deep inside my right lung, which was found to be cancer.

It has been medically proved that if a person keeps reasonably fit that their general health improves, including their mental health as it can combat depression. Exercise also improves your breathing and also helps your hear to keep going (which is a good thing!!!). I got the gym twice a week, but that is my choice, as it is not necessary for everyone to go to the gym as armchair exercise works as well. So does walking the dog, swimming, cycling and using the stairs instead of the lift, just a few normal activities that can help you to keep fit.

Please keep your exercises within your capabilities of what you can do, only concentrate on the things that you can do or change and not the things you cannot do or change. If you intend to use a gym they may require you to check with your G.P. to say that you will not suffer any medical problems doing exercise. It is a legal requirement of their insurance company, and they will require it in writing. It is sensible to seek medical advice before exercising to prevent new unnecessary problems.

In my case I go to the gym not only to keep fit but also because it is an enjoyable social activity. I have made new friends that I would not have met otherwise.

I wish you good luck and good health.

**Stay Fit - Live Long. Tony Scrase-Walters Wheelie666@me.com**

## **Loretta my hero.**

I often amuse myself when I come up with ideas. Sometimes children have imaginary friends. I had and still have a real friend. Her name is 'Loretta'.

Loretta is known by my doctors, my friends, and family. All my life Loretta has been my hero .... I take her everywhere I want to go, even when she wants to stay home. She complains, but allows me to ignore her. She is not particularly attractive, but personality? Wow!!! Miss Loretta L Twigleg to give her, her full name, has been to "war" with me, limped down a wedding aisle as a bride and once she danced and even won a jitterbug contest!

She loves to have canes decorated with stickers and a wheel chair that has a bike bell on it. Nowadays as she gets older she likes to sleep a bit more and I find that helps me too. I must respect her old age.

Yes, you guessed it. Loretta is my left skinny, frail polio leg.

Friends, Love your body, the parts that have been weak, yet live in a very brave body! Not all battles are fought on foreign lands, not all wounds are from accidents. Care and replenish things you can in your life. Now, my dear "Loretta" needs comfort, and rest. She has earned it. I give her permission to nap while Madeleine reads a book. We are so attached, and I embrace all she has done for me. It is my time to give back to "Loretta."

**Madeleine Mulkern, Florida, USA. [boomsie42@gmail.com]**

## **Inspirational update from Polio Survivor Marsha in Texas.**

Exactly 11 months ago, January 19th 2013, my husband called an ambulance, rightfully so! I was ever so close to death. Wound up having three operations and spending a full month in the hospital.

From there I was placed in a rehab facility [a nursing home - what a horror that two additional months was!] So, finally, after three months of being medically incarcerated, I was released to go home. The nursing home actually said they thought I'd never go home again and were amazed I'd fought my way back.

Well, this afternoon I finally did what even I thought was beyond hope, I transferred to and from my toilet and my electric wheelchair. This means soon I will be able to leave my house for more than an hour or so at a time! I surprised myself and actually cried this afternoon, cried for the relief of finally successfully getting back to where I'd been 11 months ago - Jan. 19, 2013. I worked SOOO HARD for this!! Physical Therapy 2 to 3 times a week, the same for Occupational Therapy and even more with a Speech Therapist for cognitive work.

What a year!!! OK, right, not a year, JUST 11 months, ha ha ha!!! Whew.....busy patting myself on my back and wiping away a few tear drops

A Doctor giving a lecture to a group of medical students pointed to an x-ray and explained 'As you can see, this patient limps because his right fibula and tibia are radically arched.'

The doctor then asked Sidney "Now what would you do in a case like this?"  
Sidney replied: "I suppose I would limp too."

## NHS England - Care.data - How to opt out of HSCIC database

Health and Social Care Information Centre - [www.hscic.gov.uk/](http://www.hscic.gov.uk/)

**Editors Note:-** This article is taken from an email provided by Trustee Chris Salter on our Members Email Discussion List, Polio Network Lincs. NB The next four paragraphs were moved to the start of the article. We have included a copy of the leaflet with form with all newsletters sent by post and as a pdf attached with your newsletter to all members that receive their copy by email.

This post is to provide information on how to opt-out of the HSCIC Database should you wish to.

**NHS England sent out a leaflet entitled “Better information means better care” via junk mail.** It was not addressed directly to you as a patient and it deliberately didn't include an opt-out form. The leaflet says you should “speak to your GP practice” if you want to opt out. This is misleading and could waste your time and potentially waste valuable GP appointments

The following page at medConfidential includes links to a downloadable form and letter, either of which once completed or personalised can be sent to your GP. It also explains the issues surrounding the 'anonymisation' of your records and you should read it and other related information before making a decision to opt-out or not.

<http://medconfidential.org/how-to-opt-out/> [Editors note:- We have included a copy of the leaflet with form with all newsletters sent by post and as a pdf attached with your newsletter to all members that receive their copy by email.]

Opting out will have no effect on your medical care. If you are unsure what to do, opt out now. You can discuss this with your doctor at your next appointment and, if you are satisfied, you can opt back in at any point.

**GP practices across England will soon be required to supply patients' personal and confidential medical information, on a regular and continuous basis, to the Health and Social Care Information Centre (HSCIC).** The data upload is due to commence in March 2014 and all households should have received a leaflet ('Better information means better care') through their letterbox about this in January.

This is separate from the Summary Care Record. The two databases are very different. Opting out of one database does not mean that you have automatically opted out of the other.

Details from your medical record will be extracted from the practice in a form that can identify you, and will include your NHS number, date of birth, postcode, gender and ethnicity, together with your medical diagnoses (including cancer and mental health), their complications, referrals to specialists, your prescriptions, your family history, details of your vaccinations and screening tests, your blood test results, your body mass index, and your smoking/alcohol habits.

This programme is called care data, and the information uploaded will be used for purposes other than your direct medical care (so-called “secondary uses”). Medical staff treating you in GP surgeries, hospitals, A&E and out-of-hours centres will not use, or be able to use, this database. However, the uploaded data is likely to be made available to organisations outside of the NHS, such as universities and commercial organisations.

Under the Health and Social Care Act 2012, GP practices have \*no\* choice but to allow the HSCIC to extract this information.

Once the data has been extracted, the GP practice is no longer the data controller for that information, and cannot control or protect in any way how that information is used, shared or who has access to it.

Although GP practices cannot object to this information leaving the practice, individual patients and their families can instruct their practice to prohibit the transfer of their data, i.e. **You have the right to opt-out.**

**If you do nothing, i.e. you do not opt out, then your medical information \*will\* be extracted and uploaded to the HSCIC.**

**Once uploaded, you \*will not\* be able to get this data deleted by the HSCIC. So if you want to opt out, you need to act now.**

Opting out will have no effect on your medical care. If you are unsure what to do, opt out now. You can discuss this with your doctor at your next appointment and, if you are satisfied, you can opt back in at any point.

### **LATEST.**

GP magazine Pulse reported on 7/2/14, "Patients who have opted out of the scheme will still have their records sent to the HSCIC stripped of identifiers" (see 4th paragraph from bottom of this article). This confirms something buried on page 9 of NHS England's recently-published care.data Privacy Impact Assessment [PDF], which states:

Where patients have objected to the flow of their personal confidential data from the general practice record, the HSCIC will receive clinical data without any identifiers attached (i.e. anonymised data). i.e. the intention is to still to extract information from the medical records of people who had opted out, just not with their NHS number, postcode, date of birth and gender attached.

**THIS IS NOT WHAT ANY REASONABLE PERSON WOULD UNDERSTAND BY OPT OUT – IF YOU OPT OUT, NO INFORMATION FROM YOUR MEDICAL RECORD SHOULD LEAVE YOUR GP PRACTICE.** medConfidential are working hard to resolve this.

This post has been compiled using information at the medConfidential site.

**Chris Salter [postpolionews@POST-POLIO.ORG.UK]**

**VERY LATEST NEWS from NHS ENGLAND.**

**LATEST  
NEWS**

**Tim Kelsey, National Director for Patients and Information... Excerpt from his Statement 19.2.2014**

To ensure that the concerns of the BMA, RCGP, Healthwatch and other groups are met, NHS England will begin collecting data from GP surgeries in the **Autumn, instead of April**, to allow more time to build understanding of the benefits of using the information, what safeguards are in place, and how people can opt out if they choose to.... <http://www.england.nhs.uk/2014/02/19/response-info-share/>

**ppn**

**POST POLIO NEWS [ppn] - [www.post-polio.org.uk](http://www.post-polio.org.uk)**

**An online news cutting service from Chris Salter that specialises in news relating to polio, post polio, disability and other health related issues.**

Twitter, Newspaper, RSS feed, Facebook, LinkedIn, Daily digest emails.

### **SAMPLE OF ITEMS FROM LAST FEW DAYS.**

- Rotary releases US\$35.9 million to fight polio, grants Nigeria \$7.7 million - Business Day.
- UK - Charity calls on East Midlands Business to support the National Indoor Games - British Polio Fellowship.
- UK - ATOS may lose fit-for-work tests contract as ministers line up rival firms - The Guardian.
- Selective disruption of acetylcholine synthesis in subsets of motor neurons: A new model of late-onset motor neuron disease - Neurobiology of Disease.
- Pakistani polio strain threatens global campaign - The Washington Post / Associated Press.
- Gunmen kidnap six-strong polio team in NW Pakistan - Agence France-Presse (AFP) via ReliefWeb.
- Fifteen years of acute flaccid paralysis surveillance in Hong Kong: Findings from 1997 to 2011 - Journal of Paediatrics and Child Health.



**11th International Conference**  
**May 31st to June 3rd 2014**  
 Hyatt Regency St. Louis at the Arch  
 St. Louis, Missouri, USA.  
 Conference Program - [www.post-polio.org/net/11thConfProgram.pdf](http://www.post-polio.org/net/11thConfProgram.pdf)  
 Registration - [www.post-polio.org/net/11thConfRegistration.pdf](http://www.post-polio.org/net/11thConfRegistration.pdf)

**Founder Hilary Boone** our Secretary and Newsletter Editor has attended and spoken at the 8th [2000], 9th [2005] and will be speaking at this the 11th PHI Conference on **Sunday June 1st. Title is 'Assessment - our Abilities'** with Beth Kowall, MS OTR and Carol Vandenakker-Albenese MD. [Also presented in San Francisco 2003, Miami 2007 and in UK]

**Life Member Jann Hartman** and her husband John [sadly no longer with us] attended the 2005 PHI Conference and presented a nutrition session and John spoke on 'Care and Feeding of Batteries' with Jean Csposso from NJ. They attended the Conference at Warm Springs in 2008. Jann will be speaking at this conference on Sunday **June 1st Advice on Solo Aging** - with Audrey King and Susy Stark, PhD, OTR-L, FAOTA. On **Monday June 2nd Jann is the Moderator for the presentation Weight Management** with speakers Kathy Davis, MSC, LCSW and Claire Kalpakijan PhD, and Michael Wheaton MD. In the afternoon she is part of the team. **Support Groups What Works**, with Jean Graber [Kentucky USA] Beth Kowall, MS, OTR, [Wisconsin, USA] Mary-Ann Leithoff [Australia], Elizabeth Lounsbury [Canada] and Micki Minner [Arizona, USA]

**Speakers from PHI Board of Directors**, are President William G. Stothers, Joan Headley, Dr. Frederick M Maynard, Dr. Marny K. Eulberg, Dr. Martin B. Wice, Allison Roller MA, and Elizabeth Lounsbury. **Doctors speaking are:-** Dr. John Bach, Dr. Michael W. Rich, Dr. William M. DeMayo, Dr. Bonnie Jo Grieve, Dr. Michael Wheaton, Dr. Selma Calmes, Dr. Tatiana Mesquita e Silva, Dr. Antonio Tonioli, Prof. Dr. Frans Nollett. There are many other health professionals and Post Polio Support Group leaders.

Full information and registration links as above. Any members without computer access who would like information please phone and we will print and post you a copy. Any members who are or would like to attend please get in touch. Plus there is a Polio reunion in Branson MO from June 6th to June 8th 2014. Richard and Hilary were able to attend in 2000 and it was great fun with rib tickling laughter, sharing info and sightseeing as well. More information on [www.postpoliobransongoers.com](http://www.postpoliobransongoers.com) We will not be able to join in this year as we are flying on to Canada to see our daughter and family in Alberta for the first time since she left in 2000.

**Brief info.**

Hyatt Conference Hotel rooms at \$119 per night. USA hotel rooms usually have two large double beds in them. My first conference in Atlanta four polio survivors shared rooms with large beds to keep the cost down. It was like having a schoolgirl sleepover we had so many laughs. Other nearby hotel prices available but that does add cost and time of travelling.

## Information from the European Polio Union

The 2014 European Polio Union Annual General Meeting will be held on the afternoon of 24<sup>th</sup> June in Amsterdam in the NH Grand Hotel Krasnapolsky. [ahead of the PPS Conference].

**The 2nd European Polio Conference in Amsterdam** from 25th to 27th June 2014 is now open for registration and abstract submission. The Conference theme 'Post-Polio Syndrome - A Condition without Boundaries' refers to the aim to exchange knowledge about the treatment of polio residuals in different age groups across the world to best preserve functioning throughout life.

The challenges for the aging European polio survivors and the young polio survivors inside and outside Europe differ. In aging polio survivors, treatment focuses on post-polio syndrome and secondary disorders of the locomotory system due to long standing overuse, with the aim to preserve independency and quality of life. In young polio survivors the challenge is to prevent these late problems, to reduce disability and to improve societal participation.

To facilitate better care and to build international connections, the Conference brings together health care providers, researchers, polio survivors, their caregivers and patient organisation representatives from Europe and worldwide. The Conference has dedicated sessions for polio survivors and for health providers emphasizing research results and state-of-the-art clinical practice.

Besides for health care professionals and researchers in the field of rehabilitation medicine, the conference program is of interest for virologists and neurologists and offers the option for one-day registration.

You are most welcome to participate in this conference and enjoy the beautiful city of Amsterdam in early summer 2014.

Kind regards Prof. Frans Nollet, MD, PhD, Chair Organising Committee

**The Main Conference Topics** are:-

- ◆ Polio Eradication Progress
- ◆ Pathophysiology of Post-Polio Syndrome, New Avenues for Treatment?
- ◆ Best Practices for Post-Polio Syndrome.
- ◆ Innovations in Orthotic Devices
- ◆ Treatment of Young Polio Survivors Inside and Outside Europe
- ◆ Nutrition
- ◆ Coping and Exchange of Experiences
- ◆ Societal and Caregiver Issues.

This Conference is initiated by the European Polio Union and the Academic Medical Centre of Amsterdam in cooperation with the Danish Society of Polio and Accident victims (PTU) Copenhagen and Karolinska Institute Stockholm.

**Registration** [early fee up to 31st March 2014]

Professionals €550, Polio Survivors & Caretakers of Polio Survivors €275 / £225, Students €200

This includes admission to the Welcome Reception. All lunches and coffee and tea breaks. Access to oral and poster sessions, participation in scientific programme and All Conference material, including Programme and Abstracts, list of participants.

Conference dinner on evening of June 26th is €100 / £81 per person, drinks & entertainment inc.

**Rooms at the NH Grand Hotel Krasnapolsky in central Amsterdam are:-**

single occupancy €214 / £176 per night, double occupancy €239 / £197 per night.

Full information and registration links are on [www.polioconference.com](http://www.polioconference.com)

N.B. PSN have started a Conference Fund and all donations will be gratefully accepted.

## Hotels, Motels and other Public Venues are they all accessible?

Member Lynn Hobday sent me a letter and newspaper article asking that I add some information in the next newsletter.

So many times we find issues that demonstrate that those in charge have not contacted a variety of disability folks to look at their plans before building. Members on our email discussion list have discussed this issue in the past. Time to bring this to the fore again.

How many times have you arrived at a hotel, motel or public venue and had problems? Members have raised issues in the past so we can kick off the list with:-

- A large London hotel advertising disabled access to the restaurant but on arrival there were 12 steps to the entrance and no other step free way even through the kitchens.
- A major Newcastle hotel that had recently had a million pound refit including the accessible rooms..

it Bath and although they had a bath lift it was still in the box and they did not realise had to be kept on charge.

No room to get round the restaurant with a wheelchair or scooter.

Bathroom door opens out and across the entrance to the room hiding the bathroom light switch behind it.

The bed was only 4'6" wide compared with 6'0" beds in all other rooms 'to give you more room to move about"... I replied " have you never stayed in a Travelodge bed room which is about half the size of this one"

- A motel in Yorkshire that had just finished refurbishing a very large disabled family room and the organisers had booked us into this as a treat. It was on the first floor and to get there you had to go through two large Push/Pull doors, up in the lift and through another set of Push/Pull doors. The bed was lower than normal and had we got down onto it we would not have been able to get up again.
- A brand new hotel in Lincoln where the sink in the disabled bathroom was so close to the toilet that you had to sit with your legs to the left at a 45 degree angle - told "but you can now wash your hands before standing up".. There was another four foot along this wall and just four more inches further along would have resolved this.
- More than one hotel in the States where all the accessible rooms are one on each floor [because its easier to design the building this way we were told] right up to the 26th at one hotel!!! When the fire alarm went off at one we were staying in we had to get help to get Richard down the fire exit staircase and then sit on the kerb in the car park for over an hour until the Fire service cleared for everyone to go back in. [Tip if you have a car in the hotel car park don't forget to put your car keys where you can pick them up easily so you can drive away or sit in your car till matters are resolved].
- How many hotels/motels have you stayed at where there is NO electric socket by the bed to run a ventilator and you end up with extension lead cable you hope no-one will trip over?
- How many handicapped toilets have you been in where the toilet roll holder has been placed so far back you have to reach under your left armpit?
- How about mirrors in disabled toilets that are only up to seated height... do they really think all disabled people sit in wheelchairs?
- How many times has the disabled toilet contained cleaning or other equipment?
- How many hospital out-patient clinics have you been to sitting on wheels and the receptionist says 'Please take a seat' and there is no space to park your wheels.

If you know of a good hotel/motel chain or public venues or have any hints and tips for how to plan for when issues like this could occur then please let us know.

## **'Copper Beech' Cabin with disabled access at Deerpark, Cornwall.**

**Recommended by electric wheelchair user.**

**A Forest Holidays venue. [8 other venues with similar cabin]**

**www.forestholidays.co.uk - 03330 110495**

Recommended by John who has been off season [prices reasonable then] and his wife with her electric wheelchair. Deep in the forest with beautiful scenery. Rare plant life and red deer. Cornish coast [pretty fishing villages of Looe and Polperro] only fifteen minutes away. Eden Project about 20 miles away

Copper Cabin equipped for the disabled. Sleeps 4. Double bedroom and toilet and twin room. Plenty of electric sockets. Wheelchair access to hob and sink. Wet room with shower and seat [if carer needs to do all then it's a bit small but doable]. Private terrace with outdoor furniture and wheelchair access. Two parking spaces.

<http://www.forestholidays.co.uk/locations/south-west-england/deerpark-holidays>

### **Memory Tips from Melissa and Charlene if you have a camera phone.**

- 1) **Shopping.** Take a shot of interior of Fridge and/or pantry before going grocery shopping. That way if your not sure if you "have that item" you can check your phone.
- 2) **Loaning a book, tool,** etc ... take a picture of the person you are loaning it to with the item in hand.
- 3) **Parking the car.** Take a picture of the floor number, etc.
- 4) **Traveling.** Take a picture of your hotel and nearest street sign. Helpful especially if you are somewhere where you don't speak the language.
- 5) **Important documents.** Take a photo of important documents that you are carrying with you when away from home in case you mislay the documents and keep them in a different place.
- 6) **Prescription names and numbers.** Take a picture of your prescription bottle or packet. Some pharmacies {USA} will even scan a picture of the barcode if you have a clear enough image. In UK if you are going away photograph and/or photocopy your last prescription before you hand it in for dispensing and take it with you.
- 7) **Receipt for items you need to collect.** Can't ever find those little slips of paper receipts for dry cleaning, coat checks, shoe repair shop. Take a picture of the receipt. I use this to remind me what I have where.
- 8) **Hotel room number.** Room key cards do not have the number on them, its only on the folder card you get with it. Take a picture of the room door.
- 9) Any other ideas?

#### **Vowel Oddities.**

- There is only one common word in English that has five vowels in a row: queueing.
- There are many words that feature all five regular vowels in alphabetical order, the commonest being abstemious, adventitious, facetious
- Rhythms is the longest English word without the normal vowels, a, e, i, o, u.
- "Asthma" and "isthmi" are the only six-letter words that begin and end with a vowel and have no other vowels between.
- I ate four large cans of Alphabetti Spaghetti and had a large vowel movement. ☺

## **The Care Bill 2013: a briefing - from Partners in Policymaking.**

**The Care Bill** brings care and support legislation into a single statute and reforms the funding of care and support in line with the Dilnott Commission's recommendations. There is a new principle of "wellbeing" being at the forefront of all care and support interventions. All aspects of wellbeing are covered: physical and mental health, dignity, respect, control over daily needs, access to education, employment. Social and domestic needs and housing. The Care Bill requires Local Authorities (LAs) to encourage the integration of care and support across health, local authorities, housing and other social care and community providers to ensure the best outcomes are achieved for people.

**The Care Bill** covers the following areas:

### **Improving information.**

The LA must provide comprehensive advice and information so that the public have a good knowledge of what services are available in their local area, can access financial advice and know how to raise safeguarding concerns. The LA will provide a commissioning strategy and a "market position statement" setting out what kinds of services are needed in the area and allowing providers to design services geared to local needs.

### **National Eligibility Criteria.**

Regulations are currently being drafted and will be published by October 2014 but it is expected that this will be set around substantial and critical. This is a subjective judgement so we wait for the regulations but it seems that it may be difficult to pin down a national benchmark from these subjective terms. The new duties around eligibility and assessment should make the LA's duties clearer. **N.B** All people will have the right to ask the LA to arrange their care irrespective of who is funding the care package and this could be a chargeable service if self-funders wanted their care arranged.

### **Personalisation.**

Everyone who is assessed and needs services should be provided with a support plan. If they are not eligible for services then they must be given advice and information on how to keep well/prevent further needs from developing. There is a legal right for all eligible people to receive a Personal Budget which sets out the full cost of the service(s). The LA has a legal duty to review all support plans.

### **Financial Assessments.**

The new regulations will ensure that everyone has their finances assessed in the same way.

### **Financial Capping Costs.**

Currently people pay their own care costs until their savings and assets reduce to a minimum. The Care Bill establishes a "cap" on care costs of £72,000 from a suggested date of April 2016. People will be responsible for their care costs, if they can afford it, up to the £72,000 cap after which they pay no more. Who can afford to pay towards their care costs is established, as currently the case, by a "means-test" process. If a person is living in a residential care home they will be expected to pay £12,000 a year towards general living costs but again only if they can afford it. People who self-fund their care but who want to start the clock ticking towards their care cap can request the LA for an assessment, a support plan and an Independent Personal Budget setting out the cost of their services. A Care Account will then be set up to track spend towards the £72,000. Care Accounts will be reviewed and updated annually. This will result in additional assessments being required in some form.

### **Safeguarding.**

There is a clear legal framework to protect adults at risk from abuse or neglect. All LAs must set up a multi-agency Safeguarding Board. This has been in place in Hartlepool for several years.

## **Carers.**

The Bill gives carers the same legal rights as service users. All carers will have their own assessment and they will be entitled to support if they have eligible needs and the person they care for lives in the local authority area. This replaces the existing law which says that carers must be providing “a substantial amount of care on a regular basis” in order to qualify for an assessment. Carers should receive a Personal Budget and be offered a Direct Payment in lieu of direct service provision. It is envisaged that this will trigger an additional number of assessments, support plans etc.

## **Moving areas.**

The Care Bill requires LAs to work together to ensure a smooth move with information being supplied to the receiving LA who must continue to deliver services against the current support plan until they have re-assessed the person’s needs. This is known as “portability” of assessments.

## **Transition from Child to Adult Services.**

Young people and their carers have the right to an assessment prior to the child turning 18 years. The Bill requires LAs to continue providing a person with children’s services until adult care and support is in place. Children who have had long term support needs will not be chargeable as adults i.e. a zero cap and working age adults will be eligible for a reduced cap

## **Provider Failure.**

LAs have a clear *temporary* duty to ensure both residential care and care services provided in a person’s home continue if the incumbent provider fails. This duty applies regardless of who is paying for the service.

## **Next Steps.**

A Programme Board will be set up with task and finish groups in place to deliver the changes required to deliver against the new requirements.

Training to prepare staff for the Care Bill and new ways of working will be commissioned in 2014.

The Care Bill will have less impact on Hartlepool Borough Council than on some LAs because adult social care in Hartlepool has continued to modernise services and embrace new ways of working over the last few years. So the relative scale of upheaval will be less than for some councils but it will still be a time of transformative change and significant challenge resulting in more assessments and work with self-funders, services that are focused on prevention wherever possible, services increasingly joined-up with our health partners and which actively work to prevent people’s needs from increasing and services that maximise wellbeing and independence. Self-help, support from families and neighbourly communities will be at the forefront of all interventions as a default position.

The Care Bill will go live from April 2015 except for the financial cap regime which is currently anticipated to run from, at the earliest, April 2016. [end of briefing from Partners in Policymaking]

## **Royal College of G.P’s calls for campaign to win support for care.data scheme**

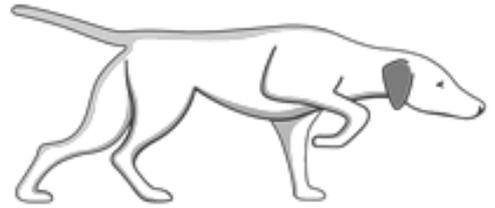
The RCGP has called for a major public campaign about the care.data scheme, warning that with just weeks to go until its official roll-out, patients have yet to be ‘properly informed’ about its benefits or their right to opt out. [Editors note. 19.2.2014 postponed till August see pages 8 & 9]

**British Medical Association** [BMA] says ‘It is the obligation of all GP practices to take action to raise patient awareness about care.data before data extraction begins in Spring 2014.’ [August 2014]

**UK PSN Members - Pages 8 and 9 have more information on CARE.DATA.** Did you receive the NHS England Better information makes Better Care leaflet? Did you read and understand the implications of this leaflet?

Have you heard anything from your GP Surgery about care.data?

# Benefits and Work Guides you can trust



## Excerpts from their February 12th Newsletter.

The first PIP [Personal Independence Payment] statistics are finally out - and they make for grim reading. Just **37%** of all PIP claims have been successful so far. And a disgraceful **85%** of claimants are still waiting for a decision, as the enormous backlog of cases grows uncontrollably.

But there is something perhaps even more worrying about the statistics - they suggest that the health professionals carrying out the assessments may have been massively nobbled after initially finding far too many claimants eligible for PIP.

Almost as dismaying is the news that, following three Freedom of Information requests, Benefits and Work can now confirm a story we originally published last October: claimants falsely accused of fraud face a strong probability of losing their DLA and being forced to claim PIP instead. In fact, the DWP have stated that even if they know that allegations are *'false and malicious'* they will still transfer the claimant to PIP if *'there remains a suggestion that the existing award is incorrect.'*

Staying with the theme of false allegations that ruin lives, many people will be astonished to learn that the former managing editor of the Sun and the disgraced and discontinued News of the World has been appointed as director of communications at the DWP. Does this mean even more references to 'handouts' in DWP press releases, we wonder?

One of the first things that the new director might want to work on is the DWP's social media campaign, after the department failed in its attempts to get a satirical twitter account closed and then take over the account for its own use.

Although the @UKJCP account was suspended by twitter, it has now been reinstated with an increased number of followers as a result of the publicity it has received. It now has almost as many as the DWP account that tried to get it closed down - and we'd be delighted if our members could push @UKJCP into the lead by following them today, before catching up on all the other benefits news below.

### ESA NEWS

Though in truth, we have almost no ESA news at all. Except to tell you that the House of Commons Work and Pensions Committee is launching an inquiry into ESA and the work capability assessment. Will you share your experiences with them?

### PIP AND DLA NEWS

For those of you who are about to claim PIP, we've updated our PIP guide for members to ensure you are as well prepared as possible.

The guide now gives you much more information about what happens at a PIP medical, including the questions you are likely to be asked and, more importantly, the questions you may not be asked but need to answer if you're to have any hope of getting the right award. Plus there's information on what's in the medical report form and what 'informal observations' the health professional is likely to be making whilst assessing you.

We're still looking for more PIP medical reports to study to help us understand what assumptions about claimants are built into the system. We're paying £10 for each one we receive, to cover your costs. But please don't send

## Your Newsletter needs your stories, hints, tips and bits

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 25th 2014**

anything without reading the details online or writing to them.

If you work for an agency and you have service users who are happy to consent to you sharing their anonymised reports, we'd also like to hear from you.

And we've also launched our PIP medicals survey, which we hope will help us monitor and dig even deeper into the truth behind PIP medicals. If you've had a PIP medical, please consider sharing information with us anonymously.

Finally, we've published clear information on the latest DLA to PIP reassessment areas which the DWP had managed to confuse everyone with.

### **BEDROOM TAX NEWS**

As the government introduces new regulations to close the bedroom tax loophole, a campaigner reveals that the number affected is likely to be massively higher than the 5,000 claimed by the coalition or even the 40,000 suggested by housing benefit specialists.

The same campaigner has also published the first decision by a first-tier tribunal bound by a recent upper tribunal ruling on the bedroom tax. Some commentators have interpreted the upper tribunal finding as meaning that a spare room is only a bedroom if it is actually used as one. It seems that the first-tier tribunal agreed, meaning that successful bedroom tax appeals may be about to skyrocket in number.

### **OTHER BENEFITS NEWS**

Channel 4 has revealed that more than 11,000 jobs on the Universal Jobmatch website which JSA claimants are forced to use may be bogus ones, put there by a businessman who then passes the applicants onto a CV library where he gets paid £1 for every CV submitted. In some areas these vacancies account for one third of all the jobs advertised.

Whilst we're looking at extraordinary statistics: so far universal credit (UC) **has cost £225,000 per person to implement**. Just 2,720 people are currently in receipt of UC, rather than the one million who were supposed to be receiving the benefit by April of this year.

Regular readers will know that we are supporters of the Wow campaign, which calls for a Cumulative Impact Assessment of Welfare Reform and a New Deal for sick and disabled people based on their needs, abilities and ambitions. Phase one was successful, and triggered the eligibility for consideration by the Back Bench Business Committee (BBBC). The next stage is to obtain the support of as many MPs as possible going into this debate, which will take place on 27 February. Michelle Maher has asked that Benefits and Work members write to their MPs to gain support. More details and links to standard letters online.

Citizens Advice have also launched their own campaign on the Work Capability Assessment which determines fitness for work and eligibility for ESA. They are calling on the Government to make Employment and Support Allowance (ESA) *fit for work*.

*"The Government is now deciding which companies will run the tests that determine people's ability to work. Without significant improvements we risk facing another five years of failure. Change is needed now to make sure the tests are fair, consistent and right first time."*

### **Benefits and Work - [www.benefitsandwork.co.uk](http://www.benefitsandwork.co.uk)**

At a time when most politicians seem proud to treat sick and disabled claimants with harshness and suspicion, independent and accurate information about how to claim and keep your benefits is vitally important.

Benefits and Work, was launched in 2002 (and became a limited company in October 2006) by advice worker turned barrister Holiday Whitehead and benefits writer and trainer Steve Donnison, to provide just such information.

It is unique amongst benefits information providers in that it asks for no funding or support from the government, local authorities, grant making trusts or large companies. Every penny of Benefits and Work's revenue comes from its subscribing members.

This complete independence means that Benefits and Work is free to publish information that makes it deeply unpopular with the Department for Work and Pensions, multinationals with an interest in benefits - such as Atos Healthcare, Unum Provident and Capita - and even other advice providers whose dependence on state and corporate funding may have made them reluctant to tell the whole truth.

Remember from 10th June 2013 adults over 16 can no longer apply for DLA you have to apply for PIP. All those in receipt of DLA will gradually be contacted to claim PIP instead most probably from 2015.

Become a member and get access to all their leaflets and advice £19.95 a year. Subscribe online or write to Benefits & Work Publishing Ltd, PO Box 4352, WARMINSTER, BA12 2AF



## Val Scrivener Photo Card sales



### Back pages of Newsletters show many choices.

You may now be familiar with the publicity given in each Post Polio Matters Newsletter to sales of Photo Cards and to the fact that the sales of these cards actually raises funds for PSN. Sadly, very little of the money is raised by sales to members. In all I have sold, since the publicity began, around fourteen packs of cards to PSN members, the rest of the money raised comes from monthly sales of cards at my local church where I have built up a regular clientele, people who come to the stall to 'stock up' for the next month's cards/notelets.

The cards take note of the seasons so current sales include snowdrops and daffodils. I am aware that animals are popular, particularly cats and horses, naturalists tend to go for wild flowers, lizards or butterflies, garden flowers/unusual garden pots etc. are always popular and shots with the gentlemen in mind include steam trains, traction engines, buses, vintage cars and even the odd bicycle.

Anyone ordering a pack of cards may specify preferences (someone recently requested 'no trains') and this is fine - I am quite happy to make up mixed packs/made to order packs - but please order something. How about 'Mixed birthdays', 'Xmas Selection', 'Animals and Flowers'. Hilary has changed the pictures on the back pages of the Newsletter many times giving you more info on the choices. The cards, by the way, do come with envelopes and a sticker sold in aid of Polio Survivors Network.

I make no gain whatsoever on the sale of these cards, in fact I would say that I probably run at a slight loss as I keep the cost low to encourage sales. It would be really heartening if, following publication of this bulletin, I am rewarded by just a few orders. Please?!!

In hope, Val [contact details on back page].

### **The End of Plagues - The Global Battle Against Infectious Disease by John Rhodes.**

A Post-Polio News Recommended Read. [See back page]

#### **The Book.**

At the turn of the twentieth century, smallpox claimed the lives of two million people per year. By 1979, the disease had been eradicated and victory was declared across the globe. Yet the story of smallpox remains the exception, as today a host of deadly contagions, from polio to AIDS, continue to threaten human health around the world. Spanning three centuries, *The End of Plagues* weaves together the discovery of vaccination, the birth and growth of immunology, and the fight to eradicate the world's most feared diseases. From Edward Jenner's discovery of vaccination in 1796, to the early nineteenth-century founding voyages in which chains of orphans, vaccinated one by one, were sent to colonies around the globe, to the development of polio vaccines and the stockpiling of smallpox as a biological weapon in the Cold War, distinguished immunologist John Rhodes charts our fight against these plagues, and shows how vaccinations gave humanity the upper hand. Today, aid groups including the Bill and Melinda Gates Foundation and the World Health Organization have made the eradication of polio a priority, and Rhodes takes us behind the scenes to witness how soon we may be celebrating the eradication of polio.

#### **The Author.**

John Rhodes is an international expert in immunology and vaccination, and has held research fellowships at the US National Institutes of Health and the University of Cambridge. From 2001 to 2007 he was director of strategy in immunology at GlaxoSmithKline, a leading multinational healthcare company. He is a fellow of the Royal College of Pathologists, has been published in *Nature*, *Science*, and the *Lancet*. He lives and works in Cambridge, UK.

#### **For Reviews and Where to Buy:**

<http://www.post-polio.org.uk/theendofplagues.html>

# Management Committee [Trustees] and Operations Team

## Management Committee [Trustees]

Chair - Simon Parritt - [simon.parritt@poliosurvivorsnetwork.org.uk](mailto:simon.parritt@poliosurvivorsnetwork.org.uk)

Secretary - Hilary Boone - [hilary.boone@poliosurvivorsnetwork.org.uk](mailto:hilary.boone@poliosurvivorsnetwork.org.uk)

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Trustee - Chris Salter - [chris.salter@post-polio.org.uk](mailto:chris.salter@post-polio.org.uk)

Trustee - Dorothy [Dot] Ives - [dot.ives@poliosurvivorsnetwork.org.uk](mailto:dot.ives@poliosurvivorsnetwork.org.uk)

## Operations Team

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Administrative Support - Gillian Bryan - [gillian.bryan@poliosurvivorsnetwork.org.uk](mailto: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](mailto: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

*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.
- Some members send us a donation with some specifying, e.g. for AGM, for Conference.Fund
  - UK Taxpayers can Gift Aid their subscription and donated amounts.
- **NEW CONFERENCE & MEETING FUND - See Editorial**

**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.

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# Polio Survivors Network

Lincolnshire Post Polio Network - Registered Charity No. 1064177

Website - [www.polfosurvivorsnetwork.org.uk](http://www.polfosurvivorsnetwork.org.uk)

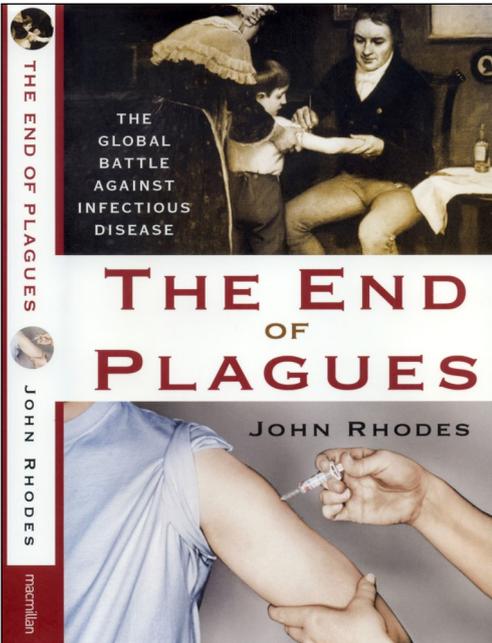
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A Post-Polio News  
Recommended Read  
**The End of Plagues**  
by John Rhodes.  
Page 9.



Some books are to be tasted,  
others to be swallowed,  
and some few to be chewed  
and digested.  
Sir Francis Bacon

## Post-Polio Health International - Polio Place - List of over 140 Books

The Books section includes volumes written by physicians and researchers about the late effects of polio and post-polio syndrome. Numerous biographical and autobiographical works about the polio experience dating from the 1950s to present are also listed.

<http://www.polioplace.org/resources/books?page=14>



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