



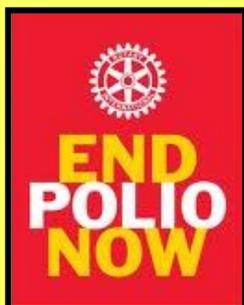
**OCTOBER
2014**

Vol 8, Issue 6

**WE'RE
STILL
HERE!**

October 12-18, 2014
www.post-polio.org

Links to
extensive
PPS info
PowerPoint
Posters
Videos
Pages 6 to 9



Home of the
Lincolnshire
Post Polio
Library



Enter 100+ articles

POST POLIO MATTERS

because on

World Polio Day - 24th October 2014

WE'RE STILL HERE!

We're Polio Survivors from before

“April 12th 1955 when Dr. Thomas Francis Jr
announces Salk polio vaccine up
to 90% effective in preventing paralytic polio”

**or caught it since then because
unvaccinated or from live vaccine.**

**Post Polio Matters because
after 15+ years of best recovery
many of us are experiencing
new symptoms of functional decline
Post Polio Syndrome**

**Since our last Newsletter
24th August to 15 October
Polio Totals 2014 increase by 66%!
from 146 to 243!**

**Pakistan 115 to 206, Afghanistan 8 to 12
Nigeria 5 to 6, Somalia 4 to 5
Equatorial Guinea and Cameroon remain at 5
Iraq at 2, Ethiopia and Syria at 1**

<http://www.polioeradication.org/dataandmonitoring/>

Polio Survivors Network Newsletter - Volume 8, Issue 6/12
n.b. Volumes 1 to 6 published under the name LincPIN.
www.poliosurvivorsnetwork.org.uk

**NEW VIDEOS
On
POST POLIO
SYNDROME**

Pages 6 and 7

**www.
polioplacement.org/
post-polio-
experts-present
-video-series**

Page 8

**polioque-
bec.org/
home**

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**Mobility
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Returns
In
2015**

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**Post Polio
News
ppn
www.post-
polio.org.uk**

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New Members and Donations received.

Thank you to all members who have recently renewed.

Thank you to the following for donations given towards our work

mid August to end October 2014.

Member donations

Ann Revell
Victor Gabriel
Ann Telford

Total of donations for 2014 so far is £1,368.50

Val Scriveners Photo Cards raised £ 75.80

See back page of all newsletters for ordering info and samples.

Thank you very much

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

Newsletter is out a month early so you receive it by **World Polio Day, October 24th 2014.**

Post-Polio Health International and **Polio Quebec** have produced some new videos for health professionals and polio survivors. For more information see pages 6 to 8.

Page 9 contains the links to the **Breathing & Sleep Symposium videos, 2009, 2010, and 2011** on poliotoday.org. I would mention that it is not just polio survivors that were told they had bulbar polio that can have sleep, swallowing and respiratory problems. Richard and I and many other polio survivors, including those who were told they had non paralytic polio have issues in these areas now. [It took me ten years and three hospital appointments and the third where I provided information before my swallowing issues were confirmed]. I have highlighted two important phrases below. It is also essential that you are adequately tested because Richard and other polio survivors have been told they have no problems to find out at later assessments that they did. Two leads is not an adequate sleep study for a polio survivor. [Richard had a few lung function tests, none on his back, in a Lung Function Center in the States told no problems then **48 hours later** following an multiple channel sleep study received a phone call, 'Sorry you were right, he has severe mixed sleep apnoea and he needs a ventilator now.]

Breathing & Sleep Symposium 2009 - People with neuromuscular conditions often encounter difficulties seeking and obtaining proper respiratory care. Too often, primary care physicians, neurologists and respiratory care professionals treat their respiratory problems as a lung issue, rather than as a muscles/nerve problem. And too often, sleep labs look only for obstructive sleep apnea and **miss under ventilation**.

Breathing & Sleep Symposium 2010 - The challenge of understanding how to correctly test and treat patients experiencing neuromuscular respiratory compromise falls mainly on pulmonary doctors, neurologists, and respiratory therapists. However, **equal responsibility lies with patients to learn all they can** to contribute to their own wellness. Putting tools in the hands of patients is a crucial first step in this learning/teaching process.

I have then added the link to the Powerpoint presentations, Posters, and Videod presentations at both European Polio Conferences, 2011 and 2014. This provides you, your family and friends, and health professionals with a lot of information and as it says above it is up to us to learn as much as we can to help us manage our lives to the best that we can.

We do appreciate that there are members who do not have access to the Internet themselves but we hope they may have a family member or friend who can help. If you do not have either then please ring our charity line so we can discuss how we can help you access these.

We include a page with some excerpts from Post Polio News [**ppn** at www.post-polio.org.uk] each newsletter. This is an online news cutting service by Chris Salter [who provided us with the Lincolnshire Post-Polio Library and manages the technical side of our email list] that specialises in news relating to polio, post-polio, disability and other health related issues. There are various ways that you can read the information. I get a daily email, I do Facebook but do not have the time to learn how to 'tweet.' Chris stepped in as a Trustee a couple of years ago whilst we sought more Trustees to continue our work. He has stayed longer than he intended but now wishes to concentrate the hours of energy he has on Post Polio News which has an international following. He is therefore standing down as a Trustee but still has a few tasks that he will complete and he will be there for advice when we need it. I would like to express my personal thanks for hours and hours of work without which Polio Survivors Network would not be what it is. See Simon's report over the page.

PSN PHONE and/or EMAIL PALS

I don't know if members realise but when a group of Polio Survivors get together at conferences, email lists, Facebook groups etc that we chat and share all sorts of things and often laugh till our ribs ache. Talking with someone who understands what it is like to live with the issues of PPS means not having to explain why you can or can't do this or that. We have tried this before shall we try again? Carers or Family members would you like to talk to others in the same position?

MESSAGE FROM OUR CHAIRMAN - Simon Parritt

I begin with a big thanks to Chris Salter, who after many years being involved in PSN, lately stepping in again as a Trustee when we were desperately in need of more Trustees, has decided to stand down to concentrate on his other pps work. As a relatively newcomer to the management side of PSN as Chair of Trustees, I will miss Chris' sharp and incisive mind when looking at issues. There have been many occasions when something will almost slip by our attention and Chris would pick it up and ensure that we are aware and give it due thought. So on behalf of the Trustees and the membership in general a big thank you to Chris and hope that this will free you up to concentrate more on other projects, like your very successful Post Polio News service.

Recently, I was invited to see the new unit in Surrey which will be a satellite of the St. Thomas Lane Fox Unit. It provides what I can only say is an amazingly light and modern friendly atmosphere, with what looks like state of the art facilities and in a rural setting. If you have to be in hospital this would be the five star hotel version. As I went round with a few others, I was thinking how much we need accurate, modern and experienced healthcare when it comes to assessment and treatment for polio and other neuromuscular conditions. There still seems so much variability and lack of understanding, not just about PPS and muscle testing, but even the basic respiratory problems associated with post polio.

I would be interested in hearing if any of you have had problems in this area. I have a concern that the assessments for post polio people has been patchy. Most especially helping us with getting used to it emotionally and practically by offering the right machine, mask or other interface and then monitoring how we get on with it not just physically but psychologically and emotionally as well. As I mentioned to someone a little while ago, I have used BiPap for 16 years and still sometimes throw my mask across the room with frustration! I guess as a psychologist, it is my 'hobby horse' that we need a little more psychological and emotional care and understanding. I know it isn't always a doctors' strong point, and then maybe we are a little reluctant to admit we need it, not a good combination for change!

We have included in this newsletter a lot of information and videos, especially on respiratory issues, that we are sure will be of interest. Please get in touch with us by email or letter if you have any concerns about any of your issues, especially swallowing, respiratory and sleeping problems.

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

Chartered Psychologist

HCPC Registered Counselling Psychologist

www.sp-psychology.com

Simon Parritt <simon.parritt@poliosurvivorsnetwork.org.uk>

Good Article on Post Polio Syndrome for health professionals

Written by Doctors for Doctors

www.patient.co.uk/doctor/post-polio-syndrome

The Bathtub Test

During a visit to the mental asylum, I asked the Director, "How do you determine whether or not a patients should be institutionalised?" "Well", said the Director, "we fill a bathtub, then we offer a teaspoon, a teacup and a bucket to the patient and ask him or her to empty the bathtub."

"Oh, I understand," I said, "A normal person would use the bucket because it's bigger than the spoon or teacup."

"No," said the Director, "A normal person would pull out the bathplug. Would you like a bed near the window?" 😊

Money saving tips by disabled people for disabled people

See Scope website - community.scope.org.uk/tips

- Go to Disabledgear.com and Disabilitybits.co.uk to buy second-hand specialist equipment at bargain prices. It's also free to advertise stuff you no longer use.

For example, say you need a Rollator – a walking aid with wheels. They cost around £265 new but on DisabledGear you can find them for £80.

- Borrow expensive equipment before you buy. A local school/college or day centre may be willing to lend it to you.
- Charities, including The Newlife Foundation for children (newlifecharity.co.uk) and Cerebra (cerebra.org.uk) offer grants towards specialist equipment, toys and services.
- Abilitynet (abilitynet.org.uk) gives free IT support including advice on how to apply for grants for specially adapted computer equipment, and a list of organisations to apply to. Its free helpline is on 0800 269 545.
- Computers for the Disabled (cftd.co.uk/cftd.htm) supplies recycled PCs and new parts to the disabled and housebound.
- Filling in the disability living allowance (DLA) claim form can be a daunting task. But the step-by-step guide from Cerebra makes the job easier. Call 0800 328 1159 or email info@cerebra.org.uk to request a printed copy or you can download it and print it out yourself.
- Some hotel groups such as Travelodge, Premier Inn and Jurys Inn allow three adults to share a family room which is ideal if you need to supervise the person you are caring for and great for cheap short breaks.
- Specialist shoes can be free. Check with your physio or orthopaedic surgeon.
- When visiting attractions, ask ahead if they offer any concessions for the disabled. Most offer discounts, special access, and carers-go-free tickets.
- Search for grants towards the cost of equipment, holidays, housing, and days out at Disability Grants (disability-grants.org).
- Sponge hair rollers are a fantastic and cheap way to help improve grip on tricky objects. Just slot the sponge hair roller through a fork, toothbrush etc.
- Some people may not be aware that incontinence aids such as pads and bed protection sheets are available free in some areas on the NHS. To find out if you are eligible, ask your local district nurse (get details at your GP surgery) for an assessment.
- Large changing mats can be expensive. Try a waterproof picnic blanket, much cheaper and easy to keep clean.
- Baby wipes cost a small fortune and we get through thousands so we buy them in bulk using Amazon's "subscribe and save" feature which offers a discount of up to 15% and free regular deliveries.
- I've been looking for a writing slope for ages but didn't want to pay £40 plus. I finally found one in Ikea called BRÄDA for £2.50 that is meant for a laptop, but does the job!
- Since therapeutic chairs are so expensive, I made my toddler a little play station with a Bumbo seat bumbo.com and a tray with legs that is used for eating in bed. The tray has a table that can incline towards him to draw or do puzzles, and I use it flat for playing with blocks.

For more tips on saving money go to community.scope.org.uk/tips

After a year of being really ill and having multiple hospital trips the doctor finally gave me some good news. I'm going to have a disease named after me.

**WE'RE STILL HERE 12th to 18th October 2014 www.post-polio.org
<http://www.polioplace.org/post-polio-experts-present-video-series>**

“Post-Polio Experts Present” informational videos by dedicated experts who have significant experience in managing post-polio problems and in advocating for the survivors of polio. The presenters provide information and advice to the health professionals who treat polio survivors and also to survivors and their families.

Oct 12th - Components of a Post-Polio Evaluation by Frederick M. Maynard, MD.

Dr. Maynard is a semi-retired board-certified physiatrist with more than 35 years of experience in the evaluation of polio survivors. He founded one of the first Post-Polio Clinics at the University of Michigan Medical Centre in 1983 and has written and lectured extensively about the late effects of polio. He has served on the Board of Post-Polio Health International for more than 25 years and has been involved with planning and speaking at all 11 of its international conferences. His current work has involved promoting Health and Wellness Retreats for aging polio survivors in the US and abroad.

Oct 12th - Relationships by Stephanie T. Machell, PsyD

Dr. Machell is a psychologist in independent practice and consultant to the International Rehabilitation Center for Polio (RCP), Spaulding-Framlingham Outpatient Centre, Framingham, Massachusetts. She specialises in working with medical trauma, physical disability and chronic illness. Her father was a polio survivor. She discussed how to deal with the fears polio survivors may face when they think about pursuing intimate relationships.

Oct 13th - Components of Comprehensive Post-Polio Management by Carol Vandenakker-Albanese, MD

Dr. Vandenakker-Albanese is a Health Sciences Clinical Professor and the Residency Program Director and Director in the Department of Physical Medicine and Rehabilitation; and the Director of the Post-Polio Clinic at the University of California, Davis Medical Center. She established a Post-Polio Clinic at the University of Miami in 1993. With her move to Sacramento in 2001, she established a Post Polio Clinic at UC Davis Medical Center. She is board certified in Physical Medicine and Rehabilitation and her clinical practice encompasses diagnosis and non-operative treatment of spine conditions and post-polio related problems. Her research and publications have focused on exercise, post-polio syndrome, and aging with disability. She lectures locally and nationally on issues regarding polio survivors and serves on the Post-Polio Health International Medical Advisory Committee.

Oct 13th - Disability Affirmative Therapy by Rhoda Olkin, PhD

Dr. Olkin, Distinguished Professor, California School of Professional Psychology and Institute on Disability & Health Psychology, is a licensed psychologist and polio survivor. She trains therapists and works as a psychotherapist. Her video is an overview of an approach to working with clients with disabilities and chronic illnesses that guides therapists through the information they should gather from clients to help put disability into the proper perspective for each individual.

Oct 14th - The Importance of Posture by Holly H. Wise, PT, PhD

Dr. Wise is a Professor in the Division of Physical Therapy, College of Health Professions, at the Medical University of South Carolina in Charleston. A graduate of Wake Forrest University, Duke University, and the University of Miami. Dr. Wise has worked with individuals with a prior diagnosis of polio for over 30 years and has co-founded two interprofessional post-polio evaluation clinics.

Oct 14th - Self-Advocacy and Community Advocacy by William G. Stothers.

William Stothers is a long-time editor and consultant on media and disability policy. He edited Mainstream, a national advocacy and lifestyle magazine for people with disabilities and worked at a major newspapers in Toronto and San Diego. He is a member of the Board of Directors of Post -Polio Health International and currently serves as Chair

Oct 15th - Polio and Anesthesia by Selma Calmes, PhD.

Dr. Calmes is an experienced anesthesiologist, now retired as Chairman and Professor, Department of Anesthesiology, Olive View-UCLA Medical Center, Sylmar, California. She has consulted on numerous surgical cases of polio survivors over the last 20 years.

Oct 15th - Developing a Personal Philosophy about Disability by Lawrence C. Becker, PhD.

Larry Becker is a Fellow of Hollins University and Professor of Philosophy Emeritus, College of William and Mary. His teaching and writing in academic philosophy has focused on ethics, social and political philosophy, and legal philosophy. He had respiratory polio at the age of 13 (class of 1952), and has had an association with PHI since its beginnings serving on its board of directors from 2000 to 20011. His most recent book is titled *Habitation, Health and Agency: a Framework for Basic Justice*. His presentation connects some themes from that book to his personal reflections on living with a disability.

Oct 16th - Ways to Avoid Respiratory Complications of Postpoliomyelitis by John R. Bach, MD

Dr. Bach is the Medical Director of the Center for Non-invasive Mechanical Ventilation at Rutgers New Jersey Medical School in Newark, New Jersey. He has written and spoken extensively about non-invasive ventilation and neuromuscular disease.

Oct 16th - Growing Older with Grace, Audrey J. King, MA (Psych)

Audrey King is a polio survivor and retired psychologist from Toronto's Holland Bloorview Children's Rehabilitation Hospital. Over the years she has served on boards, consulted to many government committees, and authored several books in addition to writing and lecturing internationally on a broad range of disability issues.

Oct 17th - Sleep Hygiene by William de Mayo, MD

Dr. DeMayo, a physical medicine and rehabilitation specialist is the Medical Director of the Post-Polio Clinic, Conemaugh Health System, John P. Murtha Neuroscience and Pain Institute, Johnstown, Pennsylvania.

Oct 17th - Spirituality in Disability by Cyndi Jones, MDiv

Cyndi Jones is a polio survivor and long-time advocate for people with disabilities. She has a Master of Divinity from the Episcopal Divinity School and current in the ordination process for the Evangelical Lutheran Church of America (ELCA). In 2013 she developed "A Place at the Table" a workshop to assist churches in welcoming people with disabilities. In 2011, her paper, "Because no one will hire us, a reflection on The Laborers in the Vineyard" was selected for presentation at the American Academy of Religion. "Will I recognise the Image of God?" was published in 2014 in the *Journal of Disability and Religion*. She is currently working on how "time as a commodity" affects the poor.

Oct 18th - Are Polioviruses playing a pathogenic role in the late consequences of polio by Antonio Toniolo, MD, FAMH [English and Italian versions]

Dr. Toniolo, Professor of Medical Microbiology, University of Insubria, Varese, Italy is the recipient of PHI's 2014-2016 Research Award.

Oct 18th - Poliomyelitis by Sheila Jean McNeill Ingham, MD, PhD [Portuguese]

Dr. Ingham, Universidade Federal De São Paulo, São Paulo, SP, Brazil, discusses the status of polio and post polio in Brazil.

The series "**Post-Polio Experts Present**" was underwritten by a grant from the Roosevelt Warm Springs Foundation.

Post-Polio Health International www.post-polio.org
Including International Ventilators Users Network. www.ventusers.org/
4207 Lindell Blvd., #110, Saint Louis, MO 63108-2930 USA 314-534-0475
info@post-polio.org (*Inquiries should include name and mailing address.*)

POLIO QUÉBEC RELEASES A VIDEO ABOUT POST-POLIO SYNDROME

Dr. Christiane Laberge, GP and television medical commentator explains this little known syndrome.

Montreal, October 14th 2014 – Thousands of Quebecers who contracted polio are at risk of developing Post-Polio Syndrome, or may already suffer from it unknowingly. This little-known syndrome is the subject of a new video released today by the Polio Québec Association.

Post-Polio Syndrome (PPS) appears in a large proportion of people who contracted paralytic polio, after at least 15 years of stability. It can take the form of increased fatigue, new muscle weakness and new pain. PPS is often overlooked because its symptoms are similar to those caused by aging. A large number of people who have had polio do not know about PPS, a syndrome that has only received greater attention from the medical community since the 80's. Still, health professionals today are generally not well aware of PPS symptoms and its recommended treatments.

The video released today presents polio and PPS to the public through the words of Dr Christiane Laberge, General Practitioner and regular health commentator on television and radio programs. Also featured are four individuals who had polio, each with a different story and background.

This launch constitutes the first step in a communication strategy designed to raise awareness in the public, those at risk of developing PPS and their families as well as health professionals. People at risk include not only individuals who had polio in Québec, but also those who have settled here from other countries where they contracted polio more recently.

Pending financing, in 2015 Polio Québec plans to launch an e-learning module for health professionals such as physiotherapists, occupational therapists and nurses.

The video is available in French and English (subtitles) on www.polioquebec.org or directly on YouTube at

Prior to visiting a new health professional

It can take a polio survivor a long time to accept that they do have new problems and do need medical help to find out what is wrong. Here are some suggestions to get the most out of the allotted time.

First find out how long the appointment is scheduled for and if there are any tests that you will have to undergo. To reduce your stress finding a parking place it is a good idea to get someone to drive you there. To make sure you are not exhausted when you arrive, if you use electric wheels let them unload them for you and if you are walking with a cane or crutches and the distance from the car is over your comfortable limit then allow them to push you there in a manual chair.

Make up a sheet of information [offering a copy to the health professional in case it would be helpful]. Start with the place, date and time of the appointment and your contact details.

The first thing a health professional needs to find out is your medical history.

Add your basic medical details:- Diagnoses and year.

Medication including the dose and frequency and why you are taking this medication.

Any allergies or intolerances.

The next thing they will want to know is why you are at this appointment.

Think about what happened in your life that triggered this. It is better not to be general, e.g. saying my legs are weaker but to be specific about the actions of daily living that you have noticed you are doing in a different way. Maybe you were able to walk up and down stairs as a normal person but now you are going one step at a time right foot first and also having to stop half way for a rest and recently noticed you are having to pull yourself up with the bannister rail as well

Write down the three most important issues starting with the most important. If there is time you can mention all three. If you can demonstrate the way you are doing it now and explain how you used to do it then that would be helpful.

Take someone with you to make notes and with agreement remind you of anything you have forgotten.

Videos at PolioToday.org Presented by the Salk Institute

The Breathing and Sleep Symposiums, 2009, 2010, 2011 hosted by the Salk Institute for Biological Studies are focused on solutions for people with neuromuscular disorders such as post-polio syndrome, ALS, MS and muscular dystrophy.

2009 - People with neuromuscular conditions often encounter difficulties seeking and obtaining proper respiratory care. Too often, primary care physicians, neurologists and respiratory are professionals treat their respiratory problems as a lung issue, rather than as a muscles/nerve problem. And too often, sleep labs look only for obstructive sleep apnea and **miss under ventilation**.

- Solutions to Breathing and Sleep Problems: Finding the right Ventilator for the Right Problem at the Right Time. Noah Lechtzin, MD and Louie J. Boitano, RRT.
- Breathing and Sleep: What's the Problem? What Tests are Needed? Noah Lechtzin, MD
- Respiratory Muscle Weakness in Neuromuscular Conditions. Geoffrey Sheean, MBBS

2010 - The challenge of understanding how to correctly test and treat patients experiencing neuromuscular respiratory compromise falls mainly on pulmonary doctors, neurologists, and respiratory therapists. However, equal responsibility lies with patients to learn all they can to contribute to their own wellness. Putting tools in the hands of patients is a crucial first step in this learning/teaching process.

- Neuromuscular Disease and Breathing, Joshua O. Benditt, MD
- Helen Kent, BS, RRT, Progressive Medical, [35 years experience in field of Sleep Disordered Breathing.
- Gladys Swensrud, Polio Survivor Award for instigating and organising the Symposium
- Anaesthesia and Post-Polio Syndrome, Selma Calmes MD and Polio Survivor.
- Successful Post-operative Course Starts Long Before Surgery, Joshua O Benditt, MD, FCCP
- Ventilation modes and special features. Angela King, BS, RPFT, RRT-NMS!
- A review of Interfaces: How to choose one... or better yet, two! Louie J. Boitano, MSc, RRT

2011 -

- Breathing A to Z - Explaining the breathing process, Joshua O. Benditt, MD, FCCP
- Explaining the effects of Sleep Disordered Breathing - Anthony DeMaria, MD.
- Which ventilation equipment is appropriate for your needs? Angela King, BS. RPFT, RRT-NPS
- How various breathing machines work, Karyl Scott, RRT.

Other Videos on PolioToday.org are Personal stories from Polio Survivors and..

Expert Opinions by Susan L. Perlman, M.D.

- "What type of physician can best diagnose PPS?"
- "What are some self-assessment tests for PPS?"
- "Are there any new PPS treatments on the horizon?"
- "Can PPS be treated with medications?"
- "What type of exercise is beneficial to PPS patients?"
- "What are the recommendations to effectively manage PPS?"
- "Which diagnostic tests are performed on bulbar polio survivors?"
- "Can blood tests help diagnose PPS?"

European Polio Conferences

PowerPoint Presentations, Posters & Videos at www.polioconference.com

All Abstracts in *J Rehabil Med Supplements*

First Conference Copenhagen 2011 - J Rehabil Med 2011; Suppl 49: 1-64

2nd Conference Amsterdam 2014 - J Rehabil Med 2014; 46: 568-608

37 Videos at www.informed-scientist.org/congress/2nd-european-polio-conference

The effects of Cold on Polio Survivors by Richard L Bruno PhD.

Polio survivors are extremely sensitive to changes in temperature. At merely cool temperatures, **most** polio survivors report that their feet have always been cold to the touch, their skin a purplish color. However, as polio survivors have aged, 50% report “intolerance to cold” and that their limbs have become more sensitive to pain as the temperature decreases. Cold was reported to cause muscle weakness in 62% of polio survivors, muscle pain in 60%, and fatigue in 39%. When polio survivors were cooled in the laboratory from 86degrees F to 68 degrees F, motor nerves functioned as if they were at 50 degrees F and polio survivors lost 75% of their hand muscle strength.

But, although polio survivors are twice as sensitive to pain as those without polio, no increase in pain sensitivity was found at lower temperatures. The reason polio survivors have such trouble with cold is that the parts of the central nervous system that should control body temperature were damaged by the poliovirus. In the brain the hypothalamus (the “automatic computer” that controls the inner bodily environment) was damaged by the poliovirus, including the body’s “thermostat” and the brain area that tells your blood vessels to constrict.

In the spinal cord, the nerves that carry the message from the brain that tells the capillaries in the skin to contract when it’s cold were also killed by the poliovirus. Thus, polio survivors are unable to stop warm blood from flowing to the surface of the skin as the outside temperature drops. This allows loss of heat from the blood near the surface of the skin and causes the limbs to cool. When the limbs cool, arteries carrying blood to the skin and veins that should carry blood out of the skin narrow passively as they get cold, trapping blue venous blood in the capillaries and causing the feet to look blue and to become even colder. The cold skin chills the motor nerves, causing them to conduct more slowly and to be less efficient in making muscles contract. The cold also chills tendons and ligaments (like putting a rubber band in the freezer) making movement of weak muscles more difficult.

As polio survivors know, it takes hours under an electric blanket or a long, hot bath to warm cold legs and regain strength. However, when polio survivors take a hot bath, blood vessels do exactly the opposite of what they do in the cold. Polio feet and legs become bright red as arteries and veins relax and blood rushes to the skin. Then, when polio survivors stand to get out of the tub, they can feel dizzy or even faint as blood pools in their legs and causes their blood pressure to drop.

The pooling of blood in the feet also explains why polio survivors’ feet swell, swelling that increases as they get older. And polio survivors’ easily losing body heat explains why they have an increase in symptoms, especially cold-induced muscle pain, as the seasons change. Polio survivors need to dress as if it were 20o F colder than the outside temperature. They need to dress in layers and wear heat retaining socks or undergarments made of polypropylene (marketed as Gortex or Thinsulate) that should be put on immediately after showering when the skin is warm.

Polio survivors need to remind doctors that EMGs or nerve conduction tests must be performed in a room that is at least 75 degrees F to prevent false abnormal readings and that a heated blanket is necessary in the recovery room after polio survivors have surgery

100th Anniversary of Polio Vaccine Pioneer birth.

Jonas Edward Salk (October 28, 1914 – June 23, 1995)

Jonas Salk was an American medical researcher and virologist. He discovered and developed the first successful inactivated polio vaccine. He was born in New York City to Jewish parents. Although they had little formal education, his parents were determined to see their children succeed.

While attending New York University School of Medicine, Salk stood out from his peers, not just because of his academic prowess, but because he went into medical research instead of becoming a practicing physician.

Disabled Motoring UK - October 2014 Newsletter Excerpts
National HQ, Ashwellthorpe, Norwich, NR16 1EX 01508 489449
www.disabledmotoring.org

The following are excerpts from the DMUK October 2014 newsletter. Always a good read and providing a lot of useful information. Membership starts at £24 per year with Joint Membership for 2 people at £36. We rang to book and pay for our trip to Amsterdam and it was an easy process and the whole process including booking in, parking and accessible room went without a hitch.

1. **Tackling Blue Badge Fraud** - Legislation introduced last year in England and Wales. Scotland introduces it this year. See DM Website for a sample letter to send to your MP if your council has not taken steps to stamp out the abuse. Estimated one in five badges being abused. Civil Enforcement Officers can now inspect and retain Blue Badges without a police presence if they think they are being misused or abused.
2. **Applying for a Blue Badge** - There is no charge to apply for a Blue Badge but if the application is successful there is an administration charge of £10 [£20 in Scotland] when the badge is dispatched. Some fake websites are charging for applications. Apply to your local council or on gov.uk/apply-blue-badge
3. **Abolition of the Driving Licence Paper Counterpart** from 1st January 2015, www.gov.uk/government/news/driving-licence-changes
4. **Air Passengers' Rights** - The Equality and Human Rights Commission (EHRC) has produced 'Your passport to a Smooth Journey', a pocket sized guide that explains how disabled people can use the law and secure best practice in order to get the best service possible when travelling by air. See www.equalityhumanrights/airtravel Also available 'Your Rights to Fly' plus a short questionnaire enabling you to share your experience of air travel.
5. **Mobility Roadshow Returns** - Donington Park from 25th to 27th June 2015. Also includes the Get Going Live event for young and novice disabled drivers with an all important test drive facility on the Donington Park circuit. Plus stands on wheelchairs, mobility scooters, and other innovative aids for independent mobility, www.mobilityroadshow.co.uk
6. **Volkswagon Panorama**. Drive-from Hi top roof, 4 berth Volkswagon wheelchair camper, www.vwpanorama.co.uk
7. **4" or 6" Buddy Car Step** by Rednewt. For those higher vehicles that are difficult to get in and out of, www.red-newt.com or phone 01332 410011.
8. **Does your car have a spare wheel?** I was shocked to learn that some new cars come without one so that they can reduce the weight of the car and lower the carbon dioxide emissions.
9. **Some of the new Taxis in London are not suitable for disabled passengers** ... a higher ground clearance too high for accessibility and/or ceiling too low for head clearance. These are very serious barriers and need to be recognised and addressed. Letter on page 14. The DMUK Editor is raising this and other issues and will continue to do so.
10. **Cars no longer require tax discs** ... If you have a mobility scooter capable of more than 4mph you need to register with the DVLA and up to now you received a tax disc. DVLA document (INF211) helps you complete the V55 form for a used scooter.
11. **Travelling to Europe with a motor vehicle**. Are you aware that there are different rules in each country as to what equipment you need to carry. We were en route to Amsterdam this June when we saw a kit in the shops and realised that we had forgotten to check this. Thank goodness the Ferry shop had kits for sale but I have just read on page 19 that we were supposed to carry the original log book with us. Phew.... Plus did you realise that if your GPS based navigation system has maps indicating the location of fixed speed cameras this function must be deactivated. Visit www.theaa.com/motoring_advice/touring_tips/compulsory_equipment.pdf DMUK sells a European Kit and a Winter Kit.
12. **Travelling in a taxi or minicab in a wheelchair**. The regulation governing taxis and private hire vehicles are the same for all vehicles up to nine seats. All persons travelling in a vehicle must have a seat belt. Occupied wheelchairs must travel forward [4 point belt system secured where possible, on the 4 star nominated securing positions shown on the wheelchair] or rear facing where it is common to secure the wheelchair with a 2 point belt system. Some very old vehicles still use the Unwin mechanical ratchet clamps only suitable for manual chairs. It is illegal for an occupied wheelchair not to be secured. Crash tested wheelchairs are fitted with securing points, generally marked with the outline of a karabiner clamp. It is however not illegal to carry non crash tested wheelchairs. It is the responsibility of the driver to carry out a risk assessment as to the safety of his passengers.

Shirley Schwartz – My Life, Polio and the Watson Home

Preface: This is the story of my aunt Shirley Schwartz and her life with polio at the Watson Home in the 1930s. Ironically, after her death, the Watson Home was the location of Dr. Jonas Salk's clinical trials in the 1950s that led to the development of a vaccine that all but eradicated polio.

Chapter 1: My life in Aliquippa, Pennsylvania before I contracted polio

I was born in August, 1928 at home on 1800 Main Street. There are no hospitals in Aliquippa. Dr. Landry was the attending physician. Mom and Dad were both 29 years old when I was born. They got married later than most of their friends.

Home is an apartment on the second floor in a detached home of light brown brick. Mom and Dad run a confectionary store on the first floor. The house is oddly shaped with separate entrances on the first floor for the store and apartment. My parents work hard at the store, with long hours. They are really busy and don't have much time to play with me. In the store, they sell groceries, meats and cold cuts. The store has a soda fountain. Some people call it an Army-Navy store. We face across the street from another store, but the rest of the street is residential.

Mom and Dad came to the United States from Austria-Hungary as children. Mom's brothers, Izzy and Sam Klein, gave my parents money to buy the store. Izzy and Sam are bachelors and they have really been helpful to my parents with finances. Sam has a successful drug and cigar company in Johnstown, Pennsylvania. Izzy is a paper salesman in Pittsburgh. Pittsburgh is about 30 miles from my home.

Mom and Dad take in borders to help make ends meet. A twenty five year old man, Joseph Elias, shares the apartment with us. Mom and Dad joke that they do not have two nickels to rub together. It makes me sad that we are poor.

The population of Aliquippa is about 25,000. The main employer is the Jones and Laughlin Steel Company. A productive steel mill dominates the town. The mill is located along the Ohio River.

I like that the town name is Indian. The name was selected by the Pittsburgh and Lake Erie Railroad for a station on its route. The town has a nice library and several churches. There are several schools nearby.

I live in the Hollywood section of Aliquippa. It is named after Hollywood, California, the home of movie stars like my favorites, Shirley Temple and Judy Garland.

There are many open fields between the streets with houses and businesses. The fields are used for circuses and carnivals when they come to town.

Chapter 2: My early life with polio

I contracted polio when I was around four. I was physically normal until then. I have no mental or cognitive problems. I don't know why I got polio. It makes me angry. Why me? My brother Norman was born at about the same time as when I contracted polio. He did not contract polio.

I lost the use of one of my lungs from polio. My spine became curved. I can walk, but it is a struggle because I had to wear a heavy metal brace. The brace goes from my shoulders down to my hips. My muscles are weak and some are paralyzed. The disease has affected my physical development and eroded my motor skills. The brace helps support my body when I am walking or standing. I get frustrated with my awkwardness and balance problems.

I can no longer do much activity physically. I am restricted by the brace. When I am at home, I share a bunk bed with my brother Norman. He is on the top bunk and I am on the bottom. I like having a brother! I am a smart girl. I learned about polio since it controls my life. I will share that with you now.

Chapter 3: What I learned about Polio

Polio is a virus disease affecting the central nervous system. The infection passed to me without symptoms or signs. It is common for polio to pass unnoticed. Some people who contract polio experience fever, headache, nausea, fatigue and muscle pains. I don't remember any of that.

I am part of an epidemic of polio that occurred in the 1930s. We don't know how polio is transmitted. My brother, my parents and our border lived with me in the apartment and they did not get polio. I think it is unfair that I got polio when I did nothing wrong!

Our community became really anxious when the epidemic came. Since it was not known how the disease was transmitted, local schools, pools, sports arenas and cinemas were closed for a while. It seems like polio comes around more in the summers.

The worst part of polio for me is that my respiratory muscles became paralyzed. I am nursed with a respirator. The machine helps me with my breathing. The machine expands my chest as air is sucked into my remaining lung.

I get physical therapy. My muscles are exercised. Wet, wool clothes are applied to my paralyzed muscles. The therapy is intended to rehabilitate my weak muscles. The treatments help relieve my discomfort and pain.

At this time there is no cure for polio. I am happy that a charity was set up to raise money to pay for research and the treatment of polio. The March of Dimes relies on small donations to combat polio.

Franklin D. Roosevelt, the President of the United States, has polio. President Roosevelt provides me with inspiration. I understand that he writes letters to children with polio, like me. He tells us to demonstrate courage in our struggle with polio. President Roosevelt helps raise money for polio patients. He is my role model. President Roosevelt helped establish the March of Dimes. He is a great President!

Chapter 4: My life at the D.T. Watson Home for Crippled Children

Most of the time I live at the Watson Home on Sunny Hill in Leetsdale, near Sewickley. I am one of many children with polio at the home. The home is one of four in the country chosen to provide care for children with polio. The others are at Harvard, Northwestern and Stanford. Dr. Landy referred me to the Home. The Home is in a suburb of Pittsburgh, about 17 miles from the city. It is a refuge for about 100 children crippled by polio, ages 3 to 16.

Leetsdale is also a steel town, like Aliquippa. The main employer is Bethlehem Steel. Leetsdale is much smaller than Aliquippa in size and population. It is also located along the Ohio River, but on the other side from Aliquippa. Industrial manufacturing is the biggest employer. The population is just under 3000.

It was scary for me to go through the entrance to the Home for the first time. This was the beginning of a new mode of life for me. I'll never forget seeing the two large American flags on either side of the entrance door. The rehabilitation part of the Home is in a low rise large, long red brick building.

The home is a hospital and school. The lawn grounds are beautiful. In addition to the Watson Home, there are other buildings on the grounds. There is a carriage house that used to hold horses and buggies. There are gate houses and lodges for the gardener and maintenance staff. The gate houses are 2 story high brown brick buildings, with grey roofs. There is also a farm house and a road house. I was told that some of these houses were built with Sears kits. One house is used as a brace shop to build braces for us. All together, the Home is on 68 acres, including a farm.

My favorite days are when we go outside lined up in hospital beds. With Pittsburgh weather, many days are cloudy, but getting outside is simply the best. I love seeing the vine entwined woodlands on the property.

Continued overleaf

There is a garden on the grounds. The plot is away from the Home on a strip near the green house. The nurses help us dig with small tools. I lean over in a wheel chair on the path and reach over. The wheels on the wheelchairs are almost as tall as I am. We helped plan and plant seeds for flowers and vegetables. We grew some strawberries and some corn which later was popped and eaten on Halloween. I could hardly believe that it was our own corn which was popped. The gardening gives us something to do to help our weak muscles. It is tiring for me. There are many weeds. Some of us think it is more work than play. The boys from the farm take great pride in the gardening. I think they are homesick for their farms. They really have fun watching the dogs that roam the grounds.

Inside we live in isolation wards. My ward is a room with hospital beds filled with other children who have contracted polio. Once per week we get to see a movie. My favorite is The Wizard of Oz with Judy Garland. We wear pajamas when we are inside. I have physical therapy at the Home. We also do some hydrotherapy in the pool. When I am well enough I attend classes with other girls at the school. There are only a few boys. We take academic courses like in a public school. The Home has a lovely library. Its walls are covered with shelves holding thousands of books, magazines and an encyclopedia.

On special occasions, I can go to one of the two wonderful living rooms in the Home. There is one in each wing of the Home. The living rooms contain log fireplaces. They are paneled in knotted pine. Each living room contains a collection of dolls from foreign countries. A beautiful sparkling silver tea set sits upon a wooden chest in one of the living rooms. I know that looking at these dolls is the closest I will get to traveling to faraway lands. Weather permitting; the windows are opened to let in fresh air and sunshine.

One of my favorite indoor activities takes place in our auditorium. I am taken there in my hospital bed. The girls who are able to stand up perform a play for our enjoyment. Sometimes they act out scenes from The Wizard of Oz. I am a little jealous that I cannot act, but I can't stand up long enough to participate.

I love hearing how the Watson Home began. Mr. and Mrs. Watson had no children. The Watson Home was their summer home. It was an estate called Sunny Hill. David Watson was a well-known business leader and lawyer. When the Watsons both died in 1917, they left the property in their will to help children with polio and other special needs. Their residence is connected to the rehabilitation part of the Home and staff stays there. The residence is a very large white house, with a grey roof on the top floor.

For part of every summer, I can go home to Aliquippa to be with my parents and brother. When I go home, Dr. Landy checks on me and gives me therapy. I take the brace home with me. It is nice to be home and see my family more often. Norman now goes to the Sheffield grade school on Sheffield Road in Aliquippa. My Mom and Dad are so busy with the store that they can only visit me on Sundays. They get a ride. They do not have a car. My Dad knows how to drive. I like when they visit. Then I don't feel so far away from home and my family. When nights are quiet, I can hear trains traveling besides the Ohio River. I dream of places where the trains go. Most of these trains carry cargo, not people. I wish I could travel to a land where there is no polio.

Postscript – (1) Shirley's tragedy

In 1941, Shirley died in a tragic accident at the Watson Home. During the night, she fell when going to the bathroom. The metal brace punctured her lung and the staff could not stop her bleeding. She was thirteen years old. The Watson staff called Shirley's Mom and Dad. They were shattered from the news, as was her brother Norman. The Schwartz family moved to Squirrel Hill in Pittsburgh shortly thereafter. They sold the store and were able to buy a house on Hobart Street. Maurice went to work in Regent's Square at a hardware store. Norman, my father, grew up in Squirrel Hill and went on to work in local banks. He married my mother Geraldine, in 1955.

(2) Salk and the Watson Home

At peak, polio affected 37 children per 100,000. Dr. Jonas Salk tested first his vaccine at the Watson Home. The Home became a research laboratory for the Salk vaccine. The first inoculations were given in 1952. Thirty eight children and adults were volunteers. Dr. Salk performed clinical trials at the Home.

The first human subjects were either had polio or were members of polio victims' families or were prominent citizens in the community near the Home. Also, some of Watson's physical therapy staff and students volunteered. Dr. Salk had earlier proved that his vaccine was effective on monkeys.

The vaccine was a great success. Salk injected then injected the vaccine into children in Sewickley, then in Pittsburgh public schools and later, throughout the country. The vaccine used killed polio viruses. Dr. Salk was considered a hero and a miracle worker. He saved children from getting this horrible disease.

Around 1960, Dr. Albert Sabin developed a vaccine that used a live polio virus. The Sabin vaccine could be orally administered with a drop of vaccine on the tongue or in a sugar cube. This vaccine was better able to withstand temperature change and superseded the Salk vaccine.

As a result of Salk and Sabin's vaccines, polio in the Western Hemisphere was all but wiped out.

The Watson Home is now a school. Many of its buildings are still used for children with special needs. Raymond B. White, the CEO of the Watson Institute allowed me to view the archives, photos and records remaining from the Home's polio days.

Saul Schwartz is an attorney for the Federal government. He lives in Germantown, Maryland.

Of Sandals and Street Fairs by Millie Malone from Polio Perspective, Oct 2014

Summer is over, but this is the best time of year for a street fair here in Iowa. September and October are beautiful with cool mornings and evenings and warm temperatures during midday. However, I must warn those Able Bodied Persons who attend these street fairs. I will attend any and all accessible activities in my area. The streets may be blocked off to vehicular traffic, but my wheelchair will still be able to toodle all over the place. Therefore, do not wear sandals to a street fair in Denison, Iowa. There may be other places that also should be off limits to anything but steel toed work boots, but definitely take heed if you are going to be in Denison.

While maneuvering my way through the crowds in an attempt to enter the supermarket, I inadvertently, really, I swear it was totally by accident, ran over a man's foot. In my defense, I completely forgot that my 180 lb. power chair, with it's bright red and yellow seat cover, and containing my own not insubstantial and also gaudily clothed body, was invisible. I did not allow for that fact when the nice couple offered to make a path for me through the crowd. How was the sandal-wearing person to know that they were making the path for an invisible, though brightly colored wheelchair? So, of course, he barged right in front of me, sticking his stocking clad, sandal shod toesies right under my wheels. To our mutual chagrin, even invisible wheelchairs are quite heavy.

It seems that pain renders invisibility null and void. As he was howling in pain, he looked right at me and said, "Hey! You ran over my foot!" I apologized several times as he hopped up and down, holding his injured foot, but he appeared to remain unmollified. Had he been wearing the recommended steel toed work boots, he would not even have noticed, but sadly that was not the case. Perhaps, once his toenail grows back, he might consider wearing those boots.

I've thought about getting an air horn to help me weave my way through crowds, but someone once told me that an unexpected air horn coming from an invisible power chair could cause a heart attack. I wouldn't want that! Running over an entire prostrate person might tip my invisible chair over! Then where would we be? I am visualizing a herd of people trying to climb over a heap containing an invisible chair, an invisible woman, and possibly a very visible sandal-wearing man. Probably not, though. I'm pretty sure that I did enough damage that Mr. Sandal Man could be driving his own invisible chair for awhile. So sorry!

<http://postpoliobrangers.org/newsletter/>

Disabled? You can work for £2 an hour in Britain ;-)

By Member Michelle Maher.

The Prime Ministers Question time today, or for those of you overseas, our weekly how to avoid answering a question by our Prime Minister and watch a bunch of school boys throwing insults across a room; and yes we pay them to do it. The head of welfare reform for the Conservative party and ex Labour member did say that disabled, because we can't get work, should work under minimum wage for £2 an hour. This is a behind the scenes look at what we know the Conservatives have been thinking about us for some time. The disabled in Britain have been hit harder than any group under the name of austerity. We also have the auspicious title of possibly being the first country in Europe to face a high level inquiry by a United Nations Committee for human rights violations concerning the disabled. [Neither confirmed or denied by the UN] Hooray for us.

Let me introduce myself I am Michelle Maher a new member of Polio Survivors Network and my side line hobby is making as much fuss as possible about cuts to disability support. How I became involved in this dark underbelly of a world was not because of myself but a cousin. She has Parkinson's and the welfare service here was determined not to give her any support. I worked previously for the civil service before my ill health retirement (should have offered to work for £2 an hour) so I offered to sort it out. It was a nightmare many many months to get to appeal and be offered a tribunal. At the Tribunal they gave her everything so it just got silly, in January no support, February everything at highest level.

I had to lie to her to get her to the tribunal, told her they wouldn't ask her a question. She was very ill at this stage and had had to move to sheltered accommodation for her own safety. I knew that one look at her the case was won. She was very nervous and confused. They asked her could she shop, she said yes an hour a week... but she hadn't been out shopping on her own in years. They asked could she wash, she said yes... but she hadn't done that in years either since she got stuck in the bath. What she did have though was her pride that they could not take away, though they tried. She won the case and got paid the money but it must have cost them FOUR times as much fighting the case. Sadly this is a reoccurring not uncommon problem here.

Following this I got involved in a campaign sourced on twitter calling for a cumulative impact assessment on the swathes of cuts to disabled peoples benefits. We were and are a motley crew mainly middle aged, well in fact all of us, I like to pretend I am twenty one. We secured first debate in history by and for sick, disabled and carers' in the House of Common's. Barely any MP's turned up; they had been told not to, which speaks volumes. In theory we won but nothing has happened so from next week we push on again to take it to a second hearing at the House Of Commons. We use social media which gives disabled people who can't get out a voice; we now also have good links with charities and unions.

The disabled in Britain have had an estimated £28.3 billion cut from support in the name of austerity. In the name of austerity we have been marginalised and pushed to the corners of society but we are not and will not go down without a fight. There are many many organisations out there fighting. They might think we are only worth £2 an hour but we know our worth. We may not be able to tap dance anymore but we can type or 'dragonspeak' and we can fight for humanity, because if they treat us like that who do they move onto next. I apologise for the rant, I am ranty in real life, should see me on tramadol, or maybe not, but the comment about the £2 an hour only came out today. Thanks for reading and thank you for inviting me into the inner sanctum of PPS it was the final piece of a long list of ailments finally having a name.

m.maher70@ntlworld.com

WOW Campaign on Facebook and Twitter <https://twitter.com/WOWpetition>

Editors Note:-

Articles from Polio Survivors and Health Professionals Welcome for future issues.

Member Tony Scase-Walters writes:-

I thought fellow members might like to know that PPS knowledge is spreading a little through the medical profession in North Lincolnshire. Three months ago I started having trouble with double vision and dry eye. I had an eye tests 6 months before and have worn glasses since I was six years old.

My optician knew that I was a polio survivor, as is her friend, and like her friend was having problems due to PPS. She referred me to an Orthoptist at Scunthorpe Hospital. She prescribed Fresnel prisms, which helped with the double vision and improved my distance vision although it did nothing for near and reading distance. I now have to use a magnifying glass to read. I have also been seen by a Consultant Ophthalmic surgeon who accepts that PPS exists and has referred me to an eye nerve specialist. I am hoping that something can be done to improve my vision. I will let you know what happened after this next newsletter.

In the meantime a little about myself, I was a cornet player at Kneller Hall Military School of Music for a year [Hilary tells me she lived round the corner and used to attend the Wednesday night concerts, and we have another member that lives nearby.] I also trained as a male nurse and eventually went into the caring role ending up as team leader. At the moment I am reading all I can about Bats. I have been able to borrow some books from the Library but they are very expensive and I can only have them for a few weeks as they have come from another Library. I wonder what hobbies other members have?

Tony Scase-Walters, North Lincolnshire.

Editors Note on Eye problems and PPS.

Whilst this has been mentioned before its worth mentioning again. Some polio survivors - including myself - have found that our visual disturbances have been triggered by muscles that move the eyes becoming weaker. For me I noticed it most when driving and having to constantly look in the rear view mirror. My Optician told me to move my head not eyes and that problem was solved. The left side of my face is weakest and if I move my eyes left to right the slight delay of left eye over right becomes visible towards the end of the day. A PPSer in Montreal many years ago advised that you should pace and rest your facial muscles as well. Just shut it down for 15 minutes. It helps.

Have you noticed that when you move from a bright lit room to a dark corridor or stairwell that it takes a few seconds for your eyes to adjust? I noticed it was taking a couple of minutes and the optician explained that the pupil aperture is also muscle controlled. It is called 'accommodation' So that you can see clearly the pupil size accommodates to the level of light. It is called 'accommodation'. It is easier to cope with when you understand why.

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 December 21st 2014

.MOBILITY ROADSHOW SET TO RETURN IN 2015



Mobility Choice is delighted to announce that the next Mobility Roadshow will be held in 2015. The show will take place from 25th – 27th June 2015 at Donington Park, making a welcome return to this popular venue.

18th October 2014

[Just a few excerpts to show the variety of information]

Canada: PM Receives The Rotary Foundation Polio Eradication Champion Award

Prime Minister Stephen Harper today received the Rotary Foundation Polio Eradication Champion Award for longstanding support and continued leadership in efforts to eliminate polio around the world. The Prime Minister accepted the award at a ceremony hosted by the Canadian Rotary Foundation in Toronto.

From the Lancet, Volume 384, Issue 9952.

World Polio Day - On Oct 24, governments and communities worldwide will make World Polio Day, which is organised by Rotary International to raise support for the eradication of polio. On this day, there will be a live-streamed global status update on the progress of the fight to end polio completely.

Misdiagnosis of multiple sclerosis - The National Institute for Health and Clinical Excellence has published new guidelines for the diagnosis of multiple sclerosis, which might mean that thousands have been incorrectly diagnosed or that the diagnosis has been missed. They are calling for thorough scans and tests to be carried out. [Editors note: research showed me there are many diseases that mimic MS and there are many comments on boards where people have had other diagnoses before finally getting one of MS. We also know of polio survivors who have been diagnosed with MS changed to PPS and others with both diagnoses.]

17th October 2014**Nigeria: Survivor Urges Increased Awareness As World Marks Polio Day - The Guardian (Lagos) via allAfrica. John Okeke reports....**

Mr. Misbahu Lawan Didi, says..... "As polio survivors, we are not praying for people, especially posterity, to experience what we passed through as victims," he said. "At 10, I was being bathed by people. I could not do what my mates were doing, and because I was not participating in some of the games they played, I felt very bad.

In fact, there was a lot of discrimination against us - you see people looking at me as if I did not belong to the society. If we polio survivors are telling people to take care of their children, it means they should take it serious. The government needs to create awareness about this disease so as to educate the masses to do the right thing to end this disease.

My message to the world is to accept polio vaccinations and guarantee good health for their children and this will enable them avoid what we passed through.....

Meet Ken Burns, the US pioneer of long-form television - New Statesman.

Erica Wagner writes... Perhaps you can't imagine why you would commit yourself to a 14-hour films about the Roosevelt. Yes, Theodore Roosevelt, 26th President of the United States, has his face up on Mount Rushmore, sure, we know that Franklin and Eleanor Roosevelt were hugely significant political figures. But 14 hours, over seven episodes? The film's creator, the American documentarian Ken Burns has a snappy one-liner to pull you in. He grins at me conspiratorially over his Caesar salad. "This is the American Downton Abbey." he says, "Except it's all true."

"The Roosevelts" began on PBS America (Sky 534 and Virgin 243) on 19 October (8pm). The DVD box set is out now

Management Committee [Trustees] and Operations Team

Management Committee [Trustees]

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

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

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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

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**

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

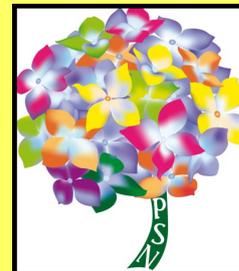
If you pay tax at the higher rate, you can reclaim tax relief on your gross donation at 20% (i.e. the difference between the higher rate of tax at 40% and the basic rate at 20%).

Polio Survivors Network

Lincolnshire Post Polio Network - Registered Charity No. 1064177

Website - www.poliosurvivorsnetwork.org.uk

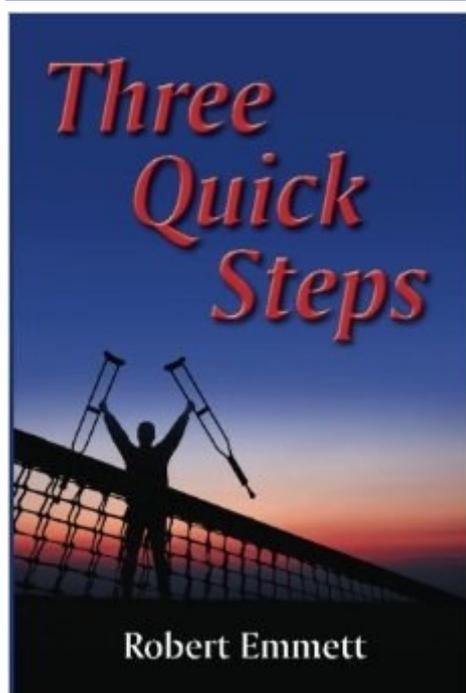
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Memoir of a Polio Life by Richard Emmett



“This memoir is about my life, the challenges of polio and post-polio syndrome, and the influence these diseases and their aftermath have had on my life. If you ask a polio victim what he wants, and he answers honestly, it is to be normal or at least perceived as normal. For some, it is to get rid of a wheelchair and walk with crutches.. At least it is a close to the goal. Some polio victims will never be able to get rid of their aids. In some instances, they may set aside their cane and accept the risk of falling. I remember the time I was in the hospital polio ward. Even then, a lot of the kids were using wheelchairs and crutches. I did not want to join them. For years, I would have an almost physical revulsion to using any aids or help. I did not want to join them. For years, I would have an almost physical revulsion to using any aids or help. Nonetheless, this memoir is not meant to be a ‘downer’. There are many triumphs, and there are some low points.

I have created a fictitious companion who has been with me ever since I contracted polio at age nine. I call him Mr. Normal (certainly not to be confused with the SpongeBob Square Pants character). He is a tough taskmaster. Suppose there is something that is very difficult for me to do, something painful or challenging or seemingly impossible to master.

Mr Normal wouldn't let me off the hook.....”

This book is mostly written in the first person allowing him more freedom in writing what he remembered and felt along his journey. There are some third person vignettes in some chapters.

Robert gained a PhD in chemistry in 1971 and was an Industrial Research Director for a number of years mostly with marketed materials for papermaking, mining, paint, adult diapers, toothpaste and food. The book is available in print £ 9.07 and on Kindle at £2.20.

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