POST POLIO MATTERS

Polio Survivors Network Newsletter
September 2020 Volume 10, Issue 4 of 12 [112]

THIS ISSUE FEATURING PENNSYLVANIA, USA

PA Polio Survivors Network
(page 8)

PA Polio Survivor's Network

Information & Inspiration
For *All* Polio Survivors and their Families

Serving the Keystone State and Beyond

Sadly we say goodbye to
Ian Radus

Photographed here on his 80th birthday surrounded by family.

Front Middle: Ian Radus

Back Left to Right: Lance Radus (youngest son), Jo-Ann Radus (daughter), Nayeli, Eagles (grand daughter, 1 of 7), Cecile Radus (wife), Marc Radus (eldest son)

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Stay Safe Online
page 11

Remember these charity donation boxes from back in the day?

See page 17

Lincolnshire Post-Polio Library 100+ articles

Polio Survivors Network is the working name of registered charity 1064177, The Lincolnshire Post Polio Network

The following donations were received in August 2020:

Mitchell donation	£ 12.50
Scarlett donation	£ 5.00
Healy donation	£ 12.50
University of Lincoln donation via Hilary	£ 50.00
Unknown/Anonymous donation	£ 30.00
PayPal Donate anonymous donations of £1 each x 2	£ 2.00
TOTAL	**£112.00**

Thank you for your kind generosity.

Editorial by Hilary Boone

Toni is completing this newsletter for me. The first time I have not had the time and energy to do this and it hurts. Why? because the powers that be in various organisations and departments that we deal with to manage our lives for health and social care have, in our and others opinion, let us down badly. They have made us use way too many of our daily energy tokens [day after day] by insisting we make formal complaints about the issues experienced in the last 15 months from other departments. Covid then delayed those responding. Treatment stopped, health professional visits and appointments stopped except for two phone calls where we updated them. Ending up with nothing left for 75% of what needs doing and that included this newsletter.

As you will remember, along with colleagues in Lincolnshire, I have been involved through PSN and LNA [Lincolnshire Neurological Alliance] in numerous NHS and Lincolnshire County Council mostly Social Care meetings for 25 years. That is time given up from a disabled life to share the issues that I, as a user and carer (along with our charity members), have experienced with a hoped for outcome of improvement in services for all. We asked for and were promised, but it rarely happened, 'round the table talks' from all departments with those working on the ground so that we could ALL share our issues and come up with possible quick wins and see improved paperwork, procedures and outcomes for all staff included saving departmental money.

Seven years ago those of us that had taken the In Control Partnership in Policymaking Course, paid for by LCC, were asked to visit the University of Lincoln to become part of the now named Together Group. We started with Social Care and were involved with 'Open Days', interviewing prospective students, some lectures, and it progressed to being involved with new courses from the start through to validation. Health and Social Care, Nursing, Pharmacy and, as new health departments started, the Together Group have increased in number and been involved. Why did/do we do this? We have found that firstly leaving home and going to University makes you feel part of life again. It is a two way process, the students learn from us what it is like to be on the receiving end of jobs they hope to do and we learn from the questions asked of us, we learn from lectures we are asked to join in to give comments. It is very rewarding and we can pass forward what we learn. We see positive outcomes.

Personally, one day when being visited by a new to me Social Worker (who had just moved from Mental Health to Adult Social Care) about a few problems that were making life very difficult, I suddenly realised he was just chatting. 'I learned this other less official but effective way of gaining information' that he was using instead of asking questions during a Uni lecture. I told him what I had realised and how much I appreciated it, I relaxed and the appointment became much easier. There is a major issue for those of us that have to deal with multiple departments of multiple organisations to manage our daily lives including our health. Each person in each department of each organisation knows their job, or we hope they do. As Polio Survivors we have at least two decades of experience that this is not always the case. Many health professionals have never heard of post polio, nor been taught anything or enough about polio by their Colleges of Medicine and many of us have had incorrect diagnoses/treatments/operations/advice for years.

Let us say they all know what their job entails, but do they know the rest of the process or how that dovetails with other organisations? Do they talk to one another? Do they read on other organisations websites what should happen and believe it does? [We know that the reablement process in Lincolnshire offers way more than we have learned happens] Have any of them ever asked how many other people we are dealing with and if we have any problems there? Covid has made all this much more difficult for us and them which we understand, but if the offers of help and paperwork for the last 25 years had been genuine then it is our belief that many of the problems we still experience should have been sorted. If there are going to be genuine outcomes I am happy to give up my time and energy. Sadly I reckon at least 90% of my time - other than at University - has been a waste of time.

Simon Writes … Are Polio Patients a Challenge to GPs?

It has become increasingly evident that the understanding and management of ageing with polio has little expertise within the health and medical communities. As new polio is rare and older polio patients die, we find ourselves in the care of our much overworked and under resourced GPs. Even if we are referred to a specialist service there is little chance they know much about polio let alone PPS.

Sensible self monitoring is not hypochondria

Therefore, the only sensible and safe way is for us to monitor and listen to our bodies and gut feelings. Don't ignore pain or new symptoms, always check them out. Ageing comes with a complex mix of conditions which require understanding their interaction and origins, but most can be helped or managed. Let me put in a plug for geriatricians, having in the past worked alongside some of the best, I can say they are often better able than most to think holistically and coordinate help.

Self monitoring, seeking advice or help if things seem consistently not right is essential. However, we can then be caught in a cycle of obsessional checking, worrying and anxiety, I know I am guilty of this! So balance is important. Equally, we cannot accept being ignored, told its just you age or worse all in your mind, as so many were told about PPS in the past. We share this last reaction with those who had ME or fibromyalgia, when it was labelled yuppie flu. I trust and hope that in the post Covid 19 environment, those who my develop ongoing fatigue and multiple issues will not suffer the same fate.

Information and Knowledge equals Empowerment

So, it is down to us to learn about ourselves. We should try a least to have a basic understanding of the recent medical facts and issues, as far as is known, and be able to present them in a way that ensures due weight and attention is given by your primary care team, GP or specialist treating you. It may help many to have an advocate there with you who is informed wherever possible. One reason we are here, is to help you in that wherever possible. This is vital so that when assessing and deciding what treatments, procedures or management is best for you, polio and PPS is fully understood, assessed and considered BEFORE anything is done.

Is polio relevant to me today given my other conditions?

As you are reading this, you are already unusual, as you are actively engaged and interested in learning more about polio and PPS and the latest information, management options and research findings. Most of the research is no longer happening in the UK and what has been done in the last 20 years is often only very small scale studies and so open to question. Of course, we hope that our web page will be able to continue to grow and contain lots of useful research and data for you and your health professionals. But remember if you need help we are here on the phone or email.

The invisible polio survivors in the geriatric population

How many polio survivors are invisible? They may have no memory of any original polio, have forgotten or didn't even known they had it as a child years ago. It may have been non paralytic or asymptomatic (a misleading term which may haunt the Covid 19 population in the future). Some clearly had a very mild version, others recovered with no obvious impairment. Many who were left with some residual weakness, found it a nuisance, but carried on with a full life oblivious to the underlying level of damage. The problem seems to be that a young body has huge reserve of muscle and growth, the damage was therefore masked as it was not enough to prevent functioning well in everyday activities. However, over time and with normal ageing it becomes evident in sometimes subtle slow loss of function, probably through a lack or reserve and or the unconscious extra damage from overuse.

Live for today but don't ignore the past

We now know that the polio virus almost certainly had a global impact on the body. It is good to live in the present but not to live ignorant of the facts. When ageing and 'collecting' other and illness impacts upon us all we must reject the narrative that your polio is irrelevant. It may or may not be, but it is probably not irrelevant to your treatment management and ignoring it could be very detrimental or worse. So, the earlier we accept this the better! Dealing with it in a crisis is not good, easy or for many without support it will be impossible. Indeed, a normal routine procedure or operation for others can trigger a puzzling decline or exacerbation of symptoms in a polio survivor who may even have been well before.

Just Remember

We are here for you and you are welcome to reach out to us. We are very few in number and resources, but we will do our very best to help and advise in any way we can.

Simon Parritt, *C.Psychol, AFBPsS, MSc, BSc(Hon), BA, CPsSC, MBACP*
Chartered Psychologist. HCPC Registered Counselling Psychologist, www.sp-psychology.com
Chair Polio Survivors Network simon.parritt@poliosurvivorsnetwork.org.uk

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'SMILE' by Barbara Taverner

First Time Wheelchair User

You do feel stupid when you first use an electric wheelchair but oh the joy and freedom it brings you. Yes people with you do disappear, they don't like/enjoy the restriction placed on them, e.g. whilst shopping, etc. as it slows them down. [***Editors Note:*** Obviously you've not been shopping with Richard when he is moving well, we certainly can't keep up with him!]

Can't always get access into shops that are crowded with goods in baskets that need negotiating which makes life more difficult. 'Normal' people become embarrassed. Stick at using wheelchairs. Eventually confidence does return and you become confident asking for help, to open a door, or bring something out of a shop that you cant get into for you to view. So what do you do if you come to the end of a path with no dropped kerb or if you cannot do a 3 or 6 point turn? … then smile… You better become good at reversing!

Seat Belt Use - Certificate of exemption from compulsory seat belt wearing

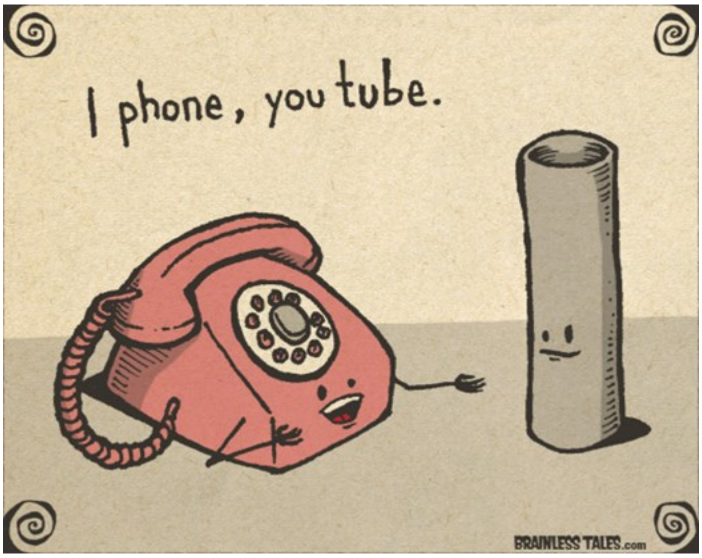
Do people know that one can get a certificate of exemption from compulsory seat belt wearing from your GP? Many don't know of its existence! I've had one since 1998 renewable every two years, until I had so many that GPs started putting 'indefinite period' or till further notice that should be sufficient. However, I've moved home so many times that I have to change GP's and my home address - causing more confusion to a GP knowledge.

I do wear a seat belt across my waist and the other part under my armpit. I cannot take pressure across top half of my body restrictions when leaning forward to reach something of change gear in the past. Not enough stamina. Neither stake pressure of strap nor clothing [polo neck collars etc] across my throat. I've been stopped twice in 1998 Lymstone Marine Camp and again S.O. Avon. Traffic lights gave me great pleasure and smugness and a concealed smile to reach into pigeon hole and show to police!

Toni Writes …

Technology – love it, hate it or simply tolerate it as a necessity at times!

During these strange times that we are living I am sure, like me, you have had to rely on technology more and more. Maybe it has been for increased online shopping, Zoom quizzes, Facetime with family and friends. It certainly can challenge us as we try to keep up to date and begin to understand how it all now works. Do you find that when you ask for a little help that the reply sometimes sounds like a foreign language! My advice – ask the youngest person you know, they often seem to have been born with the 'technology genius' gene!



With kind permission from Marcus at Brainless Tales
https://bit.ly/2RbbhPb

It is true that the internet has changed dramatically how we find answers to questions and how we research topics. We are also alert to fake news and misinformation so we are adapting to our newfound flood of information (see tips on staying safe online on page 11). Many look to the internet for help with health issues and to find others who have faced similar challenges to overcome. With this in mind, Polio Survivors Network has been keen to get its library back online. It was a space where many articles had been collated and even especially written for the charity (Lincolnshire Post Polio Network as it was known at the time) by a variety of professionals. Years of hard work were put on hold after the website hack but we are pleased to let you know that finally we have managed to get an archive library back on our website. Our special thanks go to Chris Salter for his help in providing some key files to assist with this.

We have also started a new library, one we can add information to as it is published or discovered. If there are any articles you have found interesting, websites that are especially helpful or books that have inspired or comforted you please feel free to share them with us all (contact details below).

As always we enjoy hearing from any of our members and would love to share your thoughts in an upcoming newsletter, just drop us a line when you get a moment.

Take care and keep safe

Toni x

Email	psnadmin@poliosurvivorsnetwork.org.uk
Post	PO Box 954, Lincoln, LN5 5ER
Website	www.poliosurvivorsnetwork.org.uk
Phone	01522 888601

Pennsylvania Post Polio Support Group -*Bladder Basics in Polio Survivors*

Dr. William DeMayo, MD DeMayo's Q&A Clinic

Question: *Dr. DeMayo, I have PPS. In the last few years I have experienced bladder issues. I have urine retention. On a recent CT Scan, It showed pelvic muscle atrophy. Is there a connection with Bladder problems and Polio? Were Pelvic muscles effected by the virus?*

Answer: Great Question! Unfortunately, there is not a great, short answer. Nevertheless, like most good questions, there is an opportunity to use this as a learning opportunity.
First a few basics…

1) The first Basic Bladder issue is that bladder issues in men are far different then in women. I will discuss both men and women.

By far, the most common source of urine retention (inability to empty the bladder) is obstruction of outflow caused by the prostate in men. PPS itself does not cause urine retention in the bladder. Having said that, one needs to be sure that retention is in fact the problem. This is usually done with an ultrasound of the bladder after a void to see if to much urine still remains. Of note, frequent urine incontinence (inability to control urine / wetting one's self) can be either due to urine retention with "overflow" leakage OR due to a lack of resistance to flow. The latter is far more common in PPS due to weakening of the pelvic floor as discussed below.

Also, incontinence is for more common in women compared to men due to multiple factors including a shorter urethra (the tube connecting the bladder to the outside), the urethra having less of a bend (especially when the pelvic floor drops), and lack of resistance of the prostate. Additionally, the bladder storage capacity in women tends to be smaller (partly due to presence of the uterus).

2) The second Basic Bladder issue is that neurological issues can have a major impact on urologic function. The bladder can become either over active or one can loose the awareness of bladder filling. Coordinated control of the bladder storage and emptying requires the interaction of muscles in the bladder wall, nerves from the bladder to the spinal cord, reflexes coordinated within the spinal cord and control from the brain (both with conscious awareness and without). Stroke, Brain Injury, Spinal Cord Injury, Multiple Sclerosis and many other neurological conditions can result in incontinence due to what is termed an "upper motor neuron. Since Polio is a lower motor neuron problem, we won't discuss these more other than to say that Polio patients are not immune from any of the above conditions so they should always be considered. Also, the normal aging process can create a "hyper reflexive bladder" that can mimic an upper motor neuron problem.

3) The Bladder Basic that is most pertinent to Polio survivors is that the pelvic floor muscles play a profound role in bladder function. Any older individual is subject to this issue but those who have restricted mobility or a prior reason to have pelvic floor weakness are certainly more at risk. "Stress Incontinence" results when a cough, a laugh or a sneeze increases the pressure in the abdomen and thereby increases pressure on the bladder. It occurs when the resistance to outflow is low and this is especially the case in women. Polio can certainly cause weakness in the pelvic floor muscles and this weakness can progress in cases of PPS.

Additionally, a history of child birth, recent sedentary lifestyle and weight gain can all add to relative weakness of the pelvic floor. Weak pelvic floor muscles are directly associated with less resistance to outflow. They play an important role in supporting the bladder, directly tightening the area around the urethra as well as creating a "kinking" effect with cough, sneeze or other activity which further increases resistance.

4) The last Bladder Basic is that many times bladder management is NOT Basic. Urine infection, bladder/ kidney stones, stress, physical activities, behavioural concerns and many other issues can significantly impact bladder function. As such, all significant symptoms that do not resolve, should be evaluated. Referral to a urologist should always be considered if symptoms fail to resolve with treatment by a PCP. [primary care physician]

Additionally, some Physical Therapists specialize in Pelvic Floor therapy. They can often be found through your urologist, PM&R [Physical Medicine and Rehabilitation] physician or GYN. Like any muscle, the pelvic floor can be over fatigued and so treatment of a patient with PPS should be individualized and not focused on just intensive pelvic floor strengthening.

A good PT specializing in this area can often provide lots of tips to improve symptoms. An example would be an older person who repeatedly has incontinence on the way to the bathroom. By the time they realize the bladder is full they risk an accident because the act of moving from sit to stand causes a reflex spasm of the bladder and the pelvic floor is not strong enough to resist this. Thankfully, there is an opposing reflex that inhibits the bladder (briefly) after 3 strong but quick contractions of the pelvic floor (Kegel type contraction). Thus, if this person takes 10 seconds to do these 3 contractions prior to standing, they can sometimes counteract the reflex bladder activity just long enough to get to the toilet.

A full explanation of bladder management is obviously well beyond the scope of this brief article. At the same time, I hope I have provided some insight into the way some bladder issues arise and provided hope that there are solutions.

Link to article online: https://bit.ly/33dAqOB

William DeMayo, MD
www.papolionetwork.org

PA Polio Survivors Network

We are happy to be sharing our new PPS Support Group Directory that has been designed for groups that have gone "virtual" and are using zoom technology. This opportunity allows survivors from all over the US and Abroad to come together like never before. You can easily find this new Zoom Directory in the Survivor Connections section of our website. This is an ongoing project and we will be adding additional groups as they request to join us.

In addition, we also offer additional Support Group contact information for:

- "Snowbirds" traveling to Arizona and Florida during the winter months,
- PPS Cruise Information,
- A Direct Link to the Post Polio Health International Worldwide Directory,

We appreciate your nice comments regarding the "Unsung Heroes" series in our newsletters. All five stories are now available on the Polio History page of our website. We highly recommend the moving video that accompanied the story of David Salamone.

Check out our "What's New" section, as we update it fairly often. When you see something highlighted (either in our emails, newsletters or on our website) just "click" for additional information.

www.papolionetwork.org

PA Polio Survivor's Network

Information & Inspiration
For *All* Polio Survivors and their Families

Serving the Keystone State and Beyond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Article from Trustee Verité Reilly-Collins www.aftercancers.com

Loneliness is the Hidden Disease

It is estimated around nine million people live on their own in the UK. Today, thousands of these have been facing life alone during lockdown. Now that this is easing, many say 'Covid' fears make them worried about mixing with others.

Many may have lost contact with services and friends during lockdown. Now that this is being lifted, they are fearful of making contact and frightened to go out.

Those who have cancer are probably some of the worst off; so far many have no idea when treatment is resuming, or even planned follow ups.

During lockdown there has been much talk about Mental Health, especially as the Duke and Duchess of Cambridge have spoken out about this. But, many who live on their own are resilient and able to get on with their lives, perhaps need a little more help with loneliness, but are too proud to ask for help.

So the challenge is on to try and mitigate loneliness for so many in today's world, and ensure they are not neglected or forgotten..

Making use of Volunteers In March the NHS put out a call for volunteers to help vulnerable people stay safe and well at home, and was surprised when so many volunteered. In fact numbers so overwhelmed the authorities that it was said that many were never called to help.

Now, surely is the time to make use of these volunteers. The **RVS** (Royal Voluntary Service) has volunteers that can help in all sorts of ways: practical help and companionship, deliver books to those who love reading but can't get to their local library and drive people that can't get out and about to GP or hospital appointments, shopping trips and to local social events and activities.

They run clubs and groups in local communities where older people can socialise, take part in interesting activities and enjoy something to eat and drink.

But these voluntary services need to be publicised, and potential users assured that they are not making use of 'charity', but volunteers too get something out of the interaction.

Don't let the volunteering spirit fade away. This is where Bojo and his merry mates need to think of others, rather than where they can don a hard hat for a photo opportunity. Instead of popping up around the country making fools of themselves moving boxes and getting in the way of genuine workers, isn't it time the Cabinet got down to some serious thinking about how they can harness volunteering enthusiasm to help the lonely around Britain?

Let's make sure that no one on their own feels isolated any more. If everyone over a certain age, or disabled, or living on their own, could be assured it is their right to have a volunteer do something with them once a week, whether it's taking them shopping, playing Bridge, taking to them to keep fit, etc., this might banish loneliness and prevent much mental suffering.

The Government organised food drops for the vulnerable during lockdown. Now, before it gets lost, this network could be used to give people a weekly visit or outing, and encourage more social interaction.

This should be easy to do; the annual census form has just gone out, identifying elderly people living on their own – so use this data. GPs, doctors, pharmacists, nurses, midwives, NHS 111 advisers and social care staff should all the able to point to suitable, vulnerable people, and request help for them. The RVS has a call centre who can match people who need help with volunteers who live near to them. I reckon Bojo would do more good funding this call centre for extra staff, than any Eat Out to Help Out scheme.

Schools Every Autumn it's Harvest Festival time, when our ancestors celebrated bringing in the harvest that would provide food for the Winter. Shortly after my elderly mother moved to the Oxfordshire village of Dorchester-on-Thames, there was a knock on her door. A group from the local Primary School came bearing a box of apples and some tins. "It's Harvest Festival, and we've bought you a gift from us".

Mother was enchanted, invited them all in and listened entranced whilst these kids told her all about their village. Then told all her friends about the school's initiative. There are some schools that have already made contact with elderly people, and found a terrific rapport. So if anyone is member of the PTA, or a School Governor, why not suggest 'meet elderly locals' sessions?' for this Autumn Harvest Festival?

Minister for Loneliness **Tracey Crouch** MP is the **Minister for Loneliness.** Yet since she has been appointed, she has been remarkably quiet. Does the post still exist, I ask myself?

With 9 million elderly people around, their needs are going to vary enormously. Surely the Minister could come up with some ideas? It's not rocket science, but if the Minister gets bogged down with too many advisors, committees, White Papers, initiatives, strategies etc. she is going to lose all will to improve, and the elderly will still find they are lonely as they are not being able to tick the right box.

Let's KISS (keep it simple, stupid) and let villages, schools and groups get on with doing their own thing and reaching out. Tracey could remind Councils that those who have Council House Estates could actually visit them and appoint a resident to knock on everyone's door and take a note of who genuinely lives on their own. One of the saddest aspects of the Grenfell Tower disaster was that Councillors had almost never visited the Estate, and had no idea of what went on – in their own Borough!

Schools could tell staff that they need to make contact with the local community; meeting older residents works a treat for those pupils who have already taken the initiative, and formed a living history contact. Copy what they are doing. And don't sit arrogantly behind the gates not knowing your neighbours.

The Minister for Loneliness posting is made in memory of the MP Jo Cox; it could be the start of a new era for elderly people, and help with the scourge of society today: loneliness.

Social Prescribing This was just being rolled out by GP surgeries, when lockdown called a halt. Let's revive it.

The King's Fund explains: social prescribing, sometimes referred to as community referral, is a means of enabling GPs, nurses and other primary care professionals to refer people to a range of local, non clinical services.

Recognising that people's health is determined primarily by a range of social, economic and environmental factors, social prescribing seeks to address people's needs in a holistic way. It also aims to support individuals to take greater control of their own health.

Social prescribing schemes can involve a variety of activities which are typically provided by voluntary and community sector organisations. Examples include volunteering, arts activities, group learning, gardening, befriending, cookery, healthy eating advice and a range of sports.

There are many different models for social prescribing, but most involve a link worker or navigator who works with people to access local sources of support. The Bromley by Bow Centre in London is one of the oldest and best known social prescribing projects. Staff at the Centre work with patients, often over several sessions, to help them get involved in more than 30 local services ranging from swimming lessons to legal advice.

Social prescribing is designed to support people with a wide range of social, emotional or practical needs, and many schemes are focussed on improving mental health and physical well being. Those who could benefit from social prescribing schemes include people with mild or long term mental health problems, vulnerable groups, people who are socially isolated, and those who frequently attend either primary or secondary health care.

There are Nine Million lonely people out there – don't let them be victims of the Covid 19 pandemic!

In need of cancer support? Please contact verite.reilycollins@poliosurvivorsnetwork.org.uk or see website www.aftercancers.com – you and your loved ones are not alone.

Get Safe Online

Useful resources, Q&A sessions and advice can be found here: https://www.getsafeonline.org/

Telephone Preference Service

Register your landline ***and*** mobile phone numbers here https://www.tpsonline.org.uk/ or call 0345 070 0707

Did you know you can also register your mobile number by simply texting the "TPS" and your email address to 85095 from your mobile phone? There is no charge to send a message or to receive confirmation from this number. You will receive a text message confirming your number has been successfully added to the TPS database.

Keeping Safe Online

Scammers are exploiting the pandemic to trick people out of their cash, UK banks have warned. Here is their list of some of the fraudulent schemes to watch out for:

1. Fake government emails offering grants of up to £7,500. Clicking on the links allows scammers to steal personal and financial information
2. Scam emails offering access to "Covid 19 relief funds"
3. Official looking emails offering a "council tax reduction"
4. Benefit recipients are offered help in applying for universal credit, but fraudsters grab some of the payment as an advance for their "services"
5. Phishing emails claiming that the recipient has been in contact with someone diagnosed with Covid 19
6. Fake adverts for non existent coronavirus related products
7. Fake emails and texts claiming to be from TV Licensing, offering six months free but asking people to update their payment information
8. Emails asking people to update their TV subscription services payment details by clicking on a link
9. Fake profiles on social media sites are used to manipulate victims into handing over their money
10. Fake investment opportunities are advertised on social media sites, encouraging victims to "take advantage of the financial downturn"

Report Suspicious Emails and Scams

If you receive an email that looks suspicious to you or is clearly a phishing email (an email trying to get you to give information especially financial) you can report the address that is came from. Simply forward the email you received to report@phishing.gov.uk

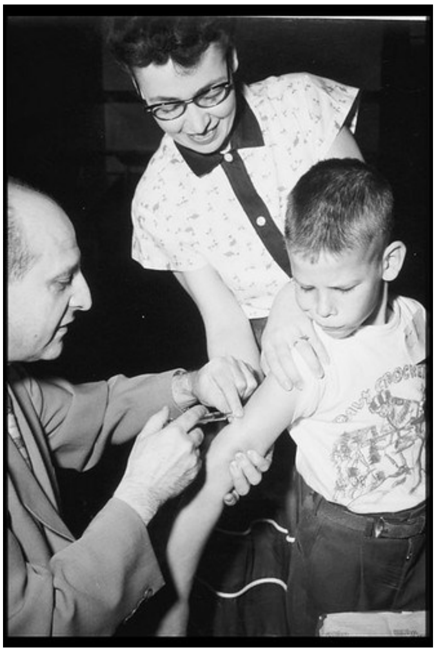
The National Cyber Security Centre act on every email they receive and they provide advice for individuals here : https://www.ncsc.gov.uk/section/information-for/individuals-families

UK National Reporting Centre Fraud & Cyber Crime

What to do and who to turn to if you need to report a fraud or cyber crime
https://www.actionfraud.police.uk/ or call 0300 123 2040

“Once Stricken, Twice Afflicted” As told by Jack Meintsma

Full article: https://wol.jw.org/en/wol/d/r1/lp-e/102004526



"Historic inoculations polio" by Sanofi Pasteur is licensed under CC BY-NC-ND 2.0

As a result of effective vaccines and diligent immunization programs, science has made great progress in its effort to eradicate polio, a debilitating childhood disease. However, even decades after recovering from polio, some survivors find themselves afflicted again, facing what is called post polio syndrome (PPS).

You may never have heard of PPS. Neither had I until it became very much a part of my life. But in order to understand the syndrome’s effects on me, let me go back to a day in 1941, when I was about a year old. My mother noticed that I was slumped over in my high chair. She rushed me to the doctor. After examining me, the doctor told my mother, “Your son has infantile paralysis.” I was soon paralyzed from the waist down.

After six months on a waiting list, I was admitted to the hospital. Years of recurring illness followed. Through intense physical therapy, I gradually regained the use of my legs. At the age of 14, I was walking again. But other problems, such as incontinence, remained. Over the years, I went through several cycles of surgery, confinement to a wheelchair, and physical rehabilitation. Still, my left foot is three shoe sizes smaller than my right foot, and my left leg is an inch shorter than my right leg. It was not until I was in my early 20’s that I got the embarrassing problem of incontinence under control. Finally, I was completely over polio—or so I thought!

Then, at age 45, I began to experience pain in my legs, followed by fatigue. Also, my leg muscles moved involuntarily at night, making it very difficult for me to sleep. The symptoms did not let up; they only worsened. You can imagine my surprise when I was diagnosed with PPS—44 years after my mother recognized my initial illness.

What Is Polio?

Polio is a highly infectious disease caused by a virus that enters the body through the mouth and multiplies in the intestines. After invading the nervous system, the virus can quickly cause total paralysis. As the virus passes along to the brain and then to the spinal cord, initial symptoms are fever, fatigue, headache, vomiting, stiffness in the neck, and pain in the limbs. Many of the nerves stop functioning, resulting in paralysis of some of the muscles in the arms, legs, and chest.

But the body’s recuperative powers are amazing. Nerves that were not affected by the virus send out new “sprouts,” as if running extra telephone lines, to reconnect the muscle cells that were orphaned when their previous nerves died. A single motor neuron in the spinal cord may also grow terminal axon sprouts, which may connect to many more muscle cells than it did originally, thus greatly increasing the neuron’s capacity. A motor neuron that previously stimulated 1,000 muscle cells might eventually reconnect to between 5,000 and 10,000 cells. This is evidently what happened in my case, so that I am able to walk again.

However, it is presently thought that over a period of 15 to 40 years, these neural muscle units may begin to show signs of fatigue because of being overworked. PPS is a condition that causes symptoms to reappear in individuals who had recovered from polio decades earlier. Many victims experience muscle weakness, fatigue, joint and muscle pain, cold intolerance, and breathing problems. Though accurate figures are hard to obtain, the World Health Organization estimates that there are 20 million polio survivors worldwide and evidence indicates that 25 to 50 percent of them are affected by PPS.

What Can Be Done to Help?

Researchers suggest that the old, overworked motor neuron becomes so exhausted that some of its nerve endings die, leaving many muscle fibres orphaned once again. To slow this process, a polio survivor needs to reduce the demand on the affected muscles. Some therapists recommend crutches, wheelchairs, and scooters. In my case, it became necessary for me to wear braces on both of my legs and feet. I also have specially made shoes that support my ankles and help to keep me from falling.

Moderate exercise and muscle stretching may also be required, depending on one's condition. Swimming or warm water pool therapies are excellent means of improving cardiovascular function without straining the muscles. It is important for the patient to cooperate with the doctor or the therapist in any exercise program.

In polio survivors, repeated demands on the neurons ultimately result in the failure of some muscle fibres to work properly. Survivors may thus experience a decrease in stamina or even suffer debilitating fatigue. Loss of stamina may also result from the stress of constant pain or of dealing with a returning disability. I have found that periods of rest during the day help me recover from fatigue. Many doctors caution their patients to pace their day to day activities rather than push themselves to the point of exhaustion.

In my case, constant joint and muscle pain has been one of the hardest things to deal with. Some may experience muscle pain particularly in those muscles that they have strained during their usual daily activities. Others experience a flulike aching in all their muscles, along with exhaustion.

Pain may lessen with anti inflammatory or other types of medication. But despite medications, many polio survivors suffer from disabling chronic pain. Physical therapy along with heat and stretching may help. A sufferer who gave up her practice as an anaesthesiologist told me, "I could get out of this wheelchair and struggle across the room, but the pain is so great, it isn't worth it." Now, even with medication that helps, I must frequently resort to my wheelchair.

Some polio survivors have lost the ability to shunt blood away from the skin, which the body normally does to conserve heat in the muscle tissues. Without this ability, an affected limb will radiate more heat and cool down. When the muscles are cold, poor communication from the motor neuron to the muscles results, and muscles do not work properly. Thus, it is important to keep the affected muscles warm by wearing extra clothing. Some use an electric blanket or a hot water bottle during cold nights. Avoiding exposure to cold weather helps. I found it necessary to move to a warmer climate.

Breathing problems are common, especially among those with a history of bulbar polio, a form of polio that affects the spinal cord in the upper neck and thereby weakens the breathing muscles. In times past, this type of polio landed many people in an iron lung. Today, a ventilator may be used to assist weakened lung muscles. In my case, it is very hard for me to breathe when I exert myself. Therefore, every day I use a small device to exercise my lung muscles.

Survivors need to be aware of another potential difficulty. It is not advisable to have surgery and then return home the same day. Dr. Richard L. Bruno, of the Kessler Institute for Rehabilitation, states: "NO POLIO SURVIVOR SHOULD HAVE SAME DAY SURGERY FOR ANY REASON except for the most simple procedures that require only a local anaesthetic." He adds that polio survivors require twice as long to recover from the effects of any anaesthetic and may need additional pain medication. Their stay in the hospital will usually be longer than that of other patients. If I had known that, I might have been spared a bout of pneumonia following a minor surgery. It is wise to discuss concerns with the surgeon and the anaesthetist before surgery.

My Life Today

When I was able to walk at the age of 14, I thought my problems were, for the most part, behind me. However, after many years I find myself experiencing the same problems all over again. For polio survivors like me who develop PPS, the situation is, as one writer put it, "once stricken, twice afflicted." Of course, it is only normal to get discouraged at times. Nevertheless, I can still get around and take care of myself. I have found that the best medicine for me is to have a positive attitude, to adjust to changing circumstances as they develop, and to appreciate what I can still do.

The Life of Ian Radus

by Marc Radus (oldest son)

Ian Radus (far left) with students of the Open Air School in Durban, South Africa.

It was at a nursery school in Belgravia, Johannesburg, South Africa when, in 1944, 5 year old Ian Radus fell out of the tree he was climbing. After being rushed to hospital the unexpected news emerged - Ian's fall was the result of muscle weakness. Ian was ill and had contracted poliomyelitis. Although this would be a defining moment for Ian it would in no way limit what was to follow.

The virus wreaked havoc throughout Ian's body, in particular his legs, right arm, muscles in his back, and his stomach muscles, and his lungs were particularly badly affected. He eventually regained movement in his right arm and some very limited movement in his legs, but his doctors warned Ian's parents that they should expect Ian to be bedridden for life. Ian remembered his time in an iron lung and how the medical theory at the time was to physically restrict the movement of the patient as much as possible. This medical approach was later proved to be completely wrong . This experience would leave an imprint on him – he would forever hate being in enclosed narrow spaces, such as going through the CAT scan machine. Something he would need to experience many times through his later life.

In order to care for Ian's physical needs, his education and family life was disrupted several times. At the age of 9 he and his mother, Lake Radus, moved from Johannesburg to the city of Durban so that Ian could attend the Open Air School. The school carries the motto "I can and I will" and was opened in 1921 to cater for the needs schoolchildren with physical impairments.

An untold number of orthopedic surgeries meant that much of Ian's childhood was spent in and out of hospital rather than at school. When he was 14 years old, he and his mother traveled to Liverpool in the UK so that Ian could receive more specialized treatment. Unfortunately, some of the surgery did not go to plan and this was a setback, but undeterred Ian carried on always hoping that the next surgery or treatment would give him a little more independence.

In 1954 Ian was transferred from hospital in Liverpool to a rehabilitation center in Southport. It was here that Ian discovered sport – something which would become a passion throughout his life. But here in Southport under the watchful eye of a somewhat tyrannical sports coach Ian learnt how he could push his body beyond what anyone could imagine and how he could master his body through physical activity. Ian would recall how the sports coach would get his charges to climb the rope using only their hands, make them do 100 press ups and endlessly wallop a punching bag. When he was told he showed promise as a basketball player, that meant the world to him. He went on to captain the wheelchair basketball team – the youngest player to do so.

On returning to South Africa, Ian attended Jeppe High School and then Damelin College in Johannesburg. Despite his limited time spent in school he matriculated and received outstanding results. Ian was accepted for medical school where he hoped to train as a doctor. Unfortunately, however, Ian was unable to take up his place at medical school because he was hospitalized and remained in a full body cast for 6 months. From a physical perspective, the operation was successful and Ian was able to start walking wearing only one caliper and using two canes.

While in hospital, and still disappointed about his missed opportunity to go to medical school, Ian decided on a career change and chose instead to follow in his father's footsteps by becoming an attorney. Ian graduated cum laude from the University of the Witwatersrand and won the Law Society prize.

Ian's motto was always if you are going to do something – do it right, or don't waste your time doing it at all.

It was at the age of 33 that Ian decided to join the Mandeville Sports Club, Johannesburg. It was here where he excelled at wheelchair basketball, table tennis, swimming and track – and received Springbok colours in all 4 disciplines. It was, he said, the fittest he had ever been.

He was soon appointed Southern Transvaal & Springbok Captain & led his team into multiple South African sports championships as well as international tournaments against Zimbabwe, USA, Canada & England.

At the time, it was common for families to keep their physically disabled children safely behind closed doors away from the rest of the world. To Ian this was a waste of life. Seeing the positive effect playing sport had on disabled people's physical, emotional and social health was all Ian needed to see to know he was right and to push past the boundaries and to do what he could to coax and encouraging disabled people to come out from the shadows and onto the sports field.

Captaining the first ever South African wheelchair basketball team in the 1976 Paralympic games against the silver medalists, Israel, was one of the proudest moments of Ian's sporting life. Ian also competed in swimming and table tennis events at the games (photo on back page).

But Ian was not satisfied with only playing sport – he later also became chairman of Southern Transvaal paraplegic organization & vice chairman of the national Paralympic organization.

After several rotator cuff injuries, Ian decided it was time to retire from sport and to focus his attention elsewhere. Having a full spinal fusion in 1979, to correct a life threatening scoliosis, put an end to any hopes of a comeback on the basketball court. While the surgery was a success, the spinal fusion created additional limitations for Ian. He was no longer able to use "trick" moments and getting up and down stairs became almost impossible. Soon after, Ian started using a wheelchair on a full time basis.

Ian was passionate about life and living life to the full. One way to do this was for Ian to do what he could for the community. For example, he joined and later became chair of Radio Rescue, a citizen band radio volunteer service. He also trained and became a crisis counsellor at the Waverly Crisis Centre in Johannesburg. In 1985, Ian decided to look more deeply at his Jewish heritage and became observant, studying the texts deeply and helped to build a now thriving synagogue and Jewish community in his neighborhood.

In the early 1990's Ian started to notice some strange symptoms which puzzled him and his family. Initially it was almost imperceptible - the weaknesses in his arms, pain in his legs, and fatigue. He once described it as feeling as though the parts of his body which had been most effected by polio had aged faster than the rest of his body. These symptoms grew gradually stronger and became more debilitating. Later they would start to effect his breathing. Ian's doctors couldn't explain it, and thought the weakness and pain in his arms and legs were due to previous sports injuries or a result of some previous surgery. It was only when Ian stumbled across the Lincolnshire Post Polio Network (as it was then) and made contact with Hilary Boone that things started to make sense – Ian had developed post polio syndrome. Ian once had an ICQ six chat conversation on the internet with Hilary and five others. A few days later Hilary was recounting this to another polio member and ended "and Ian in South Africa". Lynn said, 'Oh I know Ian in South Africa" and they both laughed. Hilary then said "Ian Radus" Lynn said, "That is the Ian I know, I met him when I was at the Paralympics in Toronto"! In 1998, Ian & Cecile travelled to London to meet their first born grandchild, a drive to Lincolnshire to meet Hilary was an essential part of the trip and Lynn drove up from the South Coast to meet him as well.

Ian enjoyed exploring and mastering alternative health and healing techniques ranging from hypnosis, reiki and meditation – both for managing his pain and to help other people. Ian was a committed and strict vegetarian for many years.

Being physically disabled never held Ian back. In his later life when his condition worsened, and despite enormous amounts of pain and suffering, he never stopped wanting to live life to the fullest. When he was bed bound, he used the time to tap the creative and intellectual parts of his brain. Endlessly reading both fiction and non fiction, learning, writing speeches and lectures for his community, and dedicated many hours to writing a book.

After many brave and heroic battles, Ian passed away peacefully on 4 July 2020. He leaves behind his wife of 56 years, Cecile, his three children, Marc, Jo-Ann & Lance and 7 grandchildren.

Yvonne’s assorted threads

Face masks…oops, I mean face coverings

Well we all knew it would come to us having to use some kind of face covering. I’m not keen on them because, being an Essex girl, you can’t see my lipstick! Joking apart, I can’t breathe very well in them, but I do wonder if it’s a throwback terror of having a black rubber mask held over my face when going for operations as a child. Why, oh why couldn’t they just put me out with the ‘count to ten’ injection and then put the mask over my face? I used to fight like a tomcat every time.

However I am trying to be a grown up about it and get over it by practising mindfulness when I put one on. Not that I’ve been anywhere except the doctors surgery in the last 4 months, so I’m not exactly getting much practice. But I do love making face coverings. My craft room is full of a wonderful selection of materials/fabrics and I’ve been challenging myself with making up patterns from You Tube. Pyrianka is good. They obviously have, in some way, to match my outfit for the day (sad, I know, but that’s me). Lately though my outfits consists of gardening clothes or gardening clothes! so when I do go out I have to match.

I made my daughter in law and two granddaughters matching ones which they loved, and the youngest ones favourite has gold elastic. Bit of Nana rubbing off on that one!

It seems the right elastic is the so called ‘earloop’ elastic, which is soft and comfortable and much better than the dreaded knicker elastic. Once you start looking at patterns you’ll find many varied styles and having mastered the patterns its very easy to make them up. I have a lot! My daughter Kerenza is my tryer and tester and is doing her best to reduce the ‘mask’ mountain. Oh and I’ve just had a thought, I haven’t got any purple ones yet!

‘Change we must’ picture

What an amazing picture by Jane Tomlinson on the front of the July 2020 newsletter. I spent quite some time finding all the objects. We do a lot of recycling here and my sewing machine is in constant use. This lockdown shows just how much we don’t need to keep going out and buying ‘stuff’. I’m so impressed by this piece of artwork that I have cut it out and put in on the pinboard in my craft room.

‘Points’ of interest

You Tube is brilliant and I’m always finding things to watch. My husband and I are interested in all things Heritage Railway related, having visited many in the past. ‘Rail Mart’ is interesting, it’s the drivers eye view from the cab sort of thing. e.g. Paignton in Devon to Exeter, Topsham to Exmouth and my favourite St. Erth to St.Ives...Escapism.

Oakley Rabbit

Kerenza, my daughter, has made her version of one of the rabbit family that we featured in the last newsletter. His name is Oakley and he is a woodland rabbit, made in lime green wool felt he was inspired by the ‘Green man’, a legendary being representing the cycle of new growth every spring. We made him some brown needlecord trousers and a waistcoat onto which Kerenza stitched various leaves. Then, Kerenza being Kerenza, made him a twig throne. At which point our friend Pauline (the knitter) got involved and also got carried away making mushrooms, acorns and oak leaves, which look amazing. We managed to make him with things we already had around, which did involve a lot of searching in my craft room. I’ve usually got things, t’s just a case of finding them! Thankfully, living in the forest Oakley doesn’t need an extensive wardrobe, a quick rub down with some moss and he’s good to go.

Polio Charity Boxes

Does anyone remember the charity ‘statuette’ mainly placed outside shops in the 50’s. The polio one featured either a boy or a girl wearing a brace or caliper, or as we called it, a leg iron. They were holding a collection box in their hands and obviously donations were welcome. They were very welcome in my case, as I stood next to one outside the ‘Home and Colonial’ store minding my baby brother in his pram, so I would be 7 at the time. Mum always seemed to be in the shop for ages, no self service in those days. Having watched a couple of people put pennies in, I placed myself next to the girl statuette and stood in the same way as her, leg iron on show. More people came and put money in. Smiling at them I decided to do a bit pro active, telling them they didn’t need to bother putting the money in there as I had the same as her and they could give it straight to me! I did really well and was quite pleased with my handful of money. I proudly showed my mum when she came out of the shop (she who must be obeyed) and then watched her face change as I told her of my money making scheme. Furious, hmmm, it wasn’t good, one of those hissing in your ear sort of telling off was delivered first, then I was made to put all the money in the box. Every last penny, I mean, surely I could have kept one penny and got four blackjacks with it, couldn’t I?

Lockdown viewing

I don’t know about anyone else but I personally couldn’t have survived all this lockdown business without the odd bit of escapism. A film or an Amazon Prime or Netflix boxset has been a real diversion from all the reality of Coronavirus. There was always an old adage in Hollywood that there were no decent roles for women over 40. Well Netflix seems to have put that idea firmly in the past! I was pleasantly surprised to find two actresses, who were firmly type cast as rom com legends in the nineties, in lead roles in captivating and binge worthy series. Renee Zellweger in ‘What if’ and Reese Witherspoon in ‘Little fires everywhere’. What a pleasure to see both break the mould and I would strongly suggest both series are well worth a watch. Is Netflix the future for older actresses?

Do you shop at Amazon?

Access Amazon through www.smile.amazon.co.uk and sign up to have Polio Survivors Network as your chosen charity .
0.5% of your purchase price is donated to PSN by Amazon.
Costs you nothing!

Did you know you can donate to PSN via PayPal fee free?

Donate here: **https://bit.ly/3eZ3NsV**

YOUR GOOD HEALTH: History of polio needn't prevent woman from getting vaccine

Full article: *https://bit.ly/35qgomE*

Dear Dr. Roach: *I am a woman in my late 70s, a 1949 polio patient. For many years, I have been told that because of poliomyelitis I cannot tolerate any preventive inoculations, including flu, pneumonia, shingles, etc. I was allowed to get flu shots when they first became available; however, when additives were included later on, I was instructed not to get it any longer. My concern is if I will be able to safely partake of the coronavirus inoculation when it becomes available. Most present-day doctors have no experience with polio, and often input is vague. P.G.*

Dr Roach replies: Poliomyelitis was, for many years, a terror that parents feared every summer. Until a vaccine became available in 1955, polio could strike without warning. Although the vast majority of people had only mild symptoms (90% to 95% of cases were asymptomatic), about one person per thousand with polio developed poliomyelitis, a serious complication of the nervous system that was sometimes fatal and two-thirds of the time led to permanent weakness. Why some people got terribly ill and died while others had no symptoms remains a mystery, although we know some risk factors for developing poliomyelitis, such as older age, excess exercise while infected and tonsillectomy.

I am surprised to hear the recommendations against standard vaccines for you. I haven't read that before and I have taken care of quite a few polio survivors. Experts confirm that standard vaccines, including flu, pneumonia and shingles, are recommended for those with a history of poliomyelitis. There are no additives in the vaccines placing polio survivors at increased risk.

It is too early to speculate on a coronavirus vaccine. Although many groups are working on a vaccine, efficacy and safety testing is extensive before a vaccine is approved and the process must not be rushed. However, I doubt that a history of polio will prevent you or the many other polio survivors from getting the vaccine when one is approved.

There are many places for you to get more information: Post-polio.org is one I often use. It has reliable information from experts, which is increasingly important as the number of physicians who have taken care of polio survivors decreases.

BEYOND BARRIERS

Anne Davey Koomans' Biography of Her Husband, David "Dave" M. Davey, Praised By Book Reviewers

Full article: *https://bit.ly/3k6X7ek*

"David Davey's body was ravaged by polio at a young age, but the footprints he left behind are of unquestionable value," says Jennifer Padgett of San Francisco Review.

Anne Davey Koomans published a biography of her late husband, humanitarian and disability rights activist David "Dave" M. Davey, titled "Beyond Barriers" (Readers Magnet; 2020). Published date June 13, 2020

"Beyond Barriers" tells the exemplary life and works of the selfless Dave, who was instrumental in the passage of Americans with Disabilities Act (ADA). As a liaison for Goodwill Industries, he worked with Senator Bob Dole on the National Barrier-Free Architectural and Transportation Board. The book also tells the author's life with Dave and their travels together.

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Operations Team

Phone Enquiries - Hilary Boone **- 01522 888601**
PSN Admin, Email Enquiries and Website - Toni Dunlop - psnadmin@poliosurvivorsnetwork.org.uk
Printing - Imprint Colour Printers, Lincoln

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The most accepted articles by NHS professionals we have found are:

1) Patient Plus article Post-Polio Syndrome

Written by U.K. Doctors for Doctors

http://patient.info/doctor/post-polio-syndrome

NB Respiratory and Sleep Problems Section very informative

Good anaesthetic article (English version used by many PPS groups)

2) Polio Patients and Surgery - Information for health staff

Lise Kay, MD, Surgeon PTU – Danish Society of Polio and Accident Victims

http://www.europeanpolio.eu/documents/13642_Polio_operation_eng_TRYK.pdf

Printed copies on our headed paper with permission are available

Editors Note: *Articles from Polio Survivors and Health Professionals welcomed*

WE'RE STILL HERE!
OCTOBER 11-17, 2020
www.post-polio.org
www.polioplace.org

Winner: Photo Competition **'This Made Me Smile'**

Congratulations!

Fran Henke of Polio Network

"Corella eating our garden light at the weekend. They move in big flocks down here (*Australia*), swinging on power lines, having fun. Lesson to us all."

See also Barbara Taverner's thoughts on 'Smile' page 5

Photo shared on the Facebook public group Polio Australia by Lyn Glover

Ian Radus, representing South Africa at the 1976 Paralympics, Toronto

Read Ian's life story (told by his eldest son) on page 14

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