POLIO NSW

formerly Post-Polio Network (NSW)

NETWORK NEWS

Incorporating – Polio Oz News

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Editor's Report:

At the Annual General Meeting the formal 2021-2022 Annual Report and Financial Report were presented and adopted. These are included along with this newsletter.

The election for the Board was also conducted. The executive is unchanged:

President:	Gillian Thomas	Secretary:	Merle Thompson
Vice President:	Susan Ellis	Treasurer:	Alan Cameron

Members re-elected to the Board: Ella Gaffney, Bill McKee, Vasa Marimuthu, Diana O'Reilly,Gail Hassall and Rosalie Kennedy. We welcome Geraldine James and Esther Smart as new members of the Board and trust they will find their involvement rewarding.

Nola Buck did not stand for re-election. Nola has served on the Board for many years over two extended periods and held a number of positions including that of President. We thank her most sincerely for her years of dedication, her wisdom and leadership. While she will miss the friendship that the Board and her roles in the organisation have provided, it is time for her to now enjoy "retirement". We also thank Shirley White for her contribution to the Board over the past few years.

Prior to the AGM a webinar entitled "The Polio Experience in Other Countries" was presented by two members of the board, Rosalie Kennedy and Vasa Marimuthu. It was interesting to note that even though there are differences in polio experiences by all of us there are also many similarities. I hope you enjoy the report starting on page 5.

George Laszuk, Polio NSW Office Manager, retired at the end of 2022 and we thank George for his dedication and support over his 19 years of service. See page 2.

On page 3 we have an article by member, Rosalie Cogger-Collins, called "Resilience – A Polio Story". Rosalie and her sister Gloria contracted polio in the early 1950s.

A report of the webinar on Feet by Kyle Perry appears on page 8. I encourage you to join the webinars, they are proving to be well attended and very educational with time to ask questions as well. We thank Gail Hassall for her efforts in organising the speakers, the advertising and hosting of these events.

Rosalie Kennedy continues to host the monthly online support group meeting on the third Wednesday and has had positive feedback from all those who attend, to join the meeting click on this link: - https://us06web.zoom.us/j/98354246536?pwd=cldkTmZXV3FzNlhnUkpHMzB5UXRaZz09

GEORGE LASZUK

By Susan Ellis

"After nearly 19 years as Office Co-ordinator, George has retired. I am sure all members will share with the Board in expressing our thanks to George for his loyalty and commitment over the years. He has been the central figure in the office and provided continued service throughout the years". – Merle Thompson, Secretary.

George along with the office staff also provided the administrative task for the many seminars; booking Northcott's conference room, arranging catering, registration of members and name tags for all attendees. In past years it was not unusual to have 100+ members attend any event that Polio NSW held. This also included the country conferences which George attended and coordinated with ease.

George's years as office coordinator will be remembered by those who worked with him as staff or volunteers. For those people nothing was too much trouble for George, one would only need to express a wish and George would be on to it to make it happen. An example of this thoughtfulness was getting a parking space closer to lift for a volunteer.

If for some reason a member of Polio NSW wished to cease their membership, George did all he could to persuade them to continue being a member, especially to receive the Network News. George could be very persuasive!

During the years since the formation of Polio Australia, four day retreats were organised across Australia and Polio NSW hosted a number of these in Sydney. George was involved in these events once again. At one particular retreat George organised a team from his Lions Club to be on hand to help attendees with their luggage and the parking of their cars, it was a service that was greatly appreciated. For many years George was able to procure donations from his Lions Club.

The mail out for Network News was also organised by George, contacting his list of volunteer to help out for a day to get this complicated job done. As years passed it became too difficult for some of the volunteer members to keep up this task and George was able to take advantage of Northcott's young people employment service (Vocational Skills Training and Employment) to help out. I remember these days well and especially the pizzas that George ordered for lunch.

George also attended disability EXPOs representing Polio NSW, to answer enquiries from the public and encourage membership to any polio survivors. He setup displays offering information about polio and post-polio syndrome.

> You cannot say farewell to George without thanking his son Robert for his assistance to the network, not only did Rob assist George physically he also helped the office staff in many ways such as lifting heavy files and boxes.

A few photos of George taken from various newsletters and promotional brochures

RESILIENCE - A POLIO STORY

by Rosalie Cogger-Collins

I have written a short story about my sister Gloria and myself both suffering from having Polio in the early 1950's. My sister suffered with Paralysis whereas I suffered with Lung, Diaphragm, Throat injuries from it and now we are both suffering with Post-Polio Syndrome. I thought this story maybe interesting for people who are suffering with this condition.

My sister was 10 when she developed Polio, I remember the morning everything changed. Our father came in and asked us to get up out of bed and get ready for school, I jumped out of bed, as I always did. But when Gloria got out of bed she fell to the floor. Dad picked her up and put her on a chair, concerned and alarmed. Gloria could not walk, she could not stand at all, her legs were paralysed.

Mum and dad started a process of taking Gloria to extensive doctor's appointments. First the GP, who quickly identified polio and then a trip to Sydney to visit the Camperdown Childrens' Hospital, where children with Polio were treated. The children were kept in isolation – away from parents and family members. They were put in wooden splints and plaster casts – often for months. These practices were usual for the time.

The hospital was very scary with long dark corridors and as Gloria saw a doctor with Mum I sat alone with Dad wondering if this place might swallow us up.

The doctors wanted Gloria in the hospital but my parents decided to treat her at home. My mother was a nurse at Kurri Kurri Hospital in isolation wards looking after children with Diphtheria. Mum and Dad became aware of a new polio treatment – the Kenny regimen developed by Australian bush nurse Sister Elizabeth Kenny. A form of physical therapy her method incorporated massage with warm olive oil to activate the affected muscles. For many months Dad used the method of massaging the legs with warm olive oil, Gloria said some time it was a little too warm but she put up with it.

Dad made a cubby house for us, it even had stained glass windows and the walls had an abundance of glossy favourite movie star photos. We were isolated from other children due to the virus but when it was safe for children to visit we spent many hours there with our friends.

Our parents owned a Sports Store in Newcastle and every night when the shop closed we went to Newcastle Ocean Baths for 1 hour of exercise which Gloria needed to help her walk again.

Mum and Dad surprised us one Saturday morning, our lounge room door was closed, this was very unusual, and when the door was opened we saw a pianola that they had purchased so that Gloria could exercise her legs.

Gloria was able to return to school but her body was still weak particularly her left foot and leg. Since suffering from polio she has never danced, been on a bicycle or been able to walk long distances or participate in any sport.

She put all of her efforts into her education finishing the Leaving Certificate and having high scores in Mathematics and Science, becoming a High School and TAFE Teacher for many years.

Gloria is in her senior years and still shows serious scars of having had polio but she never gave

up, just kept going, she always showed great resilience in whatever came her way. Gloria was very disappointed a couple of years ago that she had to give up WIRES, helping injured wildlife, due to her disability.

I was not diagnosed with Polio until 7 years ago. This was such a contagious disease and due to Gloria and I sleeping in a double bed when we were children I also contracted it. For years I had to take deep breaths, but my mother used to say "Rose just keep taking deep breaths". About 10 years ago I found that my breathing was getting worse and I was unable to continue swimming my 14 laps each day. After a few years of tests I was diagnosed with the post-polio syndrome.

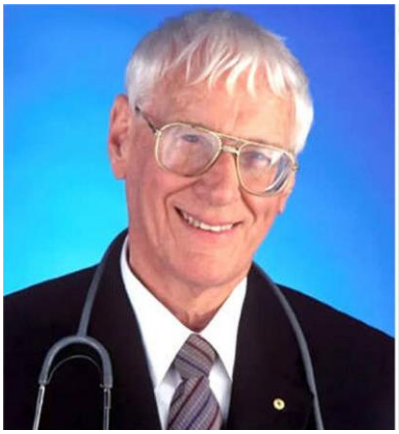
Although polio didn't manifest itself in quite the same way as Gloria's I have experienced it's after effects. My lungs are scarred, I have fibrosis of the lungs, respiratory and throat muscles are weak and the hypothalamus (our body's thermostat) in the brain is damaged all from the polio. I am unable to walk distances, can't swim anymore and if I get hot I frequently pass out.

I was employed in Secretarial work most of my life and as a customer service employee for many years I coped with the pressures of this type of work. Now with the ageing process my disability, of course, is getting worse.

I have found that people, who have suffered from having polio, and now have the post-polio syndrome, many not having been diagnosed yet, have an amazing RESILIENT attitude and push on. They always find themselves never giving up and find it very difficult to slow down even when the body tells us we should.

VALE - Dr. John Knight

by Gillian Thomas OAM, President Polio NSW



I learnt today (29th November 2022) of the death of Dr John Knight at the age of 94. Many of you will remember his weekly newspaper columns written for many years under the pseudonym "Dr James Wright". The columns were published across Australia, including in The Melbourne Herald Sun, The Sunday Telegraph (Sydney), The Sunday Mail (Adelaide and Perth), The Brisbane Sunday Mail, The Sunday Territory and The Sunday Tasmanian.

During the 1990s, in the early days of Polio NSW, Dr Knight regularly wrote snippets about post-polio syndrome, without any prompting from us.

He included our postal address, and after one of his items was published I could be guaranteed to receive new enquiries every day (often 100 letters crammed the PO Box!).

This early wide-ranging publicity helped our organisation get established as polio survivors sought information about the late effects of polio and so became members to get ongoing support. Many of you are still members today, for which we are very grateful. Thank you, Dr Knight!

AGM SEMINAR REPORT

The Polio Experience in Other Countries

On Wednesday 30th November 2022 prior to the AGM two members of the Board presented their life experience of having had polio – Vasa Marimuthu from India and Rosalie Kennedy from South Africa.

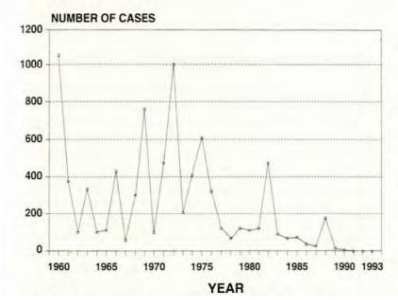
Rosalie Kennedy, a polio survivor from the 1960s epidemic in the City of Durban, Province of Natal, South Africa.

My birth and my childhood in South Africa was shaped by two catastrophic events: "Polio and Apartheid".

Large families were typical of the times, I was one of 12 children, and families were close knit communities struggling to survive.

A massive political upheaval had occurred in South Africa in 1961, it went from a Government of the Union of South Africa to a Republic of South Africa. Economic downturns in Europe fostered sea exploration and then World domination to gain and exploit the resources. A racist colonialist system introduced Apartheid to gain total control of the whole population.

<u>The Spread of the Polio Virus in South Africa</u>:
Epidemics of poliomyelitis were unknown in Southern Africa before World War I. A major Polio outbreak occurred in the summer of 1917/18, when soldiers were returning from the Great War. The next Polio epidemics occurred in the 1940's - specifically 1944/45 and again in 1947 and 1948. These ignited the drive to be one of 4 countries in the world to produce their own Polio Vaccine with USA's help in 1955.



Paralytic Polio Cases 1960-93

A Polio outbreak occurred in Durban (South Africa) in 1956/57, and in 1960, and 1972 many thousands of infants and children like myself, were infected and hospitalised in Addington Hospital - it being one of the major hospitals at the time in Durban.

Between May and September, 1982 an extensive epidemic of poliomyelitis occurred in Gazankuluin the north-eastern region of South Africa, with a total of 260 paralysed cases and 42 deaths.

An extensive poliomyelitis outbreak due to type 1 poliovirus took place in Natal/KwaZulu, South Africa, in 1987-1988, causing 412 paralytic cases. This epidemic differed from a previously described outbreak in Gazankulu, South Africa, in that it occurred against a background of relatively good immunity.

<u>Features of the Spread of Polio</u>
There was a stigma of poverty/hygiene. Polio is an enterovirus and the main route of transmission is faecal-oral. Transmission is therefore more frequent in areas where water supplies and sanitisation are poor, and where overcrowding is rife. Improvement in these areas assisted in the eradication campaign as well as the control of many other enteric diseases.

<u>A brief history of the apartheid system from 1948 to end of 1994</u>.
Apartheid was a system of legislation that upheld segregation against non-white citizens of South Africa. After the National Party gained power in South Africa in 1948, its all-white government immediately began enforcing existing policies of racial segregation. Blacks suffered decades of government backed injustice, whites were superior and blacks were discriminated against in every aspect of their lives – they could not own

land, interracial marriage was banned, they could not live or work near the white population, there were separate schools and transport. From the 1960 resistance grew with antiapartheid demonstrations in the 1980 allowing for gradual reform which slowly led the crumbling of the movement. In 1994 Nelson Mandella was elected the first black President of South Africa.

The Apartheid Era caused much anger, fear and humiliation and this included for the children who notice everything. Having a large family helped though.

My Polio Experiences:

In the 1950s and 1960s polio raged in Durban. I acquired the polio virus at the age of 10 months. I was the 11th child in my family and my mother was 10 weeks pregnant with her 12th child. My whole family was quarantined and the experience was like the COVID isolation procedures.

My mother, who was still nursing my baby brother, had to take the whole day off work, catch 2 BLACKS ONLY buses to get to the Addington Children's Hospital Out Patient Clinic, it was the only facility on the African continent solely dedicated to children and infant healthcare. I attended this clinic for 6-8 years.

Growing up with polio in South Africa was difficult, due to isolation, as there were only two other disabled children my age in my school and neither had had polio. I had lots of falls due to my unsteady weak right leg but persevered. I had close friends but still had to 'sit it out' whenever there were Sports played at school. I was never asked or encouraged, though I did take up tennis – my coach had had polio!!! I liked swimming as well but they only had one facility for my racial group.

I rarely travelled except to visit family who lived in Swaziland. In my early teens when I was in Year 6 I almost won a trip to Cape Town with my favourite teacher and her family. I deliberately under achieved so as NOT to win, I was relieved as I was terrified of her family seeing my disabled foot.

Apartheid took its toll and non-whites had their land taken including ours. In the black suburbs the violence increased as the people were crammed in and tried to resist the Regime. In March 1975 my parents and 4 youngest siblings left South Africa for Sydney, sponsored by my eldest sister and husband. I was very nervous about coming to Australia by sea, we travelled on the P & O Oronsay – it was my first overseas trip.

Adjusting to the freedom of Aussie life in my teens - 15-18 year:
Polio did not affect my fun at my new school in the western suburbs of Sydney, teasing was less because of changing attitudes. I was encouraged to take up new hobbies like music and art and was invited to join in. It was safe to travel at night with friends.

I began to experience the first signs of pain at 16 from overuse of my good leg on long walks and bike rides. I refused to wear built up shoes but I was able to use my own orthotics – I was doing it MY WAY! Little medical attention was sought for my polio symptoms in my teens. We had a family motto – **"keep on going, no matter how tough"** AND "**You've never had it so good…."**

If you are interested to know more about the history of apartheid here is a link:-
https://youtu.be/kJOU9YYMzpw

Vasa Marimuthu, a polio survivor who contracted the polio virus at the age of 10 months in India tell his story, “My Journey with Polio”.

I was born in 1977 in Pondicherry, a small coastal city in India which was a former French colony. I am the eldest of three sons in my family. I was given two polio vaccinations and when it was time for the third dose I had the ‘flu’ and missed out. Within two days I caught the polio virus. The doctor’s recommendation was to use callipers which were extremely painful for a young child.

My family spent their initial days trying every alternative medicine (Ayurveda, Siddha, Homeopathy) to find a cure or improvement. For the next 5-6 years my grandfather took me to the beach by carrying me on his back and shoulders. With no means of transport available at that time, he walked the 6 kilometres so I could exercise my polio affected leg. My grandfather dug a hole in the sand and buried my leg to strengthen the muscles. I continued using homeopathy medicines until I completed Year 10.

At school I did not play any sport, I was discouraged by my physical education teachers to participate in any activity. This affected me emotionally and I grew up with a lack of confidence and an inferiority complex. This was unintentional since my teachers thought it was best for me to avoid injuries. Out of school though I played soccer, tennis, cricket and cycled around the neighbourhood.

I developed an interest in electronics and did small repairs at home on radios and torchlights which eventually led to my completion of a university degree in Electronics and Communication Engineering.

In 2004 I got married and have 2 beautiful boys. Being born into a conservative huge family with aunts, uncles and cousins, it took 5 years to get my parent’s approval to marry.

Vasa investigated the idea of moving to the USA for a better standard of life. Since the US had a visa lottery system, I applied twice and unfortunately wasn’t successful. One of my colleagues completed a Masters Degree in Melbourne and upon his return spoke highly about Australia. This gave me the idea to explore life in Australia. I applied for permanent residency in 2007 at the age of 35 and arrived in Australia in 2014. Finally, the dream of becoming an Australian Citizen came about in 2018.

After a while I started experiencing RSI in my upper back. I had noticed lots of changes – pain, breathing discomfort, snoring, lack of sleep, knee pain etc. while working 12 hour days in IT. I learnt about Polio NSW from a pamphlet issued at Merrylands Library. I arranged to see Dr Stephen Buckley at Chatswood and underwent a sleep study at Royal North Shore Hospital. I was diagnosed with sleep apnea and have been using CPAP till date.

Next I saw Dr Helen Mackie and attended a Day Program at Mt. Wilga Private Rehabilitation Hospital. I was also treated by Catriona Clark (neurophysiotherapist).

I have always maintained an active life to keep healthy and hence participated in the City to Surf, cycling and regular walks across the Sydney Harbour Bridge. In 2019, along with friends, I did an extended trekking trip to the Himalayas. This involved 17km of hiking at 3500m above sea level. It was a proud highlight of all my activities so far.

Vasa in City to Surf

Vasa in Himalayas

Cycling with friends

Catriona advised me to slow down and preserve my muscle strength by pacing work, listening to my body, asking for help and hydrotherapy. I was referred to consult a pedorthist at Shoetech, situated in Dee Why (Karl-Heinz Schott) who has been assisting me with modified footwear. I also receive support from the NDIS for orthotics and physiotherapy which makes my life easier.

As part of giving back to the Community, I volunteer with the Wayside Chapel, Green Waste Clean-up with North Sydney Council, Aruma Disability Services (formerly House with No Steps), and Community Language School doing administration.

Being part of the Hills District Polio NSW Support Group has been very helpful since it provides me with hope and motivation to lead a better life.

FEET WEBINAR

Report by Susan Ellis

This presentation by Kyle Perry was held on 31st August, 2022.

Kyle Perry graduated from the University of Western Sydney in 2013. He is Head of Podiatry at **OnePointHealth** Penrith overseeing a team of 14 podiatrists. He also studied under a Podiatric Surgeon Ozan Amir and is currently the podiatrist for the Penrith Panthers.

OnePointHealth is located predominantly in Ryde and Penrith with smaller facilities at Silverdale, Blaxland, Katoomba, Ropes Crossing, Springwood and Lithgow. Other services include podiatry, chiropractic, nutrition, massage therapy, physiotherapy, dietetics, exercise physiology and orthopaedic footwear maker. Having a team of therapists allows for a more efficient communication between therapists to provide a holistic treatment approach and a faster outcome in treatment.

This presentation covers how the polio foot differs, fluid retention, neuropathy and the EnableNSW program.

The Polio Foot/Leg

Polio affects all muscles but not necessarily equally in terms of degeneration speeds, sometimes we do not lose muscle strength and muscle groups stay healthy and strong or they can degenerate over time. What needs to be monitored is anterior leg muscle degeneration leading to foot drop (degeneration of the muscles at the front of the leg) which makes it difficult to clear the toes when walking which leads to falls. This is normally corrected with the use of callipers/orthoses.

Orthosis inserts into shoes/jogger to lift foot

Velcro strap secured around ankle and a strap attaches onto the shoe to lift foot

The calf muscles can tighten and spasm causing the opposite of flat foot i.e. high arches with the foot leaning out as well as clawing of the toes. The rear foot could sit inward or outward. This can vary completely in a polio foot from terms of degeneration, to joint change and the way the foot sits; and we have to treat each case differently.

These are the main characteristics of a polio foot:

Foot drop is my main concern, it's the peroneal nerve that gets compressed/damaged, and this main nerve controls the front of the foot. Falls risk is so high i.e. in and out of showers, cars and it must be rectified. Callipers and AFOs (ankle foot orthoses) have been used for some time but he likes the AFOs variety (L shaped up to the knee) and gives best support. There is a new dynamic foot up which still allows muscle function but at the same time it holds the foot up.

Once the orthotic is fitted into the shoe it aligns the foot correctly i.e. foot straight ahead and not pointing to the side and allows for stability of the foot.

Correction of a foot 'deformity' to stop any further degeneration of the foot can sometimes only be done to a degree. A foot inner shoe orthotic is made after taking a plaster cast of the foot/ankle. Various materials are used to create stability; a high density EVA foam is a material that can be adjusted in depth by grinding to achieve the best outcome. Slow release open cell materials such as poron and spenco are used for top covering to accommodate 'soft spots' i.e. corns. Other considerations are differences in leg lengths and/or foot lengths i.e. size 4 left and size 7 right foot. For significant leg length differences a build up on the outer sole of the shoe would be necessary. This can be done to off the rack shoes and/or made-to-measure shoes. For an accurate measurement of leg lengths i.e. to the exact millimetre, a CT leg length scan can be ordered by your GP. Even a small discrepancy i.e. 5mm+ is worth treating.

Multidisciplinary care:

This is what our clinics aim to provide and generally are all on one site – Exercise physiology, physiotherapy and occupational therapy. OTs are brilliant for maintaining at-home and external independence, they open up all possibilities.

An exercise physiologist or physiotherapist can work on strengthening muscles around a joint which will improve support of the joint and decrease the level of pain.

Fluid Retention:

Venous Lymphatic Bursitis

High-risk based topic:

The role of the podiatrist is to identify and to flag with the appropriate sources i.e. your GP, vascular specialist or a cardiologist. It is really important to monitor and observe these things and help guide treatment in the correct way.

Flag points:

- Varicose Veins: Damage or weakened valves lead to increase in pressure in the veins. This results in blue-purple discoloration and leakage of fluid and fluid retention. This can be treated with medication i.e. diuretics and/or compression stockings.

- Telangiectasia: Similar to varicose veins however smaller (like spider veins) and can be attributed to obesity, fluctuations in hormone levels and/or trauma.

- Venous Stasis: This is more dangerous and is caused by immobility and the leakage turns pigments in the skin a dark brown (something that cannot be reversed), venous ulceration can also occur and fluid retention also occurs. Ulcers need to be cleaned, covered and kept dry.

Stages of Venous Insufficiency:

[Venous insufficiency - Improper function of vein valves in the leg, causing swelling and skin changes. Normally, the vein valves keep blood moving back towards the heart.]

Graded between C1 to C5,C6:-
C1 Spider Veins. **C2** Varicose Veins. **C3** Oedema (Swelling). **C4** Skin Changes. **C5,C6** Venous ulcer.

Deep Vein Thrombosis:

A DVT is very alarming and can be life threatening. DVT is when blood clotting occurs causing throbbing or cramping pain in one leg (rarely both legs), usually in the back of the calf muscle or thigh, with swelling, warm skin and/or red or darken skin around the painful area as well as swollen veins that are hard or sore when touched. The pain has a quick onset and after two or three steps it causes an inability to walk any further. A venous ultrasound is used to assess for DVT. DVTs can occur in diabetics with fluid attention and pain; and after long hauls on planes. It is critical to attend a GP or emergency department immediately for treatment as the clots can move and go to your brain.

Pitting Oedema:

Pitting Oedema is either caused by a localised problem with veins in the affected area, or by a systemic problem with your heart, kidneys or liver function. Venous insufficiency usually affects both legs and can be treated with diuretics.

Oedema without pitting is more likely to be caused by issues with your thyroid or lymphatic system.

Lymphatic Swelling:

Lymphedema signs and symptoms include:
- Hard firm swelling of part or all of the arm or leg, including fingers or toes generally on only one side
- caused by damage or removal of the lymph nodes i.e. removed in breast cancer surgery
- a feeling of heaviness or tightness
- restricted range of motion
- recurring infections i.e. cellulitis (inflammation of the skin cells)
- hardening and thickening of the skin (fibrosis)

This type of swelling can be treated by a lymphatic drainage massage specialist, it activates the lymph nodes to drain the lymphatic system of excess fluid, it is a light massage directed up or

down towards the heart. It can take two to three sessions before improvements are noted and the fluid starts to move. A massage might need to be on a regular basis i.e. monthly or bimonthly to keep it maintained.

Compression stockings (medical grade) for both lymphatic swelling and venous insufficiency are used to provide a venous pump motion to return blood flow up. They 'squish' the tissue so that the fluid is closer to the lymph nodes. The compression forces that fluid back up towards the heart.

Polio has caused muscle reduction and a loss of neural supply and this can cause neuritis and stasis (inactivity of muscles). We need our muscles to bring us back to that function point, we need our muscles to mobilise us but also internally to bring that fluid back up towards the heart. If there is neuropathy or a neural defect (nerve damage and/or paralysis) that is when that fluid can override and that is when a physiotherapist or massage therapist can step in.

Neuropathy:

There are many causes of neuropathy [nerve damage]. Diabetes is the number one cause. Other common causes include trauma, chemotherapy, alcoholism and autoimmune disease.

Compression can cause neuropathy/neuritis. With degeneration, with loss of muscle control and muscle strength these conditions can start to occur as well. Neuritis can be reversible if detected early enough. Immobility can cause neuropathy.

Peripheral Neuropathy:

The peripheral nervous system is the communication network that sends signals between the central nervous system (the brain and spinal cord) and all other parts of the body. In diabetics when damage to the peripheral nervous system occurs the mechano-receptors start to reduce in function. It is mostly irreversible and also causes vascular reduction.

About 60-70% of people with diabetes have mild to severe forms of damage to sensory, motor, and autonomic nerves that cause such symptoms as numb, tingling, or burning feet, one-sided bands or pain, and numbness and weakness on the trunk or pelvis.

Ulceration and loss of limb risk increases tenfold. Ulceration is always the key when it comes to diabetic control. As sensory perception is effected i.e. pain is not felt, it is therefore hard to know that something is wrong for a diabetic patient. It can be cellulitis, MRSA infection or osteomyelitis, which is bone infection. It is extremely important for diabetics to have their feet inspected regularly to prevent serious complications.

Diabetic care:

A podiatrist can assess the blood flow using a Doppler ultrasound and also assess sensation. In early diabetics a baseline Doppler is performed and repeated every 12 months if there is no change. If there is any change, reassess every 3 months if there is degeneration and change. We have multiple Doppler machines in our practices to take the burden off the public health system.

Feel and touch is also assessed in the both feet using a small strand of nylon (monofilament test), with the patient's eyes closed this checks for loss of feeling.

Bursitis:

A bursa is a fluid filled sac around our joints. Bursitis is an inflammation of the bursa causing swelling/fluid retention mechanism. The most common causes of bursitis are repetitive motions or positions that put pressure on the bursa around a joint causing pain e.g. throwing a baseball or lifting something over your head repeatedly or leaning on your elbows for long periods. In polio

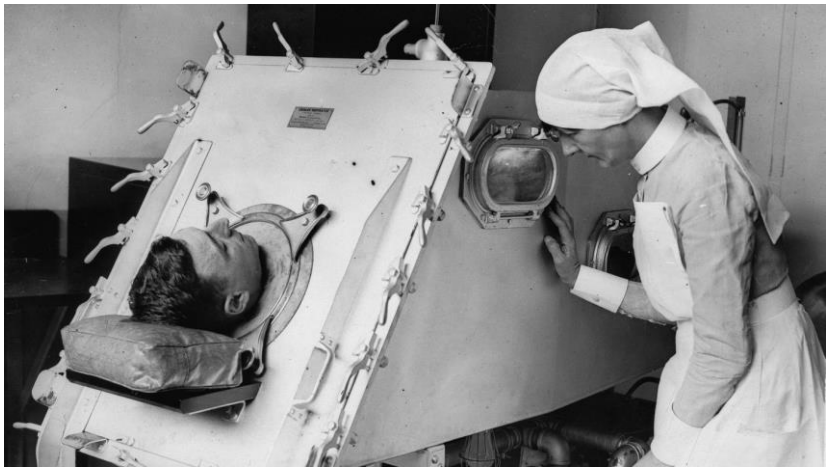
feet, clawing of the toes can add pressure to the metatarsal joints causing inflammation and swelling.

ENABLE:

EnableNSW provides assistive technology and related services to people in NSW with specific, short term or ongoing health needs to assist them to live safely at home. It is a program based around relieving the financial burden of the cost of orthotics, orthopaedic footwear, wheelchair-based and crutch-based needs, and is assessed on a case by case basis. It can be a slow process. As an example the cost of orthopaedic shoes range from $800 up to $5000 for made to measure shoes.

FOR SOME SURVIVORS, POLIO CASTS A LONG SHADOW

By Frieda Klotz, January 2, 2023, https://undard.org/undark-author/frieda-klotz/



During the polio epidemic, some patients had to use iron lungs—large ventilators. *Getty Images*

Brad Fuller was a toddler when he contracted polio in 1952 and was sent to a hospital miles from his northeast Pennsylvania home. He stayed there for nine months, enduring long stints in an iron lung, a large metallic ventilator that helped him breathe. Fuller's parents were allowed only rare visits. His earliest memory is of a nurse holding him in a mineral pool, instructing him to kick his legs.

That year marked the epidemic's peak, when roughly 58,000 American children and adults developed polio and 3,000 of them died. In this respect, Fuller was lucky. The disease spared him, leaving only a weakened left leg and right arm. He was able to play tennis and football and train as a clinical psychologist. He built a career leading non-profits while teaching part time at St. Joseph's University in Philadelphia. Despite his childhood ordeal, Fuller said, he felt invincible.

Then, in his 40s, a new doctor offered to treat his post-polio. Fuller was taken aback. It was the first time he'd heard the term. But the symptoms, like increased muscle weakness and poor balance, had been creeping up. At one point, he'd fallen and injured his knee. He now wears a full leg-brace and because he falls so often, he has taught himself to land easily. "I think if I was a typical person" — a person without a background in mental health — "I would have immediately gone into denial," he said.

Scientists believe that the poliovirus has been around for thousands of years, but it did not cause epidemics until the late 1800s, when countries like the United States and the United Kingdom began to experience waves of increasing severity. By the 1940s and early 50s, the polio terror

was killing or paralyzing more than a half million people globally each year. To treat the overwhelming number of sick people, hospitals created the first intensive care units. Many of those ICU patients were children and young adults.

Then came a pair of highly effective vaccines, the first of which was licensed in 1955. Case rates plummeted within a matter of years, and the virus was soon eradicated from entire countries. The vaccines are widely viewed as a triumph of public health. “My mother would have given anything to have a vaccine” for her children, recalls Fuller. But for those who had already been infected and survived, there was a downside. Polio “supposedly disappeared,” Fuller said. “That means research stopped.”

This history is bittersweet for patients who now struggle with post-polio syndrome, or PPS, which affects 25 to 40 percent of survivors. As adults, these individuals face an array of new symptoms stemming from their initial infection — everything from pain and renewed muscle weakness to fatigue to problems speaking and swallowing. PPS affects up to 300,000 people in the U.S., and globally the figure could be as high as 15 to 20 million people, according to some estimates. Most polio survivors in developed countries are 65 and older, said Marny Eulberg, a physician with PPS who ran one of the first dedicated clinics in the U.S. Survivors in the developing world are often younger.

Fuller was fortunate in another respect. His physician recognized the signs of PPS. Many patients struggle for years to find an explanation for their various symptoms, only to find out, once they receive a diagnosis, that there are no approved treatments and few specialists who can help them manage their condition. The exact cause of PPS remains unknown, and it has confounded researchers seeking a cure. Further research could elucidate polio’s long-term effects and stall patients’ physical decline, say the handful of scientists still studying the condition, but funding is scarce.

“The sentiment in all the funding bodies is polio has disappeared. So are we going to put money in it?” said Frans Nollet, a leading figure in European post-polio research who heads a specialty clinic at Amsterdam University Medical Centers. “It’s difficult,” he continued. “People think the disease has vanished, but the patients are still here.”

Like polio itself, post-polio syndrome is thought to have been around since ancient times. But it didn’t capture the medical world’s attention until the generation of young polio patients from the 1940s and 50s reached adulthood.

That’s when Marilyn Fletcher, a physician and polio survivor, approached the National Institutes of Health for help. In 1982, after repeated phone calls and visits to the federal agency, Fletcher landed a meeting with the neurologist Marinos Dalakas. At least 20 polio survivors in and around Washington D.C. were experiencing new symptoms, she told him. These individuals had even coined a new term, “post-polio syndrome,” to describe their condition. Thousands of people across the U.S. could have similar symptoms, Fletcher maintained. Those in D.C. were frustrated that the medical community was ignoring them.

Dalakas was initially skeptical and took no action. But a month later, he received a call to meet Fletcher at the Surgeon General’s office. Everett C. Coop, newly appointed to the position, “expressed his concern about the emerging phenomenon of PPS as described by Dr. Fletcher,” wrote Dalakas in a 1995 paper. Soon thereafter, Dalakas headed up a first-of-its-kind survey to learn more.

The survey was sent to 2,800 individuals with medical records indicating a polio-related disability. At least 2,500 people replied, often sending letters and personal photographs along with their questionnaires. “Many of the responses contained details which were highly emotional and

stimulating," Dalakas recalled in an email to Undark. For example, a 50-year-old man who'd contracted polio at 19 was struggling to drive or even dress himself. The devastating toll of PPS quickly became clear to Dalakas.

But how to define this new condition was less obvious. Collectively, the study participants reported a wide variety of ailments, with the onset of new symptoms occurring years to decades after the initial infection, often when survivors were in their 30s, 40s, or 50s. Because of this heterogeneity, experts disagree even today about what constitutes PPS. An official diagnosis requires a 15- or 20-year period of stability without new weakness or impaired movement.

Yet Frances Quinn, who contracted polio as a 1-year-old, said her symptoms have never truly been stable. At age 14, she felt growing weakness in her upper right arm and in her thumb. Her health care provider, she said, attributed these changes to adolescence and her accompanying loss of baby fat. "There's a lot of stuff said about PPS that's not really based on good science," said Quinn, who worked as a physicist in the U.K. government for most of her life. "PPS is diagnosed when the patient decides that something is wrong and also finds someone who will listen to them."

Katharina Stibrant Sunnerhagen, a professor of rehabilitation medicine at the University of Gothenburg in Sweden, raised similar objections. "My problem is that, for instance, if you had polio as a 1-year-old, when is your condition steady?" Childhood and adolescence encompass periods of rapid physical growth and development. Strictly speaking, an individual who survives polio as a baby must wait until the completion of puberty before their 15- to 20-year period of stability can even commence.

PPS was formally redefined by the World Health Organization in February of 2022, when it updated its International Classification of Diseases. The WHO now calls PPS "post-polio progressive muscular atrophy." Critics have argued that the redefinition does not reflect the spectrum of symptoms patients may endure, increasing the risks that patients will receive the wrong sort of care. Why change it at all? asked Quinn. "It took 40 years of work to get PPS recognized and creating more names only adds to confusion." Some sufferers also worry that disability payments could be affected although, for now, practitioners in the U.S. and U.K. still refer to the older classification.

Government recognition of PPS as a disability has been important because symptoms often appear in mid-life, making it difficult for some patients to sustain their careers. Carol Ferguson, a polio survivor and mother, used to work at a Pennsylvania bed-and-breakfast but was obliged to quit when she could no longer stand all day. "My physicians made it very clear that that part of my life was over," she said.

Some post-polio patients originally had mild symptoms. Others needed leg braces, calipers, or an iron lung. For the latter group, the reemergence of symptoms can feel like a deal gone sour. Eulberg contracted polio in 1950, when she was four. She recalls being promised that if she just worked hard enough, she would be able to walk without a leg brace. In junior high that promise was fulfilled. But decades later, her muscles started to weaken and she realized she needed a brace again. It "felt like a failure," she told a Medscape reporter in 2020.

There are also unexpected risks. In rare instances, anesthesia can prove fatal for those with PPS, who may need as little as half the dose of typical adults because of an increased sensitivity to sedatives and other drugs. They may have difficulty breathing or swallowing, or be slow to rouse after treatment, possibly having the same vulnerabilities as other patients with neuromuscular disorders. John MacFarlane, a campaigner and former president of the European Polio Union, had given a talk about PPS to the British Medical Association. While leaving the conference building, his wheelchair tipped into a pothole and toppled over. He later needed an operation to

pin and plate his arm. He told Undark that it took him 14 hours to wake up after surgery.

For many years, Ferguson, the former B&B worker, didn't even realize that she'd been infected with the poliovirus. When she came down with a fever at the age of two, just a year before vaccines became available, she recalls, her parents assumed it was a "summer flu." Ferguson developed a drop foot at age 11, and a doctor suggested polio as the possible cause. But Ferguson's mother was dubious, and the disease was not mentioned again. Feelings of self-blame may have contributed to the situation, said Ferguson. At the time, many parents believed that if they simply kept a clean house, their children would not fall ill.

Ferguson grew up a clumsy kid who stumbled a lot. As an adult, she fell while ice skating and had to undergo a minor surgery. She woke up three days later in intensive care. The anesthesiologist, she recalls, probed for details that might explain why it had taken so long for her to wake. When she mentioned her summer flu, he warned, "Don't ever leave that out of your medical history again." The physician suspected that the flu had actually been polio and that Ferguson was experiencing the condition's lingering effects. But he did not provide an official diagnosis of PPS.

For that, patients must undergo a battery of blood tests, scans, and X-rays to rule out other health conditions. Ferguson recalls starting along this path and encountering several doctors who thought she had multiple sclerosis; another was sure she had a brain tumor ("That's the kind of thing that really messes with your head," she said). When those conditions were eventually ruled out, a neurologist at the University of Pennsylvania conducted a diagnostic test called an EMG, which evaluates the function of motor neurons. Ferguson recalls lying in bed with needles in her leg, her husband holding her hand to ease her pain as the test recorded electrical activity in her muscles. She told Undark that partway through, the physician called his students to the room to show them what a case of "old polio" looked like.

For Ferguson, it was a moving moment. Her journey to diagnosis had come to an end. "We finally had it," she said. "Everything else had been ruled out."

For help managing her symptoms, which included deepening fatigue and a weak leg, Ferguson went to a polio clinic in Englewood, New Jersey. Like other clinics, this one provided access to an array of specialists, including rehabilitative physicians, occupational therapists, physical therapists, nutritionists, and orthotists — specialists who make braces and splints. Ferguson had been walking 10,000 steps a day, trying to keep healthy. At the clinic, she learned that she was over-using frayed muscles. This kind of insight, and the clinic's care more broadly, are what ultimately "saved me," Ferguson said.

Despite their benefits, polio clinics have been shutting down, said Carol Vandenakker-Albanese, a professor of health sciences who runs a clinic at UC Davis. Many physicians who once specialized in treating the disease have retired, she said, estimating that only about two dozen polio specialists currently practice in the U.S. With most survivors now in their 60s and 70s, few young clinicians want to take up the mantle.

Four specialists told Undark that there is a concerning lack of knowledge among their medical colleagues about PPS. Despite a steady trickle of published studies since the 1980s, many doctors are too busy to keep up with the science and simply "don't believe in PPS," said Richard Bruno, who trained in psychophysiology and led the Englewood clinic where Ferguson was treated. In Sweden, a patient told Sunnerhagen that when she asked her family physician if ankle pain could stem from childhood polio, the doctor replied, "Polio is a vaccine."

Ferguson now volunteers with a Pennsylvania-based support group that she helped establish, which offers a list of recommended specialists and publishes newsletters and personal stories. Support groups exist in other states too, providing patients with an opportunity to swap details

about symptoms and possible treatments and share tips for educating their doctors and advocating for themselves. In Germany, a doctor with PPS has argued that patients could benefit from medical cannabis, and he has developed a protocol to help patients with their symptoms. But, he said, insurers and other physicians are reluctant to accept the therapy.

Brad Fuller, the survivor whose first memory is of being in a mineral pool, would like to see the U.S. government offer more support to PPS patients. Some of them need braces or wheelchairs in order to continue living productive lives, but such mobility aids, he said, are "outrageously expensive."

"Basically," said Eulberg, who councils patients at the clinic she founded in Wheat Ridge, Colorado, "we're telling polio survivors, 'Yes, it would be wonderful if every health care provider you encountered knew a lot about polio, but that ain't going to happen. You're going to have to be your own advocate.'"

In 2001, Antonio Toniolo, a microbiologist and physician, experienced a serious car accident. To recover from his injuries, he spent two years visiting a rehabilitation clinic, where he encountered middle-aged polio survivors who were seeking help for their muscle weakness. At the time, Toniolo was working at the University of Insubria Medical School in Italy. The survivors, he recalls, started referring to him as "Doctor" and asking, "What do you know about polio?"

Then, as now, the cause of PPS was not well understood. Researchers know that the initial infection kills some of the body's motor neurons, the cells that facilitate communication between muscles and the brain. Over time, some of these neurons regrow dramatically, reaching 7 or 8 times normal size, but they are unable to maintain themselves and eventually start to die off. But why this die-off happens, and why some patients are more affected than others, remain a mystery.

Throughout the 1980s and 90s, researchers focused on defining PPS and on trying to understand its underlying causes. After studying that literature, Toniolo began to wonder if the poliovirus might still be present in the blood of survivors — something earlier research had suggested — and causing their new symptoms. In 2013, he gathered blood and spinal fluid from 100 post-polio patients and compared the samples with those from a control group of about 50 survivors who weren't experiencing PPS. He found traces of poliovirus in samples of about two-thirds of the PPS patients, compared with very few of the control group's samples. The still-circulating virus, he posited, could cause inflammation or even cell death in those patients. This would mean the condition might respond to antiviral drugs.

Toniolo shared this preliminary data at a couple of PPS-related events and in a mid-study report published in 2015. But the research was never finalized or published in a scientific journal. "This was expensive research that needed funds and competent people," he wrote to Undark in an email. "Thus, due to lack of funds and my retirement at the end of 2018, the work has not been completed."

As of yet, nobody has tested whether PPS might respond to antivirals. A major multi-center study led by Dalakas is focusing on whether certain proteins in the blood of healthy donors could help neutralize proteins called cytokines that scientists have detected in the blood and spinal fluids of some PPS patients. Researchers hope that the therapy, called IVIG, will calm the cytokines and stabilize the immune system, thereby improving patients' quality of life.

The treatment has been trialed in Sweden without conclusive results and was available for a while in some countries, Nollet from the Amsterdam University Medical Centers said, but because it was considered not sufficiently proven, insurers were reluctant to cover it. Whatever the outcome of this study — which is sponsored by a Spanish company, Grifols — it will be helpful for patients to

know whether it works or not, said Nollet, whose clinic is among those taking part.

The Swedish government is rearranging care of rare diseases so that polio survivors will be treated at expert centers, a decision driven by recent events: Last summer, health officials reported that the poliovirus had paralyzed an unvaccinated man living in an under-vaccinated community in New York. It was the first U.S. case in years. As of early October, the virus still appeared to be spreading in several under-vaccinated parts of the state. In 2022, for the first time in decades, poliovirus was also detected in Israel, Malawi, Mozambique, and the U.K., alarming public health officials and spurring calls for vaccination campaigns.

Observing the cases in New York helped the Swedish government understand that a polio outbreak "is something that can actually happen again, even here," said Sunnerhagen, whose own PPS research is part of an application for special status at her university hospital. Her clinic serves about a thousand post-polio patients, a largely Swedish cohort alongside a younger group of individuals who immigrated to Sweden from countries where the disease was never eradicated. "We need to spread the knowledge," she said, to draw attention to the fact that polio patients are still present in society. Sunnerhagen doesn't expect all physicians to be experts in the condition but she hopes that they will at least know to make the referral.

For now, patients are still driving much of their medical care.

Ferguson said she understands why a physician might be stumped by a multi-symptom disease triggered by a long-ago infection. "But to totally deny that this exists is heartbreaking," she said. "I'm a living example that a very mild or unapparent case of a virus can leave lifelong damage."
This article was originally published on Undark. Read the original article.

BRUNO BYTES

Taken from PA Polio Survivors Network www.papolionetwork.org 4th Quarter 2022

Bruno Byte
From Dr. Richard L. Bruno, HD, PhD
Director, International Centre for Polio Education
The Encyclopedia of Polio and Post-Polio Sequelae
www.postpolioinfo.com

contains all of Dr. Bruno's articles, monographs, commentaries and "Bruno Bytes" (Question and Answer articles) and his Video Library
www.papolionetwork.org/encyclopedia

On the topic of Balance:
Question: "Why do I have such poor balance"?

Dr Bruno's Response: When you rule out neurological problems causing impaired equilibrium, my simple answer is "look for hip muscle weakness". But, it's more than just hip muscles that keep you balanced. The core muscles - hips, pelvis, low back and stomach - work together in concert, which leads to better balance and stability.
So if you have your balance evaluated by a rehabilitation doctor or physical therapist, make sure that all of your muscles - including core muscles - are included in manual muscle testing.
On the topic of FDR having Polio:
Question: Did FDR (President Franklin D. Roosevelt) have PPS in his later years?

Dr Bruno's Response: FDR's son, James, attended the first PPS conference in Warm Springs. We had a conversation about the presentations and James declared, "My father had the late effects of polio".

James' conclusion is probably the most significant reminder that PPS is a diagnosis of exclusion. FDR smoked, had severe, uncontrolled hypertension, an enlarged heart with episodes of congestive heart failure and probably a malignant melanoma seen over his left eye.

Fatigue was described in early 1944: FDR "seemed strangely tired, even in the morning hours; he occasionally nodded off during a conversation; once, he blacked out half-way through signing his name to a letter, leaving a long scrawl".

FDR did appear nigh unto death while attending the Yalta summit, understandable given his medical conditions and the overwhelming stress of years spent fighting the Depression and then World War II.

Did FDR have PPS? How could he not? But, given all of his other diagnoses, how can we ever know?

On the topic of the Vagus Nerve:

Dr Bruno's Original Post:
From **Science Focus** 6th November 2022:
MORE THAN YOU EVER WANTED TO KNOW ABOUT THE VAGUS NERVE! www.sciencefocus.com/the-human-body/vagus-nerve/ by Hayley Bennett

Article Summary:

What is the Vagus Nerve?

"Your brain is connected to your body through a set of 12 crucial nerve networks that descend through your spine and branch out into your body. Of these, the vagus nerve is probably one of the most important. Its tendrils influence digestion, your heart, your reflexes and your breathing.

So you can see why scientists are so interested in what the vagus nerve does – especially when you consider how all of the above affects your mood. You could call it a superhighway between our brains and bodies."

Vagus Nerve Function

"In contrast to the rapid 'fight or flight' responses that are under the control of the sympathetic arm of the nervous system, the vagus nerve is responsible for many of the slower, 'rest and digest' responses that we collectively call the parasympathetic nervous system. The nerve itself is actually two thick bundles of individual neurons (nerve cells) that originate in the brain and pass out to the rest of the body through left and right-sided openings at the bottom of the skull."

"Most of the individual neurons that make up the vagus nerve are sensory ones –about 100,000 on each side of the body in humans –which pass messages from the organs to the brain, and are activated by sensory input from the environment. The remainder are motor neurons, which send messages in the opposite direction, from the brain to organs, and directly control . . . muscle movements", for example in the intestines.

The article continues with:

Why is the vagus nerve so important?
How is the vagus nerve connected to our wellbeing?
The vagus nerve and the heart
What happens if the vagus nerve is damaged? [This has been noted to occur in polio cases]