



# **EUROPEAN POLIO UNION**

## **Newsletter No. 1/2022**

### **September 2022**

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## EDITORIAL

Dear Reader,

It is a pleasure for us to come to you again after some break with the new issue of the EPU Newsletter. Our original plan was to have it accomplished and ready for distribution early in July, unfortunately it showed to be too ambitious and not very realistic. Also the original idea was to have a “Summer 2022” issue, but in Europe – at least from the meteorological, not astronomical point of view – summer runs from June 1 to August 31, and now we have already September. And because we as ordinary people with our lives are closer to meteorologists than to astronomers, this issue of our Newsletter is titled as “September 2022”, which seems to us more optimistic than “Autumn 2022” 😊.

The issue starts with coming back to the Annual General Meeting held in Prague, Czech Republic, three months ago, accompanied by the President’s Activity Report.

“*Osteoarthritis and polio*” by Alex Curtis – Frances Quinn – Carol Levin points out on some important aspects of this disease for us as polio survivors and might help many of us with managing osteoarthritis, as with other neurological conditions; as stressed by the authors, it “can be challenging due to muscle weakness, joint and limb deformation and ligament instability”.

Have you heard already about the Post-Polio Syndrome Advocacy Group? If not, John McFarlane, the EPU Past President, will tell you more about it, and we are sure that this initiative might be a new light at the end of the tunnel for polio survivors not only in Europe but all over the world, bringing tentative optimism to most of us, but hopefully mainly to younger generations of polio survivors.

News from the polio world are followed by the invitation from Kripen Dhrona to take part at the zoom café organised by the BPF at the occasion of the World Polio Day on October 26.

In our book review Zdzislawa Szot-Suslowska from the Polish Association POLIO+ is presenting us Marcin Stasiak’s book “*Polio in Poland 1945-1989. A study on the history of disability*”, a very interesting reading about polio pandemics and polio survivors in a central European country in the second half of the previous century, where we may find many similarities with what was happening during those years not only in other countries of the previous “Soviet bloc” but also in other parts of Europe.

In the final part of the issue we continue in introducing EPU member polio organisations and support groups, here we would appreciate if those that have not been introduced here could provide us with their brief profile, which could be subsequently published later on in the Newsletter.

The current issue of our Newsletter is the first one after many years, which due to the lack of internal capacities of the EPU Board will not be available also in German. For continuing in this useful practice we would need volunteers wishing to do this difficult and time demanding task.

**Stefan Grajcar**

On behalf of the EPU Board

### ANNUAL GENERAL MEETING 2022 IN PRAGUE

Altogether 21 delegates from 14 European countries representing 15 polio organisations and support groups, plus two guest speakers and five accompanying persons, met in Prague, Czech Republic, on June 10, 2022, at the EPU Annual General Meeting. The AGM 2022 was kindly hosted by the Czech Polio Association, represented by Marcela Stránská, Chairwoman, and Michal Haindl, CPA board member and EPU Board Director. Barrier-free and very pleasant OREA Hotel Pyramida, only twenty minutes drive from the Prague Václav Havel Airport, and less than twenty minutes walk from the Prague Castle, with all necessary facilities we could need was the venue of our meeting.



We started the day before, on Thursday late afternoon and evening, with a welcome drink in the hotel lobby bar, meeting old friends we had not seen for at least three years, as well as those few new ones, who were newcomers in our EPU community.

The AGM itself started the next morning – David Mitchell, EPU President, welcomed all delegates and guest speakers - Prof. Frans Nollet, EPU Honorary Member, from the Amsterdam University Medical Center, and Tereza Kopecká from the Charles University in Prague. David Mitchell expressed his gratitude that after two years of desperation for people all over the world we had managed to get to Prague in spite of problems that some of us had to cope with. The programme then continued with the introductory presentation of the history and the most interesting places of the City of Prague, the capital of the Czech Republic, worth visiting, provided by M. Haindl on behalf of the hosting Czech Polio Association.

Agenda of the AGM was as usual, with all planned items followed smoothly one after the another – approval of the AGM 2021 Minutes, Annual Report from the EPU President, 2021 Annual Accounts Report and 2022 Annual Budget Proposal. There were two nominations for re-appointment to the EPU Board of Directors – Robert Cordier from Polio-France-Glip, and Stefan Grajcar from the Slovak Polio Association – both candidates had received votes from all present EPU member organisations and had been re-elected unanimously for the next 3-year period (2022-2025).

Discussions on several items, some of them quite hot, were with us all the day. PoPSyCLE was the first one: David Mitchell, Kripen Dhrona, Gurli B. Nielsen, and Stefan Grajcar informed about its current state with a preliminary conclusion that according to their best knowledge this project had faded away due to severe problems with transferring obviously huge amount of financial sources to

the beneficiary. As John McFarlane, EPU Past President, and the person who was strongly involved in the development of this project idea and has all necessary information of its background, was not present at the meeting, more information on this subject could not be provided.

At the AGM 2021 questions were raised regarding research progress into PPS and its increasing effects that it have on people. According to David Mitchell, it was felt that many medical personnel throughout Europe and beyond who have been working on PPS will be diverted to research into COVID-19. One of our tasks – and this is something that was pointed out by a lot of the new as well as the old directors – we're all very aware that research into PPS and help for PPS sufferers is really what we are about. We support eradication but what we want to know is what is being done. And it's a mandate task – Frances Quinn has started with medical questionnaires that have been distributed: their purpose is to map what each country is doing in this field; the gathered information should be shared with all member organisations. In reaction to David Mitchell's comments Kripen Dhrona, Executive Director of the BPF, said: In UK there was not much emphasis on polio and PPS research, and he does not think they will get any direct input on PPS; however, BPF is working with neurological liaison, and recently more intensive cooperation has started between them and various groups of neurological patients to manage the backlog for care for patients as the result of the COVID-19 pandemic.

AGM delegates were also asked to answer the question how many polio survivors were registered as members of their organisations. All answers proved that numbers of registered members are much, much lower (approximately 10 %) than estimated numbers of polio survivors; however, in majority of countries no official figures are available and only rough estimations could be provided, usually by polio survivors' organisations themselves, not by national authorities. Delegates from few countries (Sweden, Denmark) in this context reported that due to relatively high numbers of migrants and refugees from non-European countries also quite young polio survivors were amongst them. Prof. Frans Nollet from the Amsterdam University Medical Centre noted that about 25 % of their polio patients are refugees from outside of Europe. Besides that, the current situation on the border of Ukraine with neighbouring countries (especially with Poland and Slovakia) was mentioned, too, in the sense that as a result of the war against Ukraine several million refugees already had crossed the border, mainly women with children, and it is extremely difficult to control if these children had been vaccinated against polio. In his final remark in this discussion David Mitchell told that we might have a new challenge in Europe as regards the work of the European Polio Union.

Paul Neuhaus, EPU Board Director, representing Bundesverband Poliomyelitis e. V., Germany, was so kind and brought to Prague in his own car few hundred printed copies of the EPU Brochure "*POST-POLIO-SYNDROME. How to deal with a second paralysis?*", which was prepared during the last two years under his leadership and which was originally planned to be distributed to participants of the "*3<sup>rd</sup> European Congress on Post Polio Syndrome*" in 2020 in Vitoria-Gasteiz, Spain, which due to the COVID-19 pandemic could not be organised. Delegates could bring home several printed copies, the EPU Brochure will be sent later on to all EPU member organisations also in an electronic form.

David Mitchell mentioned that we had been already invited by Polio-France to **the Congress on PPS and the AGM, which will be held on May 25-27, 2023, in Nancy, France**. Robert Cordier then provided a more detailed information about the planned programme of the congress and the AGM – the first day would be for arrivals, the second day for the congress, and morning of the third day would be devoted to the EPU Annual General Meeting. More details about the congress would be

available during the next few months, but we were all assured that we should “**save the date**” already now.

David Mitchell, EPU President, then thanked all delegates and participants for coming and for their active involvement, and subsequently officially declared that the AGM 2022 was finished.

The second part of the morning programme was open by David Mitchell who shortly explained the purpose of this act: “They are simply personal awards from the European Polio Union to those people who since our inception 15 years ago have kept us going, have worked freely, without charge, voluntarily, and worked magnificently as we have been facing problems along the way.”

Stefan Grajcar started with information that up to now there were four EPU Honorary Memberships awarded during previous years – we had started with this practice in 2018 at the AGM in Rheinsberg, Germany, after 10 years of the existence of the EPU. The key message of this practice is to celebrate people that did much, much more than they were supposed to do for polio survivors not only in their own countries, but who crossed the borders and who did quite a lot to help polio survivors around Europe. The first one was dr. Peter Brauer from Germany in 2018 in Rheinsberg, in 2019 during the AGM in Lobbach, Germany, the last time when we met in person three Honorary Memberships were awarded to Prof. Frans Nollet, Amsterdam University Medical Center, Netherlands, to Thomas Lehmann from Switzerland, and to Thomas Arno House from Germany.

Due to the fact that in 2020 and 2021 we had no possibility to meet in person, the Board of Directors decided to award five Honorary Memberships in the current year 2022 to people who – all of them – carried on their shoulders very great package of duties for couple of years, maybe even decade, not only on the national but also on the international level.

EPU Honorary Memberships were awarded to the following persons (unfortunately, only the last one of honoured members from the list below could be with us in Prague):

- **Daniel Peltzer**, Belgium, EPU Board Member and Treasurer in 2015-2018
- **Erika Gehrig**, Switzerland, EPU Board Member in 2012-2021
- **Margret Embry**, Belgium/France, EPU Board Member in 2008-2021
- **John McFarlane**, EPU President in 2011-2017
- **Gurli Bechmann Nielsen**, Denmark, EPU President in 2017-2021





The afternoon session was open by Tereza Kopecká from the Charles University, Faculty of Humanities, Prague, with her presentation on the History of Polio in the Czech Republic. In direct relation to this, delegates

The second part of the afternoon programme was filled in by the presentation of prof. Frans Nollet from the Amsterdam University Medical Center “*Ageing with Post-Polio Syndrome*” (his presentation will be available on demand to AGM participants later this year). The presentation was then followed by a vivid Q&A session with many participants involved.



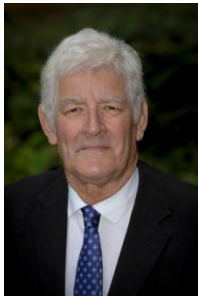
During the final session of the AGM 2022 delegates and participants discussed various aspects of lives of polio survivors and the life of their polio organisations and support groups, shared their experience in combating current challenges like increasing costs of living, migration crisis caused by the Russian aggression against Ukraine, COVID-19, (in)accessibility of appropriate health and social care for polio survivors, etc.

Programme of the Annual General Meeting of the European Polio Union was officially closed at 5.30 PM CET. The whole event ended with official dinner where all delegates, guest speakers and accompanying persons were invited.



**Stefan Grajcar**, EPU Secretary

## EPU 2021 ACTIVITY REPORT



I start by repeating the words written by my predecessor, Gurli Bechmann Nielsen, as her message to the November 2021 Zoom AGM – ‘the Covid 19 pandemic has affected us all in some way and has caused much distress in the world population, not just groups and individuals. Our polio family has lost many loved and treasured members over the past (now) 26 months.’ Gurli went on to say that ‘there will be more heartache to come as Covid attacks the respiration system in particular, just like polio.

Now for better news! Covid 19 does appear to be losing its potency and so many polio survivors everywhere may at long last be able to get out and about after being isolated, cut off and even forgotten. In my home country, the UK, branches and groups of the British Polio Fellowship have begun to meet together, swap stories and compare ailments (we all do it!!). Remember a problem shared is one halved! There is already evidence; again, here is the UK, that polio survivors, because of their natural caution when faced with dangerous infection and their disabled lifestyle, have possibly avoided contact with the dreaded Covid 19 virus. We hope that figures may show this to be the picture throughout Europe.

As in 2020, we have nearly all entered, understood and enjoyed technology and the world of Zoom! Two AGMs held by the EPU have been remote and so our plans to have an actual physical get-together in Prague are very welcome. Problems have still affected us but the ‘refreshed Board’ are working hard to move forward. You have read all about our five new Directors in the December 2021 Newsletter together with the two stalwarts who still have their period to run and two previous Directors were re-elected. We thank our 19 member and affiliated countries for their votes and support. We all sincerely thank Stefan, in particular, supported by Erika and Margret. The website relaunch is slowly progressing under the guidance of Professor Michal Haindl, Stefan and with excellent advice from John McFarlane.

Since we are registered in Belgium we must abide by their very precise rules and, again, hats off to our marvellous Secretary, Stefan, for doing all the paperwork in a short time scale due to our 2021 AGM being held six months’ later than usual. Daniel, Margret and Tine have been a great help especially with the Flemish language translation. It is bad manners to mention ages but the average age of the last Board was over 70 (some well over) and so their dedication, experience and enthusiasm has served us well. By coincidence, in most countries the average age of polio survivors is 70 years. This age figure is lower, however, in one or two countries where large numbers of refugees (mainly from Afghanistan) have been welcomed, e. g. Denmark.

Like Gurli, I need to inform you that current new polio figures in Pakistan and Afghanistan are most encouraging. Erika Gehrig, from Switzerland, another long-serving EPU stalwart, distributes weekly figures and to date just three WPV1 cases have been reported since November 2021 compared with six in 2020/21. Just wonderful combined with recent past news that Africa is nearly polio-free! Along with many others, Erika was worried that the Taliban would stop women (who have led the eradication campaign) from operating but has, thankfully, not transpired although male health workers have been attacked.



Your new Board – Ireland, Belgium, France, Germany, Czech Republic, Slovakia and the UK realise the task ahead but we will do our best to remind governments, authorities, the medical profession and decision-makers, that although polio is nearly dead – we are not!!

In her report for 2020/2021 Gurli highlighted the challenge ahead. With our present Directors and the continuing magnificent help of past colleagues we will continue. For your information I list below all of our member countries in the EPU who do so much for their members in the 27 different organisations represented. This is our strength – by getting together we can go it alone.

Best wishes to you all and thank you.

**David Mitchell**

British Polio Fellowship

EPU President

## **INVITATION FROM THE PRESIDENT**

**ON BEHALF OF OUR HONORARY EDITOR, CAN I PLEASE ASK ALL OF OUR  
MEMBER ORGANISATIONS TO CONTINUE TO CONTRIBUTE ANY NEWS FROM  
YOUR PART OF EUROPE TO FUTURE EDITIONS OF YOUR NEWSLETTER.**

**WE OFTEN ARE SO INVOLVED IN OUR OWN PART OF THE WORLD  
THAT WE DO NOT HAVE TIME TO LEARN WHAT OTHERS ARE DOING!**

**PLEASE MAKE THE EFFORT TO SEND IN YOUR CONTRIBUTION.**

**THANKING YOU!**

**DAVID MITCHELL, EPU PRESIDENT**

## OSTEOARTHRITIS AND POLIO<sup>1</sup>

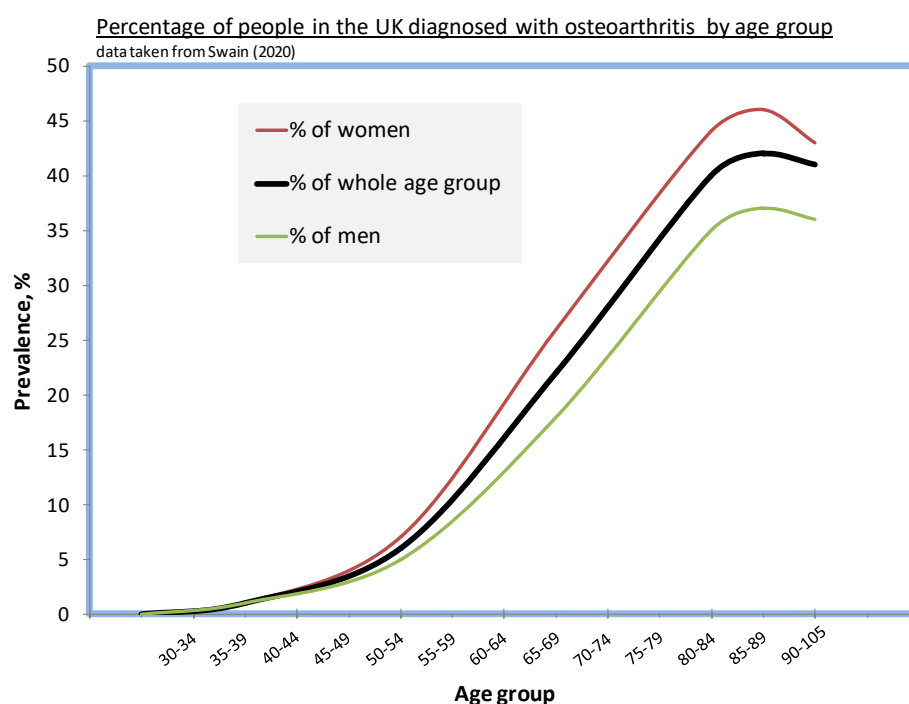
Lead author: Alex Curtis, Senior specialist rehabilitation therapist and post-polio rehabilitation physiotherapist, the Lane Fox Unit, St Thomas' Hospital, London, with contributions from Frances Quinn, BPF Trustee, and Carol Levin, BPF Communications and Information Officer.

Osteoarthritis is the most common type of arthritis (inflammation of the joints) in the UK, for those both with and without polio.

Managing osteoarthritis in people who had polio, as with other neurological conditions, can be challenging due to muscle weakness, joint and limb deformation and ligament instability.

### 1. How common is it?

Osteoarthritis in the older UK population is high and increases strongly with age. The number of people with a GP diagnosis starts to increase at around 45 years, rising to a peak of around 40% of people aged between 85 and 89 (see graph). There is an association with families and is more common in women than men. It is most often diagnosed in the knee followed by the hip, then the wrist/hands finally the ankle/ foot.



In the 2014 BPF Health Survey, 245 people (65%) reported some level of osteoarthritis, which is much higher than the national rate for similar ages (60 to 80 years). This doesn't prove it is more common in polio survivors - that would need a more detailed study. Another difference is that more people reported hip (6) than knee (3) replacements. It is clear from this that many polio survivors are

<sup>1</sup> Published previously in the BPF Bulletin, March 2022 edition. Permission to publish in the September 2022 edition of the EPU Newsletter kindly provided by the BPF and the authors.

living with osteoarthritis and that more will need treatment and management for this condition in the coming years. This article is a first look at what is known about polio and osteoarthritis.

### **2. What is osteoarthritis?**

Osteoarthritis is a degenerative joint disease, in which the tissues in the joint break down over time. It isn't known what triggers or starts the breakdown, but as it develops osteoarthritis can damage any or all parts of the joint. It affects people differently, for some it has little or no impact on their daily activities, while others experience severe joint pain and stiffness.

In simple terms, a joint is where two bones meet and allow the body to move in different ways. Some open and close like a hinge such as the knee and the elbow, whereas others allow for backward, forward, sideways, and rotating movement such as the shoulder and the hip. The joint is supported by muscles, tendons (tissues that attach muscle to the bone to achieve movement) and ligaments (tissue holding the joint bones together). These are constantly healing and repairing themselves, but for some individuals these repairs just aren't enough, either because the wear and tear to the joint was too severe or because there's an underlying problem with the repair process.

In osteoarthritis, the cartilage that cushions the ends of the bones and provides a 'smooth glide' for movement, is damaged over time and wears away until the bones are (painfully) rubbing against each other and the ligaments are put under additional stress. The joint becomes inflamed and as it swells, new bone is formed creating bumpy lumps known as bony spurs or osteophytes. This remodelling of the bone can cause the joint to look lumpy or become bent.

### **3. What are the symptoms?**

Symptoms often begin slowly in either one or a few joints. They tend to include joint stiffness, pain, joint changes that limit movement, swelling, and the joints feeling loose or unstable. As symptoms worsen over time, activities become more difficult, such as getting in/out of a chair, gripping a saucepan handle or going for a walk.

There isn't always a clear connection between the state of the joint and the symptoms that are experienced, such as the level of pain. Other factors, such as sleep quality and mood can influence pain, as can an individual's belief in their own ability to manage tasks and their health.

### **4. Why is osteoarthritis so prevalent in those with polio?**

Osteoarthritis can occur in anyone, but it is associated with an injury or area where the mechanical movements of the joints cause repetitive wear. This is often seen in those with polio because their movement pattern can be altered by muscle weakness and bone changes from surgery or lack of muscle stimulation to bones, resulting in shorter or altered bone shapes.

In those with polio, joints that are surrounded by weak muscles are less protected. Weakness can affect how a joint moves and can increase mechanical-related stress on other joints. Over time, other soft tissues like ligaments will stretch. This leads to more abnormal loading of the joints and the joint becomes more unstable. This could make the area more prone to the repetitive wear seen as part of the osteoarthritis cycle

A typical example would be a person with knee weakness. Some people can only stand by hyperextending their knee (i.e. the knee goes backwards). Over time, the knee goes further and further back to help support their body weight and the ligaments near the knee become damaged.

As the damage progresses, the result is pain, swelling and loss of joint movement. The person becomes less active leading to further muscle weakness and greater risk of joint changes. The cycle begins.

It is common to have pain from osteoarthritis in more than one joint. The polio-related changes and the pain over a number of joints, work hand in hand to alter movement patterns and make function more difficult.

Osteoarthritic changes may be seen in those with polio at a younger age than in the general population because of risk factors such as a mechanically stressful walking pattern over a number of years. For this reason, surgery following acute polio was originally focused on creating alignment and stability wherever possible.

### 5. Recommended treatments or management

There is no cure for osteoarthritis. Conservative treatments are aimed at interrupting the inflammation cycle and ease symptoms, while surgical options look to remove the arthritic joints and replace them. The ultimate goal is to reduce pain and increase function.

### 6. Non-surgical management

**Exercise** is a first line treatment for osteoarthritis. Everybody is recommended to try exercise regardless of age, other medical conditions, how severe the pain is or level of disability. The aim is to strengthen muscles around the relevant joint and improve general cardiovascular fitness. For polio survivors it may not be possible to strengthen some muscles. However, it might be possible to strengthen areas with less damage.

**Stretches** are also recommended and are particularly helpful for osteoarthritis of the hip.

It can be difficult in many areas to find suitable exercise advice for polio survivors. **Remember that for polio survivors, any exercise programme must be individually tailored, pain-free and non-fatiguing and ideally supervised by a neuro physiotherapist.**

Other treatments include:

- **Weight** loss is another core treatment aimed at reducing stress on the joints.
- **Pain relief.** Medications for pain relief include over-the-counter paracetamol and anti-inflammatories, stronger ones such as opioids (e.g. codeine) and topical creams like capsaicin. Some people may be offered steroid injections. All of these need to be discussed with your GP.
- **Hot or cold compresses** can be applied to the painful area, to be tried alongside the core treatments.
- **Footwear** that gives some shock absorption is recommended for those with arthritis in the lower limbs to protect joints.
- **Aids and adaptations** can also help, such as knee braces.

### 7. When is joint replacement surgery an option?

Guidelines provided by the National Institute for Health and Care Excellence (NICE) suggest that joint replacement surgery should be essentially a discussion between the patient and an orthopaedic surgeon, rather than due to any one trigger.

The discussion needs to focus on the pain and impact of the osteoarthritis on quality of life and function and the benefits that joint replacement may bring. The guidelines also recommend this is before the pain is severe and the limitation to function due to the pain is prolonged and established.

However, the core treatments need to have been tried before surgical options are considered.

### Considerations for joint replacement surgery

Surgery is not feasible for everyone, as it may not be likely to be successful and has the potential to lead to new complications.

There are many different surgical approaches and all have their own considerations. In general, the factors that would impact on likely success include those related to the bones and joints, such as:

- The shape of the joint.
- Have bones become rotated or are they still in alignment?
- Bone health, density and width of the bone shaft to be able to hold the joint replacement.
- Muscles need enough strength to create joint stability, specifically related to knee replacements. It has been suggested that not having enough strength to move against gravity is associated with poorer outcomes. Knee strength needs to be examined and discussed in relation to the type of replacement to be used as part of the pre-operative consultations.
- The length of the soft tissues need to allow enough range of movement, are they too lax or too tight?
- The health and strength of the whole person. Will they cope with the rehabilitation after the surgery? Immediately after joint replacement surgery weight bearing is usually encouraged but can be difficult due to pain and swelling. The area will also be initially weaker than normal, therefore other limbs e.g. arms and legs, will need to carry an increased amount of body weight while the operated limb recovers and gets back to normal strength.

A particular consideration for those with polio is the knee position following replacement surgery. If some backwards bend of the knee is required to create knee stability in standing due to lack of strength, the final position may need to be a compromise. Some backwards bend will still be required but allowing too much will increase the likelihood of excess reoccurrence and joint instability, and failure over time.

### Potential complications of joint replacement surgery

The outcomes of joint replacement surgery for those with polio have been looked at in some small-scale studies.

A review of research papers (Prasad, 2018) covering 82 knee replacements in polio survivors found that most replacements were successful and all reported improvements in function. Six operations had to be repeated (revision surgery) after some time (between 0.4 to 12 years).

If a complication did occur the most frequent issue was instability of the joint and reoccurrence of the backward bend of the knee. This is very probably because of weakness of the quadriceps muscles on the front of the thigh.

Very low numbers were found to have a new fracture as a result of the operation, a loosening of the joint replacement within the bone or infection of the joint.

However, for most people who had the surgery, it was successful and post-operative satisfaction was high.

Several other papers give a similar view that replacements for people who have had polio can be successful, in the main giving improved function and reduced pain, though like other neuromuscular conditions, there are increased chances of complications.

### Next steps

We don't currently know how many people with polio are assessed, but are found not to be suitable for surgery, and are now living with severe arthritis or how they manage. There are also few studies on less common replacements such as on shoulders, fingers or ankles.

### Key points

- Osteoarthritis is very common in the UK, particularly for people over 60
- It is often seen in polio survivors: for example, because of altered walking patterns, bone changes due to earlier corrective surgery or altered growth, abnormal stress on joints due to weak muscles.
- Managing osteoarthritis can be challenging for similar reasons.
- Joint replacement can be successful but needs a careful assessment of benefits and possible complications.

### BPF information that may help your discussions with clinicians

*Post-Polio Syndrome (PPS) - A Quick Reference Guide* - short information for professionals

*Pacing For Activity and Exercise* - may help discussions if referred for exercise

*Medication Guide* - useful if prescribed medication

*Anaesthesia Guide* - important to bring with you for any pre-operative assessment and surgery

*Managing Pain Guide* see <https://www.britishpolio.org.uk/factsheets> and <https://www.britishpolio.org.uk/guides-hc-professionals>

### Sources of information

NHS website <https://www.nhs.uk/conditions/arthritis/>

NICE Osteoarthritis: care and management. Clinical guideline, 2014

<https://www.nice.org.uk/guidance/cg177>

Prasad A, et al. (2018) 'Outcome of total knee arthroplasty in patients with poliomyelitis: A systematic review' *Effort Open Review* 2018; 3 358-362

Swain, S. et al. (2020), 'Trends in incidence and prevalence of osteoarthritis in the United Kingdom: findings from the Clinical Practice Research Datalink (CPRD)'. *Osteoarthritis Cartilage*, 28(6), 792-801.

### Further information

Arthritis Charities <https://www.arthritisaction.org.uk/> and <https://www.versusarthritis.org/>



## POSSIBLE NEW INITIATIVE FOR POLIO SURVIVORS

In 1988 there were just over 388,000 people affected by paralytic polio around the world, with who knows how many more undetected or asymptomatic. That year saw the start of the Global Polio Eradication Initiative (GPEI) backed by the World Health Organisation (WHO), an agency of the United Nations, the Bill and Melinda Gates Foundation and Rotary International. Their aim, to wipe out polio by the year 2000, well they are not quite there yet and regrettably the number of cases being reported by GPEI is on the rise again not just in the epidemic countries but further afield. The virus has been detected in London and a full blown case has been reported in New York, USA in July of this year.

The one thing that the GPEI failed to take into account, and still has not, was a legacy programme for when they achieved their goal. In other words, what came next? Ongoing vaccination was still going to be needed if the polio virus was to stay as only the second to be eradicated entirely, the first being Smallpox. No one in GPEI had given a thought to all those millions, over 20 million, polio Survivors around the globe. Even the very last person to be infected and possibly paralysed by the virus will need help for years, maybe decades, to come. Even if they do not develop Post-polio Myelitic Syndrome, better known as PPS to you and me.

Now it appears there are moves afoot inside the 1.4 million membership of Rotary International to rectify this oversight of Polio Survivors. An initiative by a few members based in the USA and further afield is attempting to start a Post-Polio Syndrome Advocacy Group to fight for and raise awareness of polio Survivors and the plight of so many of them around the world. Many in Rotary Clubs wonder when all the fund raising for the global vaccination programme(s) is going to end. More worryingly is the realisation amongst those same people that no one is addressing needs of those who came before vaccines were available or never had the opportunity to be vaccinated.

Rotary International already has an Action Group on Polio within it, chaired by Ann Lee Hussey a senior figure in the movement that has achieved a great deal in the GPEI. Talks between the nascent Advocacy Group and the Action Group are currently taking place to ensure that there is no duplication of effort and resources and each can work unimpeded to get the best results to both wipe out the virus and to help polio Survivors.

The Advocacy Group hopes, in time to come, it will be able to raise the concerns and needs of polio Survivors not just within Rotary but at national and international level, including NGO's, other agencies and Governments. If that had been in place before Spanish Survivors had to fight to have recognised Franco Regime's crime refusing the vaccine to those opposed to it and so punishing innocent children and others to be infected, their fight for recognition may have been a lot shorter with exposure on the international stage. They have been successful and legislation is set to go through the Spanish national Parliament shortly.

Rotary International's 1.4 million members wield great power and influence in all levels of society, many are medical doctors and have treated those with polio. It is to be hoped that this initiative gains credence and influence and can give a unified voice to polio Survivors everywhere so they can lead dignified, independent and fulfilling lives.

**John R McFarlane, 22 July 2022**

## NEWS FROM THE POLIO WORLD

### POLIO BACK IN GREAT BRITAIN

It is many decades since 'polio news' filled the front pages of Britain's daily, mass circulation newspapers but this happened on the morning of Thursday 23 June. From the London Times to the Daily Mail the headlines shout out "Polio is back in the UK after 40 years". This perhaps should have said nearly 60 years as I was one of the last English cases in 1965. A 'national incident' was declared.

All the reports did a good job in describing exactly what the (our) disease is with pages full of medical facts (e. g. what is polio, what are the symptoms, how does it spread, danger signs and then who is at risk?). Every single publication urged parents to make sure that all children have received the current vaccine (not a live one in the UK since 2004) but latest figures show that 100,000 children in England alone have not had their booster by the age of five, a third of them in London where the virus was found. Of the 694,000 children aged five in 2020/2021 14.7% (101,737) had not even had the inoculation which is usually given at three years and four months, one of five given in total, the last being given at age 14. The type of the polio virus found in sewage samples in north London, spotted during routine testing, was vaccine acquired virus (type 2) possibly linked to someone entering the UK from a country where the live virus vaccine is still in use. Whilst the average percentage of vaccine uptake in the UK is around 95%, in this particular part of London (population four million) there is a take-up of about 87%.

Mid-July, thankfully, has not brought any actual cases of polio but there is a great worry because only 72% of 14-year-olds have received the final booster due to the Covid pandemic, similar problems, but with much bigger numbers) have been experienced in Pakistan and Afghanistan.

Immediately the news broke our central office in Watford was prepared, led by our CEO, Kripen Dhrona, who many EPU members met at the AGM in Prague. Many radio and television interviews were given, current facts and figures supplied to the news agencies and Dr Julian Harris Bsc, MSC, one of our Trustees, was the main guest on 'Good Morning Britain' on ITV and BPF Chairman, Gordon Richardson, was featured in 'The Times' and our Rotary Ambassador, Colin Powell, appeared in 'The Independent'.

As a result, a major report appeared again in the weekend edition of 'The Times' with Dr Frances Quinn, the BPF Expert Panel Deputy Chair and also a Director of the EPU, highlighting the effects on our community of PPS and the struggle of polio victims everywhere to cope with the syndrome, very good publicity, and perhaps proving that every cloud has a silver lining. I myself gave an interview early on the Thursday to my local radio station and to our regional newspaper. I knew both the young journalists and of course they had no idea of what polio is and the dreadful havoc it can cause.

I end this report by going back to my opening title, that polio is back in Europe (not just Great Britain) and I checked with our fellow directors who all confirmed that the discovery of the virus was big news in their countries also. If all this publicity can save just one life then the whole exercise has been worthwhile. Thank goodness also for the internet as nearly every report, printed or televised had pictures of iron lungs, callipers, orthopaedic beds, splints, crutches and respirators. A graphic example of the (our) polio era.

Please keep safe.

**David Mitchell, EPU President**

### **POLIO CASE REPORTED IN THE U.S.**

It was bound to happen, polio is only a flight away. Authorities in USA have been warning of this for over a decade. See link below:

<https://www.washingtonpost.com/health/2022/07/21/polio-rockland-county-unvaccinated/>

And from USA today:

<https://www.usatoday.com/story/news/health/2022/07/21/polio-reported-rockland-county-ny-first-in-u-s-in-years/10119514002/>

See also “Updated statement on report of polio detection in United States” published on 29 July 2022 by the Global Polio Eradication Initiative (GPEI): <https://polioeradication.org/news-post/report-of-polio-detection-in-united-states/>.

**John R. McFarlane**

### **NEW YORK STATE OF EMERGENCY: WHY POLIO HAS REEMERGED, AND HOW TO STAY SAFE**

Another very interesting article on the same topic was published recently in the [MEDICALNEWSTODAY](https://www.medicalnewstoday.com/articles/why-polio-has-reemerged-and-how-to-stay-safe-experts-advise), here is the link: <https://www.medicalnewstoday.com/articles/why-polio-has-reemerged-and-how-to-stay-safe-experts-advise>.

### **NEWS SNIPPETS**

#### **LONG COVID**

Very generous funding has been announced by the British Government to help those suffering from what are called 'the effects of long Covid'. Their equivalent of our Post Polio Syndrome. A figure of £57 million is suggested with rehabilitation clinics receiving £10 million providing a one stop service for long-term physical and mental health issues caused by Covid.

It is estimated that hundreds of thousands could need treatment for symptoms such as crippling fatigue, breathing difficulties, brain fog, anxiety and stress. All this sounds very familiar to polio survivors. There will be research into long Covid, an on-line help service and an NHS task force made up of patients (good), doctors and researchers. I suppose that when polio was at its height across Europe many millions were spent on eradication and treatment but not much since then on support and funding into PPS. We are the forgotten few.

#### **EUROPEAN CO-OPERATION**

At our Watford Central Office (not too far from London) we have two wonderful ladies who have been with us for a long time, Zahida Osman and Vijitha Nathan, who are the Support Service Telephone Team giving advice on a whole range of services mainly concerning disability benefits, which can take up to one hour to complete the required paperwork, information regarding the various grants offered by the British Polio Fellowship (heating, holidays and mobility aids). Recently they received a request from a BPF member who has moved to France, as to what benefits she was

entitled to in that country. We do not know details like that but we know a man who does and so we called upon Robert Cordier, our French EPU Director, who took over from us. Good European networking.

### ROTARY IN ACTION

In my main article concerning the discovery of the polio virus in North London I mentioned our fantastic BPF Rotary Ambassador, Colin Powell, who has just been honoured by Her Majesty the Queen with an MBE (Member of the British Empire), presented to him at Buckingham Palace by Prince William. Colin also has just attended a meeting of the Global Polio Eradication Initiative (GPEI) and talked with the President of Rotary International, Shekhar Mehta, and the Polio Director of the World Health Organisation (WHO), Aiden O'Leary.

The BPF works closely with Rotary both at UK level where Coline and others give regular talks (and raise funds) and I know that there is similar co-operation throughout the EPU member countries. Rotary Foundation Trust Chair, John Germ, has highlighted the recent use of a new tool to aid eradication 'Novel Oral Polio Vaccine' (nOPV2) to counter outbreaks of the Type 2 eVDPV, the virus found in London sewage.

As a non-political organisation Rotary will continue to do all that is needed (including raising \$50 million every year) to see the end of polio once and for all, ensuring that no child ever again has to experience the devastating legacy of the disease. The EPU fully supports any initiative that reflects and enhances our aims and objectives.

### THE PAN EUROPEAN COST OF LIVING INCREASE

This ever-growing problem is as they say 'as clear as mud' and lots of research amongst member organisation is needed to work out if polio survivors throughout Europe are receiving the help that many countries have proposed (mainly financial) or if, because we already maybe getting an extra 'disability payment' we do not qualify for some of the new schemes - in other words 'given with one hand and taken away by the other'! Here in the UK most households are already in receipt of £150, taken off our Council Tax bills, with households on certain benefits have received £350 towards the cost of living with a further payment of £350 to be paid in the autumn. The £200 universal winter fuel payment will continue and doubled to £400 and disabled people will receive an additional £150 towards their heating. When the UK sorts out its next Government a promise has been made to give more help with energy bills which have already increased by 100%. I appreciate this is a problem common across Europe.

The main and ever-increasing cost of living, however, is for daily food. Official (and often out-of date) figures show a leap of about 15% but the actual current (July '22) rise is nearly 25%. However prudent we are in the polio community we need a balanced and nutritious diet with fresh foodstuffs a priority and often high price commodities to supplement our post polio needs.

The monetary future is looking bleak and our survival even worse. We have overcome one of the deadliest diseases ever known, survived wars, financial melt downs, climate disasters, Covid, PPS, failing health and now in our 'twilight' years (the average age of current European polio survivors is 76) we face austerity - sorry.

**Picked up by David Mitchell**

## NEWS FROM THE EURORDIS, GPEI AND EDF

### EURORDIS

EPU Board of Directors would like to express our great thanks to Eurordis – Rare Diseases Europe who decided to support financially the Annual General Meeting held in Prague, Czech Republic, on June 10, 2022, by the maximum allowed amount of 2,200 €. Words of thanks belong also to EPU Secretary and EPU Treasurer for successful submitting the Eurordis Application form at the end of February 2022, as well as for the Reimbursement claim form together with all required documents at the beginning of July 2022.

### COUNCIL OF EUROPEAN RARE DISEASE FEDERATIONS <sup>2</sup>

Dear Members of the CEF,

We are delighted to announce that **Rare Disease Week** is back! This second edition will be held in-person in Brussels early February 2023. We invite you to suggest candidates who could participate in this new edition. You will find [here](#) an information sheet to share and below some more details about the event:

#### When?

Brussels Rare Disease Week (RDW) will take place the week of 6 February 2023 in Brussels, organised in the lead up to Rare Disease Day 2023 (28 February).

#### What?

Brussels RDW is a 4 days-series of events organised by EURORDIS in Brussels in an in-person format. The stay in Brussels is preceded by an online mandatory programme composed of 2 training modules and 3 webinars (from November to January). Through RDW, the hope is to raise awareness of rare diseases and present a strong and united message to MEPs and other policy-makers in Brussels on behalf of the rare disease community. The week will be made up of events including interactive trainings, meetings with policy-makers and networking events.

#### Why?

More and more relevant RD policy changes take place at European level. For your organisation to be part of them, it is useful to have people within your network that can support you with this. Participating in RDW will help create a pool of people who can make the link between EU-level policy and your organisation.

#### How?

The deadline to apply is 05 October. Two options:

1. If you have an idea of an individual you would like to suggest to take part in RDW, you can share this information sheet with them and invite them to apply by 05 October, or
2. If you would like to share the application process with all your members, please do so by sharing this [information sheet](#) and the [registration form](#) in your newsletters or communication.

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<sup>2</sup> Information provided by Anja Helm, Eurordis Senior Manager of Relations with Patient Organisations

### Who can participate?

- Patient representatives from a patient organisation member of EURORDIS, affiliated to a rare disease national alliance or European federation.
- Patient representatives whose patient organisation is based in a country member of the European Union (EU).

### What is expected from RDW participants?

- To make the time commitment to participate in all events in Brussels from 06/02/23 (starting at 12.00pm) to 09/02/23 (ending at 12.00pm), the mandatory training modules (2 hours in total) and the preparatory webinars listed above (6 hours over 3 months).
- To have a level of English allowing them to actively participate in all activities, as the entire programme will be held in English.
- To be part of joint advocacy effort, thus to convey joint messages on behalf of all rare diseases during the week, and, after the week, to engage in coordinated EU-level activities (with EURORDIS/National Alliances/European Federations etc.).

For any further questions, please don't hesitate to contact:

**Julie Pernet**

[julie.pernet@eurordis.org](mailto:julie.pernet@eurordis.org)

EU Public Affairs Senior Manager

EURORDIS - Rare Diseases Europe

Brussels Office - Rue d'Egmont 11, 1000 Brussels, Belgium



### GPEI 2022-2026 STRATEGY INVESTMENT CASE LAUNCHED

Global Polio Eradication Initiative seated in Geneva, Switzerland, in cooperation with World Health Organisation, Rotary International, Centres for Disease Control and Prevention (USA), UNICEF, Bill & Melinda Gates Foundation, and Gavi, The Vaccine Alliance (Switzerland) organised a one hour webinar on April 26, 2022, titled *“Investing in the Promise of a Polio Free World”*.

The key purpose of the event was the launch of the investment case for the GPEI's Polio Eradication Strategy 2022-2026, which will be critical to end polio for good and build a healthier world. As was stressed by the organisers, “wild poliovirus circulation is currently at historic lows, and eradication is within sight, if we continue to work together to overcome the final challenges we face”.

This 60-minute event brought together global partners, leaders of polio-affected countries, donors, and health workers to present the GPEI's innovative tactics and the continued commitments needed to reach every last child and eradicate all forms of polio from the world.





The webinar with high-ranked officials from all international and worldwide organisations mentioned above and national ministries, including those from several polio-affected countries (Malawi, Nigeria, Pakistan, South Sudan) was open for participants from all over the world, but only representatives of media had a right to ask questions via chat. In spite of this restriction, I dared to post my question:

*“Stefan Grajcar (You) 03:34 PM: I am not representing any media, however, I as a polio survivor, I would like to thank all involved organisations and institutions all over the globe, for your enormous efforts to eradicate polio and make our world POLIO FREE forever.”*

*“Stefan Grajcar (You) 03:39 PM: However, I would like to post a question - after completing all these efforts to eradicate polio, do you have any plans how to support POLIO SURVIVORS in all our countries, especially in the sense of raising awareness of polio and its late effect including postpolio syndrome? Thank you very much - Stefan Grajcar, European Polio Union, Board Director and EPU Secretary, Slovakia”*

As could be expected, I received no answer, but in the light of what John McFarlane is speaking about in his article *“Possible New Initiative for Polio Survivors”* above in this edition, the answer might be there.

For more information see the [GPEI website](#) and also the following [document](#).

**Stefan Grajcar,**  
Slovak Polio Association,  
EPU Secretary



### FULL MEMBERSHIP OF OUR EPU IN THE EUROPEAN DISABILITY FORUM (EDF)

Few weeks ago there was a discussion in the EPU Board members about our ambition (or a goal?) to become full member of the [European Disability Forum](https://www.edf-fehp.org/our-members/european-polio-union/) (EDF). EPU was from the very beginning (in 2009) an associate EDF member (<https://www.edf-fehp.org/our-members/european-polio-union/>), and for receiving the status of a full member we must meet the corresponding criteria. Here is a short overview of how it currently is.

According to the [EDF Statutes](#) - article 10 - there are four categories of members, and EPU is currently in the last one:

- full members,
- ordinary members,
- observer members,
- associate members (they might be non-profit and corporate).

Let me quote some parts from the EDF Statutes:

*"Article 10: Membership criteria*

#### *10.1. Full members*

*Organisations which fall under any of the following two categories will be considered as full member.*

*1) One National Council of Disabled People from each EU and EEA Member State which:*

- 1. has an independent legal status in its own country;*
- 2. includes within its membership the most representative organisations of all major impairment groupings, as well as of organisations of parents of disabled people unable to represent themselves, and is open for inclusion of other groups of disabled people;*
- 3. has a 51% majority within its membership and within its governing bodies of organisations of disabled people and of parents of disabled people unable to represent themselves.*

*2) European Non-Governmental Organisations of disabled people<sup>3</sup> which:*

- 1. have a legal status;*
- 2. are represented in at least half plus one of the EU/EEA countries and are open to organisations from any EU/EEA country;*
- 3. has a 51% majority within its membership and within its governing bodies of organisations of disabled people and of parents of disabled people unable to represent themselves.*
- 4. principal remit of which should relate explicitly to co-operation at European level regarding disability and be consistent with the aims and objectives of the Association as referred to in Article 3 of these Statutes."*

Differences between full and associate membership are as follows:

*"Article 5: Full members*

*Applicants whose aims and activities conform to articles 3 and 4 of these statutes and who meet the full membership criteria set forth in article 10 of these statutes may be admitted to the Association as full members.*

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<sup>3</sup> EPU belongs to this category.

*The rights and obligations of full members shall be as set forth in these statutes and in the internal rules.*

*The rights of full members include full voting rights in the Association and the right to stand for election to the organisational structures of the Association in accordance with these statutes.*

*Full members have complete membership of the Association. They set the policies, guidelines and priorities of the Association and make an ongoing contribution to its activities.*

*Full members shall be informed and consulted on an ongoing basis about the activities of the Association.*

*Full members shall contribute an annual membership fee, the amount of which shall be determined by the General Assembly in accordance with article 13 of these statutes and the applicable provisions."*

### Article 8. Associate members

*"Applicants whose aims and activities conform to articles 3 and 4 of these statutes and who meet the associate membership criteria set forth in article 10 of these statutes may be admitted to the Association as associate members.*

*The rights and obligations of associate members shall be as set forth in these statutes and in the internal rules.*

*Associate members shall have no voting rights in the Association and no right to stand for election to the organisational structures of the Association.*

*Associate members shall be informed on an ongoing basis about the activities of the Association.*

*Associate members may attend meetings of the General Assembly as observers at their own expenses, but they shall not be entitled to vote.*

*At their own expense, associate members may attend seminars and conferences organised by the Association.*

*Associate members shall contribute an annual membership fee, the amount of which shall be determined by the General Assembly in accordance with article 13 of these statutes and the applicable provisions."*

Looking at the Membership criteria (Article 10.1, point 2), it is obvious that **EPU DOES NOT MEET the second condition** ("are represented in at least half plus one of the EU/EEA countries and are open to organisations from any EU/EEA country"), here is the explanation relating to this condition:

- number of EU countries: **27**
- number of EU countries where EPU has member organisations: **13** (1. Belgium, 2. Czech Republic, 3. Denmark, 4. Finland, 5. France, 6. Germany, 7. Ireland, 8. Italy, 9. Netherlands, 10. Poland, 11. Slovakia, 12. Spain, 13. Sweden) – **WE DO NOT MEET THIS CRITERION**
- number of EEA countries: **32** (the EEA includes EU countries and also Iceland, Liechtenstein and Norway. It allows them to be part of the EU's single market. Switzerland is not an EU or EEA member but is part of the single market. From 31 January 2020 the UK is no longer an EU/EEA member state. - source: <https://www.eea.europa.eu/countries-and-regions>).

- number of EEA countries where EPU has member organisations: **14** (1. Belgium, 2. Czech Republic, 3. Denmark, 4. Finland, 5. France, 6. Germany, 7. Ireland, 8. Italy, 9. Netherlands, 10. Norway, 11. Poland, 12. Slovakia, 13. Spain, 14. Sweden). – **WE DO NOT MEET THIS CRITERION**

### Conclusion:

To have a full membership in the European Disability Forum

- we need at least **one** polio survivors association or support group from EU country which is not represented in EPU yet (Austria, Bulgaria, Croatia, Cyprus, Estonia, Greece, Hungary, Latvia, Lithuania, Luxembourg, Malta, Portugal, Romania, Slovenia), **OR**
- we need at least **three** polio survivors associations or support groups from EEA country which is not represented in EPU yet (Austria, Bulgaria, Croatia, Cyprus, Estonia, Greece, Hungary, Iceland, Latvia, Liechtenstein, Lithuania, Luxembourg, Malta, Portugal, Romania, Slovenia).

It seems that we can leave this topic for a while, i. e. unless we manage to invite a few more polio survivors associations or support groups to be EPU member organisations, as indicated above :). If you know any polio survivor in countries listed above and have a contact to him or her, if you know about any polio organisation or polio support group there, just let us know, we shall try to invite them to be our members.

**Stefan Grajcar**

EPU Secretary



## ZOOM CAFÉ ORGANISED BY THE BRITISH POLIO FELLOWSHIP ON OCTOBER 26, 2022

To celebrate and mark World Polio Day in 2022 (24<sup>th</sup> October), The BPF is planning a Zoom Café on **October 26<sup>th</sup>, 2022**, at 11:00 am. This will be a unique event and we want to hear from European Polio organisations about the challenges the polio community face in their respective countries, but also sharing ideas about how we overcome them. The plan is to get 4-5 organisations at this event, each one talking for about 5 minutes, then this will be followed by a Q and A.

The British Polio Fellowship (BPF) introduced monthly Zoom Cafes in February 2021 when it realised people from the polio community were feeling disconnected during the Covid lockdowns. They have proven to be very popular amongst our members. Usually, we cover a specific topic with a guest speaker, followed by Q and A and then an open session. Past topics have included talks about orthotics, repository matters, exercise and diet. These cafés are usually scheduled for an hour but often run over, as people are enjoying the event.

So far five organisations have confirmed they want to be involved with the World Polio Day Zoom Café on October 26<sup>th</sup>, 2022. If you would like to join us, then please email me at [kripen@briptishpolio.org.uk](mailto:kripen@briptishpolio.org.uk) as soon as possible.

I firmly believe that by working together we can make the lives of the polio community better.

Yours in fellowship.

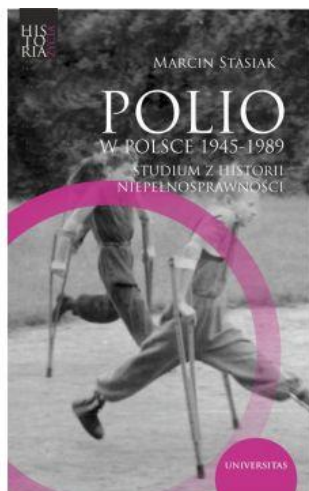
**Kripen Dhrona**

Chief Executive of the British Polio Fellowship

## BOOK REVIEW

### MARCIN STASIAK: POLIO IN POLAND 1945-1989. A STUDY ON THE HISTORY OF DISABILITY

By Zdzisława Szot-Susłowska, Polish Association POLIO+



In the book **“Polio in Poland 1945-1989. A study on the history of disability”** (in Polish: *“Polio w Polsce 1945-1989. Studium z historii niepełnosprawności”*). UNIVERSITAS, Krakow, 2021. ISBN: 978-83-242-3801-9. <https://www.universitas.com.pl/produkt/4201/Polio-w-Polsce-1945-1989-Studium-z-historii-niepelnosprawnosci->

its author Marcin Stasiak recalled the polio epidemic in the 1950s, combating the effects of this disease, creating a treatment and rehabilitation system.

It was the post-war period, when Poland had not yet recovered from the tragic consequences of the war. There were many people injured as a result of the war, who also needed treatment, orthopaedic supplies and rehabilitation.

Polish government and health service faced a major challenge, but above all, the epidemic was a tragic experience for those it affected personally and for their families. The disease mainly affected children, in some of them the result was paralysis, mainly of the motor organs. The children required treatment and rehabilitation, which was associated with a long stay in sanatoriums. There, they could get education in the field of primary school, but also patterns of social behavior and the desire to become independent in adulthood. After completing primary school, the problem of further education or professional work.

The author juxtaposed individual biographies of specific people with the activities of the state, the social structure and the historical context.

The basic question is: How has disability influenced the daily lives and biographies of polio survivors? The memoirs of Andrzej Krzywicki, an outstanding theoretical physicist and son of Irena Krzywicka, as well as the memories of Janina Ochojska, president of the Polish Humanitarian Action, contained in an long interview conducted by Wojciech Bonowicz and published in 2000, were particularly valuable and widely used here. The study also uses the statements of 23 childhood polio survivors.

Marcin Stasiak's book is based on his doctoral dissertation and was awarded the prestigious Historical Award of the weekly magazine “Polityka”.



## INTRODUCING EPU MEMBER ORGANISATIONS

### POST POLIO BELGIË VZW

**Established in:** 1996

**Chair / President (name and e-mail):** Johan Bijttebier, [joan.bijttebier@telenet.be](mailto:joan.bijttebier@telenet.be)

**Number of members:**

Post polio België VZW ([www.postpolio.be](http://www.postpolio.be)) was founded in 1996 by Johan Bijttebier, also the founder of EPU. In Belgium, the number of people who have previously had polio is estimated at 8,000 to 15,000. A number of them suffer from 30 to 40 years after their initial infection with post-polio syndrome (PPS). The association aims to provide these people with the necessary support. On the other hand, we want to raise awareness of this disease. We notice that the effects of polio are still not known or recognized by too many doctors.

#### **What are we doing?**

We are a self-help group, which is mainly focused on helping fellow sufferers through our own experience. Post polio Belgium organizes support groups in every province where members can tell their story and mutual tips are exchanged. It is also a tradition to organize a festive annual and happy gathering with food, drinks and a speaker on a certain topic.

Belgium has a solid social security. Members often get lost in the offer and information to the right counter is not easy. The priorities of our organization are information and referral. Neuromuscular centers for muscle diseases are housed in 6 university hospitals.

Three times a year we send a newsletter to all our members. This is especially important for those who are unable to attend the activities.

In Belgium there is a compulsory vaccination, but more and more people are voting to question vaccination. We must ensure that we do not forget the terrible consequences that polio can have.

**Johan Bijttebier**

Postpolio België vzw Chairman



### POLISH ASSOCIATION POLIO+ (POLSKIE STOWARZYSZENIE POLIO+)

**Established in:** 2016

**Chair / President (name and e-mail):** Małgorzata Koter-Mórgowska <malgorzata@lzinr.lublin.pl>

**Number of members:** 67

#### Short history and key milestones:

[Polish Association POLIO+](#) is a non-profit organization created in 2016 on the basis of the online support group "Club under lucky thirteen", active since 2008 and initially gathering 13 polio survivors looking for information on physical deterioration. Its moderators created an invaluable basic knowledge about the late effects of polio at [PPS Academy](#) and [Letters to polio friend](#). The Association continues to promote information and education among polio survivors and medical community. Its members are volunteers and represent various professions (including doctor, psychologist, IT specialist), which makes substantive support and advice easier. As there are no doctors in Poland who know the PPS problems, we assume that polio survivors with knowledge of their disease will be able to make reasonable decisions about their life activities. Our website <https://postpolio.lublin.pl/> contains links to original medical articles and translations. The Association undertakes additional initiatives, e. g. conducted an [online survey](#) on the life/health conditions of polio survivors in Poland. We corresponded with governmental institutions, including the Minister of Health, demanding the introduction of the G14 code for PPS into the Polish version of the Classification of Diseases ICD-10 and with National Consultant in the field of neurology, informing about difficulties with access to diagnosis and PPS treatment. Moreover, review papers were published in [Polish Journals of Neurology and Neurosurgery](#) and [Neurology after Diploma](#). Leaflets about PPS, available in [pdf format](#) on our website, have been sent to Neurological Clinics throughout Poland.

#### Main activities:

Our activities are currently focused on promoting information and education about post-polio syndrome among polio survivors and medical community in our country, in particular through our website <https://postpolio.lublin.pl/>. This website has been modernized this year and it is a valuable and unique source of knowledge about PPS in Polish. We also run [Facebook Fan Page](#) of our Association.

**Contact:** [stowarzyszenie@postpolio.lublin.pl](mailto:stowarzyszenie@postpolio.lublin.pl)

**Website:** <https://postpolio.lublin.pl/>

**(POST)POLIO GROUP OF SPIERZIEKTEN NEDERLAND**

**Established in:** 1995?

**Chair / President (name and e-mail):** International contacts: Aadje de Groot,  
aadje.degroot@planet.nl

**Number of members:** 500-600

**Short history and key milestones:**

In the Netherlands there are approximately 13,000 people with polio.

The patient association for people with polio and post-polio syndrome is part of Spierziekten Nederland (SN), an organisation for neuro-musculair diseases. SN supports us in our work and provides financing. Every year there is a conference, there are newsletters, brochures, webcasts on various topics, e-health courses, workshops and contact with fellow sufferers. Our goal is to promote the interests of people with (post) polio and to encourage research into suitable treatment. We strive to optimise the quality of life of people with polio. We work closely with our medical advisors (including rehabilitation doctor Professor Dr. Frans Nollet) of the Amsterdam UMC (location AMC). Together we have set up a Polio Expertise Center and set up a research agenda with priorities. A lot of research is being done in the AMC into the care and treatment of people with post-polio syndrome. In the Netherlands, patient participation is a very important issue. The lines between patients and practitioners and researchers are short. We are very satisfied with this. We also like that there is a focus on the psychosocial side. A great deal of value is attached to the importance (and the possibility) of guidance in that area.

Information about our association can be found on the website of Spierziekten Nederland [www.spierziekten.nl](http://www.spierziekten.nl) and on the website [www.postpolioexpertisecentrum.nl](http://www.postpolioexpertisecentrum.nl), which is full of information for patients and practitioners.

**Challenges you cope with:**

- The people on the board are getting older and replacement becomes more difficult.

## SLOVAK POLIO ASSOCIATION (ASOCIÁCIA POLIO V SR)

**Established in:** 1992

**Chair / President (name and e-mail):** Milan Dovhun, dovhunmilan@gmail.com

**Number of members:** 150

### Short history and key milestones:

- at the beginning of 2000's number of members reached nearly 400, since then number of members is decreasing, mainly due to physical limitations caused by polio and PPS, most often combined with ageing;
- number of polio survivors in Slovakia is estimated at 1,200-1,500 persons;
- polio in Slovakia (until 1992 part of Czechoslovakia) was eradicated in 1960;
- in 2017 polio survivors in Slovakia accomplished our efforts for better access to the spa rehabilitation care, according to which we are entitled to go to the spa every two years, and it is paid from the public health insurance

### Main activities:

- organising weekend meetings twice a year for 40 – 50 members, polio survivors in different parts of the country;
- organising a whole week recondition stay once a year for 40 – 50 members;
- occasional regional meetings, usually shortly before summer and also at the beginning of December

### Challenges you cope with:

- it is the same as in majority of European countries – medical professionals know nearly nothing about polio and PPS, there are no possibilities in the country to diagnose and subsequently to treat PPS

### Any other comments:

- average age of our members currently (May 2022) is 69 years and 5 months;
- contact: [stefan.grajcar@gmail.com](mailto:stefan.grajcar@gmail.com);
- website: [www.polio.sk](http://www.polio.sk)
- in May 2022 Slovak Polio Association celebrated its 30<sup>th</sup> Anniversary (see photo below)



### THE SWEDISH ASSOCIATION FOR SURVIVORS OF ACCIDENT AND INJURY

**Established in:** 1946

**President (name and e-mail):** Marina Carlsson, [marina.carlsson@rtp.se](mailto:marina.carlsson@rtp.se)

**Number of members:** 5000 of which 1000 are survivors of polio

#### Short history and key milestones:

The organization was founded in May of 1946 to support survivors of polio. In the 50's the organization contributed financially to the development of a good Swedish polio vaccine and ensured that the Swedish population were vaccinated within the frame of a vaccination program. In this way mass vaccination against polio was initiated and the number of cases decreased rapidly. In 1961, 64 cases were reported and in 1962 only four cases.

Vaccination was introduced in the childhood vaccination program in 1965. Last domestic case was in 1977.

Since the 70's the organization on the national level conducts lobby- and advocacy work for improved and accessible rehabilitation.

#### Main activities:

On national level the organization provides information about Polio and Post-polio to the society. There is an active lobby advocacy work around accessible rehabilitation and accessible health care for survivors of Polio.

The organization has been an active part in the ongoing process to form centralized care for survivors of Polio.

The hard advocacy work has paid off, Sweden is now in the process to start-up centralized centers with expertise on Polio and Post-polio in three so called competence centers. As shall act as specialist centers and be accessible to all Survivors of Polio with Post-polio in Sweden. At the centers the survivor of Polio with Post-polio will be able to receive information, treatment and a rehabilitation plan. The centers will also provide healthcare providers with increased knowledge in the field.

On local level the branches of our organization arrange member activities such as for example physical activities, warm water bath, member meetings, cooking classes, kayaking, lectures, and peer to peer support.

On local level the branches also have lobby- and advocacy work against local stakeholders, decision-makers in municipalities, regions and healthcare.

#### Challenges you cope with:

A big challenge is the lack of expertise in the field of Polio/Post-polio in Primary care (local health care).

Then the access to care in the area is unequal across the country is also a challenge.

Language- and cultural barriers is challenging when it comes to reaching out with information about Polio/postpolio and how the Swedish social- and healthcare system in the society works to people

from other countries, now living in Sweden, many of whom have had polio/have postpolio or are a relative to such individual.

### **Any other comments:**

Research in the field of Polio-postpolio is important to be able to provide updated and relevant healthcare and rehabilitation for survivors of Polio/Postpolio.

### **Contact:**

President Marina Carlsson [marina.carlsson@rtp.se](mailto:marina.carlsson@rtp.se), Board member Marianne Gullberg [marianne.gullberg@rtp.se](mailto:marianne.gullberg@rtp.se) and Head of Office Fredrik Canerstam [fredrik.canerstam@rtp.se](mailto:fredrik.canerstam@rtp.se)

**Website:** [www.rtp.se](http://www.rtp.se)



### **DID YOU KNOW?**

In the June 2022 issue of **AARP the Magazine**, M\*A\*S\*H star Alan Alda opens up about life, love, and what he's learned – here is the link to the [article](#) “*Alan Alda Opens Up About Living with Parkinson’s and His Torturous Battle with Polio as a Child*”.



## EPU MISSION

The European Polio Union is an umbrella organisation working for people with polio and Post Polio Syndrome living in Europe. It was founded in March 2007 and we currently have member organisations and individual members in 19 European countries.

Our objectives are:

- To encourage European doctors to come together to develop uniform guidelines to diagnose PPS and to conduct further research in conjunction with patient groups.
- To help to gather data on the prevalence of polio and PPS in Europe.
- To collect and share amongst all people with polio and PPS in Europe knowledge, experience and best practice of living with the disease and signpost information to health and allied professionals and polio organisations within Europe.
- To encourage relevant bodies and governments in Europe to ensure that polio immunisation levels are sufficiently high to prevent further outbreaks.

We are committed to working equally across all countries in Europe and to strive for greater recognition of the issues facing those affected by polio and Post Polio Syndrome.

### Opinion Disclaimer

The views and opinions expressed in this EPU Newsletter are those of the authors and do not necessarily reflect the official policy or position of the European Polio Union and/or its Board of Directors. Any content provided by authors are of their opinion, and are not intended to malign any religion, ethnic group, club, organization, company, individual or anyone or anything.

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Authors (in order of appearance): EPU Board  
Štefan Grajčár  
David Mitchell  
Alex Curtis – Frances Quinn – Carol Levin  
John R. McFarlane  
Kripen Dhrona  
Zdzislawa Szot-Suslowska

Editor & layout: Štefan Grajčár, [stefan.grajcar@gmail.com](mailto:stefan.grajcar@gmail.com)