European Polio Union: Newsletter – 2026/1

The Øresund bridge between Denmark and Sweden; hosts of the EPU AGM and conference 2026

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A MESSAGE FROM THE PRESIDENT

Reconnecting and Strengthening Europe's Polio Community

Dear friends

It is a great pleasure to welcome you to this new edition of the European Polio Union newsletter.

By relaunching the newsletter, we want to make it a genuine space for exchange between our member organisations, polio survivors, healthcare professionals, researchers, families and supporters throughout Europe.

The situations faced by polio survivors vary greatly from one country to another. Some have access to experienced medical teams, recognised care pathways and active national associations. Others struggle to find doctors who understand the late effects of poliomyelitis or post-polio syndrome. In some regions, survivors have little or no collective representation and may be left alone to cope with increasing fatigue, pain, weakness, respiratory difficulties, loss of mobility and reduced independence.

This newsletter should help us understand and document these differences, share solutions and make useful experience available across national borders.

We therefore invite all EPU member organisations to contribute regularly. We would welcome news about the life of your association, your achievements and difficulties, your conferences, surveys, publications and awareness-raising activities.

We also need information about medical care in each country, including access to diagnosis, rehabilitation, assistive devices, social protection and specialised services, such as dedicated polio care pathways and measures to anticipate and prevent the consequences of ageing.

Contributions may be submitted in national languages. Artificial intelligence now makes translation much easier and should allow us to share information more widely across Europe.

Personal testimonies are equally important. They can help us understand the real living conditions of polio survivors and ensure that our priorities and communications remain rooted in their everyday experience.

Contributions do not need to be long or formal. A short article, a question, a local initiative or an example of good practice may be valuable to the whole European community. What may seem normal or familiar to you could provide an invaluable example to others.

A great deal has happened since the last EPU newsletter. New members have joined the Board, and our team increasingly reflects the diversity of the polio population across Europe. Solidarity remains our core value, and we are all facing the shared reality of ageing.

(newsletter contributions to frances@britishpolio.org.uk)

We held a successful conference and Annual General Meeting in Burgos, Spain, in 2025, followed by another well-attended conference and AGM in Copenhagen, Denmark, and Malmö, Sweden, in 2026.

These events confirmed both the strength of our community and the need for EPU to adapt to changing circumstances. We are fully committed to this task.

Polio survivors must remain visible. Ensuring that no survivor, association or region is left isolated is a central part of EPU's mission and will require our continued collective effort.

With my very best wishes, Pierre Parrot,

President, European Polio Union

Highlights of the EPU 2026 AGM

Our Annual General Meeting, held in Malmö on 13 June, confirmed both the value of the EPU and the scale of the work ahead. The annual report, accounts and projected budget were adopted. The discussion nevertheless highlighted a worrying financial situation, particularly following the loss of the EURORDIS grant, and the need to identify new and sustainable sources of income.

The country reports showed how much valuable work is already being carried out by our members. Examples included patient surveys and care pathways in the United Kingdom, regional support groups: in Ireland, a network of specialised hospital doctors in France, lectures for patients in the Netherlands, and practical or medical handbooks in Germany and Hungary.

At the same time, these reports revealed major inequalities. In some countries, knowledge of post-polio syndrome remains poor, even among doctors. Specialist centres have disappeared, associations are finding it increasingly difficult to replace ageing volunteers and younger polio survivors, including people who have migrated to Europe, are not always being reached. In Italy, for example, participants reported that the former network of polio centres had been reduced to a single centre.

Three main strategic priorities emerged from the AGM

The first is to improve and update information for healthcare professionals throughout Europe. The quality of medical knowledge and care still varies greatly between countries. The EPU should help identify reliable resources, support the exchange of care pathways and educational materials, and encourage co-operation between clinicians and patient organisations.

The second priority is to improve our knowledge of the number and geographical distribution of polio survivors. Poliomyelitis is often regarded as a disease of the past, yet a substantial population continues to live with its consequences. Existing estimates are often incomplete or outdated.

We may never obtain perfectly precise figures, but even sound estimates would be better than the present lack of information. We need to encourage national surveys, epidemiological studies, anonymised statistical research, patient registries where appropriate, and co-operation with health authorities and researchers. The AGM confirmed that updating the estimated number of polio survivors in each country should be a central EPU objective.

These figures are not merely statistics. Without credible data, it is difficult to persuade governments, healthcare authorities, researchers and funders that services and research remain necessary. Better knowledge of our community is essential to its recognition and visibility.

The third priority is to collect information from every country and share it more effectively. This is precisely where the relaunched newsletter can make an immediate contribution. Member organisations should not work in isolation or repeatedly have to develop the same solutions independently. A survey, handbook, medical document or successful local initiative produced in one country may be useful in many others.

Building EPU's Capacity

The AGM also recognized that EPU's ambitions cannot be achieved by a small number of volunteers alone. Board members already carry many responsibilities in their own

organisations. We need additional people to participate in the Board and, in the longer term, sufficient funding to obtain professional support for communication, fundraising and project development. The meeting also appointed Conception Garcia-Anton Trassierra as Treasurer following Patrick McGillion's resignation due to health issues.

Fundraising will require a clear explanation of EPU's distinctive European role. Our purpose is not to

compete with national associations, but to connect them, reinforce their work and address needs that cannot be solved within national borders alone.

We must also continue trying to reach countries and regions that are not currently represented within the EPU. The AGM discussions showed how difficult this can be where national organisations have closed or attempts to create them have failed. It may require direct contact, local partnerships and outreach to younger migrant polio survivors.

Our common ambition should be simple: no region of Europe, no national community and, as far as possible, no individual polio survivor should remain isolated and without access to information, support or possible solutions.

The newsletter can become one of the foundations of this effort. I encourage every member organisation to regard it as its own space and to help us make it regular, practical and representative of the diversity of our community.

Together, we can make polio survivors more visible, improve understanding of their needs, share existing solutions and build a stronger European voice.

Pierre Parrot

President, European Polio Union

Report from the EPU 12 June 2026 Conference in Copenhagen

In 2026, the EPU AGM was co-organised by PolioForeningen Denmark and Personskadeförbundet RTP Sweden. On Friday 12th June we had the interesting experience of staying at a hotel in Malmo, Sweden, and travelling over the magnificent Øresund Bridge between these two countries to a conference at the Specialist Hospital for Polio and Accident Patients, Specialhospitalet, run by PolioForeningen and UlykkesPatientForeningen.

The accessible bus provided was excellent – having a lift at the rear for wheelchairs (see photo).

Arriving at the hospital, we were impressed by the unusual sight of polio flags welcoming us.

After a warm welcome and speech by **Gurli Nielsen, the PolioForeningen Vice- Chair** we had a presentation by **Pierre Parrot, President of the EPU.**

Pierre summarized the EPU mission: to bring together European national polio associations to strengthen their voice, to learn from and help each other and to improve treatment equality. He updated everyone on known post-polio numbers in Europe and polio sociology and listed key current challenges: refresh statistics, assess medical capacities, review existing medical pathways and protocols, encourage research, medical studies and training.

Nana Rømer Jørgensen, Head of Occupational Therapy then described the health system in Denmark and the role of the Specialhospitalet. This offers specialised rehabilitation for people with the late effect of polio, spinal cord injury, multiple trauma and others with severe functional impairments. She described how this is a collaborative process, with a multidisciplinary team including a doctor, physiotherapist, occupational therapist, counselling therapist, social worker, nurse, and psychologist. Polio patients were 39% men and 61% women, with an average age of 77 years (min 38, max 101). Services covered pain management, exercise, energy management, diet, bladder and bowel issues, swallowing, counselling on assistive devices and managing loss of function.

This was followed by a tour of the impressive facilities: a large hydrotherapy pool and a large modern well equipped gym. They also had facilities for assessment and guidance on activities of daily life, some accommodation for patients and an audio-visual suite for online classes. These facilities were all housed in a modern, purpose built, very accessible building with a cafeteria.

Chief Physician, Majbritt Almer, spoke about fatigue and post-polio. She reported how it is much more common in polio survivors, how there are many ways of measuring it clinically, though all are different and how there are both central and peripheral types. While there are drugs, primary management involves energy conservation, treating problems with breathing, sleep and pain, weight control and cardiopulmonary conditioning. She had a great memory aid – the 5 P's rule: Proper Planning Prevents Poor Performance and ended with the advice to Plan, Prioritise, Pace yourself, Positioning (posture) and finally Permission (to rest) as she feels ' many polio survivors keep fighting beyond the point when they should let go'. She answered lots of questions, which could have continued for hours.

Problems with sleep quality is a common problem in polio survivors and can increase fatigue, lower mood and affect quality of life. We were interested to hear **Natalia Suhak, Senior Hospital Physician at the Rigshospitalet,** present preliminary results of an in-depth Danish study on neurophysical conditions (including sleep). Forty two people completed questionnaires on sleep quality, fatigue, neurological and post-polio symptoms. They had detailed sleep monitoring, nerve condition and electromyography tests along with long-term blood pressure measurements. The results are still being analysed. Results so far showed

different neurophysiological dysfunctions. Sleep issues varied considerably. Nerve conduction tests were abnormal in 27 people. All polio survivors showed EMG abnormalities typical of prior polio. Sixteen had elevated blood pressure.

The study team are still analysing the large amount of data and plan to publish in medical journals. An abstract presented at the Nordic Sleep Conference 2026 is available online here - https://www.nordic-sleep.com/abstract-1 abstract 86.

Kari Loftus, Senior Physiotherapist at the University Hospital in Tromsø, Norway, spoke about maintaining physical functioning as life goes on. She emphasized that there was no 'cookbook' but the approach needed to be individual. The reasons for any health issue need to clarify the balance between normal aging, lifestyle, other diseases and the consequences of polio. It is important to take into account how extensive the impact of the acute polio was. Consider what is important for you to spend your energy on. Mapping activity to assess what gives or takes energy, plan for proactive rest and recovery. Some people have a resistance against using aids. These can reduce the risk of falling and injuries, and it might be that people need a few different aids. Some leave home adaptations too late – she recommends doing these early as they take time to complete. She talked about individual exercise programmes and setting achievable goals. Using an exertion scale such as the Borg scale can assess the degree of strain and avoid training to exhaustion. and the need for a detailed physiotherapy examination as the foundation for an exercise plan.

(examples of the Borg scale, or rating of perceived exertion (RPE) can be found on the web, https://pulmonaryrehab.com.au/wp-content/uploads/2022/06/04_modified_borg_dyspnoea_scale.pdf)

We were then linked by video to Professor Kristian Borg and Dr Eva Melin in the Karolinska Institute, Stockholm.

Professor Borg, Senior Physician and Professor of Rehabilitation Medicine at the Karolinska Institutet and Danderyd University Hospital Stockholm Sweden, reviewed the research done into immunoglobulin treatment in PPS. This covered studies of inflammation and possible biomarkers in PPS from1984 to 2010. He summarized the results as showing that inflammation is reduced by IVIG, leading to increased strength and a better quality of life mainly for general health and vitality measurements as well as pain and fatigue. These results lasted between 1 and 2.5 years. He also reported on the larger FORCE trial which demonstrated improvement in timed walking tests in March 2025 (*see the article later in this newsletter)*.

papers referenced

Gonzalez, H., et al (2002). Prior poliomyelitis-evidence of cytokine production in the central nervous system. *J Neurol Sci*, *205*(1), 9–13.

Kaponides, G., et al (2006). Effect of intravenous immunoglobulin in patients with post-polio syndrome -- an uncontrolled pilot study. *J Rehabil Med*, *38*(2), 138–140.

Gonzalez, H., et al: a randomised controlled trial . *Lancet Neurol*, *5*(6), 493–500.

Werhagen, L., & Borg, K. (2011). Effect of intravenous immunoglobulin on pain in patients with post-polio syndrome *J Rehabil Med*, *43*(11), 1038–1040.

Ostlund, G., et al (2012). IVIG treatment in post-polio patients: evaluation of responders *J Neurol*, *259*(12), 2571–2578.

Gonzalez, H., et al (2009). Identification of novel candidate protein biomarkers for the post-polio syndrome - implications for diagnosis, neurodegeneration and neuroinflammation. *J Proteomics*, *71*(6), 670–681.

Eva Melin, Medical Director of the Post Polio/Neuromuscular Rehabilitation Unit at the Danderyd University Hospital, Stockholm, Sweden, gave an overview of national highly specialised care in Sweden. Sequelae of poliomyelitis has been part of specialised medical care since 1/1/2024 and 3 hospitals hold a licence; Skanes University hospital in Lund,

Danderyds hospital in Stockholm and Sahlgrenska hospital in Högsbo. This covers assessment, diagnosis, suggested treatment, rehabilitation and follow up, but not life-long follow ups. Patients can be reassessed if their condition deteriorates. Like in Denmark, assessment is by a multidisciplinary team including a medical doctor, nurse, physiotherapist, occupational therapist, social worker and in some cases a psychologist, orthopaedic engineer and dietician. Feedback is given to the person/family at the clinic or online, with written recommendations sent to the person and the referring physician. Follow up is 3-4 months later. Common areas of rehabilitation are increased knowledge adaptations, medical and technical aids.

Jerónimo González Bernal then gave an additional talk on the progress from Spain and the University of Burgos (*see the following article*).
Marina Carlsson, President of Personskadeförbundet RTP gave a closing speech, thanking the contributors and closing the conference.

Talks from the EPU AGM in 2025; Burgos, Spain

In 2025 the European Polio Union AGM was held in Burgos on the 31st May with a conference hosted by the Universidad de Burgos on the 30th May. We thank Jerónimo and his team for their excellent hosting over the weekend. The talks from the conference include:

- *Strategies of Vaccination against Poliomyelitis in Europe,* María-Isabel Porras-Gallo/María-Victoria Caballero. Universidad de Burgos
- *Quiet Presence: Disability in Prehistoric Societies. Evidence and Challenges-* Laura Rodríguez García Universidad de Burgos
- *IVIg for post polio: an overview of published research*, Frances Quinn, BPF
- *To vaccinate or not to vaccinate?,* Michal Haindl, Asociace polio Czechia
- *Access to hydrotherapy for polio survivors in the UK,* Frances Quinn, BPF

Videos available at https://www.ubu.es/european-polio-union-annual-general-meeting-2025.

2026 Activity report from Spain and the University of Burgos

The project "Assessment of functional status and quality of life in people affected by polio in Spain" is being developed within the framework of a national grant funded by the Ministry of Territorial Policy and Democratic Memory, running from 1 December 2025 to 1 December 2026. Its purpose is to improve knowledge about poliomyelitis and post-polio syndrome, with the aim of supporting more appropriate care and better assistance for affected people.

As part of this initiative, researchers from the University of Burgos are carrying out assessments of people affected by polio and post-polio syndrome in collaboration with the Spanish Federation of Polio and Post-Polio Syndrome (FEP) and affiliated associations. The study invites interested individuals to take part in a simple, non-invasive evaluation designed to gather useful information about their functional status and quality of life.

Study objective

The project seeks to generate evidence on the functional situation of people affected by polio in Spain and to explore aspects relevant to their health and well-being. This information will help advance scientific knowledge about the condition and contribute to improving the quality of life of the affected population.

Variables assessed

The evaluation includes several health and functional domains:

- Muscle strength.
- Body composition using bioimpedance.
- Respiratory function using spirometry.
- Health and quality-of-life questionnaires.
- Functionality and mobility.

These measurements provide an overall picture of participants' status and potential care needs.

How to participate

Participation is straightforward and begins with direct contact with the research team to arrange the assessment. The study also allows the team to travel to association venues, partner organizations, or participants' homes in order to make participation easier.

Social relevance

This initiative has a strong applied and social focus, as it aims to collect rigorous information to support future lines of care, research, and support for people with polio and post-polio syndrome. In addition, collaboration with associations and federations helps disseminate the study and engage the affected community.

Jerónimo González Bernal, Catedrático de Universidad,
Director del Departanmento de Ciencias de la Salud, Universidad de Burgos

Efficacy of Immunoglobulin in Participants with Post-Polio Syndrome: Results from the Multicenter, Randomized, Placebo-Controlled FORCE Trial

At the 12th Congress of the European Academy of Neurology, held 27-30 June this year in Geneva, the results of the FORCE trial, sponsored by Grifols, were presented in an e-poster session by prof Frans Nollet from the Amsterdam University Medical Center, the Netherlands.

Background

The FORCE trail was initiated to investigate whether immunoglobulins administered intravenously (IVIG), every four weeks for one year could slow down the progressive decline in muscle function due to post-polio syndrome (PPS). The rationale to investigate IVIG was that immune mediated inflammatory mechanisms play a role in the pathophysiology of PPS. There have been some studies done in the past with one or two consecutive doses of IVIG from which no definite conclusions could be drawn on the effectiveness, as was concluded in a Cochrane review in 2015.

Aim

The aim of the FORCE trial was to demonstrate the efficacy of IVIG (Flebogamma® 5% DIF by Grifols) in participants with PPS in terms of improvement in timed walking distance. The primary outcome was the distance walked in 2 minutes at self-chosen speed. This outcome was chosen because it is a measure of physical ability that captures strength and endurance. The other outcomes which were measured were endurance with a six-minute walking test at maximum speed, fatigue, muscle strength, and pain.

Study design

The design of the FORCE trial was an international multicenter, randomized, double-blind, placebo-controlled study. This means that a draw decides whether a participant gets IVIG or a non-working substance, a placebo, and that both the participant and the investigators do not know what one receives. In the first phase of the study the study had 3 arms, which means 3 different treatment possibilities, which were IVIG 1 gram per kg bodyweight, 2 grams per kilogram bodyweight or placebo. The aim of this phase was to determine the optimal dosage. An analysis that was made after the first phase of the study decided that the study was continued with IVIG 1 gram per kilogram bodyweight, thus in the second phase of the study participants received either IVIG 1 gram per kilogram bodyweight or placebo.

Results

In total 149 participants received IVIG 1g/kg (75) or placebo (74). Mean age was around 63 years, and around 60% were female. The legs were most often involved. The baseline performance was on average a distance of around 107m walked in 2 minutes, which corresponds with a walking speed of around 3 kms an hours, which is considerably slower that non-affected individuals who walk at a speed of 5-6 kms per hour.

The results showed that IVIG 1 g/kg improved walking speed significantly by 6 meters compared to placebo, which is an effect of about 6%. A comparable effect was seen in increase in distance walked in 6 minutes of 15,8 meters, however this effect was not statistically significant. Statistically significant means that it is very unlikely that an effect is coincidental. Normally the cut-off value for this is 5%, which implies that it is for at least 95% certain that the effect found results from the intervention, in this case IVIG. The other outcomes showed a small but significant effect on muscle strength in favor of the participants treated with IVIG. No effects were seen for fatigue or pain.

Conclusion

The conclusion of the FORCE trial is that IVIG taken monthly for one year improves walking capacity as measured with the 2 minutes walking test. This effect is clinically meaningful and statistically significant, in other words the magnitude of the effect is relevant and true.

There are some comments to be made, such as is an improvement of 6 meter really worthwhile? The answer to this is that we know that PPS progresses rather slow on an annual basis. Thus the effect that could be expected, has to be considered in view of the natural rate of decline. Therefore, it was decided that this study should take a long treatment period of one year and the study was designed in such a way that the statical analysis could detect an effect size of 5% (or more). If the study had found an effect that was far larger than 6 meters, one could doubt this outcome because it would not have been very likely.

Next steps

Presently, Grifols is presently preparing the documentation for the European Medicines Agency for authorization of Flebogamma for application in people with PPS. This will take some time. Of the EMA approves Flebogamma for PPS, each European country decides whether it becomes available, at what cost and whether it is reimbursed. This will take time, but the longest period lies now behind us, with the finalization of the FORCE trial and scientific presentation of the results. A full scientific publication is currently in progress.

This QR-code links to the e-poster presentation held at the EAN congress with an explanatory video.
Direct web link CLICK HERE

Polio Survivors Ireland at Leinster House

On Tuesday, 21st October 2025, just ahead of World Polio Day, representatives from Polio Survivors Ireland along, met with TDs and Senators in the AV Room at Leinster House. It was an important event, giving an opportunity to share real-life experiences and challenges of polio survivors as they grow older.

For many polio survivors, turning 66 brings an unexpected setback. Once they reach pension age, they lose access to disability supports that they've relied on for years and are moved onto the State Pension. Yet their needs don't disappear, if anything, they often increase. Many survivors are left trying to get help from Primary Care services that are already overwhelmed, with long waiting lists and limited resources.

During the presentations, politicians were urged to act, first, by requesting they look at the age limits that prevent older survivors from receiving specialist disability and rehabilitation services. Secondly, calling for more transparency around Primary Care staffing and funding. Thirdly, calling for better awareness of polio and Post-Polio Syndrome (PPS) among doctors and students. Finally, calling for a permanent Cost of Disability payment with more realistic and fairer medical card income limits.

One of the most moving moments came when polio survivor Mick Keegan shared his story of going through losing disability supports and being moved onto state pension. "I retired at 66…this polio didn't," he said, capturing what so many survivors feel. His words reminded everyone that you cannot retire from a disability, therefore support shouldn't stop at retirement age. Together, we will keep pushing for the fairness, care, and understanding every survivor deserves.

With thanks to Belle Patterson, Polio Ireland

How to Really Slow Down the Evolution of Post-Polio Syndrome:

Proposal for a Strategy and Justification

What assumptions did I make when creating the design?

The primary cause of post-polio syndrome (PPS) is widely believed to be an imperfection in the recovery and adaptation processes of neurons that survive poliovirus infection. In the initial stage of polio, the poliovirus inactivates a portion of motor neurons in the skeletal muscles. This leads to a reduced number of functional neurons and a corresponding decline in the patient's mobility.

In the subsequent stage, the surviving neurons attempt to compensate the initial killing effect. Their axons branch at the ends, increasing the number of synaptic terminals required to activate additional muscle fibres. Some of these fibres regain function after reinnervation, resulting in temporary improvement in motor ability. However, this adaptation leads to chronic overloading of the neurons, eventually neuronal burnout. This process is accompanied by muscle wasting and other characteristic symptoms of PPS. The result is their premature exhaustion and subsequent death ("neuronal burnout"), which is accompanied by muscle loss and other characteristic consequences for PPS (*doi:10.3389/fneur.2017.00188 and www.mayoclinic.org/diseases-conditions/pps/symptoms-causes/syc-20355669 www.mayoclinic.org/diseases-conditions/pps/diagnosis-treatment/drc-20355674*)

The details of theory that PPS results from the gradual death of overburdened neurons (e.g. neuronal "burnout") has yet to gain full consensus. PPS is not limited to neuromuscular deterioration—it also involves degenerative changes in the musculoskeletal system and psychosomatic impacts, such as chronic pain, fatigue, and psychological stress related to declining self-sufficiency.

Ironically, the success of the global polio vaccination campaign led to premature assumptions about the complete eradication of polioviruses, which in turn caused declining interest and investment in PPS research. As a result, attention to polio, PPS and polio survivors, now mostly elderly, has faded in many healthcare systems.

Current PPS treatment primarily focuses on symptom management and delaying further neuronal "burnout". However, these efforts appear insufficient, and sometimes even contradictory, when viewed alongside emerging research, including findings from space medicine. In addition, it remains unclear whether the flawed process of neuronal adaptation described above is exclusive to poliovirus damage or whether it could also be triggered for example by some neurotropic viruses, radiation, mechanical trauma, or genetic disorders.

New knowledges coming from space:

Recent studies have shown that astronauts exposed to prolonged weightlessness experience rapid muscle loss and slower bone demineralization. This is due to reduced physical strain and easier movement in microgravity environments. Alarmingly, similar effects to cosmic causes can occur under specific conditions on Earth. For instance, patients with respiratory muscle weakness who spend extended periods in iron lungs experience calcium loss from bones. Individuals using orthopaedic aids or support devices for prolonged periods also often show muscle atrophy. These observations are well-known among orthopaedic specialists. Even healthy individuals experience significant declines in fitness after long periods of inactivity. Muscle loss and reduced physical fitness have become widespread especially in developed

countries. Unintended consequences of a sedentary lifestyle are enabled namely by modern transportation, communication technologies, automation and/or laziness.

Interaction between neuronal burnout and "cosmic causes" during PPS:

The discovery of PPS prompted a shift in therapeutic strategy. As a result, individuals with PPS are advised to reduce physical activity, avoid fatigue, use assistive walking devices early, and engage in water exercises, water aerobics and other exercises without effort. However, these recommendations are not without trade-offs. While they may protect neurons from "burnout", they can inadvertently encourage muscle atrophy and physical decline due to disuse, essentially swapping one problem for another. This contradiction calls for a reassessment of current treatment approach.

A notable contradiction arises also between recommendations to avoid resistance exercises and the unavoidable resistance encountered during normal walking. For example, the strain involved in supporting body weight during walking may exceed that of some resistance training exercises. Yet excessive rest -or replacing walking with sitting or lying down - accelerates loss of fitness and independence in patients.

Thus, it appears to be crucial to find strategies that prevent both neuronal "burnout", and disuse-induced physical decline. One challenge lies in identifying the optimal type and amount of exercise. However, it might be a very uneasy way to solve this problem, because the variation based on the individual's specific condition and capabilities is very large. That is why I focused in the next section on different procedures based on the removal of "cosmic effects", increasing the stability of neurons and maintaining a reasonable body weight by proper medication for PPS patients.

Promising directions in research and treatment

If we could develop methods to mitigate the "cosmic" effects of disuse, such approaches can really slow down physical decline in PPS patients who respect current recommendations from physiotherapists. Recent research offers several promising findings. For instance, during spaceflight, muscle loss in mice was significantly reduced using the antibody YN41, which inhibits myostatin, a protein that limits muscle growth (doi:10.1371/journal.pone.0230818). In addition, research on hibernating ground squirrels shows that certain gut microbes can recycle muscle breakdown byproducts to support new muscle tissue synthesis. These microbes could potentially be used in human therapies. Notably, squirrels retain muscle function after hibernation unless treated with antibiotics, which disrupt their gut flora (Regan M.D, et al. Science 375(6579), 460-463, 2022). Furthermore, several compounds under investigation can promote muscle mass gain without physical activity, though many are currently unsuitable due to side effects. Derivatives with reduced toxicity may hold future potential (Zhu & Singh, J. Exercise Sci. and Fitness, 2024).

Many substances also show promise for protecting neurons in various ways. One example of interest is Exendin-4, an oligopeptide derived from venom and structurally similar to GLP-1. It has been synthetically produced as Exenatide, a medication used in type 2 diabetes. Besides its glucose-lowering and weight-reducing effects, Exenatide has demonstrated neuroprotective properties (e.g. doi:103389/fneur.2017.00188). As obesity is a common comorbidity in PPS, reducing body weight could significantly ease movement and potentially slow the progression of the syndrome.

Other important recommendation of the mentioned procedures

Research into the mechanisms and treatment of PPS is not only vital for those already affected but may also benefit a broader segment of the global population. As sedentary lifestyles continue to rise, muscle loss and reduced physical function are becoming widespread. Moreover, these findings hold significant implications for the health of astronauts after long-duration space missions, making this area of research medically and strategically important for the future of human spaceflight and its practical benefits to humanity.

In addition, there are several groups of disabled people (e.g.: after accidents) who are due to their handicap, limited in movement and so they might be affected by "cosmic causes". Moreover, it cannot be ruled out that there is a similar diagnosis to PPS, which is, however, triggered by e.g. a different neurotrophic virus. This part of the global population could show "burnout effect" similar to PPS patients. Both types of causes mentioned above are likely to affect the health of seniors.

Vladimír Vondrejs, Czech Republic

The Next Chapter for Polio Survivors Network UK

"Our voices still matter" - A recurring sentiment across recent PSN newsletters.

For many, polio is a disease relegated to history but for members of Polio Survivors Network the effects remain a daily reality affecting mobility, energy, identity and the need for a community that understands. Our newsletters have become more than updates. They are a record of resilience and the determination to ensure that polio survivors in the UK continue to have a voice and a network that stands with them. We continue to try to balance remembrance and lived experience with the urgent need to plan for the future.

"We carry forward the work of those who built this network, we feel their absence."

The passing of our founder Hilary Boone cast a long emotional shadow across the network. Her work remains the backbone of PSN's mission. Newsletters paid tribute not only to Hilary but also to other long standing contributors, including Verite, whose dedication shaped the organisation's culture of compassion and persistence.

These reflections were not simply memorials; they were reminders of the extraordinary individuals who carried the torch through years when polio survivors were often overlooked by mainstream healthcare. These losses remind us of the importance of continuity. They also highlight the reality that many of us who lead this charity are aging with post polio ourselves.

"When we share our stories, we share our strength."

PSN's newsletters continued to be a lifeline for members navigating the long-term effects of polio and Post-Polio Syndrome. Recent articles have explored:

- The deep sensitivity to cold many survivors' experience
- The unpredictable fatigue that shapes daily routines
- The emotional legacy of childhood illness and lifelong adaptation
- The shrinking availability of specialist polio clinics

We love the contributions from our members who share the same message that survivors are not alone. Articles are written from lived experience and this is our strength, the reason we continue our work.

"Healthcare must listen, not just treat."

PSN has also been pushing harder to bring survivor voices into professional spaces. Zsuzsi our trustee delivered a presentation to Chartered Physiotherapists, emphasising the need for clinicians to understand the lived reality of PPS. Newsletters continue to highlight concerns about diminishing specialist services, urging members to advocate for themselves in increasingly generalised healthcare environments.

"Our lives are bigger than our symptoms."

The newsletters also celebrated the cultural contributions of polio survivors, featuring:

- The Design and Disability exhibition at the V&A
- A tribute to blues musician Brownie McGhee
- Personal reflections, poetry and historical pieces from members

These stories remind readers that polio survivors are artists, thinkers, innovators and people whose identities extend far beyond their condition.

Change and Welcoming New Members

With the closure of the Scottish Post Polio Network, PSN welcomed Scottish members seeking continuity of support and ensuring we respected the legacy of SPPN's work, acknowledging both the loss of a dedicated organisation and the opportunity to strengthen the UK-wide community.

Looking Ahead

"We need new hands to carry the torch not because ours are letting go, but because the journey must continue."

One of the most important messages we have shared recently is our need to recruit new trustees. Many of us who currently serve as trustees are aging with post polio. We recognise the physical challenges that come with PPS. To secure the future of our charity, we must bring in new voices and new energy. This is not just organisational planning it is essential to safeguarding the future of polio survivor support in the UK.

Polio may be a disease of the past, but its survivors are very much part of the present. Through Polio Survivors Network our members' voices continue to shape the future of awareness and support.

With thanks to Polio Survivors Network UK

Spot4Dis - new app to help find parking places

Spot4Dis is a new app in the test phase in pilot cities: Valencia, A Corña, Badajoz, Zaragoza and Genoa. It aims to optimize the functioning of the Park4Dis app and help people with reduced mobility find parking spaces. Spot4Dis is looking for people to help test it before launch.

https://asopmr.org/en/index/

THE EPU Annual Report for the year 2025-2026

(the period between the 2025 and 2026 AGMs)

Dear friends, dear members,

Our EPU is at a crossroads, as is our polio community. This past year has made this very clear. Many of us who contracted the polio virus during the last epidemics in Europe are now in our late sixties or older. However, a significant number of people living in Europe with polio sequelae are much younger, having encountered the virus during late outbreaks either in Europe or elsewhere. The first generations who built this community brought a great deal of energy and expertise to our polio associations. The question now is how we can keep serving those polio survivors and, in the long term, the second and hopefully last generation of polio survivors across Europe.

Over the past few months, the EPU Board of Directors has tried to gain a better understanding of what our future could and should be. We met monthly and devoted three meetings to brainstorming and lively discussions about the options ahead.

Although we dedicated considerable effort to developing this vision, our usual polio-related work continued.

The period covered by this report began with our gathering in Burgos for the last AGM. There, we witnessed the creation of the first University Chair in polio in Europe. This is good news for our community, and an outstanding example set by Spain for Europe. Its academic director, Jerónimo González-Bernal, organized a wonderful event for us at the University of Burgos and we are delighted to see him here today.

Due to ill health, Patrick McGillion had to step down as our Vice-President and Treasurer, after David Mitchell had very recently stepped down as President. Our Secretary, Stefan Grajcar, also had to cease his activities as EPU Secretary. This is a concrete example of generational change. Everyone knows how efficient, committed and competent they were. I humbly accepted the position of EPU President, understanding that it would be impossible to perform as well as these outstanding predecessors. Macrina Clancy agreed to become Vice-President and to share with us the benefit of her extensive experience in association leadership. We welcome any help in the future, and Caroline Gordon-Wilson is already doing excellent voluntary work in EPU administration.

Despite all these changes, our commitment remains that of our founders: to serve the community of polio survivors' associations in Europe; to fight isolation and medical inequalities; to exchange information; and to continue combating the invisibility of polio in our societies.

Our world is changing rapidly. Violence seems to be taking the place of law and diplomacy in many parts of the world, which makes associative endeavours like ours even more crucial and necessary.

Technology, science and collective human intelligence and solidarity also offer huge opportunities. I am convinced that we, at the EPU, can use some of these opportunities to be a modest but meaningful part of the solution for a better future for the polio community and, perhaps, beyond.

Pierre Parrot President of the European Polio Union, on behalf of the Board, April 2026

General EPU information and links

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. 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.

EPU Purpose and Activities

The Association, which waives any pursuit of profit, has the provision of assistance to European citizens who suffer from polio or post-polio syndrome as its non-profit-making purposes of international utility. The pursuit of this purpose includes the carrying out of the following activities:

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

The Association may carry out any activities directly or indirectly associated with its purpose. It may also give its cooperation to and show its interest in every activity that has a purpose similar to its own.

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We welcome helpful feedback on format and content of this newsletter