EUROPEAN POLIO UNION

Newsletter No. 2/2024

Autumn 2024

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EUROPEAN POLIO UNION STATEMENT / PRESS RELEASE

On August 28, 2024, we published and sent to all our member organisations, honorary and individual members, as well as to partner organisations (WHO, GPEI, Eurordis, EDF, EFNA) the following EPU Statement / Press Release as our immediate reaction to shocking news that vaccination campaign in the Gaza strip was stopped as a consequence of the war conflict in this part of the world.

The situation has changes in the meanwhile but remains extremely difficult for all living on both sides of the war conflict, and we cannot imagine how challenging it is for children, elderly people, women, people with disabilities and all other disadvantaged groups of population.

* * * * * * *

TO WHOM IT MAY CONCERN

Dear Ladies and Gentlemen, dear all,

The European Polio Union is extremely worried about the situation in Gaza and its direct consequences for children who do not have access to vaccination against polio virus for more than ten months.

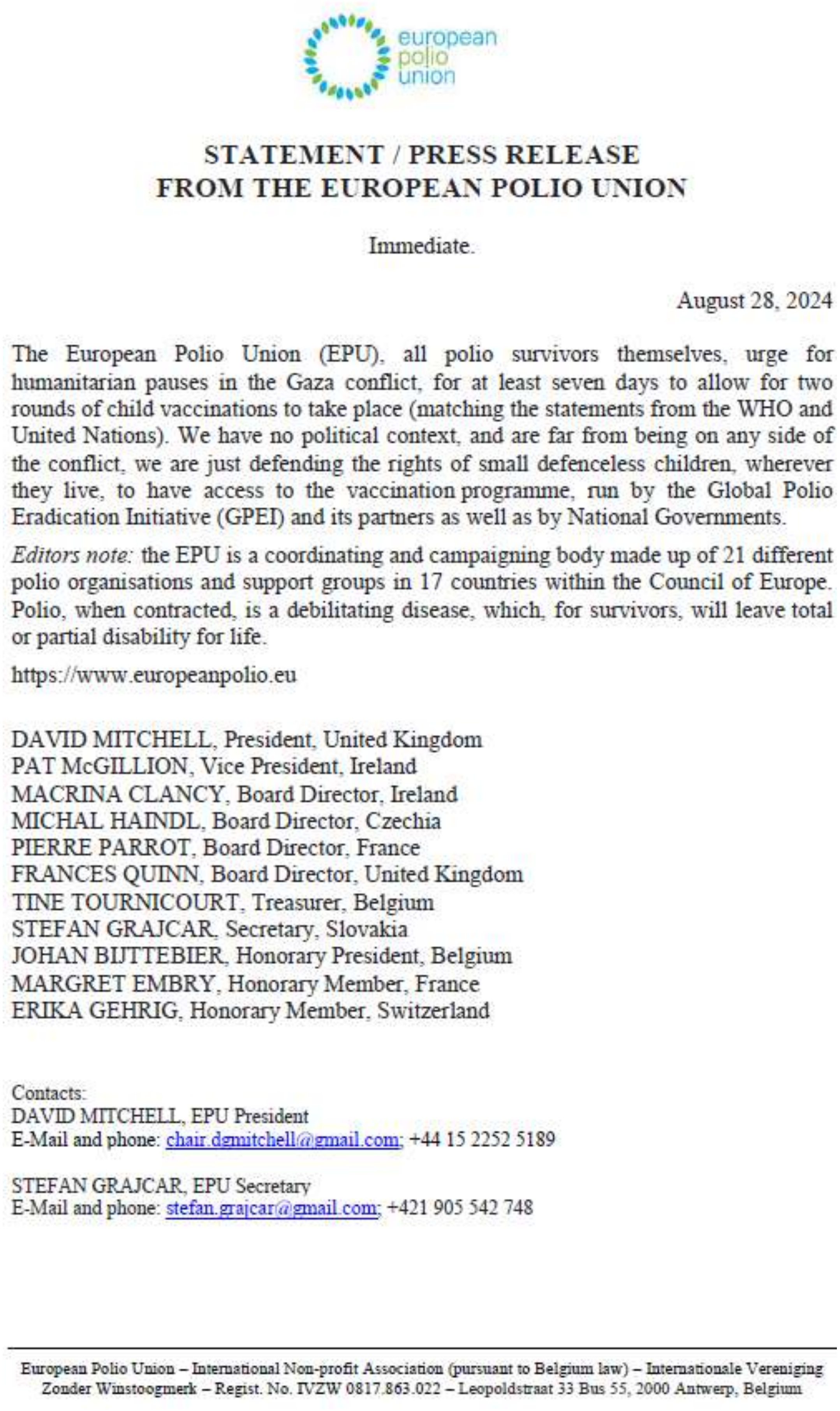
Find attached, please, our Statement / Press Release, which is the expression of our support to the Statements of the WHO and several other international organisations and authorities, and which is mainly supporting the right of all children, no matter where they live, to have access to polio vaccination programme.

This Statement / Press Release is sent out to all partners of the Global Polio Eradication Initiative, to signatories of the Statement / Press Release, and in a blind copy also to our medical experts, all member organisations and Honorary Members of the European Polio Union.

Feel free to use the attached text in communication with national governments, relevant ministries and authorities or to any other national or international organisations and institutions, press agencies to support our common effort for the call from the UN / WHO for a vaccination truce in the Gaza strip.

Thank you for your support and understanding,

DAVID MITCHELL, President, United Kingdom; PAT McGILLION, Vice President, Ireland; MACRINA CLANCY, Board Director, Ireland; MICHAL HAINDL, Board Director, Czechia; PIERRE PARROT, Board Director, France; FRANCES QUINN, Board Director, United Kingdom; TINE TOURNICOURT, Treasurer, Belgium; STEFAN GRAJCAR, Secretary, Slovakia; JOHAN BIJTTEBIER, Honorary President, Belgium; MARGRET EMBRY, Honorary Member, France; ERIKA GEHRIG, Honorary Member, Switzerland



STATEMENT / PRESS RELEASE
FROM THE EUROPEAN POLIO UNION

Immediate.

August 28, 2024

The European Polio Union (EPU), all polio survivors themselves, urge for humanitarian pauses in the Gaza conflict, for at least seven days to allow for two rounds of child vaccinations to take place (matching the statements from the WHO and United Nations). We have no political context, and are far from being on any side of the conflict, we are just defending the rights of small defenceless children, wherever they live, to have access to the vaccination programme, run by the Global Polio Eradication Initiative (GPEI) and its partners as well as by National Governments.

Editors note: the EPU is a coordinating and campaigning body made up of 21 different polio organisations and support groups in 17 countries within the Council of Europe. Polio, when contracted, is a debilitating disease, which, for survivors, will leave total or partial disability for life.

https://www.europeanpolio.eu

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REPORT FROM THE PRESIDENT OF THE EUROPEAN POLIO UNION OF THE AGM HELD AT THE NOVOTEL BUDAPEST DANUBE HOTEL

SATURDAY 25 MAY 2024

To an organisation like ours it is difficult to year after year organise and finance a worthwhile AGM and mini-conference due to aging, infirmity and travel problems; making the support of family, friends and carers vital. There are also the financial challenges and the regular financial support from EURORDIS is just fantastic. One of our aims is to try to support attendance from smaller member organisations often with aid from our own limited funds or from private members. Some member groups support their attendees but most delegates pay their own way. This year's gathering looked at one stage to be in doubt but due to the excellent organising of our Director/Secretary we managed to gather 36 attendees including all nine Directors and Daniel Koller from Germany who was voted onto the Board to replace long-serving member Paul Neuhaus who steps down after six years' service.

Our hotel, Novotel Budapest Danube, situated on the banks of the Danube opposite the stunning Parliament building was excellent with good rooms, good food and attentive staff with easy access to the conference rooms. Some guests, like myself, booked in for an extended period to sample the delights of Budapest. We started with a 'get together' dinner on the Friday night with official delegates from 13 member organisations, joined by Klára Schweitzer and her Hungarian members.

The AGM started on Saturday morning with an official welcome from myself at 9.00 am and we then paid homage to members who had died during the past year. Four member organisations sent apologies but the meeting was declared quorate.

The official business, see separate agenda, followed with members being reminded that the year's activities had been distributed via the President's Christmas message and the Annual Report. A vote of thanks was given to our Treasurer, Tine Tournicourt, from Belgium who presented our financial report for 2023 which showed a healthy balance. As indicated, the Directors do not claim any expenses and all of our nine Board Meetings have been by Zoom.

Macrina Clancy from Ireland gave a full explanation behind the revision and renewal of our Statutes and after many questions, these were voted on to be published in the Belgian Official Gazette. All eight Directors, candidates for their second or third period in service, were unanimously voted in; Daniel Koller for the first time and Pierre Parrot from France who replaced Robert Cordier, the organiser of the very successful 2023 Congress in Nancy, Northern France. These Directors will serve for another three-year term. Three proxy votes were received.

Voting cards were used throughout for the five main notions and resolutions. A presentation was made to Paul in appreciation of his service and congratulations all round for his forthcoming marriage. There then followed an Honorary Membership award to Klára Schweitzer for her work in keeping together the Hungarian polio group (Magyar Polio

Alapítvány). We also welcomed immediate past President, Gurli Nielsen from Denmark. There has not been a decision yet as to where to hold next year's AGM with Spain being mentioned and an appeal to member countries to promote themselves.

The AGM closed at 11.00 am and before lunch Cathy Davies from the University College of London gave an excellent talk about assessing the long-term effects of polio.

After lunch we had four presentations from Kripen Dhrona, aided by Director Frances Quinn (both from the British Polio Fellowship); from Pierre Parrot, Director (Polio France); Professor Michal Haindl, Director (Czech Polio Association), and Erika Viktoria Miszory, Heviz Spa, Hungary.

The final and very interesting session was compiled of brief, lively updates from all 13 delegate member organisations plus a letter from Spain with lots of questions and observations. All in all a good AGM with lots of participation and interest.

We finished the day with a dinner in the restaurant with much laughter and conviviality which sums up the polio spirit.

David Mitchell
EPU President
(British Polio Fellowship)

Lincoln, UK, June 19, 2024

THE EPU ANNUAL GENERAL MEETING 2025 IN BURGOS, SPAIN – THE FIRST ANNOUNCEMENT

Source: https://en.wikipedia.org/wiki/Burgos#/media/File:Braun_Burgos_UBHD.jpg

At the AGM in Budapest, on May 25th, 2024, it was proposed to organise our next Annual General Meeting in Burgos, Spain, in close cooperation with the University of Burgos and its Department of Polio and PPS set up just in autumn 2023. This Department is the very first one in Europe, and most probably also in the world, and it is absolutely unique.

During the last few months the EPU Board of Directors is intensively communicating with the University as well as with Spanish polio organisations, namely the *Euskadiko Polio Elkartea* (EPE) and just recently formed *Federación de Entidades de Polio y Síndrome Postpolio de España* (Federation of Polio and Post-Polio Syndrome Entities of Spain), to find the best solution for the venue of our AGM, the date, and also the programme of the whole event.

All information about the date, accommodation, venue, agenda of the AGM and the programme of the whole event will be sent to you in January 2025 at latest.

Source: By Jardoz - Own work, CC BY-SA 3.0; https://commons.wikimedia.org/w/index.php?curid=15795579

NEWS FROM EPU MEMBER ORGANISATIONS

BELGIUM

AccessAndGo-ABP asbl works on a daily basis to improve the accessibility of our society and provides a number of services aimed at helping people with reduced mobility at different stages of their lives.

Through our wide range of services, we work on a daily basis to improve the independence of people with disabilities:

- Organisation of leisure activities for groups and individuals
- Organisation of holiday camps for adults with motor disabilities
- Advice on home adaptations and technical aids
- Ergojob: adapting workstations
- Rental of an adapted vehicle (without driver)
- Allocation of adapted housing at the Cité de l'Amitié (Woluwe-Saint-Pierre)
- “Impulsion à l'Autonomie service”: this service was created to help people with physical disabilities in Brussels to regain their independence
- www.access-your-job.be is a website designed to support people with disabilities in Brussels who wish to become self-employed
- Management of the Personal Assistance Budget for people living in the Brussels-Capital Region
- Information:
  - about polio: in Belgium, there are still some 5,000 to 7,000 people suffering from polio. As a member of the EPU, we share our knowledge of polio and post-polio syndrome
  - About technical aids www.access-at.be
  - about services www.access-services.be

Would you like to find out more about our different services? www.accessandgo-abp.be
info@accessandgo-abp.be

Facebook : https://www.facebook.com/accessandgoabp
Instagram : https://www.instagram.com/accessandgo.abp/
LinkedIn: https://www.linkedin.com/company/accessandgoasbl

Daniel Peltzer, AccessAndGo,
EPU Honorary Member

In the forest to listen to the stag bellow during a group activity

Our director, Stéphanie Herman, defending the rights of people with disabilities

A day at the Louvain-la-Neuve Christmas Market

CZECHIA

New insights into post-polio syndrome inspired by cosmonauts or hibernators

Vladimír Vondrejs

A poliovirus infection damages or destroys many motor neurons in the human body. The remaining neurons grow bigger and sprout new axon endings during the next growing phase. This process promotes recovery of the muscular system, but it also may stress the nerve cell body. This stress may cause the gradual breakdown of the sprouted axon endings and, eventually, the overloaded neurons. “Neurons burnouts” are believed to be the leading cause of post-polio syndrome (PPS). PPS is a set of symptoms manifested by a significant decrease in the health status of the disabled person. It starts 30 to 40 years after the polio infection stage. As a result of the PPS discovery, it was necessary to change the strategies for treating the polio effects. The use of electrotherapy was discontinued. Movements against resistance and exercise to exhaustion were prohibited. Timely use of walking aids or various braces was recommended. Watchword: “The harder the training, the greater the improvement in physical condition“, was replaced by: “Enough rest for each day!“ Please note that all these changes are targeted against the exhaustion of overloaded neurons. It was expected that the down effect of these changes would reduce the delayed rapid decline in fitness within PPS.

The current progress of global vaccination against polio is fascinating, but it also has negative consequences: a) lack of interest in disabled polio survivors from the time before polio vaccination and b) premature attenuation of PPS research.

Fortunately, new knowledge about PPS comes from cosmonauts

It turned out that reduced gravity in space flights causes a decrease in the mass of cosmonauts´ muscles and the density of their bones. These phenomena accompanying load reduction of body mobility are also common in the life of all polio survivors, and they play an essential role in causes of decline in physical condition even before the onset of PPS. Because the polio survivors' difficulties are similar to the cosmonauts' problems. We will continue to use the term "cosmic" for their designation. This label will also help us distinguish between the two competing causes of delayed fitness decline, which shows up within PPS. "Cosmic difficulties" competes with the leading cause, which will be designated as "burnouts of neurons”.

Were the changes in therapy induced by the discovery of PPS optimal?

It follows from my experience and from the testimony of members of the Czech Polio Association that both mentioned types of causes of deterioration of physical condition showing a decrease of muscle and bone mass, often occurring in parallel to individual disabled persons. However, loss of bone mass (osteoporosis) is rarer and evolves more slowly. For now, it cannot be decided to what extent these causes are different or partially related in the details of their mechanism. However, it seems indisputable that in one characteristic, both causes differ. While „cosmic difficulties "appear (according to the experience of cosmonauts) reversible, "neuron burnout" is not one. It follows from that: *the therapy changes that occurred after discovering PPS were not optimal, because they were set appropriately only in favour of slowing down the "burnouts of neurons". To correct the changes, the suitable level of exercise load needs to be discovered. It has to limit the danger of "neurons burnouts" and also eliminate the "cosmic difficulties".* Another possibility is, of course, the search for still unknown medication and new procedures. Thanks to the global successes of vaccination, the research is not very supported because the results would serve only a few million polio survivors, mostly reaching retirement age. However, this opinion seems completely pointless. To support our statement, we will try to discuss both competing causes of the PPS mentioned above separately.

A new insight at the leading causes of decline in physical condition within PPS

"Burnout of the overloaded neurons": A heavy load on motor neurons occurs after some motor neurons have been inactivated by poliovirus. A partially destroyed nervous system cannot simply be repaired by replacing the damaged neurons with newborn cells of the same type, so a different remedy must be used. The surviving neurons become larger and enriched with a more significant number of axon endings, which is a step that allows fewer neurons to innervate more muscle fibres. This action is the basis of muscular function recovery and a source of improvement in physical condition, but also of an increase in the load on surviving neurons. This manifestation of the repair mechanism's imperfection is the source of the late "burnout of neurons" (1), which polioviruses have not killed at the beginning of infection. This circumstance suggests that infections with different neurotropic viruses could cause a similar collection of symptoms that are included in PPS. It does not have to be just existing viruses but also viruses that evolved in the future. Other neuron-killing factors may also start this recovery reaction. This reasoning is the seed of expectation that there is or will be a diagnosis similar to PPS, which can make many other people sick even at the time when there will be a worldwide removal of polioviruses completed.

"Cosmic difficulties": These problems of knowledge come from cosmonauts whose number is very small, but their contributions and importance are great. In addition, it is spreading around the world right now like a pandemic infection. We do not just mean a group of people who are confined to wheelchairs or beds because of accidents or some lingering illness, nor the disabled whose injuries were caused by the war. We believe that the pandemic of contagious immobility, accompanied often by excess weight and so-called civilization diseases, is the main danger to the future. We do not have statistics of phenomena providing these matters in individual countries of the world, but each of you can easily find such data to support the meaning that thorough research in this area will help not only those who suffer from PPS but also many inhabitants of this planet. It is even necessary to start the research as soon as possible, because the threat is rising quickly.

Further knowledge practical for solving PPS problems comes from hibernators

Surprisingly, hibernators wake up from winter sleep with very little atrophy, although muscle and bone mass loss is usually expected after prolonged periods of inactivity or starvation. Preservation of the skeletal muscles and resistance against starvation is combined with the down-regulation of glycolytic pathways and increased reliance on lipid metabolism. Furthermore, while protein synthesis rates are reduced during hibernation, balance is maintained by correspondingly low protein degradation rates. Maintenance of skeletal muscle strength and fatigue resistance enables hibernating animals to realize active behaviours such as predator avoidance or mating immediately following awakening in the spring.

These facts indicate that hibernating animals have unique properties, unlike humans (2), that would allow them, under certain circumstances, to undertake long-term journeys through space without worrying about losing muscle mass and without such great demands on the daily supply of food and drink. Human hibernation of this type is only a dream, which could become a reality later through genetic engineering. However, results from the last decade suggest that some lessons obtained from hibernators could be used much earlier. Primary consumers could be cosmonauts and other people who encounter the problem of muscle loss in their lives, mainly due to aging or lack of movement. Auspicious results from Regan´s laboratory, which observed urea nitrogen recycling via gut symbionts increase in hibernating ground squirrels over the winter fast, were published in 2022 (3). Regan et al. observed that squirrels break down proteins to produce urea, which is poisonous. Urea passes into their intestines where is converted into compounds that return to the bloodstream and are used again to build muscles. When animals are given antibiotics against intestinal bacteria, the mentioned recycling, which is most intense at the end of winter before awakening, stops. These findings suggest that if people with „cosmic difficulties“ use capsules with suitable bacteria, their muscle wasting could be suppressed. Unsurprisingly, even NASA agency is very interested in this research.

Dear attentive readers, you must have understood that even if everything went well and such miracle pills were already produced for those who are suffering the consequences, it would not probably help them because it is a preventive measure.

Recommended papers:

(1) Vondrejs, V.: Vesmír 100(151), 770-772, 2021
(2) Cotton, C. J.: J. Exp. Biol. 219, 226-234, 2016 (review).
(3) Regan, MD at al.: Science 375(6579), 460-463, 2022

Associate Professor RNDr. Vladimír Vondrejs, CSc. (*1937) studied chemistry at the Faculty of Science, Charles University in Prague. He introduced or co-introduced the teaching of molecular biology at several universities in the Czech Republic and Slovakia. At the Faculty of Science and Technology he introduced teaching and was the first to conduct research in the field of non-traditional methods of genetics, induced fusion of protoplasts and especially genetic engineering in microorganisms. Gradually, he devoted himself to cell cycle research, development of gene modification methods and DNA repair in microorganisms. In his spare time, he is very passionate about painting and sculpturing.

Vladimir Vondrejs is a polio survivor and a member of the Czech Polio Association.

DENMARK

POLIOFORENINGEN

News from PolioForeningen Denmark

In September and October 2024 PolioForeningen arranged an event for our polio members at six different venues in Denmark. The arrangements were a combination of an online webinar with an occupational therapist and a psychologist from our Special Hospital and a physical meeting for our polio members where we watched the webinar together. The topic was fatigue – a definition of fatigue and how to cope. The experts described the physical, psychological and social factors that might play a role in the polio survivors' experience of fatigue. They also talked about identity, values, management of energy and stress.

After the presentation we had a good lunch, and then the psychologist came online to answer questions from the participants. We ended the event with coffee and plenty of time for sharing experiences and memories.

As our polio members no longer have the energy and resources for long distances, we decided to hold the same event six places in Denmark – 2 events on Zealand, 1 on Funen, and 3 in Jutland. Unfortunately we had to cancel one event on Zealand and one in Jutland due to too few participants, but the other 4 events were held with great success. Approximate 100 polio survivors participated, and they expressed their gratitude that we had arranged the events locally.

PolioForeningen will also in future arrange similar events, as our polio members want us to do so. It makes good sense to combine a webinar and a physical meeting.

Nordic cooperation meeting in Gothenburg

Representatives from LFPS Norway, RTP Sweden and PolioForeningen Denmark had a meeting in Gothenburg Sweden on the 5.-6. September 2024. The meeting was arranged by RTP and funded by Nordic Welfare Organisation. During the meeting each organization had arranged a presentation. From Norway Lillian Festvåg, Sunnaas Rehabilitation Hospital had a presentation about a survey on Polio and Post Polio Syndrome in non-Western immigrants: a New Challenge for the Health Care System in Norway. From Sweden was a presentation by Åsa Jidhage, Högsbo Sahlgrenska Universitetshospital about national highly specialized care of post polio syndrome in Sweden. From Denmark a psychologist from Special Hospitalet in Copenhagen gave a presentation of the psychological aspects of polio survivors suffering from post polio syndrome.

We all find our Nordic meetings very fruitful, and we are planning a new meeting in Copenhagen next year.

Gurli Nielsen – PolioForeningen Denmark,
EPU Honorary Member

HUNGARY

Magyar Polio Alapítvány

My name is Klara Schweitzer and I would like to inform you about some events organized by the Hungarian Polio Foundation during this year, after the spring eddition of the EPU Newsletter.

First and foremost, our Foundation became the full member of the EPU, thanks to Mr. David Mitchell, EPU President and a financial sponsor who we do not know. We were extremely happy and we cannot thank them enough for their help.

One of the most important events was the EPU AGM in Budapest at Hotel Novotel on 24-26 of May, 2024. 36 people from 13 countries participated in the meeting and we were happy to be the hosts of this event. There were some Hungarian guests invited to the meeting by the EPU and we were busy with the translation of several presentations into Hungarian so that they could understand what was going on. We could listen to interesting presentations in different subjects, and we were proud of the Hungarian physiotherapist Dr. Erika Miszory who gave a presentation in English with the title of Poliomyelitis in Hungary. As she works in the Rehabilitation Institute in Hévíz, which is nearly the only institution dealing with polio patients (about 10-12 persons every month), she knows a lot about us, polio patients. In her lecture she presented our polio status, spoke about the treatments we get and of course, about the curing effects of the world famous Hévíz lake medicinal water.

I was really surprised when Mr. David Mitchell, EPU President, called my name and handed me a document, namely an EPU Honorary Membership Certificate. So on 24th May 2024 I became an Honorary Member of the European Polio Union. I was so awe-struck that I could hardly say anything. I highly appreciate this privilege and I feel really thankful for it. I would never have thought that anything like that can ever happen in my life.

In June we got a phone call from Rotary Club Hungary that they would like to invite us to a meeting in order to hand us over a certificate about Paul Harris Fellow Prize. I think the last year I have written about our Polio Day gathering in October, when we collected 100.000 Forints for polio eradication. We transferred this money to Rotary End Polio Now programme and we got the possibility to hand over the proof of the money transfer personally to Rotary last November. Mr. Herbert Ederer, a former Austrian Rotary governor saw us (Tamás Kertész, President of the Foundation and me) and he was so moved by our donation, considering that it came from a group of polio patients who themselves have low income, that he decided to recommend us for this Paul Harris Fellow international Rotary Prize. A lot of famous people received it, who donated a lot of money to Rotary. For example Jimmy Carter, American President, Boris Yeltsin, Russian president, James Lowell, American astronaut, Jonas Salk, the inventor of polio vaccine and so on. We were proud of our community and when I thanked for the Fellow I emphasized that the honour belongs to all the people who donated the money, we are only a part of this polio community who got the possibility to forward it.

On 26th October we had a very successful reunion with more than 60 polio patients, some invited guests and relatives and we had a superb programme. We managed to invite a 2-persons-team, a doctor and an assistant nurse, from the National Korányi Pulmonology Institute to carry out breathing function tests (spirometry) of the whole group. They were kind and worked from 10 in the morning to 6 in the afternoon to finish this job. The result was surprising even for them. 70% of the tests were normal or even very good, only 30 % of patients got worse results.

The programme started with little schoolgirls, presenting an acrobatic dance programme. Everyone loved them, they were clever and cute.

We invited also a world famous jazz singer – niece of one of us – Veronica Harcsa who gave her first concert for us after having her baby in June this year. She thanked for this possibility and was moved to sing again in front of an audience. She is a lovely person and a brilliant singer.

After her production I reported about the job of our Foundation during the past year. Then my daughter arrived, who is a physiotherapist and we had to move a bit doing exercises sitting on our chairs or wheelchairs. Dr. Nora Schweitzer was the author of the book Polio 2.0 which was published in 2016. Now she announced that in some weeks it will be available on the internet as all printed copies are sold out.

We got a lovely and healthy lunch and then we were enchanted by the production of a well-known (in Hungary) catholic priest and a mental health professional in one person Ferenc Pál. He is famous for his shows in different topics, all concerning mental health or psychology. He spoke about helping both ourselves and other people. The performance fitted to our situation and it was encouraging and informative. Our friends said it was superb. After the show we could talk to him and he was really nice, helpful and like an energy bomb.

We had a wonderful day with our friends and we said good bye to each other saying “See you next year at the same place!”

Klára Schweitzer, Hungarian Polio Foundation Board Member, & EPU Honorary Member

Dr. Nóra Schweitzer, physioterapist

Veronika Harcsa, jazz singer

Pál Ferenc catholic priest and a mental health professional

IRELAND

World Polio Day at the Irish Parliament

Ahead of World Polio Day, Polio Survivors Ireland was invited by Senator Mary Seery-Kearney to present to members of the Oireachtas (our parliament) at Leinster House on the 23rd October. Our panel included Dr. Deirdre Murray, who discussed the physiotherapy needs of polio survivors; Siobhan Banville, Polio Survivors Ireland’s Research Officer, who shared new research insights; and Johnny O’Sullivan, a polio survivor, who spoke about the challenges he faces as he ages. Polio survivor and former Senator, John Dolan, facilitated the presentation and spoke about his own experiences as retired CEO of the Disability Federation of Ireland.

Throughout the event, Polio Survivors Ireland highlighted our recent pre-Budget submission. We have called on the Government to address the eligibility criteria for the Medical Card (which entitles holders to free medical care) means testing process to reflect recent increases in Social Welfare payments. These modest income rises could lead to polio survivors losing their Medical Cards. We have also urged the government to address the inequity faced by polio survivors when they reach retirement age and are moved from disability benefits to State Pension. This transition results in the loss of vital cost-of-disability payments and erases their disability status. Additionally, we asked the Department of Health to address the serious inadequacy of available physiotherapy. It is essential for managing the long-term effects of polio, but it must be tailored to each individual to minimise adverse effects.

In media activity for World Polio Day, we reminded the government to not leave polio survivors behind. As a majority ageing population, polio survivors continue to live with the lifelong impact of a childhood disease. The significant health inequalities that result must be addressed.

By Lauren Kavenagh, Polio Survivors Ireland Intern

NETHERLANDS

SPIERZIEKTEN
NEDERLAND

On Friday June 28 2024 Frans Nollet, EPU Honorary Member, ended his working life with a day-symposium and a farewell speech.

(Impression of the day by Els Symons, EPU Honorary Member)

The symposium was held in the Amsterdam Medical Centre where Frans Nollet worked most of his professional life, as a rehabilitation doctor and as head of the department of rehabilitation medicine.

The lectures offered an in-depth insight into the complex world of muscle diseases, with special attention to polio and post-polio syndrome. This event was extra special, because it was organised in honour of the farewell of a pioneer in this field, prof. dr. Frans Nollet. Various experts gave their views on this condition and shared their knowledge, research results and experience. In doing so, they also put Frans in the spotlight. In addition to Frans and his family, both experts and patients were present in the well-filled lecture hall.

A recurring theme was the multidisciplinary approach. Not only the medical aspects were looked at, but also the social and psychological impact of this condition on patients.

One of the most impressive presentations was that of Frans Nollet himself. His dedication and passion for the subject were clearly visible. He discussed the historical context of polio, the fight against the polio disease worldwide, and the enduring challenges associated with post-polio syndrome. His knowledge and years of experience gave us a unique perspective on the progress that has been made and the obstacles that still need to be overcome.

A special moment during the symposium was the speech by the chairman of our Postpolio Syndrome (PPS) working group, Theo Martens. He praised Frans Nollet not only for his scientific contributions, but also for his ability to include the working group as a valuable contributor in his work. Theo emphasised how Frans always had an eye for the person behind the patient, and how he took the input and experience of the working group seriously and integrated it into his approach.

After the symposium Nollet gave his official university farewell speech (valedictory lecture).

The speech was held in a beautiful church building in the centre of Amsterdam. It was quite official with lots of university professors in their black robes. Also there were a lot of other medical professionals, friends and family. And off course the members of the postpolio patient group.

The title of his speech was: “**Rehabilitation, a master word in medicine?”**

It was an impressive speech, followed by a well-deserved applause.

What distinguishes Frans Nollet is his tireless commitment to always put the patient at the center. He emphasised again and again during his farewell speech that the needs and well-being of the patient must be paramount in every decision. During his career, this regularly led to struggles with health insurers, who often questioned his medical advice and recommendations. Despite the extensive justification he gave of the necessity of certain aids for the patient, he often had to face opposition from health insurers. Yet he remained determined and combative, always fighting for what was best for his patients.

During his speech, Nollet gave some examples to illustrate his points. For example, he spoke about a patient who urgently needed an advanced orthotic device, but had to wait months for approval from the health insurer. The response from the health insurer was: 'Why a Mercedes when the patient also advances in a Trabant?'

Another example concerned a patient who benefited from specific physiotherapy, in which it had to be proven again and again that this therapy was necessary. These personal stories made it clear how bureaucratic obstacles can affect the quality of life of patients. It was intense to hear these stories and I was touched by them. It emphasised the need for compassion and understanding in the provision of care.

Frans named the fundamental goal of rehabilitation medicine: to improve the functioning of people, their participation in society and their well-being and quality of life. He emphasised that good tools and psychological help are central to this. Again, the patient always comes first, followed by the doctor and the caregiver. The patient is in control, not the other way around.

Many conditions cannot be prevented or cured. It is therefore crucial that an interdisciplinary team makes every effort to make the patient's life more bearable. The collaboration between doctors, therapists, nurses and other healthcare providers ensures that patients receive the best possible care, tailored to their individual needs and circumstances.

Royal award

An unforgettable moment was that after his farewell speech, the deputy mayor of Amsterdam decorated Frans with a Royal award. This recognition for his years of commitment and dedication to the field was a wonderful tribute to him.

We will miss Frans dearly.

Providing care and providing medical help is an art, and Frans Nollet is an expert in this. His ability to combine science, empathy and perseverance makes him a true artist in his field. He has shown that the essence of good care lies in seeing the person behind the patient, understanding their unique needs and fighting for their well-being, regardless of the obstacles.

The farewell of Frans was an emotional moment. His contributions to the field of polio and post-polio syndrome are invaluable. He has not only contributed to scientific research, but also helped countless patients achieve a better quality of life. He has inspired many colleagues and students.

NORWAY

LFPS
Landsforeningen
for Polioskadde

Unfortunately, I have not had the opportunity to participate in EPU's meetings. It has been a bit difficult when you are a wheelchair user, and also a bit expensive.

Here in Norway, we still have a fairly active association. We work hard to maintain good rights for our members with polio. In particular, we are concerned with opportunities for rehabilitation and training. This has deteriorated in recent years. We are also concerned that disabled people should have good financial living conditions. Unfortunately, we see that co-payments in connection with illness are increasing, while pensions are falling. We also have active Nordic co-operation with a joint meeting in Gothenburg in September 2024.

SLOVAKIA

Asociácia polio v SR

republiková špecifická organizácia SZTP

Exceptional visit of the US Ambassador to Slovakia with Slovak polio survivors

This year's annual weekend meeting of the Slovak Polio Association in Trenčianske Teplice was enriched by an exceptional visit – on Friday, May 3rd, we welcomed the US Ambassador to Slovakia, Mr. Gautam A. Rana who has been in Slovakia since September 2022. He has been affected by polio since his early childhood, and it was very kind of him to find time for us, members of the SPA, during his visit to Trenčianske Teplice and official meetings with local authorities. After a short introduction in which the ambassador introduced himself, we had a chance for a short discussion with him.

Members of our Association spontaneously and very naturally captured our childhood years, when we used to meet in various facilities as patients, polio survivors. We recalled how we were socialised, rehabilitated, but also how we experienced various funny or sometimes serious situations. His Excellency was not so lucky to have such experiences, but he shared with us a few pearls from his life as a politician, diplomat and a polio survivor.

We presented him our activities not only in the domestic field of the world of people with disabilities, but especially our activities within the European Polio Union and other international relations.

The Ambassador found this short discussion with a group of Slovak polio survivors as very interesting and beneficial. He learned about our rich experience with this disease, which has affected also his own life.

His Excellency Gautam A. Rana, US Ambassador to Slovakia

Slovak polio survivors in a discussion with US Ambasador Gautam A. Rana to Slovakia in Trencianske Teplice

Mária Mruzková, member of the Czech and Slovak Polio Associations

CZ & SK District Conference of Rotary International in Bratislava

Just a few days later, on May 17-18, there was a District Conference of Rotary International, District 2240 for Czech Republic and Slovak Republic in Bratislava, which was very special this years due to the personal presence of incoming Rotary International President Stephanie A. Urchick from the USA (BTW, her grandmother was born in eastern Slovakia).

Štefan Grajcár greeted the RI Conference participants on behalf of the Slovak Polio Association, as well as of all polio survivors, and here are the words he addressed to the audience:

“I am honoured to speak to you on behalf of the Slovak Polio Association of the Slovak Republic, a civic association representing people who contracted polio in early childhood many decades ago.

Rotary International is one of the largest and oldest club organizations in the world. The mission of Rotary International, as stated on your website, is 'to provide service to others, promote integrity, and advance world understanding, goodwill, and peace through a community of business, professional, and community leaders'.

Polio eradication has long been one of Rotary International's priority programs for nearly 40 years, since 1985, three years later, in 1988, Rotary International became a part of the GLOBAL POLIO ERADICATION INITIATIVE - a joint initiative with five other partner organizations – the World Health Organization, the United Nations Children's Fund, the US Centers for Disease Control and Prevention, the Bill and Melinda Gates Foundation and Gavi, the Vaccine Alliance – whose ultimate goal is the eradication of polio worldwide and which, according to a strategy announced in 1985 and updated in 2021, would be to eradicate polio in the world by 2026. Since 1988, this global initiative has achieved an incredible reduction in the incidence of new polio cases to a few tens to hundreds per year, with only Afghanistan and Pakistan being the last two countries where polio is endemic.

Behind these results is also Rotary International, the long-standing activities of hundreds of its districts, thousands of clubs and hundreds of thousands of its individual members, including of course those in the Czech Republic and the Slovak Republic – thanks to you and to us, living polio survivors not only in our country, but all over the world, people who were not lucky enough to get an effective vaccine in time.

We are an association that is one of the few that paradoxically enjoys the fact that we are not gaining new members – we are glad that this is the case, and we hope that thanks to the vaccination programme supported also by Rotary International, it will remain so.

In addition to a big THANK YOU, let me conclude by expressing our wish that Rotary International, in addition to its other important activities, will not forget us, the living polio survivors, even after achieving the stated goal of the final polio eradication. We are somewhat of a forgotten patient group, we are faced with the ignorance of medical people about our diagnosis and the nature of the health problems that most of us currently have, especially in the form of the late effects of poliomyelitis, including post poliomyelitic syndrome, and this ignorance is really not helping us at all.

The motto of polio survivors around the world is POLIO IS DEAD BUT WE ARE STILL HERE – we would be very grateful if you would give us some of your attention and if we can continue to be part of your world, here at home and everywhere in the world.

Thank you for your attention.”

Štefan Grajcár, Slovak Polio Association,
EPU Board Director

SPAIN

ASOCIACIÓN
AFECTADOS DE POLIO Y SÍNDROME POST-POLIO
www.postpolioinfor.org
informacion@postpolioinfor.org
Tel. 686 000 171

We continue to do our daily work and we also have to say:

One of the most important questions in Post-Polio Syndrome (PPS) is why we have no answers.

We do not know what the real cause of PPS is, although there are indications from many years ago.

We need continuous research in time, coordinated, courageous, solidarity and some should not be so linked to money and if to show it, to the pharmaceutical industry it would have always been a great business, the millions of people in the world, who would receive, if there was a treatment or cure for PPS.

In these circumstances, who understands the industry's lack of interest in investigating and finding solutions for post-polio syndrome?

There are no treatments that cure or stop PPS. Is there more than one PPS? In our opinion yes.

The European Union should have initiated years ago, a joint and effective action, to help those affected by PPS in the scientific and social field, but this has not occurred, although have existed attempts since the 1990s.

We think that Europe does not have a project for the PPS and is limited to following the USA, which we all know how it is.

Unfortunately there are people who work in the confusion, hide what happened in the past and alter what the PPS consists of. Prejudices, discrimination can be appreciated, in our opinion they have violated our human rights.

Time passes and they have robbed us of a better future. Very few people are interested in continuing to survive, but we are very grateful to those who fight for our lives, health, until the last day of their lives, as we will do.

In spite of everything, we must continue fighting, being strong and trusting in the possibilities of human beings and science.

Lola Corrales
President

SPAIN

EPE-Euskadiko Polio Elkartea

My view on the Polio and PPS situation in the Basque Country and the rest of Spain

European Polio Union, asked me to write an article about the situation of Polio/PPS and Polio Survivors in Spain for their Newsletter. I thought I would start with a part of the foreword written by Dr. Juan Antonio Rodríguez-Sanchez in the book ‘Sueños de Escayola’, written by fellow Polio Survivor José Vicente García, which expresses very well the past and present of Polio/PPS Survivors in Spain.

> *… Pero quedaban décadas de activismo, de lucha continua para que el concepto de “diversidad funcional” comenzase a fluir por los resecos cauces de la sensibilidad institucional. Pocos colectivos podrían ejemplarizar mejor que aquellos “niños de la polio”, el concepto de resiliencia, esa capacidad para crecer desde la adversidad. …Esta ha sido también la trampa: en su lucha para conseguir que se asumiese un modelo social de discapacidad, el colectivo perdió el nombre y sin él la sociedad olvidó bien pronto la poliomielitis. Un olvido obstinado, un rechazo al recuerdo, incluso una negación de la memoria: una resistencia a asumir responsabilidades, a reconocer errores y a entender que muchas de las personas que sufrieron la poliomielitis fueron víctimas de decisiones sanitarias inadecuadas, pese a lo cual siguen vivas y se enfrentan a un problema denominado Síndrome Post-polio. Ya no son “pobres niños” que despierten compasión, sino adultos que hablan de injusticia porque no hallan proporcionalidad entre el esfuerzo realizado para responder a lo que la sociedad les exigía para integrarse y el desinterés y olvido que ahora reciben a cambio*[1]

As founder and member of the Polio Association of the Basque Country, EPE-Euskadiko Polio Elkartea (I will call it EPE from now on), I will start with its presentation. EPE started its activity in Bilbao on 2014-11-22, and it was as a consequence of the ‘denial of the PPS’ by the Basque Autonomous and Spanish National Health Institutions, and the ‘negative discrimination’, caused by this denial in the disability assessments and consequently in the application of social policies of the Basque Provincial Institutions and the Spanish National Institutions.

In 2000, with two Polio/S entities present, the Spanish National Health Institutions took the disastrous decision not to consider PPS as one of the diseases for the National Plan for

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[1] *But there were still decades of activism, of continuous struggle for the concept of ‘functional diversity’ to begin to flow through the parched channels of institutional sensitivity. Few groups could exemplify better than those ‘polio children’ the concept of resilience, that capacity to grow from adversity. ...This has also been the trap: in their struggle to achieve a social model of disability, the group lost its name and without it, society soon forgot polio. A stubborn forgetting, a refusal to remember, even a denial of memory: a reluctance to take responsibility, to acknowledge mistakes and to understand that many of those who suffered from polio were victims of inadequate health decisions, despite which they are still alive and face a problem called post-polio syndrome. They are no longer ‘poor children’ who arouse compassion, but adults who speak of injustice because they do not find proportionality between the effort made to respond to what society demanded of them in order to integrate and the disinterest and neglect they now receive in return. (Translation: deepl.com)*

Neurological Diseases, and later for the National Plan for Neuromuscular Diseases. Even so, despising the Polio/PPS Entities present there, the National Health Institutions of Spain took the disastrous decision not to take into account PPS as one of the diseases for the National Plan for Neurological Diseases, and later for the National Plan for Neuromuscular Diseases. That is where it all started against PPS, and it is still going on 24 years later. 24 years ago, PPS was known in Spain, but 'someone' decided that it was not worth allocating resources for its treatment.

The Spanish Polio/PPS associations have been fighting for 24 years, EPE joined them 10 years ago. But after these 10 years of EPE's fight against denialism and negative discrimination and after having succeeded:

- that the PPS will be known and recognised as of 2019
- that there is a Law of Memory, both in the Basque Country and in Spain, which RECOGNISES (but without REPARATION), the damage caused by the Franco Dictatorship to the Victims of Polio between 1939-1978 in all of Spain. This aspect is important to seek understanding and support in society and for the Institutions to assume their subsidiary responsibility, as we did not have to suffer Polio and not now suffer the PPS and suffer a disability.
- that the eleventh Additional Provision of the Law of Memory states that the Government will offer health and social measures to improve the Quality of Life and that a person with Polio/PPS, from the Federation is on the working commission studying the issue, although the work has begun two years late.
- that the Federation of Polio and PPS Organisations 'PolioEspaña' has been set up, which EPE has worked hard to create.
- that EPE members with PPS have shown solidarity by offering blood samples to the Biobank of Bilbao for PPS research.
- that there is a Polio Chair in Spain, in which EPE had a role in this
- that EPE collaborated with ROTARY and EPU to organise a European Congress on PPS in the capital of the Basque Autonomous Community, Vitoria-Gasteiz, and that COVID aborted it.
- that the next General Assembly of EPU will be held in Spain, for the first time.
- …

we continue to suffer from PPS denialism, but now by avoiding testing. In addition, negative discrimination continues, as the effects of the PPS in the assessment of the degree of disability are still not recognised.

In the Basque Country and Spain there is no integral public health care for Polio Survivors with PPS and the aid for People with Disabilities does not take into account the effects and consequences of PPS. We are the same as 24 years ago, it has all been a failure.

In short, everything seems to indicate that there is a 'hidden' order, to do nothing, waiting for the Polio Survivors to disappear and with them the Polio/PPS problem in Spain to end.

Thus, the Surviving Polio Victims of the Basque Country and Spain:

- They have been Victims of a Dictatorship, when we were children, there was “abuse of power; censorship and lies; false account; omissions and neglect of their duties consciously and voluntarily” instead of “preventing and vaccinating”.
- We are Victims of Democracy, now that we are adults and grandparents, because of its fear of disclosing the truth, especially about Franco's Eugenics, its reluctance to assume its responsibility (it was not us) and its hypocrisy (recognising, but not making reparations and not wanting to allocate the necessary resources).
- We will be Victims of Neoliberalism, in Spain and the European Union, now of grandparents, as a consequence of its expansion in the European Union, and which will affect all People with Disabilities, through the application of ableism and biopolitical policies.
- We will be Victims of Neo-Francoism, in Spain, now of grandparents, that when they reach power together with the Neoliberals, there will be censorship, oblivion, a false narrative, punishment and stigma.

All the suffering we and our families went through as children is now being repeated as grandparents for us and our families. It's like going back to the beginning.

Faced with this situation, it is not surprising that no member of EPE, has wanted to take on the management responsibilities of EPE. Unfortunately, after 10 years, on 2024-10-18, in Eibar, the decision was taken to dissolve the Association. We have been naive in believing that the Christian-Democratic and Social-Democratic government, with a majority, would understand us and assume its subsidiary responsibilities with health and social measures, an error. We have been defeated.

What next? I hope:

- That the Polio Victims Survivors of the Basque Country, who want to continue fighting for their rights and human rights, will be able to find a place in the Federation of Polio and PPS Organisations of Spain, among other Organisations.
- That the Federation ‘PolioEspaña’ achieves that throughout Spain, there is a comprehensive public health care for Polio/PPS and that aids are implemented to improve the Quality of Life of all Polio Survivors.
- That the people affected by Polio in Spain, during the dictatorship, be Recognised by the Institutions of the European Union and the United Nations as Victims of the Franco Dictatorship with the right to Reparation.
- That the next EPU Newsletter, will announce:
    - ➢ That all Polio Survivors in Europe, receive comprehensive health care and support to improve their Quality of Life.
    - ➢ That there should be a European network of laboratories researching PPS.
    - ➢ That the European Union, has put the brakes on the ableism building and biopolitics, that were intended to destroy a Humanist and Social Europe, and has opted for increased social policies.
    - ➢ That polio has been eradicated in the world

My thanks to all EPE-Euskadiko Polio Elkartea partners, good luck and my support to the PolioEspaña Federation and EPU – European Polio Union.

Best regards,

Mario Feijóo Anakabe
Polio Survivor Victim with Disability
Founder and Former-President of the Polio Association of the Basque Country,
EPE-Euskadiko Polio Elkartea

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SPAIN

Federación de Entidades de
Polio y Síndrome Postpolio de España
PolioEspaña
G19356781

Introducing Spain's New Polio Federation

In July 2024, the **Federación de Entidades de Polio y Síndrome Postpolio de España** was officially launched. Formed by eight founding associations, our federation unites polio survivors across Spain with a shared mission to advocate for their needs and build a strong, supportive community. We look forward to connecting with organizations like the European Polio Union to strengthen our efforts and explore ways to collaborate in the future.

Contact Information:

Website: https://sites.google.com/view/polioespana/inicio **Email**: fepolioyspp@gmail.com

Phone: +34656946232

Contact Person: Concepción García-Antón Trassierra

Social Media:

Facebook: https://www.facebook.com/profile.php?id=61564632504223

Instagram: https://www.instagram.com/federacionpoliospain/

X (Twitter): https://x.com/polioespana

Associats de Pòlio i Postpòlio de Catalunya, APPCAT; Mesa de Trabajo de Afectados por Poliomielitis y Síndrome Postpolio de España, MAPPE; EPE-Euskadiko Polio Elkartea; Asociación Cordobesa de Polio y Postpolio, ACOPyPOS; Asociación Malagueña de Afectados Polio y Postpolio, AMAPyP; Associació de Polio i Síndrome Postpolio Comunitat Valenciana, APIPCV; Asociación de Post-Polio y Discapacidad de Cádiz, APODI; Alianza por la polio - postpolio en Andalucía, APPA

SWITZERLAND

ASPr-SVG | Polio.ch

Programme 2024 for Polio and Post Polio survivors in Switzerland

Exercise and Movement in warm Water, April 2024 Kerenzerberg (Glarus). This course is appreciated by our Polios.

Breathing weeks for Polio and Post Polio survivors in Walchwil on the lake of Zug. In April 2024.

Mandala and Art course in Interlaken for Polio and Polio Survivors in May 2024. This course is well liked by our Polios.

A SIPS Day in Berne. Seminary organized by SIPS and Thomas Lehmann.

Reduce suffering through Knowledge. This course was fully booked and was appreciated by our members.

SIPS Day in Pomy for our French speaking members. Orthopedic intervention and support aids.

Swimming week for Polio and Post Polio Survivors in Leukerbad. Thermal Water. After the epidemic many Polios Survivors went there and stayed at the Polio Clinic. Unfortunately it is closed now for Polios and you have to go privately.

A Sips Day in Reinach /Basle Orthopedic intervention and support aids. Thomas Lehmann was present and held a speech regarding Orthopedic intervention and support aids. After lunch Professor Dr. R. Schlaeger at the University Hospital and University Basle explained what they are doing at both places in Basle. They are looking for test persons with Polio and Post-Polio-Syndrome. The tests will take place at the University Hospital in Basle. The study lasts for about 4 hours and expenses of CHF 400,- will be paid. An MRI of the brain and spine will be done. The muscle strength of the muscles will be measured. Some electrophysiological tests will be done as well. After finalizing the studies, we will be informed with the results.

Swimming Course in Näfels GL will be held in German and French. 5 days in September

SIPS Day in Zurich Mattenhof, orthopedic intervention and support aids. Thomas Lehmann spoke about Polio and PPS. A specialist from the orthopedic clinic Balgrist Zurich explained about support and the various aids. She spoke to several polios and gave advice. She told me to apply tapes to my shoulders to support them for the many transfers I do during the day. She gave advice about shoes, crutches, etc. Date: 28th September 2024.

SIPS Day in Hinterkappelen/Berne with orthopedic intervention and support aids. Thomas Lehmann spoke about Polio and Post-Polio and an assistant Doctor from the Clinic Sonnenhof in Berne. Three of our members informed me that they already got a date for an appointment at the Praxis of this Doctor. It took place on the 19th October 2024.

That is what we need, Doctors who know about Polio and Post-Polio-Syndrome. I had a talk with two experts from WHO Geneva and they know that this is a problem finding Doctors in Switzerland with knowledge about Polio and PPS.

In our Sunday Press certain articles will be published about Polio, Post-Polio, vaccines, etc., all in honour of World Polio Day 2024. We always celebrate it from 24 – 28th October every year.

Sing and Music course together with breathing and movemets of our arms and hands took place last week in the morning. After a coffee break we started a brain jogging course with a trained expert. It was nice to see old polio friends from all over the German part of Switzerland. The course took place in the Hotel Artos in Interlaken. It is very well equipped for handicapped people.

Nice Christmas Holidays from 23rd December to 2nd January 2025 for members who are lonely.

Best regards, to all of you,

Erika Gehrig
President of SIPS
Schweizerische Interessengemeinschaft für das Post-Polio-Syndrom

UNITED KINGDOM

BPF website is accessible - www.britishpolio.org.uk

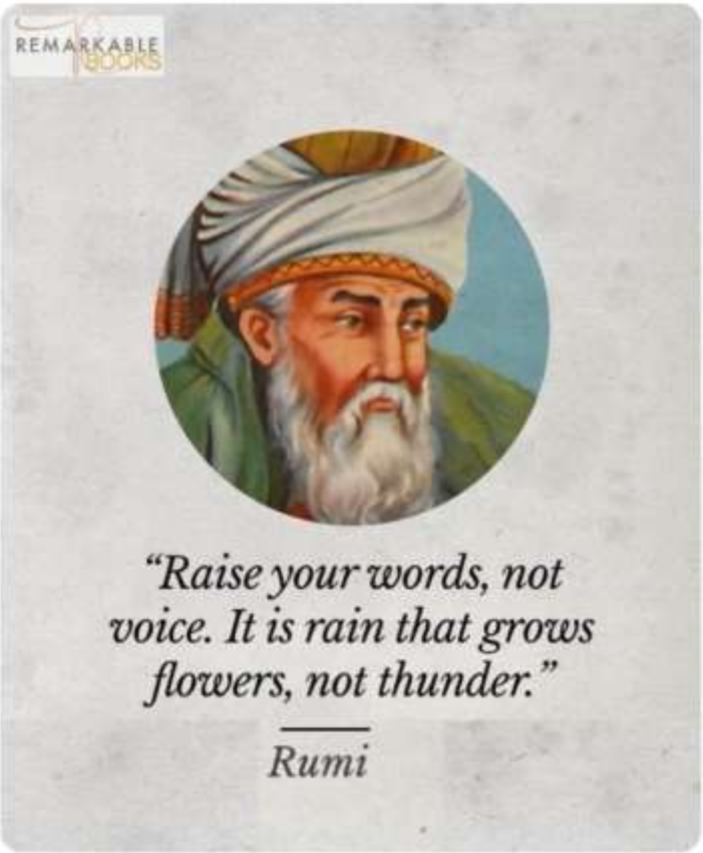
Communicating with polio survivors and all affected by polio continues to be a crucial cornerstone of our work. We communicate with members through various ways, such as The Bulletin (quarterly member magazine) , monthly members update emails, at events etc, but a key communications tool is our website. *The website is open to all in the polio community, regardless of your status as a member or where you are in the world.*

However we were very keen to ensure that our website was open and easy to you use by everyone, so earlier this year, The British Polio Fellowship website www.britishpolio.org.uk launched a new toolbar to make it more accessible and inclusive for visitors. The toolbar can be switched on or off by selecting the *Accessible Tools* button found in the top right corner.

Click here to access the tool

You should try it. There are a range of functions to allow you to use it to:

- have the text on our website read aloud (including PDFs).
- download the text as an MP3 file, to play where and when it suits you.
- change font sizes and colours.
- customise background colour.
- translate text into more than 100 different languages.
- access a fully integrated dictionary and thesaurus.



Source: LinkedIn, 19. 9. 2024; https://www.linkedin.com/in/manousos-maropakis

IN MEMORY OF THOSE WHO PASSED AWAY…

Hilary Boone

Polio Survivors Network are very sad to announce that our founder and tireless advocate, Hilary Boone, passed away on 15 July 2024.

We send condolences to family and friends at this difficult time.

We will update with any funeral arrangements as we know many wish to show support.

A tribute page has been set up here: **https://hilaryboone.muchloved.com/**

Sending love to you all

Polio Survivors Network
Lives lived with healthcare lessons for the future

Source: https://poliosurvivorsnetwork.org.uk/new/2024/07/18/hilary-boone/ (14/11/2024)

See also: https://www.poliosurvivorsnetwork.org.uk/library/files/original/7bf0eff6bdc9583b0c82d627ab9cd093.pdf

* * * * * * *

Richard L. Bruno

It is with great sadness that we mourn the death of Richard L. Bruno, HD, PhD. He passed away on Monday, October 14th.

His devotion to each and every one of us was like no other.

Dick trusted our organization (**www.polionetwork.org**) to hold and maintain his work: The Encyclopedia of Polio and PPS.

Polio Network
Polio Survivors Serving Others

Source: FB Polio Network – Polio Survivors Serving Others, October 17, 2024

See also: https://polionetwork.org/bruno; https://www.dignitymemorial.com/obituaries/westwood-nj/richard-bruno-12028728 (14/11/2024)

NEWS FROM EPU PARTNER ORGANISATIONS

GLOBAL POLIO ERADICATION INITIATIVE

On the occasion of the World Polio Day 2024 the World Health Organisation in cooperation with Rotary International, District 1990, and other partners published at the beginning of November a short video (https://youtu.be/OjlA72J-gOY?feature=shared) published a short video with appeals for the adoption of steps leading to the complete polio eradication in the world. In the time slot 2:42-4:25 you can see Erika Gehrig from Switzerland, President of the Swiss Interest Group for Post-Polio Syndrome (SIPS), past Board Director and since 2022 also Honorary Member of the European Polio Union, presenting her own experience of living with polio and its late effects including PPS. Thank you, Erika!

As you are regularly informed by Polio weekly global updates produced by the WHO and GPEI, which the EPU are subsequently forwarding to you every week, the year 2024 has not been an easy one for polio eradication, with an increase in wild poliovirus transmission in the remaining two endemic countries and new and high-profile outbreaks including in Gaza. And yet global commitment to polio eradication remains as high as ever. For more information on this read the article published on November 14, 2024: https://polioeradication.org/news/global-leaders-undaunted-in-face-of-rising-polio-cases/.

EUROPEAN DISABILITY FORUM

On November 7, 2024, it was decided by the Membership Committee of the European Disability Forum that our European Polio Union changes its status in this European organisation from associate membership to full membership.

The EPU as the EDF Full Member wants to be an active part of what the EDF is doing in defending rights of people with disabilities in Europe, as an Associate Member it is not possible so much.

We already support and will continue to work with the EDF’s strategic plan in promoting the UN Convention on the Rights of Persons with Disabilities. The issue of accessible transport, access to public buildings, restaurants, appropriate housing etc., is of special concern to our members across Europe. The freedom to live and participate fully in civil society without prejudice is a major priority.

Štefan Grajcár, EPU Secretary

EURORDIS – RARE DISEASES EUROPE

EESC right to reaffirm call for European Action Plan for Rare Diseases

23 October 2024, Brussels

EURORDIS-Rare Diseases Europe today warmly welcomes the European Economic and Social Committee’s (EESC) adoption of two Opinions relevant to the rare disease policymaking and affirming the need for greater solidarity with the rare disease community both in the EU and within the Member States.

Namely, the Opinions adopted by the EESC include:

- An Exploratory Opinion at the request of the Hungarian Presidency titled “*Leaving no one behind: European Commitment to Tackling Rare Diseases*”. (Rapporteur: Alain Coheur.)
- An Own-Initiative Opinion titled “*Devising a European flagship initiative for health*”. (Rapporteur: Ágnes Cser.)

Collectively, the two opinions emphasise the need for a more integrated and inclusive health framework within the European Union, with a particular focus on solidarity and addressing health inequalities and the challenges faced by the rare disease community.

(For full report see https://www.eurordis.org/eesc-reaffirms-rare-disease-solidarity/; 14/11/2024)

EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS

Event recap: Pain treatment, management, and prevention – is Europe providing adequate access?

On 16 October 2024, we participated in the event entitled ***“Pain Treatment, Management, and Prevention – Is Europe Providing Adequate Access?”***. Organised by the European Pain Federation (EFIC), Societal Impact of Pain (SIP), and Pain Alliance Europe, this important gathering centered on the accessibility of pain treatment, management, and prevention across Europe.

The event served as a key platform for an influential group of participants, including policymakers, pain experts, and patient representatives, to exchange ideas and collaborate on pressing issues in pain care. Among the notable attendees were EU and international policymakers, including MEP Tomislav Sokol, MEP András Kulja, MEP Andriuakaitis, who emphasised the importance of prioritising health at the EU level as did MEP Saliba in a video-message.

A major focus of the discussions was the implementation of the International Classification of Diseases (ICD-11) and its potential to enhance accessibility to pain care services. This was complemented by insights into the gaps in current pain management approaches and the need for innovative solutions to improve patient outcomes.

As pain is a significant challenge, particularly for individuals with neurological conditions, the event highlighted the often 'invisible' impact of pain and sparked meaningful discussions on how to better address these issues.

This gathering emphasises the importance of ongoing collaboration among policymakers, healthcare professionals, and patient communities to ensure better access to comprehensive pain management across Europe.

Source: https://www.efna.net/event-recap-pain-treatment-management-and-prevention-is-europe-providing-adequate-access/; 14/11/2024

LINKS TO USEFUL SOURCES AND INTERESTING READING

- Prof. Alain Yelnik, EPU Honorary Member, together with Daniel Levy-Bruhl published an article "*Myélites aiguës flasques à entérovirus ; des poliovirus aux entérovirus D68 et A71; épidémies et circulation dans les eaux uses*" [EN: "*Acute flaccid myelitis; From poliovirus to enterovirus D68 and A71; Outbreaks and wastewater circulation*"]. The article was published in the Bulletin de l'Académie Nationale de Médecine (ELSEVIER - https://doi.org/10.1016/j.banm.2024.05.009), but not with an Open Access status. We are not to be allowed by the copyright to distribute widely this text. The pdf in French and its translation can only be given punctually to individuals, the abstract and the link can be displayed, but the full text could only be individually given.

- All you want to know about polio and its late effects including postpoliomyelitic syndrome you can find in these sources:
  - Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors (Post-Polio Health International; online access)
  - The Encyclopedia of Polio and PPS by Richard L. Bruno (The International Centre for Polio Education and the PA Polio Survivor's Network; online access)

- Polio Australia´s Post-Polio History Form (Polio Australia; source: https://www.facebook.com/story.php?story_fbid=951687266990997&id=100064491981846&_rdr; 17/10/2024)

- Link to Newsletters of the Polio Network – Polio Survivors Serving Others: https://polionetwork.org/newsletter-archive

- Polio survivors face biggest fight of their lives – an article written by Neena Bhandari, a journalist, polio survivor, and the creator of Post-Polio India

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.

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