



EUROPEAN POLIO UNION

Newsletter No. 1/2023

Spring 2023

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EDITORIAL

Dear Reader,

We are happy we can be here again with a wealth of information and observations from and about the life of polio survivors in Europe, but also worldwide – before the discovery voyages of Marco Polo, Christopher Columbus, and many, many others before and after them, most Europeans could think (and many of them really thought) that their physical, geographic world is limited to what we now use to call the Old Continent. We now know, however, that we are just a grain of sand in the universe, and with the help of all these new technologies we are much closer not only to the stars above us, but mainly to each other. Of course, only if we wish to be... Thanks for all these achievements and amenities!

As usual at this time of the year, we start with the Annual Report 2022 by David Mitchell, EPU President, summarising what we have managed to do during the last few months, and also what challenges we are trying to cope with.

Polio-France, our Member Organisation, is inviting us all to Nancy, France, to the European Polio Conference 2023 on May 26, which will be a joint event together with the National Meeting Day of Polio-France and their guests (the first day, May 25), and EPU Annual General Meeting (the third day, May 27). Though the Conference and the AGM is just behind the corner, until May 15 it is still possible to register and not to miss this unique opportunity to meeting old and new friends from many countries. After Copenhagen 2011, Amsterdam 2014, and the cancelled conference in Vitoria-Gasteiz in 2020, this is only the third such an event during the short and happy history of EPU.

BTW, history – Margret Embry, EPU Honorary Member and a person who was with us long before the EPU could officially exist, comes with her notes and short comments on how it all started many years ago. We could call it also as “back to the roots”, and if we are trying to find our way forward, her article can help us to know where we came from, and realise that it was not a simple rose garden walk.

Advocating the rights and needs of polio survivors all over the world is the key mission of the Post-Polio Syndrome Advocacy Group established last year, and John McFarlane, EPU Past President and EPU Honorary Member, presents what the PPS AG is all about, and mainly how we all can join the group and contribute with our own views and thoughts to this unique communication.

Pictures from our member organisations and support groups are presented by Polio Hungary, SIPS Switzerland, Association of Paralytics – ABP asbl Belgium, British Polio Fellowship Great Britain, and Polio Survivors Ireland. Here, however, together with our President we are just reminding you that we would be happy to bring as many pictures from the life of our member organisations as possible, therefore do not hesitate to send to the editor your inputs, the more the better!

Polio is a rare disease, and we are glad that we can present here two articles from Eurordis relating to data collection and their sharing with those who may need them and use them as a source of information for potential measures, which could lead to make our lives less challenging.

Book reviews by John McFarlane could prove that as years are passing by and we’re getting older/more experienced, we prefer non-fiction, and also that our own personal life stories are quite similar to these two recommended to read. The final section, “Miscellanea”, is not less interesting, we are sure 😊.

Stefan Grajcar

Editor

**THE EUROPEAN POLIO UNION
ANNUAL REPORT FOR THE YEAR 2022**

Dear Fellow Members and Supporters,

Greetings from the directors of the EPU, we all come from our own national polio organisations and usually serve a three-year term. At present we are from the Czech Republic, France, two representatives from Polio Survivors Ireland, Germany, Slovakia and two from the British Polio Fellowship, Great Britain. We are looking forward to holding our AGM as part of the Polio France Convention in Nancy in May organised by Robert Cordier (one of our directors) and his stalwart supporter and observer Sylvie Tararbit. All the details have now been sent out and we greatly look forward to your participation.

2022 was a difficult year for the EPU as we were just coming out of the Covid pandemic which had taken a huge toll on lots of our 24 affiliates from 17 countries. Most polio groups had been in virtual lockdown, not many meetings, fundraising or recruiting, etc. However, the EPU, due to the wonderful efforts by directors Prof Michal Haindl (Czech Republic) and our indefatigable secretary, Stefan Grajcar (Slovakia), held its first physical AGM in beautiful Prague after a hiatus of two years. Considering travel problems (Covid) and our increasing ages we had a good turnout in an excellent hotel. Once again, Eurordis (the Rare Disease Europe) gave us much welcome funding support and, alongside the actual AGM itself, monies were designated to enable disadvantaged members to attend. Your Board continues to meet using Zoom, arranged by willing helpers.

Our finances are now well controlled and it must be emphasised that we are a not-for-profit association registered under Belgian law (IVZW).

This leads me to a current task which is greatly exercising our brains. One of our directors offered to look in depth at our Articles of Association with regard to the Belgian legal changes in 2019 and at the end of 2022 we are fully involved in identifying just what legal work is necessary whilst keeping a close eye on costs. Great work has been carried out on our upgraded [website](#), a long time task which has involved past directors and currently Prof Haindl and Stefan Grajcar. Dr Frances Quinn (GB) has led our medical panel with an urgent task being to try to ascertain the present number of polio survivors in our member countries. Also, an in-depth questionnaire about individual national statistics, polio clinics, rehab, research, websites and any practical help given to members. (Please try to answer this as quickly as possible). Stefan continues to produce an excellent and interesting newsletter of over 30 pages and we invite and urge our member organisations to write in with details of their activities and initiatives, possibly unique and useful, something we can all learn from e. g. the growing use of hydrotherapy pools not just for young racehorses but beneficial for us old workhorses. Paul, our director from Germany, produced a sponsored brochure sent out to all members which explains Post Polio Syndrome (PPS) in clear terms and methods of therapy. We intend to publish the results when collated.

Our strategy working group have stepped back until we know if any changes are needed to our Mission Statement and Articles of Association under the possible Belgian legal changes. Probably the most unusual and interesting part of our Board Zooms (held about every six weeks) is under 'Any Other Business' where our strength is in our breadth e. g. travel problems for the disabled, good in some places, shocking in others, fuel and heating costs all over Europe, rising food costs and, something which is very fragmented, health and social care shortcomings. Our medical survey is

already showing how time consuming and problematic it can be for a person with disability to access financial benefit/support and special treatment, if it exists. In Great Britain we are now down to just one excellent polio clinic in London. We are lucky, however, to have a dedicated team at the BPF central office continually advising members regarding support services. Again, our medical questionnaire will hopefully identify whether this service is available across Europe and where, if anywhere it is funded and provided by the state.

Our members in Poland, Slovakia and Hungary are in the front line for receiving refugees from the terrible Russian offence against Ukraine. We are very proud to be members of Eurordis who have set up facilities at post crossing points in order to give expert advice on how to deal with those affected by a rare disease. Since many who have left Ukraine are elderly there must be a certain percentage of post polios. Despite long term efforts the World Health Organisation have been unable to gather any polio statistics from Russia or many of the countries in the old Soviet bloc.

It is now 65+ years since the polio vaccine was produced and although eradication is still very much on the agenda worldwide, most of our member organisations now prioritise dealing with PPS and the legacy issues (with huge thanks to GPEI, the WHO, The Gates Foundation and, of course, Rotary International). A new initiative in 2022 (driven by John McFarlane, our past President) called the Post Polio Syndrome Advocacy Group, is already well established and surging ahead fronted by activists from Rotary International. You can register your interest at ppsadvocacy@gmail.com. This group is not set up to cut across eradication but to highlight the, sometime appalling, legacy of polio.

NB We are also members of EFNA, European Federation of Neurological Associations.

The current 'pan-Europe' steep rise in fuel and food costs, already mentioned, must be left to our individual member countries but for those with chronic PPS who need constant warmth it must be a huge burden.

I close by thanking my fellow directors, all those members wherever they may be in Europe for what they do for polio survivors everywhere and to clinicians and carers and able-bodied supporters. The recent discovery of the live polio virus in sewage samples in London and the alarming wild polio virus (WPV1) cases reported in 2022 (30 cases compared with six in 2021) tells us that our fight goes on. On that sombre note can I wish you all a wonderful 2023.

David Mitchell, EPU President

On behalf of the Board of Directors

February 2023

“Polio survivors have a certain advantage over the able-bodied when it comes to ageing... We do not confuse the quality of our life with the quality of our tennis game. We know that happiness is not dependent upon activity nor is meaningful defined by trophies. A meaningful life may be hampered – but need not be defined – by pain or disability.”

Hugh G. Gallagher, 1998

Posted on the FB of the PPS Advocacy Group by John R McFarlane on April 3, 2023



POLIOMYELITIS, A CONGRESS TO BUILD THE FUTURE!

Polio-France is the only national association that gathers and represents exclusively the people carrying sequelae of poliomyelitis. It is also an active member of the Board of Directors of the European Polio Union (EPU). After the serious epidemics of the 1950s and 1960s, the introduction of compulsory vaccination in 1964 marked the end of cases of poliovirus. Some children died at that time, and about 50,000 survivors in France are in various situations of disability due to the after-effects of the disease.

After leaving the rehabilitation centres and reaching adulthood with their disabilities stabilized, all of them were able to study, work, start a family and pursue a career. Many of them are now reaching retirement age. They have blended into the national landscape, fully integrated, and are no longer visible to the point that 40 to 50 years later, it is common to hear people say: “polio no longer exists!” This is true of the viral threat. Yet the survivors with polio scars are among us; in our neighbourhoods, our businesses, our families. They continue to fight, as they always have.

No scientific hindsight allowed us to imagine that, 40 or 50 years later, the natural effects of aging could play a major role in the life process of these disabled people, degrading their remaining capacities as early as 45-50 years old, with more or less brutality and rapidity. Impoverished by the lack of transmission among most health professionals, the body of knowledge on the management of the after-effects of poliomyelitis is such that there is an urgent need to reinitiate the circulation of this knowledge. It is necessary to create (or perpetuate) spaces for the dissemination of scientific knowledge and management methods. This can only be achieved through events that encourage this type of exchange, as proposed by the Nancy conference.

Contrary to most scientific and/or medical conferences, the particularity of polio congresses lies in the sharing of knowledge and experiences, especially the fruitful exchange between health professionals and people with polio sequelae. They have been immersed in the medical world since early childhood and, like expert patients, they often represent half of the audience of this type of conferences. They produce a highly productive interaction that is much sought after by professionals. Most professionals agree that sharing life experience is at least as important as the body of scientific knowledge.

This congress is not a congress like any other with a learned society that addresses its colleagues. We are a patient association that wishes to create the necessary conditions for the exchange of knowledge in order to perpetuate its dissemination, but above all to motivate research and innovation in care. This congress is aimed at people with polio sequelae from all over the country, whether or not they are members of the association, but also at their European counterparts, via their organizations, members of the EPU. Its main target remains the health professionals of the whole country and of the European countries concerned by the management of polio sequelae.

It already benefits from the support of:

CDCA54, CD54, CRSA-GE, Région Gd-Est, Ville de Nancy, Métropole du Grand Nancy, UGECAM-NE/IRR, CNSA, ARS-GE, ARS-DT54, OHS de Lorraine, AGIRC-ARRCO, Rotary District 1790.

Its steering committee is composed of representatives of these bodies (in bold) as well as two administrators of Polio-France and its president.

All relevant information about the Conference including registration fees, detailed programme, accommodation and other useful information can be found on the Conference website both in French and English: <https://www.polio-france.org/european-polio-conference-nancy-2023/>.

MAY 25.26TH 2023
POLIO-FRANCE NATIONAL MEETING DAYS
workshops, debates, conferences
Polio-France

MAY 26.27TH 2023
EPU ANNUAL GENERAL Meeting / Debates
European Polio Union

CONFERENCE COMPLETE PROGRAM

	MORNING	AFTERNOON
THUR.25 TH	-	NMD POLIO-FRANCE
FRI.26 TH	NMD POLIO-FRANCE CONFERENCES EPU - AGM	
SAT.27 TH	EPU - AGM	-

OVERVIEW OF CHRONOLOGICAL EVENTS LEADING TO THE FOUNDING OF THE EUROPEAN POLIO UNION

Years before the EPU was founded in 2007 and before its legal status as an international charity according to Belgian law in 2009, a number of meetings and conferences took place to debate and discuss a possible cooperation between the polio support groups in the European countries. E. g.:

In March 1998 at an International Polio Congress in Jena, Eastern Germany, mainly addressed to medical professionals, but also attended by delegates of national polio support groups. Casual get-together of polio survivors to talk about a possible cooperation.

In March 1999 at a meeting in Wiesbaden, Germany, with delegates of polio support groups from Belgium, Germany, Denmark, Switzerland also representing Italy, the Netherlands, Finland, Hungary and Austria.

All these countries had more or less official polio support groups except for Austria and Hungary. Subjects discussed:

- medical professionals ignorant of late effects of polio
- Each country reported about their health system
- Possible role the EU could or might play in research funding and social matters
- Any matter taken before the EU to be well thought over, well organised and well presented
- Important to establish good connections with a certain group of politicians
- Polio or Post-Polio – which name to choose to describe late effects of polio
- What is more important to concentrate on – a European cooperation of polio groups or a decision about the organizational structures, the latter was decided upon.

A task force was set up called **Polio Network Europe** – to deal with above subjects. Regular telecons to be held.

In 2001 at an AGM of the Bundesverband Poliomyelitis in Kassel, Germany. No info available

In 2003 at an open discussion at the Düsseldorf International REHA FAIR, Germany. No information available.

At all of the afore-mentioned meetings and conferences interest was on working with other polio support groups across borders, to exchange knowledge about PPS, experience, and how to cope with these relatively unknown late effects of polio rather than actually founding a European union as an umbrella organization.

In 2003 at a conference in Brussels, with delegates of polio support groups from Belgium, Germany, France, Great Britain, the Netherlands and Ireland participating, the concept of all national support groups in Europe to join into a union seemed to take some sort of shape to carry more weight in realizing their

Objectives such as:

- Create a committee as a contact and information facility for the European polio support groups.
- Improve the quality of life for the polio survivors
- Develop a general awareness about the post-polio syndrome in cooperation with the medical professionals of the European Health providers.
- Work out a program of measures to be submitted to the EU Commission, giving reasons why PPS should be a matter of the European health policy.
- To agree on a name for this new European organization, amongst several suggestions it was decided to adopt the name '**European Polio Union**'.

Between 2003 and 2007 no more attempts were made to make the European Polio Union a reality.

Until

24th March 2007

at an international polio conference in Como at lake Como in Italy, organised by Rotary International and Polio Support Group Rome, delegates of polio support groups Belgium, the Netherlands, Hungary, Ireland, Italy, Spain, UK, and Switzerland joined up in breathing new life into this concept of a European union of polio support groups.

An action plan was hammered out, amongst others including items such as

- to get PPS recognised in all European countries,
- to get the EPU recognized
- to seek funding for PPS research and develop a research centre
- to seek funding from the EU for an EPU website and administration

Action groups were appointed to ensure the actions were taken as set forth in the action plan.

On 7th June 2007

Meeting at the EU Brussels with 3 members of the EU parliament to get advice about how to proceed to get recognition of PPS and funding for research. It was suggested to issue a petition and get the support and signature from MEPs in all European countries.

Comment: Petition was set up and sent out, 72 MEPs supported and signed it, but the matter hasn't been taken any further, because the EPU had no legal status at the time.

15th October 2007

A manifestation of polio survivors was organised starting in front of Brussels Luxembourg station and proceeding from there to the European Parliament building, with banners showing the **WE ARE STILL HERE** slogans. Press and Media were invited but did not turn up.





16th October 2007 – morning

Meeting of the delegates of the national polio support groups in the European Parliament, all MEPs who had signed the petition were invited, but only 3 turned up. Speakers were Prof Frans Nollet and Prof Christian Borg, the subject was about polio, PPS and any studies about medication that was going on in the Amsterdam Medical Centre and at the Kalinska Institute in Stockholm. Problem about research was that there were not enough funds.

Interesting comment by Prof Nollet: polio survivors don't complain enough !!



European Parliament - from right to left: Prof Frans Nollet, Prof Christian Borg, EPU President Johan Bijttebier
As press and media did not turn up at these events to create awareness for PPS, it was suggested to create a video of polio survivors and the late effects of polio and publish this video on Youtube. The

estimated cost for this video of 15,000 Euros, however, was far beyond the available funds, thus it was never made.

16th October 2007 - afternoon

General Meeting at the Sleepwell Hotel in Brussels

Agenda points: Statues, rules, objectives, registration.

- The rules set up by the BPF were discussed and accepted and to be circulated to all national polio support groups for comments.
- Website to be created by Polio Association Rome. First drafts were unsatisfactory and the website project was transferred to the English mother-tongue polio survivors group in Ireland.
- EPU Flyer to be created by Polio Support group Ireland.

The following committees were set up:

- Honorary committee
- Management council
- Organisation sub-committee
- Register Sub-committee
- Research sub-committee

Great emphasis was on research to find solutions for the polio survivors to alleviate their polio-related health issues. In order to find funding for research projects it was considered important to know how many polio survivors there were in Europe and what polio-related health issues they suffered from. Hence a questionnaire was to be worked out and to be distributed to the polio groups for forwarding to and completing by their members.

During 2007 and 2008 EPU board meetings were held in Antwerp, Dublin, Copenhagen, Brugges (Belgium).

On 24th October 2008

a first official EPU **annual general meeting** was held in the Seehotel Rheinsberg, near Berlin, Germany.

- EPU Objectives were re-formulated
- Register Sub-committee (francophone Belgian polio group and GLIP France) presented a draft questionnaire, but was rejected by BV Germany for reasons of data protection. Questionnaire was to be revised and to leave out personal data and be made computer-friendly.
- BPF was to register the EPU in the UK and to apply to the EU for funding.
- Presentation by Prof Dr med Paschen (Germany) on the subject 'What do we need to know about polio and post- polio syndrome.'

In February 2009

- an EPU Board meeting took place in Leicester, UK. It revealed that the BPF was unable to get funding from the EU
- and that the EPU didn't meet the conditions required for the registration of a charity in the UK.

- The two BPF members in the EPU board resigned.

At this moment in time the EPU seemed to be doomed to fail.

The driving force behind of all the various stages of EPU historical development was the chairman of Post-Polio Belgium, Johan Bijttebier. His tenacity and determination at this critical point kept the EPU alive. He took action, found a treasurer for the organisation, had the statues translated from English into Dutch and adapted to Belgian law and managed to register the EPU with the notary in Brussels on 9th June 2009, thus giving it the legal status which it needed.

Now was the time the whole concept of a European umbrella organization needed rethinking and re-assessing. Where to go from here was the question. It was decided to get advice from a medical professional. The few remaining EPU board members travelled to Amsterdam to consult Prof Frans Nollet. It was his suggestion for EPU to organise an international polio congress, inviting medical professionals, polio support groups and polio survivors and their families from all over the world.

In the year that followed organising and scientific committees were set up with the support of the Danish Polio association PTU and the 1st EPU International Congress was held in September 2011 in Copenhagen.

NOTE: Special thanks to Johan Bijttebier (BE), Dr med Peter Brauer (DE), Els Symons and Aadje de Groot (NL), Katleen Trybou (BE), and Klaus Kunert (DE) for their feed-back on the events.

Margret Embry, France

EPU Honorary Member

April 2023

For Whom the Bell Tolls

by

John Donne

No man is an island,
Entire of itself.
Each is a piece of the continent,
A part of the main.
If a clod be washed away by the sea,
Europe is the less.
As well as if a promontory were.
As well as if a manor of thine own
Or of thine friend's were.
Each man's death diminishes me,
For I am involved in mankind.
Therefore, send not to know
For whom the bell tolls,
It tolls for thee.

John Donne (1572 - 1631) was an English writer and poet. As a Catholic in a time when that denomination was illegal in England, he endured constant prejudice and harassment and was ultimately forced into joining the Anglican church by King James I. Early in his life, John earned a reputation as a playboy and spendthrift, but at 25, he fell in love with Anne More. Despite her father's scorn, the couple married, had a dozen children, and John became a devoted—if not financially successful—family man. His career forays included law, diplomatic service, and church leadership, but he is best remembered as the founder of a group called the "metaphysical" poets. Popular during his lifetime, then dismissed for many years as inferior because it was so different from other poetry of that time, John's work is today considered brilliant and his influence on literature legendary.

Source:

https://www.yourdaily-poem.com/listpoem.jsp?poem_id=2118

POST-POLIO SYNDROME ADVOCACY GROUP

Around the world there abounds a host of support group looking after the needs and wants of polio Survivors, whether paralytic or asymptomatic but no one group exists to fight their corner in every corner of the globe. Around 14 months ago a group was formed, mainly by Rotarians, to correct this omission. Thus the Post-Polio Advocacy Group (PPSAG) was born out perceived necessity and what soon became apparent – NEED.

Its Mission Statement reads:

OUR MISSION is to create Polio Advocacy Awareness and provide sources of Polio information to Polio Survivors, those with the late effects of Polio, those with Post-Polio Syndrome, their Support Groups, and those with similar disabilities, statutory agencies, the professional medical communities, Governmental and Non Governmental Organisations and other interested parties.

We have been asked are we a support group in the model of the members of the EPU, the answer to that gone is a very emphatic NO. Advocacy it's defined in the Oxford English Dictionary as "**public support for or recommendation of a particular cause or policy**" (*Oxford Dictionaries, Oxford University Press*). Perhaps a better way of describing it is "**getting support from another person to help you express your views and wishes, and help you stand up for your rights**". Someone who helps you in this way is called your advocate and that is what the PPSAG is and will transfer the required skills to others to fulfil that role.

If looking at the numbers of polio Survivors around the globe the numbers fluctuate enormously from that of the World Health Organisation of 15 million to perhaps the more believable figure published in a 2015 paper in the International Journal of Infectious Diseases – 2015 P e108-e116, Denmark, entitled "[Post-poliomyelitis syndrome as a possible viral disease](#)" Authors: Andreina Baj, Martina Colombo, Antonio Toniolo (all of them Laboratory of Clinical Microbiology, University of Insubria Medical School, Viale Borri 57, 21100 Varese, Italy), Joan L. Headley (Post-Polio Health International, Saint Louis, Missouri, USA), John R. McFarlane (European Polio Union, Antwerp, Belgium), Mary-ann Liethof (Laboratory of Clinical Microbiology, University of Insubria Medical School, Viale Borri 57, 21100 Varese, Italy, and Polio Australia Incorporated, Kew, Victoria, Australia).

Their findings included in this peer reviewed and published paper suggests the polio Survivor population to be around 26 million with the vast majority in sub-Saharan Africa and the Indian sub continent.

That in itself set another problem as the vast repository of knowledge about Post-polio Syndrome lies in Europe, N. America and Australia and that knowledge includes how to get what you need, in other words become advocates not just for yourself but also others.

To date the PPSAG does not have a physical base, where would you put it around the globe? Nor does it have any money but it has attracted a huge amount of interest around the world and in a short time has accumulated over 600 groups and individuals from every hemisphere of the world to both its email mailing list, Facebook page and other social media. It also issues a Newsletter every month to those on the mailing list and holds an open meeting on the 2nd Thursday of each month via a ZOOM link that is sent out as well as being on the Facebook page. The meetings are recorded and are available to view via Facebook in their entirety, examples are 'Post-polio Advocacy Around the World' with Shiela Meta Jain, a powerful business woman and advocate from India, 'What is going on in the world with polio' with Mike McGovern, Rotary Internal Chair of Polio Plus, to 'Myths and Truths of Post-Polio Syndrome' with John McFarlane, ex President of the European Polio Union. Each

and every session, and there are plenty more on Facebook, draws huge attention and generates many emails that if they cannot be answered by one of the PPSAG organisers will be passed to a competent authority for resolution.

PPSAG as yet does not have a formal registration in any country so the “Board” is called the Steering Committee and comprises 9 members of which 3 are polio Survivors. The 9 members are based as far apart as Columbia in South America, to Quebec, Canada, to Ireland and Cape Town in South Africa, the others being based in the United States. Each bring a particular talent to the table, for example the SA member specialises in Social Media, one of the US members and a polio Survivor herself runs the “PA Polio Survivors Network” publications, the representative in Canada runs Polio Quebec and as one person put it the others provide the “grunt”, in other words in the background doing the necessary manual labour in the form of paperwork both to keep PPSAG going as well as growing it into a credible international tool for all polio Survivors.

Although not affiliated to Rotary International, as many of the “Steering Committee” are Rotarians, it shamelessly uses its contacts amongst the 1.4 million Rotarians around the world to promote its message. Rotary, through the Global Polio Eradication Initiative (GPEI) is committed to that task, not just wild polio but also circulating Vaccine Derived Polio Virus (cVDPV), but it has a network that can also be utilised to assist polio Survivors. Through GPEI, those on ground know where to find Survivors and pass on information as well as help find answers to needs and benefits.

Most Survivors say the most pressing need is to train medical professionals how to diagnose and treat those with Post-polio Syndrome and it certainly needed and forms part of advocacy but it goes so much further. Many are housebound due to the lack of a mobility device, unable to use the bathroom through the lack of a toilet seat raiser, a shower chair or as can be seen in Tom Roberts 2014 Pakistan based documentary film “Every Last Child” even more basic needs as shown by the lack of facilities in Pakistan for polio Survivors where many do not even have a basic wheelchair but use a reclaimed buggy or pram carts or even skateboards to get around. Perhaps the PPSAG will never be able to get to those but it will be able to help assist others to act as advocates for them, whether they be medical professionals or other polio Survivors.

This project, to promote advocacy for polio Survivors, is global. It is in its infancy and we know that many feel we are not moving quickly enough but just like a convoy of ships we can only go as fast as the slowest otherwise it will break apart and fail. The PPSAG does not have the word “fail” or “failure” neither in its vocabulary or dictionary. Those living in areas where polio is still endemic, or it has only recently been eradicated are looking to others to help them achieve their rights, treatment and care so that they can live their lives with dignity and independence. The PPSAG, and its advocates and training may not always get it right or even be able to help but it will not be for the lack of trying!

PPSAG email: ppsadvocacy@gmail.com

Facebook: Post-Polio Syndrome Advocacy Group

Newsletter sign up: <http://eepurl.com/h5nea5>

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To join the mailing list send an email to ppsadvocacy@gmail.com

Facebook Page search for Post-Polio Advocacy Group

John R McFarlane

EPU Past President and EPU Honorary Member

email: johnmcf@popsycle.eu

EUROPEAN POLIO UNION WEBSITE

The European Polio Union (EPU) [website](#) was frozen for a long time in 2012, and therefore much of its content has not been valid for years. Since organisations' websites have long been the primary source of information about a given organization, such a state of affairs indicated that polio and polio survivors no longer exist in Europe and the EPU. Since a person must be punished for every good deed he deserves, the website was added to my tasks in the EPU committee in the spring of 2022.

Updating the EPU website was more complicated than I thought after learning about its status. The EPU domain and its own website were owned by Denmark's UlykkesPatient, who was willing to transfer both to EPU ownership free of charge. The transfer of ownership of the domain and its registrar took some time. After that, the website's data could also be transferred, this time to a Slovak web company, which offered the most financially advantageous conditions for placing the website on its server and, at the same time, allowing me full access to its editing. In the meantime, I designed a new structure for the EPU website and gradually updated its content. After the last step, which was mapping the new EPU website to the new IP address, you can now access our new website by clicking on www.europeanpolio.eu. However, the work on the website continued. Every website needs to be constantly updated. Otherwise, it will soon return to its previous non-functional state. However, updating the website must be something other than the work of one person. It depends on the holders of interesting information so that the website administrators also provide it on an ongoing basis and point out the necessary changes. It is more than just an administrative information; despite the little interest in post-polio syndrome, medical recommendations are sometimes changed. Medicine is not mathematics. While the Pythagorean Theorem has been valid for nearly three millennia, Hippocrates' balance of the four elemental bodily juices does not help much in treating polio.

Michal Haindl
EPU Board Director

INVITATION FROM THE PRESIDENT

ON BEHALF OF OUR EDITOR, CAN I PLEASE ASK ALL OF OUR MEMBER ORGANISATIONS TO CONTINUE TO CONTRIBUTE ANY NEWS FROM YOUR PART OF EUROPE TO FUTURE EDITIONS OF YOUR NEWSLETTER. WE OFTEN ARE SO INVOLVED IN OUR OWN PART OF THE WORLD THAT WE DO NOT HAVE TIME TO LEARN WHAT OTHERS ARE DOING! PLEASE MAKE THE EFFORT TO SEND IN YOUR CONTRIBUTION.

THANKING YOU!

DAVID MITCHELL, EPU PRESIDENT

NEWS FROM EPU MEMBER ORGANISATIONS

Report from the International Polio Day in Budapest, Hungary, 22. 10. 2022

My name is Klara Schweitzer, some of you may remember me from the EPU AGM. I work for the Hungarian Polio Foundation as a volunteer and a trustee, too. There are only three of us but we have some helpers among our fellows and family members when we want to organize a meeting for our polio community, which we usually do every second year with a programme that give them useful information about PPS and other health topics.

After two years of COVID we just wanted to celebrate that we are still here and successfully survived the pandemic. The Polio Day was a good occasion for getting together. The headmaster of a secondary grammar school in Budapest run by the Reformed Church was so kind as to let us use the premises which are nearly brand new and fully accessible. The invitation aroused interest and we were really happy to be able to receive nearly 50 guests coming from all over Hungary. After the opening words of the Foundation's president, Tamás Kertész, Anna Alpári greeted us with some moving sentences recalling our youth, the difficult childhood, the times when we were trying to find our spouse, have a family with children and a job, how much we worked – more than our colleagues - just to prove that we are able to work and just because we wanted to be accepted by the „able-bodied” majority of the society we lived in. Anna said she was very proud of us and we should also be proud of ourselves for what we have achieved in our life, because we had a life with full of struggles and we managed to prove that we are worthy members of the community. The meeting went on with a dance show of two young students of the school. After the show we had two guests giving lectures about interesting topics: a dietician who spoke about healthy diet for people, especially for those with disabilities and a herb specialist who gave advice about herbs, especially for cough. After a delicious healthy lunch I gave an account about my journey to Prague and the EPU meeting, and “gave a lecture” - better to say – forwarded information – based on the lecture of Prof. Frans Nollet about “Aging with Polio”. I think I don't need to introduce him, he is well known among polio survivors in Europe. He was a guest at the EPU AGM in Prague and I was very happy to meet him personally. After my lecture I got a lot of questions and I tried to answer them to my best knowledge, starting a lively conversation. The issue that most participants proposed was the decreasing of our moving capacity after an accident. As the risk of falling and having a serious accident is quite high in our case, we discussed about this topic a lot, gave and got advice how to prevent falling and what to do if it still happens.

The event was really successful, we got a lot of congratulations and everybody was happy to meet long not seen friends.

Below you can see the word cloud which we used to make our invitation more promising. It is full of words connecting with our polio life: places, people, objects, feelings.

The mission of SIPS is to fight for our members, for their bio-psychological and medical aspects; to organize yearly seminars for members, physiotherapists, skilled specialists and Doctors. The SIPS board meets once or twice yearly, runs phone conversations or visits events.

At present we plan to meet the flower show in Morges, near Lausanne. A beautiful tulip field will be presented with our “END POLIO NOW”, with many other flower beds. Our ASPr-SVG | Polio.ch office will send a few representatives German and French speaking to our stand at the tulip show.

Information can be found on our webpage: www.polio.ch where you find much information on all our various Swiss sections.

Challenges to cope with:

The board members are getting older and replacement becomes more difficult year by year.

Our board:

Erika Gehrig, SIPS President

Dr. med. Madeleine Hofer, Lifeconsultant, psychiatrist

Dr. med. Theres Peyer, reliable for medical questions

Martin Stokar

Dr. med. Thomas Lehmann; EPU Honorary Member

Erika Gehrig

EPU Honorary Member



Bad mood note

At the beginning of February I visited the annual Antiques Fair in Brussels.

This exhibition is of very high quality, has an excellent reputation on a European level and one goes there as if in a very beautiful museum.

This year's Antiques Fair was held at the Brussels Expo site, which hosts numerous exhibitions throughout the year, such as the car show, the holiday show, a film festival and a whole series of national and international exhibitions.

This meant that many visitors were expected and that it was necessary to organize myself to get there without difficulty. As a result, I chose to go by taxi - to avoid the problems of occupied PRM¹ spaces - and to be accompanied by my wife. Those of you who know me are aware that I use a rollator, which allows me to remain independent and to walk for a long time, at least for me.

We arrived in front of the entrance to the palaces of Brussels Expo, home of the Antiques Fair. After the controls, we found ourselves in front of **a staircase of about ten steps with no handrail either on the right or on the left to ensure easy access 😊!** No indication either to an accessible route for PRMs!



Brussels Expo

In Belgium, the law requires that any event open to the public be accessible to people with motor disabilities via an inclined plane or a lift. In the case of these buildings dating from 1933, we speak of "reasonable accommodation" ... when it is possible and when we have thought of it!

In this case, nobody has thought of it yet 😊!

Having said that, in a case of blockage like the one I describe, one either gives up or hangs on. Me, I hung in there and asked for help from a minibus driver who had just dropped off some visitors in front of the staircase in question. He took the rollator to the top of the stairs and helped me up the steps without incident.

And that was it, we were able to visit the stands, one after the other, for about 2 hours. What a pleasure!

At the end of the visit, I met the general manager of the fair to whom I asked if there was not an exit without stairs, easier for me. She immediately had me escorted to an exit with a lift and escalator, but **reserved for the fair's exhibitors only**. Unfortunately for all the other disabled visitors, there was no indication either inside the Antiques Fair or outside the buildings to indicate possible access for disabled people. Shame on the organizers!

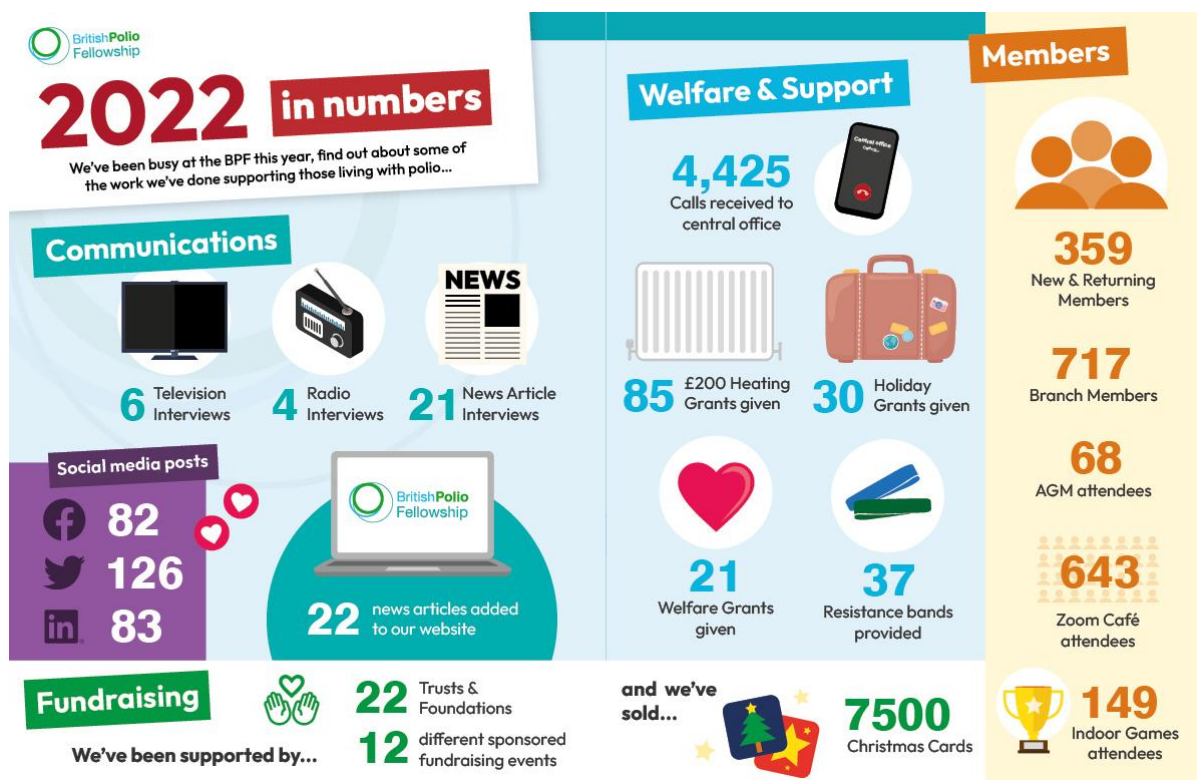
Any conclusions from this experience? Despite all the effective awareness-raising work of associations such as ours, there is still a lot to be done to finally achieve a fully accessible society. For

¹ PRM stands for "persons with reduced mobility"

the organization of the next Antiques Fair in 2024, we have received a commitment from the person in charge to take into account the recommendations on accessibility that our association will ensure are sent to her in good time to be applied. We will pay particular attention to this.

Daniel Peltzer

Honorary President of the Belgian Association of Paralytics – ABP asbl
EPU Honorary Member



British Polio Fellowship 2022 in numbers

Polio Survivors Ireland - News

Polio Survivors Ireland is delighted to announce that our updated edition of our book, Polio & Us, is available to purchase online through our website www.polio.ie. Polio & Us is a time capsule of the stories of Irish polio survivors and how they overcame the challenges of polio. This is a re-issue of the 2007 'Polio & Us' – personal stories of polio survivors in Ireland.

The book has been refreshed with a modern look, helping to ensure it maintains the interest of people who would like to know more about the history and legacy of polio in Ireland. Indeed, EPU members will no doubt see familiar recollections and histories to their own, in an Irish setting.

This year, 2023, Polio Survivors Ireland is also celebrating our 30th anniversary, with plans for media activity to raise awareness of survivors and their challenges and we hope some other celebrations. We look forward to many more years of transforming the legacy of polio.



Pictured are members of Polio Survivors Ireland helping us to promote the book

National Polio Register – an overview

The Polio Survivors Ireland National Polio Register was piloted in County Galway, in the West of Ireland in 2017. It was decided that if the pilot was successful, we would roll it out on both a national basis and on a regional basis over a number of years.

Along with promotional material, we arranged a link on our website for people to join the register. We also highlighted the register at various Expos aimed at older people, who were of course our target audience. We contacted physiotherapists and Occupational Therapists and began the process of advertising it in regional media around the country.

A key part of our success was placing leaflets in GP's surgeries around the country for a period of six months. We advertised on a mix of national radio, regional radio and did some photo opportunities. Our numbers grew fast and by 2018 we had a total of 261 polio registrants. People who had never before engaged with Polio Survivors Ireland.

Continuing our campaign, with ongoing media activity including articles and interviews, by the end of 2019, we had another 97 new polio registrants. We ran the promotional activity for another year and while we are no longer actively promoting the register, it continues to gather new people, with a total of 444 now signed up. Ongoing conversion to membership remains a priority, with our service coordinators working through the list of people yet to fully join. We continue to engage with those who are not members yet, by sending them 'Polio Register News' three times a year.

The Polio Register has been a valuable way for us to reach more polio survivors, to raise awareness of polio and polio survivors' issues in the media and on social media, as well as helping us to engage with people who might potentially support the organisation by getting involved.



Pictured are members of Polio Survivors Ireland at one of our early launches of the Register.

Emma Clarke Conway

Communications & Development Officer

Polio Survivors Ireland; <https://polio.ie>

EURORDIS CONTACT DATABASE

In order to do a better job of representing the rare disease community across the globe, EURORDIS – Rare Diseases Europe with RDI – Rare Diseases International have created a brand-new contact database, including all the contacts across all stakeholders that are relevant to our community.

What will it be used for?

The aim of this contact database is to share contacts internally, codify them based on skills and areas of interest in order to send targeted information or invitations to our community.

Shared with whom?!

The content is shared amongst EURORDIS and RDI staff members. Data will not be shared with other organisations.

Why not use existing tools on the market?

We wanted our contacts to be linked to the Orphanet classification - OrphaCode - in order to be able to search by disease or group of diseases.

Apart from contact details, what does it contain?

Organisations and contacts with their expertise in some areas of rare diseases - such as patient organisations, hospitals / HCPs / ERNs, academic entities, institutions, competent authorities, companies. It includes diseases represented by patient organisations and any other skill relevant to the patient engagement context, such as membership of groups as well as participation in EURORDIS' events or activities. It also allows us to manage our different networks such

as memberships, national alliances, European federations, helplines, Eurordis Round Table of Companies, European Parliamentary Advocates for Rare Diseases, Open Academy Alumni, academic partnership, and collaborations.

What does it not contain?

Your condition, religious or sexual orientation or any other information not useful to do a better job of contacting our stakeholders based on their areas of interest.

Where is it hosted?

EURORDIS is the sole owner of this precious data. It is hosted on a dedicated secure server in Paris, France, compliant with EU storage regulations.

Can I access my data?

Any time, just ask and feel free to ask for a correction, we would be happy to improve the quality of the information.

Can you remove my data?

Sure, just ask for your contact details to be removed (e-mail contact-database@eurordis.org). We will confirm by return.

Is this database linked to a mass mailing tool?

Yes, we synchronise it to Mailchimp to be able to send targeted communication messages.

Why use a mass mailing tool?

It enables you to unsubscribe to any of our emails and enjoy the serenity of not being bothered.

At what frequency will I receive emails from you through that channel?

You may already receive the [EURORDIS eNews](#) or the Members' News. Those are our most recurrent ways to be in regular contact with you. You may also receive ad-hoc targeted messages, but we will do our best to keep it as rare as possible.

Is it GDPR compliant as per EU regulations?

Yes, we inform all the people who are added to the database, and you can at any moment ask to have access to your data and modify it, if need be. You can also ask to be removed and you can unsubscribe from the Mailchimp mailing lists at any time if you feel overloaded.

Why take all these precautions?!

Because we care about your privacy!

We have done our best to be informative and concise, but you may feel the need to know more about it. Don't worry, it is fine to be curious. Please send us your questions; we will do our best to answer you timely.

Have a good day

The EURORDIS contact database team

contact-database@eurordis.org

Source: email sent from contact-database@eurordis.org through the domain gmail.mcsv.net to the EPU Secretary in January 2023

WHITE PAPER ON INTERNATIONAL RARE DISEASE DATA COLLECTION

It is perhaps only by chance that information on the White Paper on International Rare Disease Data Collection reached me when I started to collect articles for this issue of the EPU Newsletter. Maybe I do not understand it properly but I think that it has something to do also with the National Polio Register presented on previous pages by Emma Clarke from Polio Survivors Ireland.

Below you can find copies of emails I received from George Reynolds, Managing Partner of RareData EU, during January – March 2023, and I hope you find there information which might be of some use for you and/or your polio organisation or support group.

Stefan Grajcar

EPU Secretary and Board Director

* * * * *

28/02/2023

Stefan Grajcar
European Polio Union

Dear Stefan,

In honour of Rare Disease Day, we are pleased to announce the release of our 2023 white paper, now available for complimentary download. This annual publication is our flagship resource, and it contains a wealth of practical information about setting up and managing registries and real-world data (RWD) studies.

Our white paper is the result of more than ten years of experience and research in the field of rare disease data collection. In particular, this year's edition features new sections on cutting-edge topics that are relevant to the needs of rare disease professionals, including:

- *Patient self-enrollment and eConsent to aid in clinical trial recruitment*
- *International federated registries as a platform for pharma studies*
- *Integration with hospital-based electronic health care records (EHR-EDC)*

These new sections offer insights into the latest trends in international rare disease data collection, helping you stay up to date with the most innovative techniques and technologies available.

To request your complimentary copy of our 2023 white paper, simply click [here](#) or reply to this email. We look forward to sharing our experiences and expertise with you. However, if this information is not of relevance, please reply with "remove" in the subject line.

Best wishes,

George Reynolds
Managing Partner
www.RareData.EU



03/03/2023

Dear Stefan,

I am writing to follow up on your request for a copy of the 2023 edition of our White Paper on International Rare Disease Data Collection. Please click [here](#) to get to our public drop box. This will enable you to access the white paper, along with the slides and video from our conference, which was conducted in advance of the last Orphan drug conference held in Barcelona in November.

We are pleased to report that there has been a tremendous response to this publication since its launch on Rare Disease Day last Tuesday. We have already received over one hundred requests for the white paper from our rare disease partners and colleagues across Europe and beyond. Most of these requests have outlined various challenges and posed several questions, which we plan to address individually next week. We will also prepare a summary of these issues that we believe may be of general interest, which we will email to you as soon as it is completed.

In the meantime, we hope that you find the White Paper informative and engaging. Please do not hesitate to contact us if you have any questions or concerns.

Thank you for your interest and continued support.

Best wishes,

George Reynolds

* * * * *

23/03/2023

Dear Stefan,

Thank you for your interest in our 2023 edition of our [White Paper](#) on International Rare Disease Data Collection. As a follow-up to my previous email, I would like to share with you a summary of the common questions and challenges that we received from other rare disease partners and colleagues, as well as some possible solutions that may be useful for your work in this field:

1. How can a small patient organization secure funding from pharma companies for developing and maintaining a registry?
2. How can the data quality be improved when the patient cohort is very limited due to the rarity of the disease?
3. How can the data collection software be updated quickly to adapt to expanding needs for clinical data?
4. How can historical and current hospital records be imported and accessed by patient organizations?
5. How can GDPR compliance and personal data protection be ensured when collecting and sharing data?
6. How can long-term data sharing and cooperation agreements be established between rare disease researchers, patient organizations, and pharma?
7. How can FAIR principles be implemented and data from different registries be consolidated?

We have prepared some suggested approaches to address these topics based on our experience and best practices. You can find them on our website by clicking [here](#).

I hope you find this information helpful and relevant. If you have any questions or feedback, please feel free to contact me at any time.

We appreciate your support and collaboration in advancing rare disease research.

Sincerely,

George Reynolds

BOOK REVIEWS

[Push: My Father, Polio and Me](#)

by Sarah Passingham (Author)

The vast majority of the books that have been published in recent years looks at life, effects and solutions from the perspective of the person who contracted and was affected by the virus. This book looks at the effects and how polio affects the whole family.

Sarah Passingham's father, nicknamed Push (read the book to find out why) was a rowing oarsman destined for the UK Rowing Team of 1952 going to the Helsinki Games. That was until 6 weeks before the games he contracted paralytic polio that left him paralysed in both legs and lower torso. Add to that he was newly married with a young wife, and they were moving into their first home, a modest post WWII property.

The story is told by Push's wife from contemporary sources, namely the letters he wrote her every day from isolation hospital, and from her replies. Later it calls upon the memories of the author, and her interviews with her mother, and father.

Push was determined he was going to walk again, and move into his new home. His parents were affluent with a large house more suited to the type of facility and mobility equipment available at the time, so they adapted a down stairs room and Push and his wife moved in. This placed strain on their marriage, as you can imagine for a newly married couple and wife moving in with mother-in-law!

Eventually after much work, heart searching and the occasional disagreement they move into their own home and all that entails. The author describes her life with her father who she adored. This book is not the polio Survivor, it's for their family and friends. At the end it left me emotionally drained when due to circumstances Sarah was prevented from being with her father, with whom she had been through so much, at his end, albeit at a ripe old age.

- **Publisher** : Gatehouse Press Ltd (1 Nov. 2019)
- **Language** : English
- **ISBN-10** : 1912665026
- **ISBN-13** : 978-1912665020

Polio Girl: It Only Takes One

by Susan L. Schoenbeck MSN RN (Author)

Susan Schoenberg is both a registered nurse as well as being a polio Survivor and this is the one book that every polio Survivor must read. It tells her story as a little girl both before she developed paralytic polio, her parent's fight for her to be treated properly and the social stigmas that confined her to her home and garden whenever a polio case was detected in their home town. In essence both she and her parents were treated like pariahs. It describes her efforts to be accepted for nurse training and how she has gone on in N. America to become perhaps the most respected authority on the treatment and attitudes to Post Polio Syndrome.

The book is split into two separate and distinctive parts. The first being her story, the second detailed descriptions of the effects and forms of treatment for Post Polio Syndrome. It should be the bible for every doctor and medical practitioners who deal with PPS, and Late Effects of Polio, patients. It covers not just the usual physician's side of things but also those areas that impinge on physiotherapy, occupational therapy, speech and language therapy, social effects and the need for aid and adaptations as well as the distinction between PPS and ageing as well as where they overlap. It also looks at diagnosis as well as misdiagnosis of PPS.

It sits on my bookshelf with stick on markers showing me the most frequently used parts, in fact its open on my desk more than on the bookshelf as I reply to queries and requests for help from fellow polio Survivors and support groups.

If you have Amazon you can get it in a Kindle edition, certainly from www.amazon.co.uk (Free with Kindle unlimited otherwise £6.75 to buy) but if you want a physical copy, and it's just over 400 pages, log onto www.amazon.com (US based), log on as normal, buy from there (\$15.99 plus P&P if not a Prime member) and it will be shipped to you. That's how I bought it and I bless the day I did!

Product details – Kindle (www.amazon.co.uk)

- ASIN : B0B9LN5FLZ
- Publisher : Springwater Press (13 Aug. 2022)
- Language : English

Product details – Paperback (www.amazon.com)

- ASIN : B0B6L9TDR3
- Publisher : Independently published (July 16, 2022)
- Language : English
- Paperback : 430 pages
- ISBN-13 : 979-8533926980

Both book reviews were prepared by:

John R McFarlane, EPU Past President and EPU Honorary Member

28th – 29th March 2023

MISCELLANEA

Vaccination chaos?

If we compare vaccination legislation and polio vaccination calendars in EU member states and similarly in other parts of the world, we cannot help but be surprised by the significant differences between individual countries. Even in the EU, which otherwise loves to normalize often even trivial nonsense, there is a varied selection of polio vaccination options. At first glance, it would seem that solid scientific arguments support vaccination against polio, and therefore vaccination will be carried out according to the same scenario everywhere. However, the reality is different. In only 40% of EU countries is, vaccination against polio compulsory; outside the EU, it is 45%. Elsewhere vaccination is only recommended. So far, fortunately, the population in countries with optional vaccination is responsible, and the average vaccination coverage of the population does not differ much between the two groups. The difference is between 2-3%. Nevertheless, this idyllic situation does not have to last forever. Given that the goal of eradicating polio in the world is still not being met and its dates are still moving from the original year of 1988 to 2005, 2009, 2015, 2018 to the current year of 2027, there is a real threat of a polio epidemic in under-vaccinated European or other population. For example, the percentage of vaccinated children in Bosnia and Herzegovina, Mexico, and Brazil is (73%) or in Ukraine (33%). There are around 22 million unvaccinated children worldwide. Also, the number of vaccination doses varies between 3 and 7. France is interesting, where the three mandatory doses are followed by four recommended doses and possibly others according to the age reached. The median number of doses in the EU is 5, and in the world, 4. In Europe, inactivated vaccines of the IPV type are practically exclusively vaccinated in some non-European countries with weakened live OPV vaccines. Vaccination dates also vary. In Europe, the 2nd, fourth, and 18th months of age prevail; elsewhere, it is the second, third, fourth, 12th, and 72nd months. The duration of acquired immunity after vaccination is individual, and even the average duration is not known. This is probably many years. The known side effects of vaccination are minimal; they are exceptionally more serious allergic reactions.

If we summarize the current approach to polio vaccination in the world, there is still a lack of serious scientific information not only about its treatment but also about the optimal method of vaccination. There are still fewer paraplegics in the world, so there is not much hope for financing more complex research that would answer at least some of the questions associated with our disease.

Michal Haindl

Asociace polio / Polio Association, Czechia

EPU Board Director

Another snippet from Great Britain

European polio members may recall hearing about the discovery of the live polio virus traces in North and East London sewerage in early 2022. This caused much worry as it meant that polio was back in Europe. An immediate and urgent vaccination booster campaign last summer reached more than 370,000 children. Tests in early November found less of the virus but recent figures have shown that only 88% of London children have had three doses by the age of one compared with 92% in the rest of England. To combat any increase the vaccination is being offered through schools to those

who have missed out. Also, special attention is being paid to three-year olds who should have had the next booster, and 14-year olds who qualify for the final booster.

NB: The uptake for the pre-school booster for children aged five is even lower at 70% compared to 84% in the rest of England.

The NHS London has announced that during the school summer term, it will begin a “catch-up campaign”. Polio and other routine childhood vaccines will be offered to unvaccinated and partially vaccinated children aged one to 11 years. “Covid and school lockdowns have disrupted polio vaccination programmes, but we need to get back on track, especially in London. In some London boroughs vaccination rates are far too low.

“Clearly, polio is still around and when the virus strikes, if you are unvaccinated, it can be life-threatening. It can result in paralysis and serious later-life health problems. The vaccination programme has worked for decades, and it can continue to work, but all children must be vaccinated.”

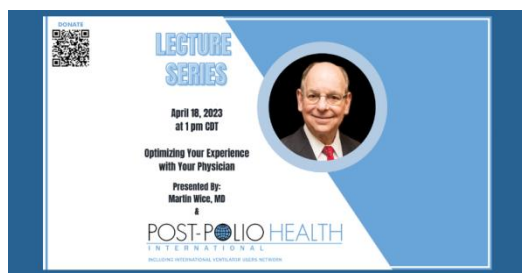
To date, no clinical cases of polio have been reported and the poliovirus strain found in London has not been detected at any of the other sites.

David Mitchell, EPU President

British Polio Fellowship

POST-POLIO HEALTH
INTERNATIONAL

Post-Polio Experts Present



“A series of timely informational videos are presented by dedicated experts who have significant experience in managing post-polio problems and in advocating for the survivors of polio. The presenters provide information and advice to the health professionals who treat polio survivors and also to survivors and their families. Check out additional videos on [PHI's YouTube channel](#).”

“For those unable to attend our recent April lecture with Dr. Wice, the recording is now available to watch on our website at <https://post-polio.org/education/post-polio-experts-present/>.

It is also available on PHI's YouTube channel along with many additional videos at <https://www.youtube.com/@post-poliohealthinternational>.

And follow PHI's [Facebook page](#) for the latest news concerning upcoming offerings.”

Source: Post-Polio Health International, links presented above



EPU MISSION

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

Our objectives are:

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

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

Opinion Disclaimer

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

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