



## 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 Slovakia, Germany, the Czech Republic, France, two representatives from Polio Ireland and two from the British Polio Fellowship. 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 (Rare Diseases Europe) gave us much welcome funding support and, alongside the actual AGM itself, monies were designated to enable disadvantaged members to attend (see Eurordis article in our Newsletter. Your Board continues to meet using Zoom, arranged by willing helpers.

Our finances are now well controlled (see separate accounts) 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 ([www.europeanpolio.eu](http://www.europeanpolio.eu)) long time task which has involved past directors and currently especially Prof. Haindl. 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. (Please try to answer this as quickly as possible). Also, an in-depth questionnaire about individual national statistics, polio clinics, rehab, research, websites and any practical help given to members. 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 eg 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 eg 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 disabled person 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](mailto: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**

**On behalf of the Board**

**EPU Board of Directors 2022-2023:**

David Mitchell	President	British Polio Fellowship
Patrick McGillion	Vice President	Polio Survivors Ireland
Tine Tournicourt	Treasurer	Post-Polio Belgium
Stefan Grajcar	Secretary	Polio Association Slovakia
Macrina Clancy	Director	Polio Survivors Ireland
Robert Cordier	Director	Polio-France
Michal Haindl	Director	Polio Association, Czechia
Paul Neuhaus	Director	Bundesverband Polio, e. V., Germany
Frances Quinn	Director	British Polio Fellowship

In the period from AGM in Prague, Czechia, on June 10<sup>th</sup>, 2022, and AGM in Nancy, France, on May 25, 2023, there were seven online zoom meeting of the EPU Board – three in 2022 (July 19, September 19, November 15), and four in 2023 (January 13, February 21, March 29, April 25).

Stefan Grajcar  
EPU Secretary