



EUROPEAN POLIO UNION

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EUROPEAN POLIO UNION
ANNUAL REPORT FOR THE YEAR 2023

Once again greetings from the nine directors of the Board, all of us polio survivors coming from seven different countries within the Council of Europe. We are a co-ordinating and communicating body made up at present of 20 national polio groups from 17 countries. As with many volunteer groups worldwide we encounter problems with old age, health restrictions, mobility and financial worries limiting our work. Members (who can be individuals in countries where there are no national bodies) pay subscriptions based upon numbers and I thank all involved for their financial support. You can see over the years from our published accounts that we are very frugal in our spending. (The directors pay all their expenses). We have adopted a policy of subsidising members' attendance at the AGM and this resulted in us supporting 36 attendees at our 2023 AGM held in Nancy (Northern France) alongside the excellent Polio France Congress. In fact, 31 visitors joined us at our AGM mainly from Polio France delegates and we were happy to have them as our guests. Something which we hope to replicate this year (2024) at our AGM in Budapest.

What has happened in 2023? Sadly, we said goodbye to Robert Cordier (France) but welcomed his replacement, Pierre Parrot who has already taken over as Co-ordinator of the Medical Committee. Much hard work has been out on the reviewing and, where necessary, rewriting our Mems and Arts (Statutes). Huge thanks to Macrina Clancy and Patrick McGillion from Polio Survivors Ireland backed up by the effort and knowledge of Stefan Grajcar (Slovakia) our director Secretary. We were fortunate to be advised by several past directors and two excellent sets of Belgian notaries (solicitors) who advised us on a pro bono basis. (NB: our registered address is in Antwerp and any significant change must be published in the official Belgian Gazette). We bank with 'Belfius' and our accountants are 'Santaks Bu'. At this stage I must thank Eurordis for their continued financial support of our AGM. As well as Eurordis we also subscribe to EFNA (European Federation of Neurological Alliances), and to EDF (European Disability Forum). We are taking a growing interest in the international Post Polio Syndrome Advocacy Group another welcome voice in the fight to highlight post polio syndrome.

We have weekly polio figures from the World Health Organisation and their Global Polio Eradication Initiative. We also have regular contact with our medical advisors, most of whom are honorary members. Another growing link is with Polio Australia whose energetic management have embarked on a 'medical pathway'. This is very similar to research and conclusions from the British Polio Fellowship's 'pathway' and we hope for greater co-operation.

As previously mentioned, we are still working on our re-jigged website, a task which will not be costly but requires many hours of hard but interesting work. One bright spot continues to be our excellent newsletter of which we can be proud; over 30 pages of excellent news, articles and information. As always, we urge you, our members, whether group or individual, to send in your news ranging from new equipment to alternative therapy, to what your national health authorities are providing for us 'post polios'.

We only meet once a year in person at the AGM but about every five weeks via Zoom, again at no cost to us being provided by a Board member. We are still very aware of those polio survivors stuck in their homes in Ukraine. Eurordis plays a role in monitoring these unfortunate colleagues. With Covid now in retreat in Europe we hear news of research into 'long Covid' and talk of large sums of

funding in many nations. Did we ever receive such largesse to look into PPS or LEoP (Late Effects of Polio)??

In closing this report, I have some happier news. In 2023 there were just 12 WPV1 polio cases reported worldwide compared with 30 in 2022 and 503 cVDPV2 (vaccine derived cases) reported in 2023 compared to 878 in 2022. Fortunately, the discovery of the live virus in sewage in eight London boroughs has not caused a single case of the disease.

I close by thanking my fellow directors for all their effort and hard work, to clinicians and our able-bodied supporters. The biggest thank you, however, goes to you, our members, for your interest and your support both financial and in person and for your friendship.

David Mitchell

EPU President, on behalf of the Board



WORLDWIDE POST-POLIO EDUCATION SURVEY

By Michael Jackson

Polio Australia Clinical Educator

Late in 2023, we reached out to known post-polio organisations internationally. This was to determine the features and needs of any post-polio education activities they engaged in, and also their position on education models, funding, health support, knowledge loci, and advocacy effect. Organisations and groups were asked to submit responses to an electronic survey. 20 responses had been received by March 2024.

A summary of results was created by Polio Australia that did not identify those who responded, and did not include any interpretation by Polio Australia. This summary was then shared with those organisations and groups who provided responses. Their individual interpretations have been encouraged, and we hope to receive or read about them. The summary of results can be found via this link: <https://bit.ly/ppedu-survey-results-0324>

What follows is Polio Australia's interpretation of the results. Keep in mind that neither Polio Australia nor its state member organisations completed the survey; Polio Australia was the facilitator of this process.

Response Rate

The response rate was low for the number of organisations and groups we contacted. 80% of responses were from small regionally acting groups. Ideally, we would like to see another 15-20 responses from unrepresented regions to be more confident in the strength of what appear to be

shared concerns, but also to better see any differences between post-polio organisations and post-polio support groups/networks.

Trend Areas

The following areas had high group responses, or agreement in a particular direction:

- Education is primarily provided to fit groups' purposes, resolve education demands, and fill a recognised education gap
- Education is predominantly provided to all members, and to non-members and community groups
- Polio experts are a major source of education content
- The top modes of education were support group discussion, newsletters and electronic resources
- Most felt they managed education well, but would like to improve it
- For half, funding comes from donations or from local government
- Measuring, monitoring and evaluating education is mostly informal
- There is an agreed need for education of the polio-affected and their clinicians
- Confidence is low in the post-polio support provided by large health systems
- Those affected by polio are seen to hold loci of knowledge on post-polio conditions
- Member satisfaction is oriented to a mix of factors related to advocacy work
- Member dissatisfaction is strongly oriented to lack of knowledge amongst local medical and health professionals
- Almost half favoured a national program model - they may be seeking leadership or cohesion with post-polio education
- The majority of organisations and groups are willing to share their education experiences with others

Problem areas

- Cohesion of post-polio organisations and groups needs to be established around the most common or most-restricting concerns about education
- Three quarters of the responses obtained were from North America and this may have skewed some of the results
- 45% to 70% do not educate health professionals, yet 'lack of education of clinicians' is the strongest dissatisfaction theme for members
- Post-polio experts are a main source of content, but they may be inaccessible to members and clinicians given the level of dissatisfaction with clinicians
- About half see the value in a professional registry, yet there appears to be limited formal education of clinicians enabling them to qualify for a registry
- The factors limiting post-polio education provided are diverse for these organisations and groups – only two options reached a level of 35%

Synopsis

Polio Australia's mission is *to standardise quality polio information and service provision across Australia for polio survivors*. We have a two-pronged education approach – one arm for each of the two key audiences highlighted in this survey: polio survivors and their families and carers, and multidisciplinary clinicians.

The responses from other organisations and groups to this survey highlight the same barriers, problems and frustrations that we have recognised. Yet what we have in Australia is a structured, formal and professionally-led approach, already enacted, to reduce that which has been recognised.

This survey has enabled us to obtain new ideas and observe context that will advance our own education programming, but most importantly it confirms that we are not alone in wanting or trying to resolve what we face. We know education is much more than having information on a topic – it is also about the delivery and

contextualisation of information so that information is put to best use.

We recognise that some aspects of post-polio education and the approaches to it are quite varied. There is likely no ‘one-size-fits-all’ solution internationally. But, this survey provided evidence that there is good potential and motivation across organisations and groups to make improvements in what they do with their education, and to work together to benefit those affected by polio more broadly.

What’s next?

We will try to establish a path forward with international post-polio organisations and groups, based on what the survey showed and how it was interpreted by those who have done so. Ultimately, we endeavour to progress the following:

- Raise the profile of collective need for post-polio education here and abroad
- Advance the scope and delivery of education for those seeking it worldwide
- Secure support for post-polio education activity across nations as a means to constrain health-costs and improve care efficiency; and - fundamentally -
- Increase the quality of life and participation ability of those affected by polio

The survey is still open and accepting international responses – we continue to establish contact with previously unreached groups and organisations. Click [here](#) for a link to the survey.

Keep an eye out for an infographic about this survey on social media – it will be circulating in the next week or two.

February 2024

Published in the Polio Oz News, Volume 12, Issue 1, March 2024 – Autumn Edition;

<https://www.polioaustralia.org.au/polio-oz-news-2024/>



OPTIMAL CLINICAL PATHWAY FOR POLIO SURVIVORS (INCLUDING THE LATE EFFECTS OF POLIO AND POST-POLIO SYNDROME)

The British Polio Fellowship has launched a pathway to outline how good treatment, care and support looks like for polio survivors in England, Wales, Scotland and Northern Ireland.

The British Polio Fellowship, a national charity supporting and empowering polio survivors unveiled its clinical pathway during an event held yesterday (20 March), attended by more than 100 people.

Healthcare commissioners, general practitioners, clinical specialists, and therapists working locally and in neurological rehabilitation centres and specialist centres will have a much better understanding of the pathway polio patients should be following, to enable them to provide more effective care with earlier diagnosis, improved treatment, and better outcomes.

“For many years polio survivors have reported delays in diagnosis, a lack of awareness by healthcare professionals of the late effects of polio and post-polio syndrome and poor levels of care beyond specialist centres.

“With the support of clinicians and people affected by polio across the UK, the pathway has been developed to show what is needed to provide good healthcare for the polio community.

“The pathway has been endorsed or approved by numerous clinical, professional organisations and this is a major step forward” explained Kripin Dhrona, Chief Executive Officer at the British Polio Fellowship.

In the UK, over 76,000 cases of polio were recorded between 1932 and 1962, significantly dropping after the vaccine was introduced in 1956. Today, it is estimated at least 47,000 people are living with the late effects of polio. It is anticipated this figure is even higher, because many polio cases were not recorded at the time, either because the person fully recovered, or polio simply was not reported.

Polio was eradicated in the UK, in the 1980s. Those who had contracted polio, were left with varying levels of disability such as paralysis, a shortened or withered arm or leg, sleeping or breathing issues, or twisted and bent spine.

As they grow older, survivors are beginning to notice worsening or new symptoms. Post-polio syndrome (PPS), as it is known, is quite common amongst those who have had polio. Around 60% will go on to develop new muscle weakness, leading to further muscle atrophy and worsening pain, fatigue and breathing issues.

The Fellowship advise polio survivors experiencing deteriorating or new symptoms to take a copy of the pathway with them when they visit their GP. They may need to be referred to a neurologist or specialist centre, such as the Lane Fox Unit in Guy’s and St Thomas’ Hospital in Westminster, London.

Dr Simon Shaw, Clinical Lead for the pathway and former Consultant in Rehabilitation Medicine at Lane Fox said, “Once a patient has a very clear care plan, they can be referred to a whole multitude of people. For example, at Guy’s and St. Thomas', we have some very specialist orthopaedic

consultants who work with polio patients, who are adept in looking at knee replacements and joint replacements.

“There is very specialist experience around pain management, but also respiratory management, sleep disorders, and a whole range of other people. And then obviously, there’s the ongoing therapy and some very esteemed colleagues at Guy’s and St. Thomas’ lead that through the Lane Fox post-polio service.”

Dr Shaw has gone on to become Clinical Director at The National Spinal Injuries Centre in Stoke Mandeville, Buckinghamshire.

Shaw added “Polio patients are very deserving of this tailored and specialist care, and I think it shouldn’t be underestimated. Even though a lot of the symptomology is in common with other neuro disabilities, the polio cohort come with a unique set of circumstances. So socially, psychologically, historically, I think there’s a real role for a specialist service.”

The polio community in the UK is a broad church of people with various needs. It includes young people, older people, people with children, people still at work and survivors from other countries.

“The pathway is a guide and will need to be flexible and tailored to the individual for it to be used locally and regionally – or adapted to local population needs” commented Dhrona.

“We very much hope it will raise the level of awareness and prioritise the needs of survivors with late effects of polio or post-polio syndrome.

“But equally important, it needs to direct Commissioners of Health Boards and Integrated Care Boards to ensure healthcare services can meet the needs of this very important population.”

The pathway document is now available on the British Polio Fellowship website:

www.britishpolio.org.uk

- [Optimal Clinical Pathway for polio survivors \(PDF\)](#)
- [Optimal Clinical Pathway for polio survivors: summary \(PDF\)](#)

Source:

<https://www.britishpolio.org.uk/post/charity-sets-out-an-optimal-pathway-for-polio-survivors>

HOW MANY OF US ARE THERE?

ESTIMATION OF THE NUMBER OF POLIO SURVIVORS IN THE UK IN 2024

Frances Quinn

British Polio Fellowship (BPF)

A key question we get asked is 'How many polio survivors are currently living in the UK today?' The answer is that this may never be accurately known for several reasons. Many records were lost. Infection recording varied, cases that did lead to distinct paralysis were not always recorded; mild polio cases could not always be diagnosed, especially in infants. However, to help communication

with the health care system, we do need some estimate of possible numbers. Previous attempts 24 years ago ranged from 70,000 to 154,000¹.

Accounting for the change in notification of non-paralytic polio in 1950, there were 80,000 cases reported in England and Wales from the start of recording in 1912, giving about 90,000 in the UK. For some time, the BPF has used an estimate of 120,000 polio survivors in the UK to include an allowance for under-reporting of mild or asymptomatic cases. Given that those who contracted polio in the UK epidemics from 1947 to 1962 are now over 60 years old, that number is reducing.

I have aimed to estimate both the current numbers of polio survivors and those likely to develop PPS based on 1) the available notification data combined with 2) published survival projections. I hope this exercise is of interest to other support groups being asked the same question.

Statutory notifications for the UK and their limitations

Polio became notifiable in England and Wales in 1912. The data for England and Wales is shown in Figure 1 below. These are now available on the UK National Archives², and give the number of acute poliomyelitis (paralytic), acute polioencephalitis / (non-paralytic), total deaths and, from 1951, deaths excluding late effects. Before 1951 all deaths were recorded in the year of the death and not linked to the date of infection and so distort the numbers. In later years, more deaths are recorded than cases as shown by the black curve in the enlarged inset in Figure 1. If the number of total deaths is simply subtracted from number of cases, this would give negative values for survivors in the later years of the epidemic.

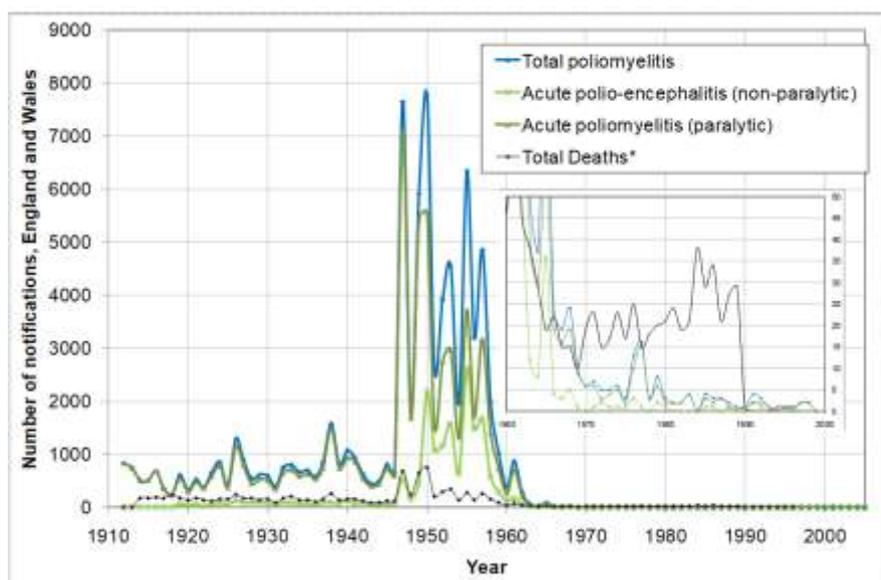


Figure 1. Notification data for England and Wales

Poliomyelitis became a notifiable disease in Northern Ireland in 1913 and in Scotland in 1926. The published data for Scotland and Northern Ireland is not as complete as for England and Wales and will be added to the estimate differently.

¹ Salter, C. (2000). Post-Polio Population Statistics - A Review. Retrieved from <http://www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/uk/pppopstats.html>

² Follow /infections A-Z/polio/epidemiological data on <https://webarchive.nationalarchives.gov.uk/ukgwa/20120528151721/http://www.hpa.org.uk/Topics/InfectiousDiseases/>

There are gaps in all the information. Especially before the major epidemic in 1947, the true incidence was likely to be much higher than statutory notifications. For example, Simpson comments in 1947³:

"but there are good reasons for believing that the true incidence was much greater than the numbers of statutory notifications. Four of the sixty-seven local authorities in Northern Ireland did not make the disease notifiable until recently; three in 1941, and one in 1948."

There is evidence to show that the percentage of non-paralytic cases reported was lower in non-epidemic years and areas.

"To sum up: any estimate of the incidence in previous years in Northern Ireland must be speculative. The indications are that 50 per cent. or more of the cases with some degree of paralysis are not notified in non-epidemic periods, and that many more cases occur in winter and spring than the recorded figures show."

Diagnosis of the class of polio cases was inconsistent and not everything was recorded. A common classification included:

- asymptomatic - no visible symptoms, sometimes referred to as 'silent' or inapparent
- abortive - some symptoms, no meningitis or paralysis
- polio-encephalitis (non-paralytic) - sometimes called aseptic meningitis, which is confusing as aseptic meningitis can be caused by other viruses as well as polio.
- poliomyelitis (paralytic) - originally called infantile paralysis, though other viruses can cause paralysis in children, and polio could also infect and paralyse adults

What was statutorily notifiable along with paralytic polio was changed in 1950 from polioencephalitis to non-paralytic polio (bright green curve in Figure 1). As a result, the ratio changed from ~10% before 1950 to between 20% and 45% (red curve in Figure 2). As 1947 and 1949 had many notifications, a more typical ratio of non-paralytic to total cases of 35% was used for all the years prior to 1950 for this estimate.

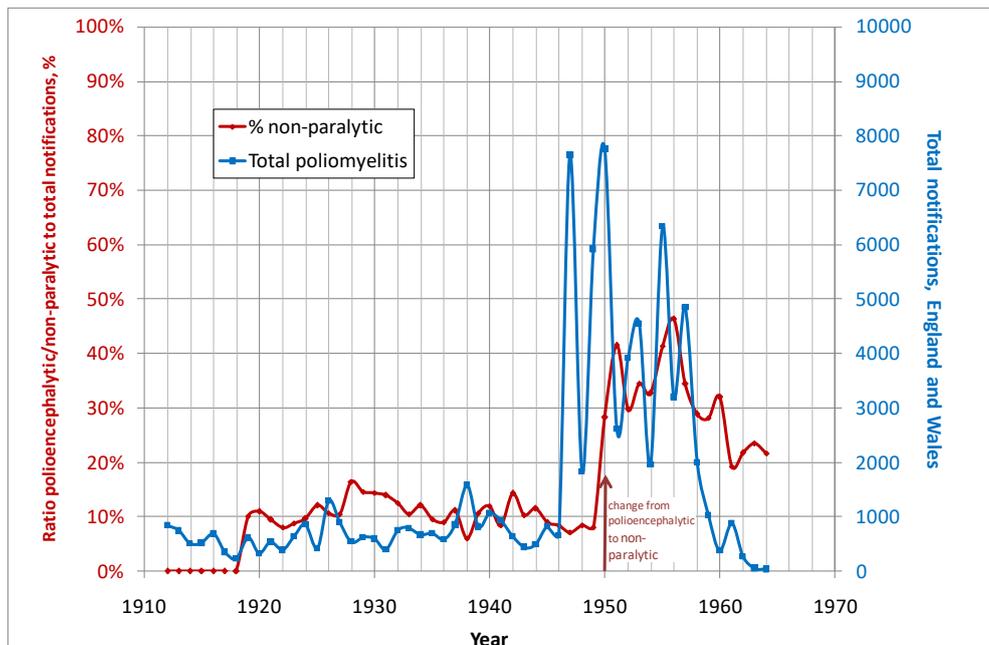


Figure 2. Ratio of non-paralytic/polioencephalytic cases (red curve) to total notifications

³ Simpson, N. J. Y. Poliomyelitis in Northern Ireland - 1947 with Special references to Epidemiology. *Ulster Med. Journal*, 67-80.

Survival data from Office of National Statistics (ONS).

The ONS publishes survival data (probability of having survived to a particular age) for the UK every 2 years, the most recent release was in July 2022 and presented data up to 2020⁴.

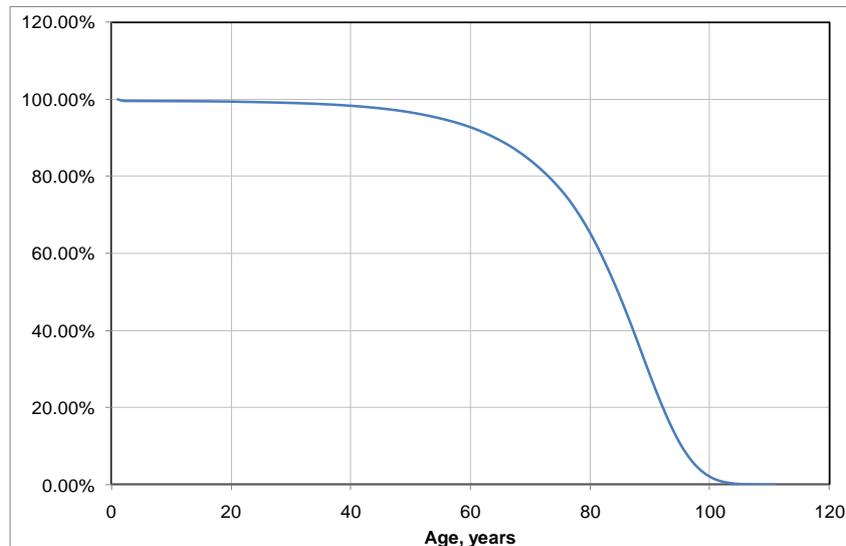


Figure 3. Office for National Statistics survival curve (average of men and women). This shows, for example, for 100,000 people born in 1950, who would be 70 in 2020, that 82.9% are likely to have survived.

Year of birth/age

To use the notification data and survival percentages to estimate survival to 2020, we need to link the notification data to the age people were when they contracted polio. Knowing an approximate age spread for polio survivors in 2020 will enable calculation of their probability of survival from the ONS data. Age at contracting polio is not available on the published England and Wales notification data, though it does exist and has been requested.

A first estimate was done in 2020 using the 2020 survival data release and assumed an age of four years for contracting polio. This gave a figure for the UK of 47,000. Four years is the peak age year for contracting polio in published papers⁵. Using this single age simplified the calculation but would have overestimated the survival for those over four and underestimated it for those below four.

I have now found published numbers for 7 age bands varying in span between 1944 and 1954, which covers about 60% of the relevant notification cases (1932 to 1998)^{6,7} and is consistent with published UK data for 3 age bands from 1910 to 1962⁸ (see Figure 4).

The age bands, representative age, and percentage in each band are shown in Table 1.

⁴ <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/lifeexpectancies>

⁵ WHO, Freyche, M.-J., & Nielsen, J. V. (1955). Poliomyelitis. *Who monograph*.

⁶ Payne, A. M.-M., & Freyche, M.-J. (1956). Poliomyelitis in 1954. *Bull. Wld Hlth Org.*, 15, 43-121.

⁷ Logan, W. P. (1952). Distribution of poliomyelitis by sex, age, and geographical area. *Mon Bull Minist Health Public Health Lab Serv*, 11, 147-173.

⁸ Lee, M. (1963). Price of Poliomyelitis: OHE Monograph. Available from <https://www.ohe.org/publications/price-poliomyelitis/>.

Table 1. Overall percentage in each age band and representative year used, with the variation of age in each band.

band	% of total notifications	Age used, yr	Age variation in band
<1	3.7%	1	-1yr
1-2	15%	2	-1yr
3-4	13.9%	4	-1yr
5-9	22.9%	7	±2yr
10-14	12.3%	12	±2yr
15-24	14.5%	19	-4 to +5yr
25+	17.2%	35	-10 to +65yr
unspecified	0.5%	n/a	unspecified

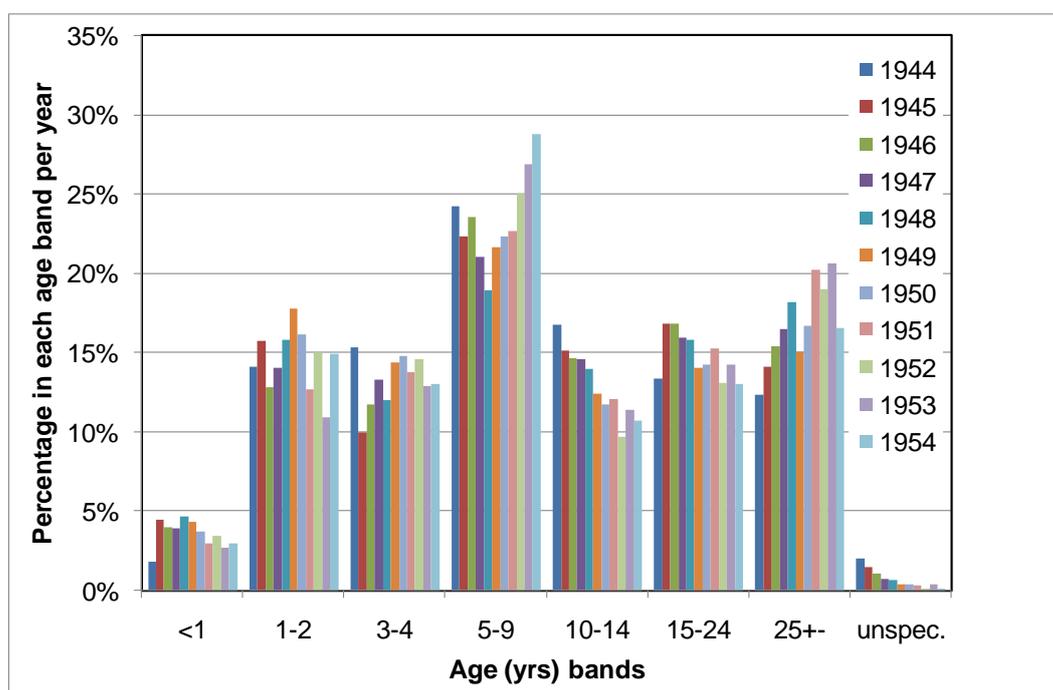


Figure 4. Variation of percentage of polio notifications per year in each age band for the years 1944 to 1954

As the percentages are relatively constant over the epidemic years, it is reasonable to use an average percentage and representative year for each band and link to an approximate year of birth. For example, in 1951, there were 2423 notifications (total-death); using 3.71% for age<1 gives 89 polio cases with year of birth 1950 and thus $89 \times 82.3\% = 74$ polio survivors 70 years old in 2020 who contracted polio in 1951. This is then repeated for each of the 7 age bands in each of the years from 1912 to 2005, then adding together survivor numbers of the same age in 2020. For age 70, that gives 1652 survivors in 2020.

The 2020 ONS period life tables (life expectancy) can then be used to estimate the numbers surviving to future years. For age 70 in 2020, the period life table gives a survival rate to 2022 of 96.5% giving 1594 survivors age 72 years in 2022. The latest period life table data from 1981 to 2020 are based on historical mortality rates and from 2020 assumed mortality rates which stay constant into the future. If cohort life tables are used, these include assumed future changes in mortality, which generally improve, but become less reliable if projecting further into the future.

Number of UK polio survivors

The results for polio survivors still around in 2020 are given in **Table 2** below, giving the numbers by age band and by pre-epidemic, post-epidemic and epidemic years. As expected, the survival is lowest for higher age bands and pre-epidemic years. Also as expected the survival rate for age bands above 4yrs reduces sharply as people infected in the UK are now reaching the critical ages between 70 and 100 yrs. This is also when they are most in need of good care and when even mildly affected people can start to see significant effects.

Table 2. Estimated number of polio survivors in 2020 for England and Wales - ratio of polioencephalitis/non-paralytic cases (NP) before 1950 adjusted to 35% of total notifications.

Age bands	Notification year	Notifications less deaths, ratio of NP = 35% before 1950	Number in 2020	% survival	total age band survival
age band <1 yr (band range 1yr) (age used 1yr)	1912-1946	1260	537	43%	67%
	1947-1962	1711	1453	85%	
	1963-2005	12	11	96%	
age band 1-2 yrs (band range 2yrs) (age used 2yrs)	1912-1946	5133	2074	40%	65%
	1947-1962	6970	5834	84%	
	1963-2005	48	46	95%	
age band 3-4 yrs (band range 2yrs) (age used 4yrs)	1912-1946	4752	1706	36%	62%
	1947-1962	6452	5225	81%	
	1963-2005	44	42	95%	
age band 5-9 yrs (band range 5yrs) (age used 7yrs)	1912-1946	7810	2269	29%	56%
	1947-1962	10604	8051	76%	
	1963-2005	73	68	93%	
age band 10-14 yrs (band range 5yrs) (age used 12yrs)	1912-1946	4198	755	18%	45%
	1947-1962	5700	3661	64%	
	1963-2005	39	35	90%	
age band 15-24 yrs (band range 10yrs) (age used 19yrs)	1912-1946	4959	285	6%	26%
	1947-1962	6733	2727	41%	
	1963-2005	46	38	83%	
age band 25+ yrs (band range 75+yrs) (age used 35yrs)	1912-1946	5861	0	0%	1%
	1947-1962	7958	114	1%	
	1963-2005	55	24	45%	
all age bands	1912-1946	33972	7626	22%	43%
	1947-1962	46128	27065	59%	
	1963-2005	316	264	84%	
totals	all years	80417	34955	43%	

Numbers were projected forward using ONS life expectancy data to compare to the numbers from The Big Survey conducted by the British Polio Fellowship in 2022, see Figure 5 below. This shows excellent (even remarkable) agreement in the shape of the curve with the current estimates. The Big Survey was of all members, had 1000 responses and includes those who contracted polio abroad giving higher numbers for ages less than 60.

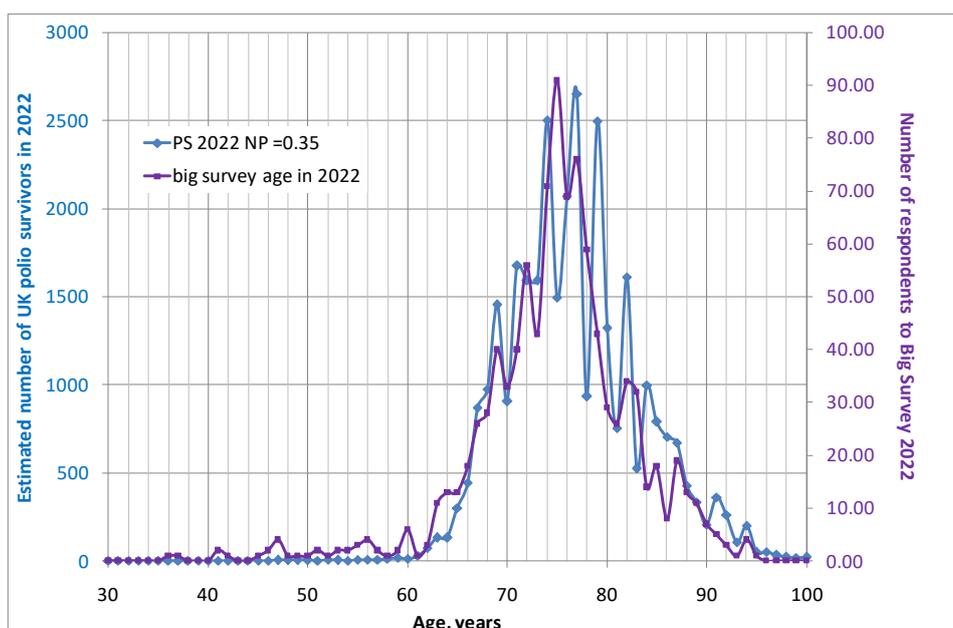


Figure 5. Comparison of the estimate numbers by age to BPF Big Survey 2022 responses.

I have not yet found complete data for Scotland or Northern Ireland, so to estimate numbers for the UK, I have used the ratio of notifications during 1947 to 1962 (including deaths) for those countries^{9, 10} compared to England and Wales. There were polio cases in the Jersey, Guernsey and the Isle of Man, but I have not found any comparable data to use. It is expected that based on the much lower population, this would add a small number of cases to the UK total.

Table 3. Notification data for England+Wales, Scotland and Northern Ireland.

country	Notifications inc. deaths	Notifications exc. deaths
England and Wales	79287	69986
1912-1946	23815	18661
1947-1962	55106	50993
1963-2005	366	332
Scotland	7836	
1926-1946	1898	
1947-1962	5938	
Northern Ireland	1797	1616
1938-1946	152	93
1947-1962	1638	1517
1963-1967	7	6
Scotland/E+W	10.78%	
N.Ireland/E+W	2.97%	

Using a ratio of 10.78% for Scotland and 2.97% for Northern Ireland gives a total figure for the UK surviving to 2020 as 32,858 (see Table 4).

⁹ Hedley-Whyte, J., & Milamed, D. R. (2019). International Contributions toward the Conquest of Polio. *Ulster Med, Journal*, 88(1), 47-54.

¹⁰ Lee, M. (1965). Residue of Poliomyelitis. OHE Monograph. <https://www.ohe.org/publications/residue-poliomyelitis/>

The largest, most recent epidemiological study by Kay et al¹¹ gives a ratio of 57% of people with a history of polio experiencing some PPS symptoms, giving an estimate for the UK of 22,664 with post polio symptoms.

Table 4. Estimated numbers of polio survivors in the UK, including PPS cases.

country	2020	2024
England and Wales	34,955	28,886
Scotland	3,767	3,113
Northern Ireland	1,039	859
total UK	39,761	32,858
PPS estimate, 57%	22,664	18,729

The estimate of 39,761 for the UK using 7 age bands is lower than the estimate done in 2020 of 47,592 and used in the Optimal Clinical Pathway for Polio Survivors¹². This assumed contraction of polio at 4 years for all cases. Table 2 shows that the survival rate at 4 years is 62% with the rate for <4 slightly higher, but the rate for the older age groups is much lower, giving a lower number overall.

Projecting survival forward to 2024, the total number reduces to just under 33,000. For the health care system in England with 28886 survivors, this would mean about 600-700 per Integrated Health Board, 4 per GP practice, and less than 1 per GP. Experience managing the late effects of polio or PPS will be very low at general practice level.

Preliminary figures for Scotland for people registered with a GP and with a recorded condition code related to polio is just over 2000 - 60% less than the 2024 estimate here, but of a comparable scale.

How 'real' is this estimate?

The estimate of 32,858 in 2024 is based on available data which has limitations. The recording of deaths and especially late deaths changed during the relevant epidemic and could not be properly interpreted perhaps giving an overestimate of 1% (328).

The projection forward from 2020 uses life table data that assumes the 2020 mortality rate. While the general trend of reduction in mortality was impacted by Covid-19, survival rates are still likely to increase. This would increase the projected figure for 2024. There has been some suggestion from epidemiological studies that mortality is slightly increased in polio survivors and could affect the projected figures¹³.

The recording of non-paralytic cases also changed, only being notifiable from 1950. This estimate used a rough average ratio of 35% over all the cases.

The percentage of recorded non-paralytic cases varies from country to country with some above 60%. It tends to be higher in epidemic years and in autumn. It tends to be lower in infants (as low as 10% for age<1 when it was >30% for over 5yrs). Increasing the ratio of non-paralytic cases to 35% in all age bands<5yr over all years would

¹¹ Kay, L., Nielsen, N. M., Wanscher, B., & Jennum, P. (2019). Neurological Symptoms in Danes with a History of Poliomyelitis: *Eur Neurol*, 80(5-6), 295-303. doi: 10.1159/000497483

¹² <https://www.britishpolio.org.uk/optimal-clinical-pathway>

¹³ Kay, L., Nielsen, N. M., Wanscher, B., Ibsen, R., Kjellberg, J., & Jennum, P. (2017). Morbidity and mortality following poliomyelitis - a lifelong follow-up. *European journal of neurology*, 24(2), 326-333. doi: 10.1111/ene.13201

increase the total estimate by 8% (2,600). To assume a figure of 50% for non-paralytic cases would increase the total by 25% (8,000).

Payne and Freyche¹⁴ caution about the percentage of non-paralytic cases....

"....not only is the percentage distribution of virus types the same among paralytic and non-paralytic cases within a given year even when studied in two years of widely different prevalence of types, but also that the percentage of paralytic cases for each of the three types remains approximately constant at 60 %-70 %. It should, however, be stressed that this refers to the percentage of paralytic cases among persons suffering from readily recognized clinical disease and not, of course, to the percentage of paralytic cases resulting from infection."

This estimate covers only those who were notified as contracting polio in the UK. Polio continued to be endemic widely into the 21st century and is still not fully eradicated. Global migration will contribute to total polio survivor numbers in the UK and will keep a requirement for health care for decades, but at lower numbers. It will be difficult to estimate these numbers.

So, what is the real number?

The UK figure of 32,858 for 2024 can be considered the 'hard' number of officially reported cases¹⁵. The predicted age spread is consistent with BPF Big Survey results. For Scotland in 2024, the estimate of 3,113 is higher than the preliminary data from the 2022 health record search, but of the same scale¹⁶.

Due to the limitations of the notified data, the 'real' number will be higher. Even the conservative increase justified above in the percentage of unreported/undiagnosed non-paralytic cases would increase this number to over 40,000.

The impact of 'silent', 'abortive', or 'inapparent' cases is unknown - with an infection rate 100 times the notified case rate, this impact on total numbers could be very large, even 1% of these would double the estimate. These cases are increasingly important as more mildly affected people only seek help much later in life.

The most realistic way to present the UK number is:

We do not know for certain, but it is a minimum of 33,000 and likely more than 50,000.

Contact for any feedback and comments: frances@britishpolio.org.uk.

¹⁴ Payne, A. M.-M., & Freyche, M.-J. (1956). Poliomyelitis in 1954. Bull. Wld Hlth Org., 15, 43-121.

¹⁵ Becker, L. C. (2006). Polio Survivors in the U.S., 1915-2000 Age Distribution Data: Post-Polio Health International.

¹⁶ Preliminary information from Scotland thanks to George Allan.

**EUROPEAN FEDERATION OF NEUROLOGICAL ALLIANCES,
LONDON HEATHROW, APRIL 2024**

EFNA is a pan-Europe organisation made up of 20 groups ranging from polio to strokes, to epilepsy, multiple sclerosis, ME, Parkinson's, ataxia, neuropathies, brain tumours, meningitis, ADHD, encephalitis, Huntingdon's disease etc. As the EPU is a full member of EFNA then you, as EPU members in your national bodies are also members.

On the first day, the Annual Report (available on line) was published, discussed and approved together with the financial results. The EU and global policy and advocacy action for neurology were featured. Led by Executive Director, Orla Galian from Ireland, all the groups present gave an outline of their activities. A new group of 12 community advocates was presented to us and other than a change of Treasurer, all nine board members (the same number as the EPU) continued in post. The meeting and round-table interaction was very ably led by President Mrs Astri Arnesen from Norway.

The second day was very useful with three medical presentations, a good video and round-the-table exercises that produced many ideas, good thinking and much humour! EFNA is involved in many areas of research and has links with some major pharmaceutical companies. EFNA has a total income of €499,212, a huge amount compared to the EPU. Their budget expenditure is €442,876!

Delegate travel, food and accommodation were paid for by EFNA. We will continue to update EPU members as to future co-operation both with EFNA and EURORDIS. Two good and useful contacts.

David Mitchell

EPU President

April 8, 2024



**EURORDIS LAUNCHES PRE-ELECTION CAMPAIGN
FOR RARE DISEASE EQUITY**

Thursday, 29 February 2024, Brussels – On the occasion of Rare Disease Day EURORDIS - Rare Diseases Europe has launched its [Championing the Rare \(#ActRare2024\)](#) campaign, which is calling on the EU's next leaders to take specific policy actions to make sure that the 30 million people living with a rare disease in Europe can have longer, healthier and better lives.

In the face of the persistent inequities and systemic failures facing people with rare diseases across the EU, the policy recommendations of the EURORDIS Championing the Rare campaign emerge as a clarion call for urgent, transformative action.

Targeting prospective European Parliament members in the June 2024 elections, nominees for the next European Commission, and other prospective EU policymakers, the *#ActRare2024* campaign outlines [eight vital policy domains](#) where advancements are imperative for the rare disease community and the building of a truly inclusive European Health Union.

These proposals are grounded in the findings of the landmark [Rare 2030 foresight study](#). Commissioned by the European Parliament, financed by the European Commission, and spearheaded by EURORDIS, the two-year *Rare 2030* study concluded in 2021, setting forth precise policy recommendations designed to meet specific objectives by the year 2030.

The eight key policy calls of EURORDIS' *Championing the Rare* campaign include:

1. Establishing a comprehensive **European policy framework** on rare diseases.
2. Promoting earlier, faster, and more accurate **diagnoses**.
3. Integrating national and European **healthcare pathways**.
4. Ensuring timely access to affordable and **innovative treatments**.
5. Delivering integrated, person-centred and lifelong **holistic care**.
6. Boosting innovative and needs-led **research and development**.
7. Optimising **data** for patient and societal benefit.
8. Supporting sustainable and resilient **treatment development**.

Concurrent with the launch of the Championing the Rare campaign, EURORDIS and more than 20 national rare disease alliances from across the EU have [penned a letter](#) to Ursula von der Leyen, President of the European Commission, urging the adoption of the proposed European Action Plan for Rare Diseases in the Commission's work programme for 2024-2029.

The campaign launches one year after **Frédérique Ries MEP**, Chair of the [Network of Parliamentary Advocates for Rare Diseases](#), was the lead signatory of a [letter \(23 February 2023\) sent from 48 MEPs](#) to the European Commission President calling for a European Action Plan for Rare Diseases.

Reiterating the particular message about the need for a European Action Plan for Rare Diseases, the letter sent today from EURORDIS and national rare disease alliances – whose publication coincides with the *Championing the Rare* campaign launch – emphasises that the Action Plan should “bridge national and European legislation, policies and programmes across the Pharmaceutical Package, the European Health Data Space, European Reference Networks, Europe's Beating Cancer Plan, EU4Health, Horizon Europe, the European Pillar on Social Rights, the European Disability Strategy, and beyond”.

For additional details on the calls of the Championing the Rare campaign and information on how you can lend your support to the rare disease community, visit the [#ActRare2024 campaign page](#).

You can also [read the letter](#) sent from EURORDIS and national rare disease alliances to President of the European Commission Ursula von der Leyen on the need for a European Action Plan for Rare Diseases.

Source and more information on the subject: <https://www.eurordis.org/actrare2024-launch/>

February 2024



EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS' (EFNA)

Upcoming EU Elections

Between 6 and 9 June 2024, millions of people in the European Union vote for Members to represent them in the European Parliament. EFNA considers this to be a key moment: MEPs take decisions that affect the daily lives of everyone, a considerable amount covering important healthcare issues that have a direct impact on patient organisations and patients' lives.

Read more about why the European Elections matter [here](#).

We need your voice!

The resources below have been created to assist individuals and organisations in advocating for neurology among Europe's future policymakers.

Please feel free to use and adapt these resources in the way that is most suitable for you, or your organisation. You are encouraged to include information relevant to your region or to the disease area you represent.

[Contact information for currently serving MEPs](#)

[Contact information for MEP research and health committees](#)

[Details of Political Groups serving in the EU Parliament are available here](#)

[Details of candidates running in each country can be accessed from this page](#)

ELECTION MANIFESTO SUMMARY

The EFNA Election Manifesto presents a comprehensive roadmap toward prioritising optimal quality of life for people with neurological conditions and their carers. Neurological conditions are the most frequent, disabling and costly of all non-communicable diseases in the EU. This manifesto outlines the urgent need for enhanced research, patient engagement and equitable access to treatments to support neurological patients. It emphasises the importance of collaborative efforts, including setting up an EU Joint Action on Neurological Conditions, launching a European plan to promote brain health, optimal living for neurology patients and combat neurologic and brain disorders, leveraging the upcoming Brain Health Partnership for the benefit of neurology patients and implementing the WHO neurological action plan, to improve outcomes for individuals with neurological conditions.

EFNA calls on EU policymakers to:

Implement a well-resourced EU Joint Action on Neurological Conditions and Brain Health.

Revise European pharmaceutical legislation to encourage advancements in neurological treatments.

Better resource and integrate the European Reference Networks in national healthcare systems.

Launch a patient-centred Brain Health Partnership with adequate resources from EU Institutions, Member States and for-profit actors.

Create the European Plan to Promote Brain Health, Optimal Living for those with Neurologic Conditions and Combat Neurologic and Brain Disorders.

Ensure active and equal patient participation in R&D activities and decision-making processes.

Adhere to the European Pillar of Social Rights, supporting neurological patients facing socioeconomic challenges.

Align the EU NCD Initiative's neurological strand with the targets of the WHO IGAP.

Prioritise IGAP targets to raise policy prioritisation and strengthen governance.

Develop national and EU-wide awareness campaigns and plans for neurological conditions.

Strengthen neurological patients' capacity at a national level through a dedicated EU project.

Foster national neurological alliances to facilitate the implementation of the IGAP.

Source: <https://www.efna.net/eu-elections-toolkit/>; 15. 4. 2024



BRIEFING ON THE APPROVAL OF THE EUROPEAN DISABILITY CARD PROPOSAL FOR EDF MEMBERS AND PARTNERS

Summary report of the webinar

27 February 2024

Introduction

André Felix, EDF Communications Coordinator, introduced the topic and the housekeeping rules for this briefing. He gave a short summary of what has happened in the legislative procedure so far. The Disability Card started as a pilot project in 8 countries in 2016. The European Commission then published a legislative proposal in September 2023 after more than 10 years of campaigning – a big

success for the disability movement! The negotiations on the proposal were completed in record time and the provisional agreement was adopted on 8 February 2024.

Main presentation

European Disability Card

Marie Denninghaus, EDF Senior Policy Coordinator, presented the update on the text of the political agreement that was reached. The text is final, but it is not an official EU law yet. It still needs to be voted by the European Parliament, which will hopefully happen in April.

First of all, a short recap was given of the content of the original proposal. The text is still a Directive, which is the second “strongest” type of EU legislation and which still needs to be transposed into national law. It also includes the Parking Card for persons with disabilities („blue badge“), which is sometimes forgotten because we mainly talk about the Disability Card. The legal bases of the text are internal market, transport, and non-discrimination and it is still based on the principal of mutual recognition of disability status.

As opposed to the pilot project, the current proposal includes all services and not only culture, leisure, sport, and transport (which was optional). Transport is now explicitly included and we do not have a restrictive list anymore.

There is a second legislative proposal which will extend the card to third country nationals, so people from outside of the EU who live in the EU legally would also then be able to apply for the card. For technical reasons, this was separated from the original proposal, so we don't know yet when or if it will be adopted.

EDF has achieved many good improvements of the text such as:

- Inclusion of transport services, even if some exceptions will apply.
- Inclusion of provisions to access support when taking part in EU Mobility Programmes.
- The European Disability Card will be issued and renewed free of charge.
- EU-level website and national websites with information on the Card.
- Safeguards to protect the Cardholders' privacy
- Ensuring that the Card is not obligatory to access rights under other EU laws (like passenger rights).
- Member States can decide to extend the use of the Card to longer stays.
- Commitment from the European Commission to further explore remaining gaps related to the free movement of persons with disabilities, such as the portability of disability-related support when moving to another EU Member State

We are very happy about this last point because we did not manage to get anything related to social security directly into this text because it is not in the scope of the Directive. But with this commitment we have at least our next goal already set for our work on freedom of movement.

The main negative aspect is that there is a new exception that can exclude certain services from the scope. We fought against this exception, which came from the Member States, and we tried to narrow it down, but in the end we did not succeed. What we understand is that in some Member States to get specific discounts, for example for public transport, this can be based on either the type of disability you have or a “level of disability” that the States determine. As the Disability Card does not indicate any of these differentiations, Member States are afraid that too many persons who are visiting with a European Disability Card would get this benefit, which is not even available to all persons with disabilities in their home country. This is where we believe the exception was based on,

but since the wording is quite vague we there is the risk it will open doors to add more services to this exception.

Finally, some aspects are still competence of the different EU countries: The disability assessment procedures will not be changed by the European Disability Card, and also who receives the Disability Card or the Parking Card, or who receives certain Social Security benefits or support is not affected by the new law either.

European Parking Card

The Parking Card has already been established since 1998. But what we have seen is that because the rules were not binding, the Parking Cards have developed very differently in each country. This includes, for example security features that have changed in every Member State and not in a harmonized way. Even the design has sometimes changed, and so we saw this causes problems in recognition of the card when going abroad. With the new Directive, we have achieved a clear harmonization of the national systems.

Some things are also still left to the Member States. For example, it is optional to also have a digital version of the card. But what the directive now says is that there is a clear timeframe for how long public authorities can take to deliver the card, because in some cases there could be long waiting times. Now it is a maximum of 90 days, which is still long, but before there was no time limit.

There is also the possibility to include digital features to prevent fraud, such as a QR code. We insisted that if there is an additional digital feature it should only contain the same information as on the card because we wanted to be sure that the privacy of persons with disabilities is protected and that not more personal information would be available than on the physical card. What exactly the digital card will look like has not been decided yet. New rules will be developed by the EU institutions to accompany this law with practical information on how a digital card can be set up.

Also, there will be Braille included on the physical card, a specific amendment that we asked for. Furthermore, we achieved that when issuing of the card to citizens, this can only be done for an administrative fee so that they cannot charge some exaggerated amount to earn money.

Finally, similarly to the European Disability Card, the new Directive will not affect the National Parking Rules. So, for example if in your country or municipality you are allowed to park for free in a normally paying zone with the Parking Card, this might be different if you go to a different municipality or country. This is still a local or national rule that it will not change. Who will be eligible for the card is also still usually national, regional, or even local competence, so there will not be a change about this.

What we tried to include as well, and which we did not succeed, is to include minimum quotas on the disabled parking spaces.

Practical implications

What are the practical implications of the new law?

First of all it will facilitate travel for short stays. If you now go on holidays and you go to France, show your card, you can enter the public swimming pool and you will pay the same price as a national with a disability. Or if you use public transport, you should get the same discount as a national with disability.

We tried to keep the scope very broad on purpose. There is no list of services that are included, so you should assume that any service with a discount or an advantage available should also apply to you when you visit another country. And it is not only that you would get a discount in the price, but it could be that you have access to priority seating in the cinema or not paying for road tolls in some Member States.

Also, it will, of course, provide proof of disability which is recognized throughout the EU in museums, cinemas, public transport, et cetera. And if you participate for example in an Erasmus exchange, you can you also use that card even if it is for longer than just a holiday.

Timeline for the next steps

The European Parliament will hopefully officially adopt the text in April plenary session, which is the last one before the EU elections. Once the final text is adopted and translated it will be published in the Official Journal of the EU.

From the day of publication, the deadlines will start counting down:

Member States have 30 months to create or amend the national laws and after that, Member States have 12 more months to set up the Card systems. This seems like a long time, but at the same time the EU still has to develop the additional rules on the digital formats, etc. so in fact a lot has to be done in this time.

If everything goes well, we will have the Cards in our pockets at the end of 2027!

EDF's next steps

We will publish our official analysis of the final text that we have presented today. Following the provisional agreement, we will now advocate for adoption in the Parliament in April. We will also push for quick agreement on the additional proposal on Third Country Nationals which is still in the inter-institutional negotiations (Update: after the briefing took place, the provisional agreement was reached). Once the Directive is officially adopted and the transposition process into the national laws starts, we will support Members in this procedure.

On EU level, we will be further advocating for technical measures for example for the digital version of the Cards, setting up the EU level website, etc. And we will also continue our advocacy on further legislation to allow for full freedom of movement in the EU in the future.

For more information see <https://www.edf-feph.org/eu-disability-card/>

Contact

Marie Denninghaus | EDF Senior Policy Coordinator | marie.denninghaus@edf-feph.org

THE ETHOS FILM FESTIVAL AWARD TO NIELS FRANDBEN'S DOCUMENTARY
"THE ECHO OF EPIDEMIC"



Dear Stefan.

I hope you are doing fine and you've had a good start in 2024.

Thank you so much for the mention of my film in the EPU newsletter.

I hope my documentary will come around and be used in many ways.

The documentary has been screened at the Ethos film festival in Los Angeles. It was a really good experience. "[The echo of the epidemic](#)" won the 1st prize at The Ethos Film Festival for best documentary. I am very happy.

For your information, I have previously also made the film "The Epidemic – I do not remember anything, but I will never forget". Please find a link below. The doc is available in all the main European languages.

"The Epidemic - I don't remember anything, but I'll never forget"

<https://vimeo.com/299298643>

Here in 2024 I'm planning to make a new documentary "*The last polio survivor*" - I'm doing research and writing the script. It will be my last film in a trilogy about polio. If you have any input on this please let me know.

Best regards Niels

January 24, 2024

BOOK REVIEW: POLIO ACROSS THE IRON CURTAIN: HUNGARY'S COLD WAR WITH AN EPIDEMIC

By Dóra Vargha. Cambridge: Cambridge University Press, 2018. Pp.254.

Dóra Vargha's history of Hungary's fight against polio in the 1950s combines social, cultural, and political history to demonstrate how Cold War politics were central to this story. She also challenges generally held perceptions of the iron curtain as impenetrable and demonstrates, at least in the case of polio, that the border between east and west was much more porous than generally thought. By highlighting contradictions, such as the global acceptance of Hungary's epidemic control methods at the same time as the Hungarian government was *persona non grata* in the West, Vargha demonstrates the complicated and paradoxical nature of Hungary's relationship with western countries at this time.

Like many countries, Hungary suffered from a shortage of iron lungs to treat polio patients. Western countries were prepared to donate iron lungs to Hungary, and the Red Cross played a role in sharing iron lungs between countries in what it termed "mutual assistance."

Vargha argues that it is too simplistic to see the arrival of iron lungs in Hungary as a technological transfer from west to east. It was a network of assistance, conceived in the West, where all countries were potential givers and takers. When shortages occurred, innovation became necessary, and Hungarian doctors transformed iron lungs into devices that could serve three infants at a time. In another example of innovation, Hungarians produced a machine called the *Electrospirator*, which became the most widely used device in treating polio in Hungary.

At the center of this history is Hungary's use of the Salk vaccine, and then the Sabin vaccine. Vargha highlights how the Salk vaccine was important beyond the United States as it quickly became used on a global scale, but Hungary struggled to produce it. Then, with a second major outbreak in 1959, the assumed success of the Salk vaccine had to be re-evaluated.

There was disagreement over the method (intracutaneous or intramuscular) and the amount of vaccine to use. The intracutaneous method used a fraction of the dose. This method was used until Spring 1959, when administration changed to intramuscular. Vargha shows that these decisions were significant, as many Hungarians later blamed the state for the 1959 outbreak, thinking it had halved the required dosage in an act of frugality. While this view remains unsubstantiated, it was a widely held belief and has persisted to this day.

In December 1959, Hungary became one of the first countries in the world to begin mass vaccinations with the Sabin vaccine – four years before the United States, where it had been developed. The development of a live vaccine demonstrated that polio vaccine development was not just an American story, with trials of the Sabin vaccine being conducted across Eastern Europe, including in Hungary. Vargha shows scientists and public health authorities worked together as a global community to stop the polio epidemic; they "transcended Cold War barriers and defied the world order" (p. 161). Science had the potential to unite humanity and stop the Cold War. At the same time, the Sabin vaccine was accepted much more readily in Hungary than the Salk vaccine as trials had been conducted on the "right" side of the iron curtain.

In her final chapter, "After the end of Polio," Vargha asks when epidemics finish. She makes the point that many histories of epidemics have not considered; what happens once the disease is considered to have been eradicated in a particular area? "The end" is not a fixed point, but can

depend on one's position. In the Hungarian case, the state "forgot" about polio and ignored polio survivors with disabilities from the 1960s onwards, rendering them invisible.

Vargha shows that polio care was seldom discussed or advanced after the 1960s; medical students were no longer taught about the disease and patients were hidden away. Vargha convincingly makes the point that to end the history of polio in Hungary in the early 1960s is both to repeat the mistake of the Hungarian state and medical establishment in ignoring these patients and results in misunderstanding the long and enduring nature of polio and other diseases. Vargha extends this argument by providing a nuanced discussion of attempts at eradication of diseases, and the limitations of such attempts. By problematizing the periodization of epidemics, Vargha suggests a new approach for historians of disease and recentres the stories of survivors of epidemics.

This excellent book will interest those working on the history of vaccinations, medicine, and public health more generally as well as those interested in cold war politics and post-war Eastern European history.

Hayley Brown

Dr. Hayley Brown is a research fellow in the Centre for History in Public Health at the London School of Hygiene and Tropical Medicine. She is currently researching the history of the New Zealand health system and its transnational links.

Source:

https://www.academia.edu/77518162/Polio_across_the_Iron_Curtain_Hungarys_Cold_War_with_a_n_Epidemic_by_D%C3%B3ra_Vargha

NOTE of the editor: Dóra Vargha's book *Polio Across the Iron Curtain: Hungary's Cold War with an Epidemic* is available here (open access): <https://library.oapen.org/handle/20.500.12657/49614>

NEWS FROM EPU MEMBER COUNTRIES



Latest news for Sweden according to polio and postpolio

The Swedish Personal Injury Association, RTP has long sounded the alarm that knowledge about polio and post-polio in primary care is low and in many parts of Sweden non-existent. Many living with effects after polio have unfortunately been left without care and rehabilitation. But thanks to The Swedish Personal Injury Association, RTP pointing this out, a decision was made in June 2023 that the Region Skåne, Stockholm and Västra Götaland will be tasked with providing highly specialized care for residual conditions after polio. From and including January 2024, all operations must be in place. This means that people with suspected or diagnosed post-polio, regardless of age,

must be referred to one of the country's three clinics for national highly specialized care for residual conditions after polio. National highly specialized care's main responsibility is investigation and diagnostics as well as taking a stand on treatment, rehabilitation and follow-up. We from The Swedish Personal Injury Association, RTP are incredibly satisfied that our advocacy work has yielded results. Our hope is that people living with residual conditions after polio will now have access to the best care regardless of where in the country they live in Sweden.

Marianne Gullberg

Board member of The Swedish Personal Injury Association, RTP
and Member of the Polio Drafting Committee in The Swedish Personal Injury Association, RTP

The British Polio Fellowship celebrates its 85th anniversary



The British Polio Fellowship (BPF) is celebrating its anniversary today, Monday 29 January with a host of events taking place throughout the year.

People affected by polio were invited to attend a virtual meeting a few days before the anniversary to kick off celebrations. The virtual (Zoom) Cafe was an open forum for anyone to attend and speak openly about their polio and the problems they face.

In March, polio survivors from across the UK will join the BPF for its National Indoor Games at a hotel in Leicester (15 - 17 March). Everyone will be encouraged to share memories and take part in sports and games that mark the 85th celebrations.

Kripen Dhrona, Chief Executive of the BPF since 2022, commented: "We want polio survivors everywhere to be able to join in on the British Polio Fellowship 85th Anniversary festivities this year. We have lots of exciting opportunities that will allow those affected by polio to 'join the party' and have a memorable experience."

An overview of our story so far

1939: On 29 January, The British Polio Fellowship which, back then, was called The Infantile Paralysis Fellowship, was founded by Frederic Morena and Patricia Carey. Frederic Morena, contracted the disease at the age of 42 and Patricia who had contracted polio aged eight, created the charity as a self-help and mutual aid society for those affected by polio.

Membership grew quickly and meetings of around 30 people in London soon grew to almost 400 people going along to the Tea House in Kensington Gardens.

During the war years: The Chair, Roby Spence wrote a letter to Ernest Bevan MP, then Employment Secretary, and pointed out that people with polio had functioning brains as well as problems with their limbs, so why couldn't they work? Bevan replied that the Government would henceforth adopt a strategy of employing people with disabilities.

1945: The Fellowship arranged activities for members around London and member, Michael Flanders successfully mounted a campaign which changed legislation so that cinemas became wheelchair accessible.

A London-based Christmas party, attended by people from around the country, sparked the idea that the Fellowship should be local as well as national. From this moment, branches were established throughout the UK. The first branch was in Reading.

1947: The Constitution was formally adopted, and the Fellowship moved in to its first office in Tavistock Place, London. There were now 2,000 members.

1955: The polio vaccine was deemed successful and exported to the UK.

1956: The Newcastle branch opened a hostel; a place where people with polio could live and work.

1959: Some 9 million Christmas cards and 80,000 advent calendars were produced by the Fellowship to both raise funds and employ members.

Early 1960s: The cosmetic calliper became available. People with polio could now wear everyday shoes, rather than thick soles.

1960: Frederic Morena was the subject of "This is Your Life". Patricia Carey flew in from Zimbabwe to appear on the show. Frederic died at the end of the year.

End of the 60s: The first National Sports Day took place on a rainy day in Birmingham in 1968 and the Fellowship decided to change course and concentrate on helping people with polio to live fulfilled lives.

1973: The National Sports Day and Swimming Gala took place on the same day, at Stoke Mandeville Sports Stadium in Buckinghamshire.

1983: The first National Indoor Games was held at Birmingham University, an annual event which continues to this day.

1985: The Fellowship donated £100,000 towards the cost of opening a new unit at Guys and St. Thomas' Hospital in London, The Lane Fox Unit. This provided therapy for people with Post-Polio Syndrome.

1998: The Fellowship produced a video about Post-Polio Syndrome.

2005: The British Polio Fellowship became incorporated as a company limited by guarantee.

2007: The Fellowship now had 8,000 members. The European Polio Union (EPU) was formed, and the Fellowship was chosen to co-ordinate events. The first Members' Handbook was produced.

2013: The first Post-Polio Syndrome Day was celebrated and became an annual event.

2016: Dr Robin Luff and Trustee, Frances Quinn launched the much-respected publication Post-Polio Syndrome (PPS) Management Guide for Healthcare Professionals.

2017: The Royal College of General Practitioners (RCGP) introduced a training module to educate GPs on PPS.

2018: This was the start of a difficult financial period for the Fellowship when regrettably, a compulsory membership fee had to be introduced. The Central Office team reduced to six people and membership fell, but member services were largely unaffected by the changes.

2020: The COVID pandemic resulted in a national lockdown. Fellowship staff worked from home and continued to support members. The National Lottery funding was secured for emergency Covid relief efforts.

2022: Kripen Dhrona was appointed Chief Executive Officer. The Board introduced a new 10-year strategy to guide the Fellowship into the next decade. The Board introduced a new membership policy to make membership fees voluntary.

2023: The Fellowship began work on developing an Optimal Clinical Pathway for people affected by polio (including late effect of polio and Post-Polio Syndrome). The project involved clinicians and healthcare professionals from multiple disciplines across the UK.

2024: The British Polio Fellowship will mark its 85th anniversary with events across the UK.

Photo: *Gaelle Marcel on Unsplash*

<https://www.britishpolio.org.uk/post/the-british-polio-fellowship-celebrates-its-85th-anniversary>

Pioneering MP hails disability reform in Spain

Thomas PERROTEAU

25 January 2024

Addressing Valencia's regional parliament, Mar Galceran's confidence is striking: she is Spain's first lawmaker with Down syndrome and one of just a few elected across Europe.

She is fighting to change Spanish society's approach to people with disabilities, the formal description of which was amended in the Constitution on Thursday.

Galceran, 46, was voted into Valencia's regional parliament in September, the first person with Down syndrome to be elected in Spain at regional or national level.

Elected as an MP for the right-wing opposition Popular Party (PP), she wants "to change the way society views people with disabilities".



Galceran says she wants 'to change the way society views people with disabilities' (JOSE JORDAN)

And she has welcomed the rare move to revise Spain's Constitution to replace the word "handicapped" ("disminuido") with "people with disabilities" which was approved by the Senate upper house on Thursday.

Using the term "disminuido" or its colloquial equivalent "minusvalido" ("less valid") has long been "offensive and insulting to the collective of people with disabilities", she told AFP.

"Because we are not 'diminished' nor are we 'less valid'. We are not worth less than other people."

The reform, which also expands their rights, is only the third-ever change to Spain's Constitution since it was approved in 1978, and the first of a social nature.

"Words matter," she said, explaining the importance of "seeing the people and not the disability they have".

- A 'necessary' reform if late -

A member of the PP since she was 18, she spent many years as a civil servant, and always took a stand against the discrimination she faced over her genetic condition.

She spent four years as head of Asindown, a foundation in the Valencia region which helps the families of children with Down syndrome.

An avid runner who loves dancing and once worked in childcare, Galceran says her teenage years were marked by "rejection".

Growing up, she had "acquaintances but never friends, because they saw me as different and didn't really count me as a friend".

Her network of real support always came from her family, who "have always supported me in my decisions".

Since being sworn in, Galceran has been active in the parliamentary committee on people with disabilities, which she believes needs a "cross-party" approach within the healthcare sector, within families, within work and education.

"And there's still a lot left to be done."

For her, the constitutional reform was one of the top priorities.

While it remains largely symbolic, Galceran sees it as a "fair" and "necessary" step – even if it should have happened earlier.

- 'With different abilities' -

Until now, the wording of article 49 of the Constitution has said that Spain's public authorities are responsible for policies involving the "treatment, rehabilitation and integration of the physically, sensory and mentally handicapped".

The new version says "persons with disabilities are entitled to rights" that must be exercised in "freedom and genuine equality, without discrimination", and stresses the importance of attention to "the specific needs of women and girls with disabilities".

A large majority of Spanish Senators approved the reform in its final reading on Thursday. Only the three from far-right party Vox voted against, arguing they did not want to vote in unison with the ruling left.

Socialist Prime Minister Pedro Sanchez said the measure settled "a moral debt owed to more than four million Spaniards" with one degree or another of disability.

"There is still a long way to go to achieve full inclusion, to embrace the diversity that defines us and to make visible what for so long was painfully ignored," he added during a debate in the lower house of parliament last week, acknowledging the reform was "late".

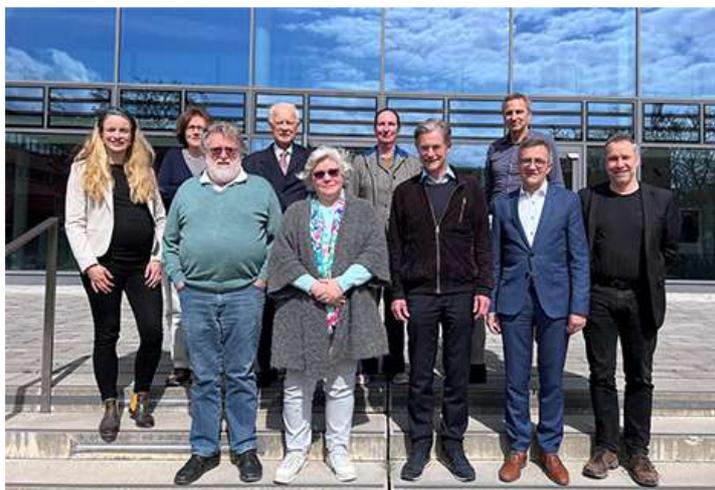
"The first thing we must do is ask their forgiveness" for using "such an offensive term for so many years," he added.

For Galceran, the debate over language needs to go even further: one day she hopes that even the term "disabled" will be changed to refer to "people with different capacities".

Source:

<https://uk.news.yahoo.com/pioneering-mp-hails-disability-reform-172408842.html?qucounter=2>

Committee for Poliomyelitis Eradication in Germany



Members of the National Commission for Polio Eradication in Germany: back from left to right: Dr Victoria Weiner; Prof. Anna-Maria Eis-Huebinger; Professor Peter Wutzler; Dr Alexandra Barth; Professor Peter Huppke; front from left to right: Prof. Thomas Mertens; Gunhild Kilian Kornell; Prof. Hans-Iko Huppertz; Dr Fabian File; Dr Klaus Jahn; present via Webex and not on the picture: Prof. Uta Meyding-Lamadé; Photo: Viktoria Weiner (Commission Member)

Poliomyelitis (polio) was once a disease feared worldwide, striking suddenly and paralyzing mainly children. Since 1988, the Global Polio Eradication Initiative has worked towards the millennium goal to eradicate polio globally and has reduced polio case numbers by more than 99.9%. There are just two countries which have never stopped transmission (Afghanistan and Pakistan) from which polio can spread to infect people in other countries with inadequate vaccination levels.

The certification process for polio eradication is overseen by the Global Certification Commission of the World Health Organization (WHO) and is conducted on a regional basis. Each WHO region can consider certification only when all countries in the area meet specified criteria:

1. absence of indigenous wild poliovirus (WPV) transmission for at least three consecutive years monitored by a sensitive, certification-standard surveillance such as Acute Flaccid Paralysis (AFP) surveillance, environmental surveillance or enterovirus (EV) surveillance;
2. ensure highest possible immunity levels;
3. capacity to detect, report, and rapidly respond to any imported WPV; and
4. implementation of containment measures according to the global action plan for laboratory containment of WPV.

The WHO European Region was certified polio-free in 2002. The member states have committed themselves to take all required measures to survey and preserve this status until the global eradication will be achieved. Each country has an independent National Certification Committee (NCC) to collect, verify and submit country documentation related to polio eradication activities to WHO.

In Germany, the Robert Koch Institute (RKI) is responsible for these activities and hosts the office of the NCC. Assurance of polio-free status is based on EV surveillance which offers EV testing to all hospitals for patients with viral meningitis/encephalitis or AFP independent of age. For implementation of EV surveillance a Laboratory Network for Enterovirus Diagnostics (LaNED) was established which is supervised by the National Reference Laboratory at RKI.

The German NCC was founded in 1997 and comprises ten experts representing all relevant fields such as public health, virology and clinical medicine. The members are appointed by the Ministry of Health for four years. The NCC meets at least once a year. It is their duty to support and advise RKI on all activities to maintain polio-free status, to evaluate the effect of measures taken, and to review and certify polio-free status until the circulation of WPV has been interrupted globally.

Further information

- [Members of the National Certification Committee for Poliomyelitis Eradication in Germany \(in German\)](#)
- [Office of the National Certification Commission for Poliomyelitis Eradication](#)
- [National Reference Centre for Poliomyelitis and Enteroviruses \(NRC PE\) at the RKI](#)

Date: 09.06.2023

Source: [RKI - National Certification Committee for Poliomyelitis Eradication in Germany](#)

Pain induced by the dull thud of a "verbal tomato"

(I would like to apologize in advance for the unusual title and personal tone of this post.)

A friend of ours alerted us to a conference to be held at a business and community center in Budapest, the theme and purpose of which was to make previously mandatory vaccinations, including polio vaccinations, optional. We believe that as polio survivors, we are rightful participants in the polio vaccine non-mandatory controversy and therefore have a duty to speak up and make our views known. We have therefore decided to organise a subtle and well-intentioned awareness campaign at the conference venue (but without disrupting it). We had t-shirts printed and leaflets issued, warning of the dangers of this option, especially the fact that the abolition of compulsory vaccination may leave many young children unvaccinated.

We expected to cause confusion by our appearance, and we also expected an unkind reception, as we represented the opposite view and indicated this in the leaflet. However, we did not expect uncontrolled anger and unacceptable obscene insults.

It was appalling and shocking. I repeat, we did not disrupt the event, we lined up in the corridor leading to the event hall, nor did we disrupt traffic. We behaved discreetly and politely at all times. Those who wanted to took a leaflet with the text at the end of the post.

Finally, I would like to explain the strange title of the paper: on the back of our leaflet is an unrepresented speech at a fictitious conference. At the end, there is an opportunity to reward the speaker by throwing a tomato for a dissenting opinion. Well, that's what actually happened, in the form of a verbal tomato, and they threw anger and emotion at us, and I didn't think that one punch inflicted by a verbal tomato could cause that level of mental anguish. And we didn't say a word...



*The writing on the T-shirts:
"I wish I'd gotten the vaccine!" and the tall gentleman's T-shirt reads
"I got the vaccine!"*

At the event we handed out leaflets with this text:

We are survivors of the polio epidemic that raged in the 1950s, we are those who have struggled with the effects of paralysis all our lives.

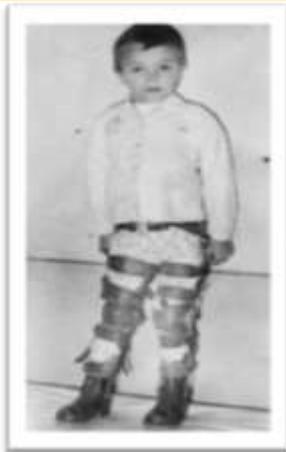
We are saddened to note that there is a group in Hungary that is protesting against compulsory vaccination. By making compulsory vaccination optional, parents would be endangering the health and lives of innocent children.

How will they deal with their consciences in the event of a tragedy?

Unpresented paper at a fictitious conference against compulsory vaccination

When I was two years old, in 1958, I contracted the polio virus, which causes polio (at that time there was no effective vaccine available for this disease). Both my legs were completely and one arm and my respiratory muscles were partially paralyzed. By the time I was fourteen, I was living in the wards of various hospitals, and I completed my primary schooling there. While my healthy peers were running around the playground, I was subjected to numerous corrective surgeries, which I now know were completely unnecessary, and when I was upset, it was not my mother who comforted me, but a nurse or a physiotherapist...

I won't go on, please believe me, I know well every single moment of the often difficult life journey that a person with polio has to go through, from childhood to old age. My fate, I believe, entitles me to express an authentic opinion on the rejection of compulsory polio vaccination.



That is why I am asking you to have your child vaccinated with the polio vaccine so that your child grows up healthy in your loving care. To NOT "give" your child a wheelchair or ventilator for Christmas, but rather a soccer ball, scooter or roller skates. So that your child will not be lonely, like many disabled children. So that your child can play sports. So that your child can dance at their own wedding. So that your child can help and support you as an adult when you need it. And most importantly, so that you can live without feeling guilty for not getting your children vaccinated with the polio vaccine, thereby protecting them from the effects of a terrible disease.

Thank you for your patience that is all I wanted to say. To those who sympathize with me and are now applauding me, please don't do this. On the other hand, I encourage and understand those who would boo me, maybe throw a tomato at me, please feel free to do so... After all, I disrupted the congress against mandatory vaccinations by placing a piece of sober reality between beliefs and misconceptions.

Kertész Tamás

Magyar Polio Alapítvány

Translated with DeepL.com (free version)

Lincoln College presents former BPF Chair with an award

Lincoln College presented David Mitchell, President of the European Polio Union and former Chair of The British Polio Fellowship (BPF) with an award at an annual graduation ceremony in Lincoln Cathedral, on 9 October.

At the end of a busy ceremony to celebrate students graduating from Lincoln College, a further education college based in Lincoln, East Midlands and in front of a 500-strong audience, David Mitchell was escorted onto the stage by Sarah Adams, Clerk to the Corporation.

“As a former member of the lecturing staff, I have always maintained contact with the college and helped out on several occasions. So, I thought that Sarah needed details for profiles that are often published in the college magazine. I was amazed when she led me onto the stage”, explained David Mitchell.



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David’s award was in recognition of services to the college and the wider community. It was presented by Lincoln College Group Principal and Chief Executive Officer, Mark Locking. This special award, made of glass, is only presented on average every five years.

Before handing David his award, the Principal praised him for his devotion to the college, and for supporting other organisations and charities over the years. These included War Widows Association (46 years), a long involvement with the Federation of Small Businesses where he was Editor of their national magazine, working with Lincolnshire Police as an ‘independent custody visitor’ (36 years) and Membership of the County Council’s Education Committee. In addition he is a former Chair of the British Polio Fellowship and current President of the European Polio Union.

“I’m very grateful for this award and to the charity group of the college staff. In the past, they have awarded grants of £2,000 to the Lincolnshire Branch of the British Polio Fellowship and the European Polio Union. Most generously received” commented David.

“It was a huge surprise to be honoured in such style. It was quite something to meet some of my adult exstudents who were in the Cathedral to see their children graduate. It is rare to achieve something alone and I must thank family and friends who have supported me over the years”.

“Congratulations to David for this award. We’re grateful to him for all the work he did when he was Chair of the BPF. As President of the EPU he is already making his presence felt in the polio community. I don’t think he will ever let the effects of polio stop him from getting involved” added Kripen Dhrona, BPF Chief Executive Officer.

Source: The Bulletin – The official magazine of the British Polio Fellowship, Winter 2024, p. 30

A FEW DROPS FROM THE WHOLE OCEAN OF INTERESTING READING

[Polio outbreak in Ukraine closed - a success story for public health despite extreme challenges of war](#) (Relief web)

[Post-Polio Health Care Considerations for Families and Friends](#) (Post-Polio Health International)

[Global trends in poliomyelitis research over the past 20 years: A bibliometric analysis](#) (Human Vaccines & Immunotherapeutics, 2023)

[The hidden ways our car-obsessed culture is especially hard on disabled people](#) (Salon)

[Polio Dashboard](#) (European Centre for Disease Prevention and Control)

[20 Questions with... Stefan Grajcar](#) (BPF – Polio Association Slovakia / Asociácia polio v SR)

[April 2024 Newsletter](#) (Polio Network – Polio Survivors Serving Others)



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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