



EUROPEAN POLIO UNION

Newsletter No. 2/2023

Autumn 2023

TABLE OF CONTENTS

Editorial	3
Resume of the President’s Address to the 2023 EPU Annual General Meeting held in Nancy on May 27, 2023	4
European Polio Conference Nancy 2023 / European Polio Union Annual General Meeting 2023	5
EPU Honorary Memberships Awarded in Nancy, May 26, 2023	8
AGM 2024 in Budapest – the first announcement	10
Remembering Aadje	11
Polio Health Literacy and Post-Polio Clinical Education – Program Synopsis	13
Post-Polio Education Survey – Organisations’ Perspectives	17
An Investigation into the Global Burden of Disability Caused by Polio: Everything We Don’t Know	17
European Leaders Announce New Financing Partnership to Deliver a Healthier, Polio-free world	19
European Parliament Congress for people with disabilities	20
European Disability Card	23
Presentation of the Chair for the Study of People Affected by Polio and Post-Polio Syndrome at the University of Burgos, Spain	25
The First “Polio Day” at the University of Burgos	27
World Polio Day 2023 in Slovakia	30
The Echo of the Epidemic	31
Interesting Reading	
Global polio eradication effort struggles with the end game	32
Closing on Zero. Adapting to Complexity and Risk on the Path to End Polio. Independent Monitoring Board / Global Polio Eradication Initiative	32
For Some Survivors, Polio Casts a Long Shadow – Frieda Klotz	32
The Autumn Ghost: How the Battle Against a Polio Epidemic Revolutionized Modern Medical Care – Hannah Wunsch	33
How to be a Self-Advocate	33
The Goals and Objectives of Advocacy	35

EDITORIAL

Dear Readers,

We are happy to bring you again our newest Newsletter. EPU has always an ambition to come to our members – member organisations, support groups as well as individuals and supporters – with a package of news, good and interesting reading twice a year. It is not easy, nor obvious. As you can notice in this, Autumn 2023 edition, as well as in previous editions of our Newsletter during the last five – six years, a vast majority of all articles are from EPU Board members, and really very, very few of them from our member organisations and support groups, from you. But we all know that nearly all of you administer your own websites with plenty of interesting and most probably also inspiring reading for others, sometimes on the other side of the continent or even on the other side of the world – you never know where our electronic medium can find its readers 😊. Language barrier should not be a bigger problem in these times of high-tech tools, including Artificial Intelligence. If you do not have time to translate what is worth forwarding to others, just send us your suggestion or a link to it, we all will appreciate it.

And what can you find here now?

European Polio Conference in Nancy in May was the key event of the year for all polio survivors, not only for those who had a chance to be there in person. A part of this three-day event we had our Annual General Meeting – articles describing what it all was about you can find at the beginning. And as was promised before, all presentations are already available on the website of Polio-France.

The Nancy event was the very best opportunity for us to award Honorary Memberships to a few respected either EPU founding members or distinguished and to all polio survivors well known experts dealing for decades with polio and its late effect as practitioners, researchers, and academicians. Read their short profiles on pp. 8-9.

Aadje de Groot was a long-time member of the Dutch organization of polio survivors and was very actively involved in EPU activities from its very beginning. *“Since she joined the EPU in 2007 Aadje became one of our best known members, a tireless and respected worker, a fierce advocate of all polio survivors and a true and happy comrade. Her sudden loss has affected us all and we can only hope that memories of happy times and of a formidable lady will carry us, forward.”* A few words to and about Aadje are on pp. 11-12.

Polio Australia allowed us to present to our readers their newly adopted initiative focused on polio health literacy and post-polio clinical education. Presented Program Synopsis is an excellent example of a comprehensive approach in this field, and might be very inspirational for all our member organisations. The article is followed by a link to a survey initiated also by Polio Australia, the aim of which is “with regard to assessing and advancing post-polio education (health literacy and professional competency) internationally”. Good news for all of us is that a closer cooperation between EPU and Polio Australia is on the agenda on the both sides of the globe. At the end of this section you can find an abstract of a research paper describing the global burden of disability caused by polio.

For us as Europeans, it is important to know something about initiatives, which may influence, let’s hope positively, our lives as polio survivors, or lives of all people with disabilities – three articles will inform you what we can looking for in the nearest future.

We have noticed a unique initiative in Spain where the Chair for the Study of People Affected by Polio and Post-Polio Syndrome at the University of Burgos was recently established – nothing like

that we have had here before and this might be very inspirational also for other countries. The world Polio Day 2023 in Slovakia is another piece informing us about news from our member organisations. As we indicated at the beginning, we hope that in the next issue of the Newsletter we will present much more news from you!

Originally we planned to present The Echo of the Epidemic, a short film by Niels Frandsen, a Danish polio survivor, in May 2023 in Nancy to Conference participants but due to time constraints it was not possible. View the touching life story of the author and his sister Lisbet.

The last part of our Newsletter offers you a few tips of interesting reading, mostly picked up from various relevant online sources.

Let me wish you all an engaging reading!

Stefan Grajcar

Editor

RESUME OF THE PRESIDENT'S ADDRESS TO THE 2023 EPU AGM HELD IN NANCY; SATURDAY, 27 MAY 2023

President David Mitchell welcomed 55 delegates with special mention of the guests from Polio France. He praised fellow directors Robert Cordier (President of Polio France) and his committee for delivering such an excellent Congress on the Friday. So much hard work and so many problems had not deterred Robert and his team and the EPU were pleased to stage our AGM alongside 'Nancy 2023'. David thanked all those present for making the effort to attend and was full of praise for Stefan Grajcar (Director/Secretary) for his role in ensuring such a good turnout. All member groups are having difficulty in arranging events, old age, increasing disability, travel problems and finance, so to see 15 member organisations from 13 countries present was very pleasing. We had all enjoyed our dinner at the Mercure Hotel the previous evening.

You have all received our Annual Report for 2022 in your delegate pack with news of events, especially the war in Ukraine) some of our initiatives, current global polio figures and some details of our Board of Directors (eight of whom are present). Sadly, Patrick McGillion was unable to be present. This official welcome is our chance to greet you and to thank you all for flying the 'polio flag' around members of the Council of Europe and you will all be given the chance to introduce yourselves and give a brief description and news of your member organisation. A special thank to Eurordis who once again has provided vital funding for this AGM. We also welcome and acknowledge the efforts of some 'polio legends' present today: Els Symons from the Netherlands, one of our three founders in 2007 and Honorary Members Erika Gehrig from Switzerland, Daniel Peltzer from Belgium and immediate Past President, Gurli Nielsen from Denmark.

Just before we come to our official business can we look at some figures. Even now, some 70 years after the discovery of the vaccine, the legacy of what is a dreadful disease lingers on, possibly over one million survivors in Europe (so difficult to get any details from the Soviet Union bloc) and possibly 15 million worldwide. Current cases up to 17 May 2023 report two new WPV1 cases in Afghanistan, making just three cases so far this year compared with a total of 30 in 2022 and 859 cases of circulating vaccine derived polio this year. Our fight goes on.

David Mitchell,

EPU President

EUROPEAN POLIO CONFERENCE NANCY 2023 / EUROPEAN POLIO UNION ANNUAL GENERAL MEETING 2023

At the Annual General Meeting (AGM) of the European Polio Union (EPU) in Prague in 2022, Robert CORDIER, Président de Polio-France-Glip informed everyone that Polio France was planning an International Conference in Nancy France for 2023, and EPU delegates voted to hold its AGM at the same time.

We were extremely honoured to be invited to attend both the Polio France Conference and the EPU's AGM, as guests of the EPU. Through targeted fundraising work (by Gordon Richardson and David Mitchell) we managed to meet the costs (such as travel and hotel costs) at almost zero expenditure to the Fellowship. As well as Frances, David and myself being there, Carol Levin was also able to join us.

We arrived on Thursday 25th May and the EPU hosted an informal networking dinner.

It was lovely to be able to catch up and talk to our colleagues from all over Europe. We were struck by how similar the challenges faced by the polio community are across the continent. It was great to catch up with delegates from previous years, but also to meet some new people. Many went up early to get a good night's rest, as we had a packed schedule at the conference the next day.

An early start at 8:15 am, saw the conference open with remarks from the President of the Meurthe and Moselle Departmental Council, Ms Chayness Khirouni.

The day was split into sections, as follows

Scientific aspects and technological innovations

A fascinating section covering research being undertaken at Trinity College, Dublin to understand how deterioration in motor neurons effect the health of a polio person – research is ongoing. We also heard about development of a new inactivated oral polio vaccine. Finally, the session looked at the orthotics and how a new C-Brace may help polio survivors.

Organisational aspects: experiences of care networks

A very intense session which explained how the different polio networks have developed in France. We also learnt about Centres of Excellence for polio care in France and in The Netherlands.

Surgical aspects: the peri operatory

The afternoon started with looking at what polio patients need to know, when they require surgical intervention. And we heard a lot about anaesthesia and the best way to handle hip and knee surgery.

A healthy debate took place with the different healthcare professionals about how these care patterns can be shared across Europe and the World.

How to live my polio better: preventing disability deterioration

The day was rounded off by talks in relation to controlling diet, exercise, and the benefits of hydrotherapy.

We were thoroughly impressed by the medical professionals who spoke, and we all learnt so much through the day. Lots of networking could be done during the breaks. You can see the full programme for the day on this link – <https://www.polio-france.org/european-polio-conference-nancy-2023/pre-program-european-polio-conference-nancy-2023/>.

The delegates could then unwind and relax at a reception hosted at the City Hall in Nancy. The evening started with awards being presented by the EPU Committee, who have served the polio community well over the years. After which we could continue to network with colleagues from the polio community. A thoroughly thought-provoking and entertaining day.

Saturday morning saw EPU delegates meet again to hold their formal AGM. It was a privilege to be there and hear how the EPU is doing and how the project they are involved with are developing. Following a quick lunch, we said farewell to our European friends.

Next year the EPU is planning to hold its AGM in Budapest.

I would like to take this opportunity to thank the EPU for inviting us. Thanks must also go to Stefan, from Slovakia who works extremely hard as Secretary and ensures these events go smoothly. Further thanks to Robert from Polio France who ensured a wonderful event was organised and the hope is, the benefits will be felt across the polio world.

Kripen Dhrona

British Polio Fellowship

24th November 2023

Dear all

As planned in the objectives of the European Polio Conference - Nancy 2023, Polio-France and its president are pleased to announce that the replays of the recordings of the conferences of Friday May 26, 2023, are now online; accessible from the Polio-France website (www.polio-france.org).

You can access them in two ways. One in French and the other in English.

In the center of the home page, the left-hand button (purple) gives access to the French-language video page. For the English version, use the central button (blue).

In the event of an error, you can switch to the other language version on any page by clicking on the appropriate version in the top right-hand corner.

The second option is to move the mouse pointer over "European Polio Congress 2023" in the top menu bar. A drop-down menu shows "Programme" and "Le Congrès en vidéos". When you click on "Programme", it opens the page for the French version. Then click on "English version" in the top right-hand corner to open the English program page. From this program, you can find a conference by time, subject or speaker by clicking directly on its title. On this page, by clicking on the green button in the top right-hand corner "The conference", you can open a page dedicated to the presentation of the conference, and then return to the program.

In the drop-down menu, when you click on "Le Congrès en vidéos" you access the French version. Then click on the top right-hand corner to access the English version.

Share as widely as possible. The more survivors and professionals share this knowledge, the more effective care will be.

We wish you an excellent viewing experience.

Kind regards

Robert Cordier

Président de Polio-France



Photographs taken by Kripin Dhrona, BPF

EPU HONORARY MEMBERSHIPS AWARDED IN NANCY, MAY 26, 2023

As was mentioned on previous pages, the Nancy event was the best opportunity for us to award Honorary Memberships to a few respected either EPU founding members or distinguished and to all polio survivors well known experts dealing for decades with polio and its late effect as practitioners, researchers, and academicians. Here are short profiles of all of them.



C E R T I F I C A T E

Johan Bijttebier

is hereby officially declared

HONORARY PRESIDENT

of the European Polio Union

Johan, the founder of Post-Polio Belgium and the founder father of the European Polio Union had the vision for all the polio support groups in Europe to unite to a big European umbrella organisation to exchange knowledge, experience and treatment methods. His vision became his mission. Internet networking kept him in touch with all the polio survivors he had met at polio conferences right from 1998 and his determination and enthusiasm to make his mission a reality was catching and convincing to many of us. His 10 years of efforts in making his vision come true were finally crowned with the successful creation of the European Polio Union. To show our gratitude and appreciation to you, Johan, the EPU has nominated you

HONORARY PRESIDENT OF THE EUROPEAN POLIO UNION.

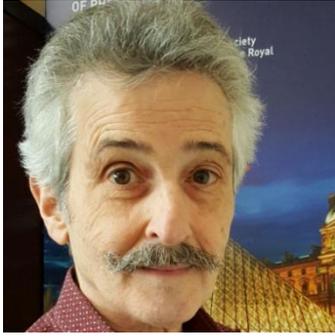
HONORARY MEMBERSHIP CERTIFICATE

This certificate is awarded by the European Polio Union to

Els Symons



Els Symons, one of the core members of the EPU founding team, was co-instrumental in formulating vision and mission of the EPU as well as its objectives. Many years as a member of the EPU Board Els played an important role in all of the EPU's development stages. With gratitude for and appreciation of her work the EPU Board appoints her an Honorary Member of the European Polio Union.



HONORARY MEMBERSHIP CERTIFICATE

This certificate is awarded by the European Polio Union to

Prof. Alain Yelnik

Professor Alain Yelnik, dedicated to improving polio patients' lives, has contributed, thanks to his unfailing involvement and his influence among the medical community, to enhance knowledge, understanding and treatment of polio survivors. His excellent book "*Poliomyélite: histoires humaines et histoire scientifique*" is an eminent testimony to this. By this certificate and honorary membership, the EPU expresses its gratitude to him for the work accomplished.



HONORARY MEMBERSHIP CERTIFICATE

This certificate is awarded by the European Polio Union to

Dr. Axel Ruetz, Medical Director

Dr. Axel Ruetz has distinguished himself over the past 25 years through his tireless medical care of polio survivors. Through polio outpatient clinics and the establishment of the unique polio department in Germany at the Polio Center of the Catholic Hospital Koblenz • Montabaur, he treated more than 10,000 polio and postpolio patients over the recent 15 years. By constant exchange with patients and colleagues on national and international level, he has contributed significantly to the consolidation and dissemination of adequate treatment methods.

This certificate and honorary membership of the European Polio Union is in recognition of his outstanding work and achievements to improve the lives and conditions of so many polio survivors.



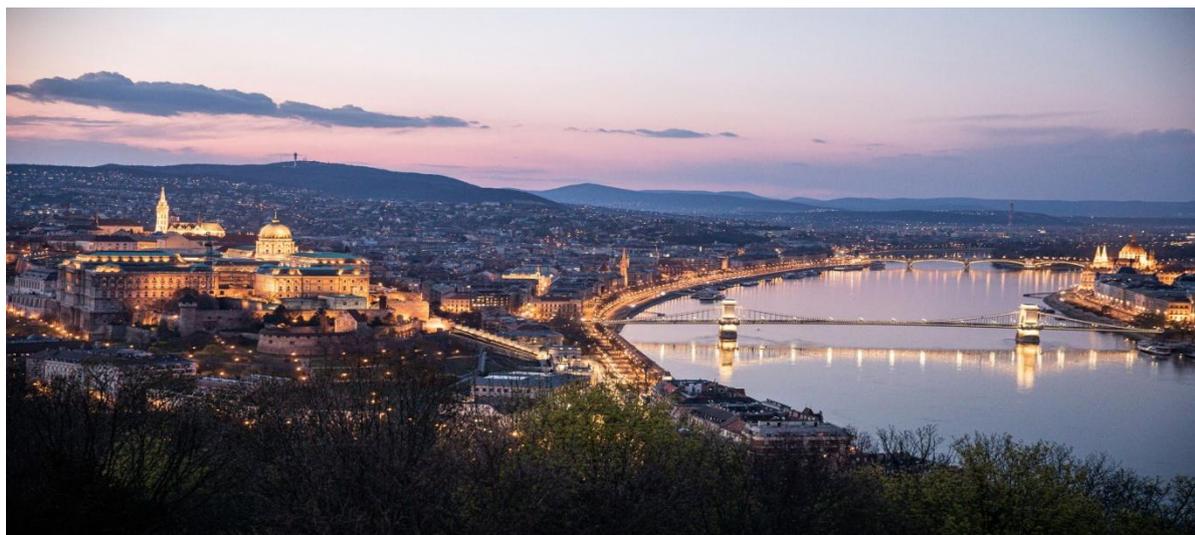
HONORARY MEMBERSHIP CERTIFICATE

This certificate is awarded by the European Polio Union to

Prof. Pierre Van Damme

Professor Prof. Pierre Van Damme is a recognized pioneer and expert in the domain of vaccination. In 2017, he managed successfully at Antwerp University an international project to assess the safety and immunogenicity of two novel oral polio vaccines against type 2 polio (nOPV2).

This certificate and honorary membership of the EPU is in recognition of his contribution to the definitive eradication of polio viruses.



Source: bloomberg.com

AGM 2024 in Budapest

SAVE THE DATE: MAY 25th, 2024

The 1st announcement of the Annual General Meeting of EPU

The AGM 2024 in Budapest will be hosted by the [Hungarian Polio Foundation](#) (Magyar Polio Alapítvány). The meeting will be held on **Saturday, May 25, 2024** in the [Novotel Hotel Danube](#) Budapest, Bem Rakpart 33-34, located in the city centre on the right bank of the Danube river and just opposite to the famous building of Hungarian Parliament, and about 30 minutes drive from the Liszt Ferenc International Airport.

More and detailed information to EPU member organisations, support groups and individual members will be sent at the beginning of January 2024.

Stefan Grajcar
EPU Secretary





Aadje

Adriaantje Johanna de Groot

1950 - 2023

Memories of my dear friend Aadje

I am so very sad about the loss of my dear friend Aadje.

We shared a lot of time together. We met each other about 25 years ago when I joined the Dutch (post)polio group. Since then we always did many things together. We went to (post)polio meetings and other gatherings. We led discussion groups and gave talks at, for example, the Rotary. Together we always wrote newsletters of up to 24 pages of which Aadje always took care of the layout. We helped organise multi-day conferences, such as in Hotel Krasnapolsky in Amsterdam where Aadje inspected the rooms in advance for accessibility. That is typical of her, always thinking about her fellow survivors. Even during one of the last days of her life she woke up and said: “what will happen at my funeral, with people who have difficulty walking, that must be properly arranged”.

Together we worked very hard for two years on our book: “Polio, a disease never to forget”. From financing, approaching the writers of the various chapters, collecting images, consultation with the printer, etc. and above all, approaching and interviewing people to record their life stories, so that they are not lost. The whole thing ended with a nice book-presentation and miniconference in the Boerhaave museum in Leiden. It was very intensive, but fantastic to do this together.

Aadje even arranged for the book to be placed in the hospice where she stayed during the last week of her life, so that she could let people there know what post-polio is all about. Even then she was still spreading knowledge about this condition which is still not yet known to everyone. A condition that she always dealt with in an admirable way. She never let her disability hold her back. She always dealt with it positively and energetically.

I also have very fond memories of the annual multi-day meetings of the EPU. We have visited many places in Europe over the past 15 years. We always shared a room and had a great time. We often had a lot of fun and laughter after the formal meetings. Aadje created a nice atmosphere with her good sense of humor.

Our last trip was to Nancy where she drove us in her car. She had no health complaints at that time. I don't know if and how I will continue going to EPU meetings. Without her it will never be the same again.

Aadje meant so much to what we call “our kind of people” in the Netherlands. What she accomplished was phenomenal. I think almost all our Dutch members know who she is and what she looks like. She was the face and voice of the (post)polio group for so long. She was a contact point for the members and knew many of them personally. She played as a photo model in brochures and videos and told her life story in a very moving way on a stage in a theater on World Polio Day. I am sure she will be dearly missed.

I will carry all the memories of Aadje with me forever.

She was such a beautiful person, a true friend. We never had any friction or disagreements in all those years. We could talk about anything, whatever the subject. I am glad that we were able to say

goodbye in such an intimate way shortly before she passed away. I will love her forever. I have lost one of my very best friends.

Els Symons

Spierziekten Nederland

For over 30 years I have known Aadje, both as patient and as very active in the Dutch and European patient union. It is very sad that she passed away. Due to PPS she had to adapt over the years to the consequences of her increasing physical disabilities, which was not always easy but did not affect the person she was: optimistic, realistic with a great sense of humor, good and critical observation skills and decisiveness.

...Aadje was strongly committed to the post-polio case and went often on stage for this... Memorable moments include receiving Princess Beatrix together with Aadje at the 2nd European Polio Congress in Amsterdam in 2014. And in 2019 her performance in the Flint theater in Amersfoort on World Polio Day, which is held every year on October 24. She told her personal story in a beautiful way, to continue to emphasize the importance of vaccinating against polio and eradicating the polio virus worldwide, but also to make clear what it is like, to live with the consequences of polio and its late decline, the post-polio syndrome, and the need to pay attention to this...

The last time I saw her was a few days before her death in the hospice. We reminisced about the past, all the good moments and finally we said goodbye to each other. Aadje, such a beautiful person. She is not to be forgotten.

Prof. Frans Nollet

Amsterdam UMC

I will always remember Aadje in the following thoughts, and in her way of being.

She always looked at the bright side of life.

She could find the right words and the best solution in difficult situations.

She was a bridge builder.

She could analyse situations very well and find the right conclusions.

She was straightforward and did not tolerate injustice.

She enjoyed life.

She would help where she could.

She had a great sense of humour.

She was a family person.

She was a VERY GOOD FRIEND.

In short,

we lose

a Beautiful Person

a Wonderful Friend,

a Great Lady

Big hug

Tine Tournicourt

Post-Polio Belgium



POLIO HEALTH LITERACY AND POST-POLIO CLINICAL EDUCATION

- Program Synopsis

“Due to efficient vaccination programs, acute poliomyelitis is no longer common. Nevertheless, polio survivors are still common worldwide. As post-polio syndrome is prevalent in these survivors, it is prudent to raise the awareness for this condition. Ignoring this significant morbidity can lead to unnecessary tests, delayed diagnosis and mistreatment with potential harm.”

(Enghelberg et al., 2020)

BACKGROUND

As polio eradication approaches successful completion, those who were not beneficiaries of the 45-year global vaccine rollout - those who were clinically and sub-clinically affected by polio infection globally - are experiencing a lower than typical quality of life and function due to the chronic and progressive health conditions known as:

- ✚ Late Effects of Polio (LEoP), and
- ✚ Post-Polio Syndrome (PPS)

“For this population, therapeutic education is essential and the development of specific education tools is highly necessary” (Laffont et al., 2010). Polio Australia has developed and tested a post-polio education program that addresses this problem and can serve as a template for broad international implementation.

PROJECT AIM

To enable all people experiencing post-polio conditions to understand and manage their condition via improved health literacy, while concurrently improving clinicians’ post-polio screening and intervention competency to accurately identify and safely help these people on their post-polio health journey.

PRIMARY OBJECTIVES OF THE PROJECT

- ✚ **Community Development Arm** – *Ensuring health literacy for persons with post-polio conditions and for those who co-exist with them* (is funded to June 2025)
 - People affected by polio infection are accurately identified
 - They are well informed about their risk for post-polio conditions
 - They demonstrate health literacy and report successful ageing
- ✚ **Clinician Education Arm** – *Ensuring post-polio clinical competency development for clinicians and health workers* (requires 14 months funding to June 2025)
 - Clinicians in medicine and allied health are aware of post-polio conditions
 - They have the knowledge and skills to screen for polio exposure
 - They reliably educate and care for people with post-polio conditions

COMPLEMENTARY NATURE OF THE TWO PROJECT ARMS

The table below outlines the ideal structure and implementation of the two arms in a national program, presented side by side for contrast, and the investment required.

	COMMUNITY DEVELOPMENT ARM (CD)	CLINICAL EDUCATION ARM (CE)
AUDIENCE	<ul style="list-style-type: none"> • People exposed to polio, unidentified • Identified polio-affected people • Partners, families, carers of polio-affected people • Culturally and linguistically diverse (CALD), and disadvantaged populations' support organisations 	<ul style="list-style-type: none"> • Clinicians who provide direct interventions to clients • Hospital and surgical clinic administrators • Workers employed to care for the elderly • State, national government bodies
OPERATIONS PERSONNEL	Roles supporting both arms: National Administrator, Communications Officer, Learning Design Officer	
DELIVERY PERSONNEL	CD Program Manager (CD-PM) CD Outreach & Delivery Officer (CD-ODO)	CE Program Manager (CE-PM) CE Outreach & Delivery Officer (CE-ODO)
NETWORK AND PARTNERSHIPS	<ul style="list-style-type: none"> • International CD programs' personnel • State/regional post-polio support group leaders • Community organisations • Traditional media outlets • Disability support alliance organisations 	<ul style="list-style-type: none"> • International CE programs' personnel • Public and private health networks • State/regional governments • Clinical Advisory Group personnel • Post-polio researchers • Neurological condition alliance organisation
PROJECT COMPONENTS	See page 16	See page 16
	<ul style="list-style-type: none"> • Web portal to these arms: https://www.poliohealth.org.au/post-polio-education-navigator/ 	
CURRENT AUSTRALIAN PROJECT EXAMPLE METRICS	<ul style="list-style-type: none"> • Delivered 28 in-person and 26 tele-conference community education sessions over the last 2 years • Directly educated 1778 people affected by polio and their caregivers or partners during the last 4 years • Hosted three one-day post-polio education conferences 	<ul style="list-style-type: none"> • Delivered 220 clinical education sessions over the last 6 years • Directly educated 2369 clinicians of 14 professional types and numerous support staff and clinical students • Hosted booths at medical conferences; presented at local and international conferences
NATIONAL PROGRAM OPERATIONS	Resource Development:	
	<ul style="list-style-type: none"> • Print, publish, postage, office supplies, marketing, subscriptions, consulting. 	
	Education delivery:	
For transport, transfers, accommodation, meals, luggage, travel insurances.		
<ul style="list-style-type: none"> • CD Arm - 45 in-person education activities • CE Arm - 45 in-person education activities • Sector Participation – 8 in-person attendances 		
Budget:		
Annual program cost for a country of <30 million population: USD 0.6 million.		
CURRENT STATUS OF AUSTRALIAN MODEL	The Community Development Arm is currently funded by the Australian Department of Health until June 30th 2025.	The Clinical Education Arm requires funding up to June 30th 2025 to continue the refinement of the program to prepare the product for international implementation.

GLOBAL POTENTIAL OF THE PROJECT

Our vision for this program is to enable those people experiencing post-polio conditions globally to understand their health, and to receive higher quality care at lower risk from well-informed health teams.

The existing Australian program is unique worldwide, having been developed to serve Polio Australia's mission to *standardise quality polio information and service provision across Australia for polio survivors*. In serving only one population, its reach and impact are limited. Globally, about three people in every thousand (Jones et al., 2017) would benefit from post-polio education. A similar number of healthcare workers would additionally be reached, based on WHO's Skilled Health Professionals data.

Internationally-based post-polio organisations and people affected by polio who come into contact with the Australian program see it as a desirable solution to challenges faced within their own populations. The fundamental shared frustrations expressed by these parties are both health literacy specific - *we have to find out about and decipher our condition ourselves and there is no one to guide us*, and healthcare intervention specific - *clinicians are unaware of post-polio conditions and so they make assumptions in care plans which worsen post-polio symptoms and amplify risks*.

For implementation, propagating the Australian post-polio education program within an existing global or regional education infrastructure presents as a rational approach, however, instigating a novel approach may be required.

To achieve this vision - *advancing post-polio education* - we seek consultation with global health stakeholders.

PROGRAM CONTACT

Mr Michael Jackson, BEd, MPT

Clinical Health Educator, CE Program Manager

Polio Australia Incorporated

1 Fennell Street, Parramatta NSW 2151

PO Box 2799, North Parramatta NSW 1750

Phone: +61 466 719 013

Email: michael@polioaustralia.org.au

Websites: www.poliohealth.org.au / www.polioaustralia.org.au

“Elimination of new polio cases should not also signal an end to worldwide engagement with polio. As many as 20 million continue to live with the disabling consequences of the disease.”

“Given the number and diversity of health concerns among the millions disabled by polio and the existence or emergence of PPS, these issues realistically will be something many clinicians will regularly encounter during their professional careers.”

(Groce et al., 2013)



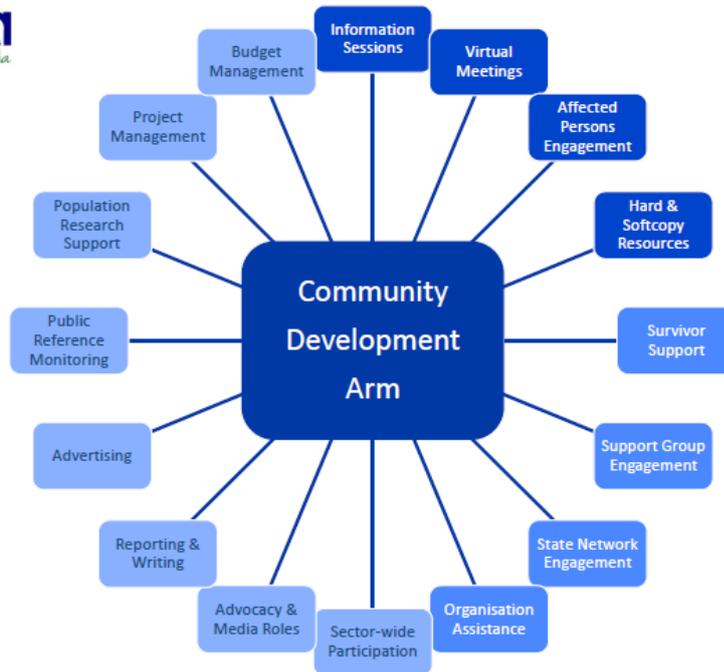
2023 STRUCTURE

PERSONNEL:
CD Program Manager and Administrative Officer

ACCOUNTABILITY:
Polio Australia Board, State Members, Grantees, Funding Providers

SUPPORT:
Executive and other Polio Australia Staff

STAKEHOLDERS:
Polio-Affected People
State Network Organisations
Support Group Leaders



2023 STRUCTURE

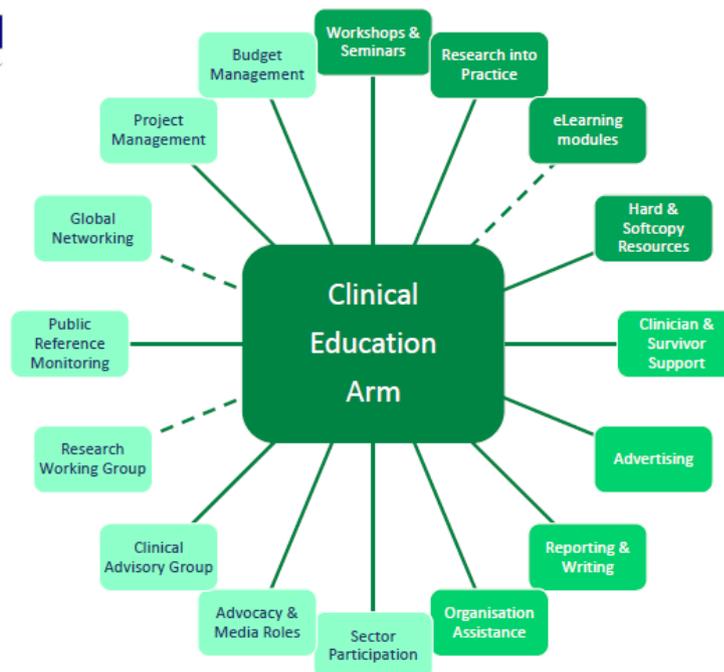
PERSONNEL:
CE Program Manager and Administrative Officer

ACCOUNTABILITY:
Polio Australia Board, State Members, Grantees, Funding Providers

SUPPORT:
Executive and other Polio Australia Staff

STAKEHOLDERS:
Polio-Affected People
Clinicians
Clinical Advisory Group
Research Working Group

KEY:
Components requiring further development - - - - -



POST-POLIO EDUCATION SURVEY - ORGANISATIONS' PERSPECTIVES

Michael Jackson

Polio Australia

Hi everyone! On Friday, 10. November, Polio Australia released a survey for leaders within post-polio orgs and support groups to complete. The survey is with regard to assessing and advancing post-polio education (health literacy and professional competency) internationally. Please encourage your local organisations and groups to submit their response. We emailed it to 154 known contacts however know that we are likely unaware of others or unable to establish a contact email. Survey can be accessed here: <https://bit.ly/Post-PolioEduSurvey>.

This survey is for **post-polio organisations and support groups** from any country. The information in this survey will inform Polio Australia on how to act with regard to advancing post-polio education support internationally.

We ask for only one response from each organisation or group. Where we use the term 'you' we mean 'the organisation or group that you represent'. The person filling out this form should be in a leadership position within your organisation or group.

Please pass this survey on to other post-polio organisations and groups in your network.

If you do not provide post-polio education, please also complete this survey. We would like your input as well.

We ask for your contact information so that we can send you a summary of all responses, and update you on developments related to this topic.

Questions about this survey should be directed to michael@polioaustralia.org.au.

This survey takes about 20 minutes to complete. **We hope to have most responses by about December 8th, 2023.**

CONTEXT: Polio Australia has a unique post-polio education program which benefits those affected by polio in Australia. We believe this program may advance and support education internationally as the education benefits for people affected by polio are near universal. This program was described in the email you received.

AN INVESTIGATION INTO GLOBAL POLIO-RELATED DISABILITY GLOBALLY: PAST, PRESENT AND FUTURE

C Davies, N E Groce

UCL Institute of Epidemiology and Health Care – London (cathleen.davies.19@ucl.ac.uk)

Abstract

Initial polio infection is, for most, either asymptomatic or characterised by fatigue, fever, and pain. For a small minority it leaves behind a stable, lifelong paralysis. The Late Effects of Polio (LEoP) appear in polio survivors decades after their initial infection: Of these, Post Polio Syndrome (PPS) sufferers will typically exhibit pain, fatigue and new weakness, sometimes leading to breathing and swallowing difficulties. Other polio survivors are at increased risk of a wide range of symptoms

groups together as LEOp including cardiovascular and autoimmune conditions. Even relatively minor asymmetry from the effects of polio can affect gait, creating tissue stress and causing musculoskeletal damage.

Our recently completed narrative literature review considers the prevalence of disability amongst polio survivors globally. The review has included a wide source of literature, using academic publications and published data, but also drawing on grey literature where appropriate. Relevant organisations have also been contacted directly.

Our study found that the global numbers of polio survivors is not known. Most surveys of polio survivors record only those with lasting paralysis, around 1% of those infected. PPS and LEOp are found in non-paralytic polio survivors. These conditions can develop in those never officially diagnosed with initial polio infections, suggesting that the pool of polio survivors potentially at risk of LEOp and PPS is far greater than currently estimated.

With no definitive test, PPS is a diagnosis of exclusion. Polio survivors report far higher incidence of PPS than do their physicians, and report concerns of a lack of training for healthcare professions in this area. The literature suggests that PPS may be significantly underreported.

Our literature review also found that the United States dominated research and publication on the topic throughout the 20th century. Despite evidence to the contrary, US racist beliefs that those of African descent and other non-white populations were virtually immune from polio prevailed in the global response to polio until the 1950's and 1960s, delaying the roll out of the vaccine to non-white populations. It was only with the lameness studies of the 1970s in Africa, Asia and Latin America that a previously unidentified high prevalence of polio-related disability was found, and global immunization efforts, up to and including the Global Polio Eradication Initiative (GPEI) were put in place. . Polio vaccination programmes have been slowest to roll out in areas of conflict and poverty. With attention focusing on incidence of new infections, there is a lack of data on LEOp and PPS prevalence, particularly in low and middle-income countries. The scale of polio related disability may therefore be far greater than generally acknowledged, particularly amongst the poor, the isolated and those with the least access to health care.

The review suggests further research to systematize data collection on polio survivors and improve diagnostic pathways. Clinicians should be trained in recognising polio sequelae as patients will be presenting with them for decades to come.

This review is the first in a linked series of studies we will be undertaking to better understand the lives of people living with polio-related disabilities and their current and future need for services, support, advocacy and an active say in their lives and their futures.

EUROPEAN LEADERS ANNOUNCE NEW FINANCING PARTNERSHIP TO DELIVER A HEALTHIER, POLIO-FREE WORLD

BRUSSELS, 11 October 2023 – Today, the European Commission (EC), the European Investment Bank (EIB) and the Bill & Melinda Gates Foundation (BMGF), along with the World Health Organization (WHO) and the United Nations Children’s Fund (UNICEF) announced a new financing partnership to advance polio eradication efforts and strengthen healthcare systems. Of the expected €1.1 billion, €500 million in new funding will go to the Global Polio Eradication Initiative (GPEI) – specifically to its implementing partners, WHO and UNICEF – and €500 million to programs that expand innovation and research capacity in low- and middle-income countries.



This announcement comes at a critical time for global eradication efforts. When the GPEI was established in 1988, wild poliovirus paralyzed an estimated 350,000 children in over 125 countries every year. Today, only two endemic countries remain – Pakistan and Afghanistan – and 80% of variant poliovirus cases are found in only four subnational regions. Promising trends in affected countries, like shrinking genetic diversity of the virus and increasingly geographically confined outbreaks, suggest that in most places the virus is on its last leg.

Now, new commitments from European leaders puts the program one step closer to seizing the historic opportunity we have to overcome final hurdles and end polio for good. The expected funds will allow polio vaccinations to reach nearly 370 million children annually, with a focus on targeting remaining un- or under-vaccinated children who typically live in some of the world’s hardest-to-reach areas.

By focusing on such communities, the program is able to deliver broader health benefits to low resource settings, including routine immunizations, counseling on breastfeeding, Vitamin A supplementation and more. This not only fosters healthier communities today, but also strengthens health systems to better prepare for and respond to emerging health threats, as the polio program and workforce has done against COVID-19, Ebola, and other diseases.

Partners announced the new financing partnership at the “Healthy Hopes: Reasons for optimism in science and global cooperation” event in Brussels. The event featured a keynote speech from Stella Kyriakides, European Commissioner for Health and Food Safety, remarks from Dr. Tedros Adhanom Ghebreyesus, Director-General of WHO, and a panel discussion featuring Catherine Russell,

Executive Director of UNICEF and European leaders – Koen Doens, Director-General at the EC's Directorate General for International Partnerships, Werner Hoyer, President of the EIB, and Caroline Gennez, Belgium's Minister for Development. The event concluded with a fireside chat with Bill Gates, Co-Chair of the BMGF.

European leaders re-affirmed their commitment to ending polio for good and called on the rest of the world to join them and the GPEI partners in the fight for a polio-free world. They underscored the need for global cooperation in the final stretch to eradicate this devastating disease.

In his remarks, Dr. Tedros reminded attendees about the incredible progress that has been made toward a polio-free world, the tools and strategies we have at our disposal that will get the job done, and the importance of donors like the EC and EIB in unlocking the GPEI's ability to utilize them. Catherine Russell reinforced the ever-narrowing window of opportunity we have to end polio for good and affirmed her confidence in the program's ability to stop all virus transmission in the immediate future while meeting the broader health needs of communities now.

During the fireside chat, Bill Gates expressed his optimism about what this new investment represents for the future of eradication efforts and global health. By finding innovative ways to partner, European leaders are helping us achieve a world where no child is paralyzed by this preventable disease.

Increased support from donors, leaders of polio-affected countries and partners is essential to protect the incredible progress made so far, achieve high vaccination coverage and end polio for good. A polio-free world is in sight, but stakeholders at all levels must stay committed to achieving this goal and building strong health systems to protect children today and future generations.

Source: <https://polioeradication.org/>

700 DISABILITY ADVOCATES CALL ON THE EU TO ENSURE “NOTHING ABOUT THEM WITHOUT THEM”

23. 5. 2023 | Andre Felix, European Parliament of Persons with Disabilities



On 23 May, the hemicycle of the European Parliament in Brussels hosted the “5th European Parliament of Persons with Disabilities” – an event during which 600 disability advocates from across the EU came together to discuss the European Union’s role in advancing Disability Rights.

The event was marked by the adoption of the European Disability Forum’s Manifesto on the 2024 European Elections” – the roadmap of the European Disability Forum’s campaign for next year’s scrutiny.

It shares the movement’s demand to be fully involved in the political process – from having the right to vote (still denied to many) and being able to stand as a candidate, to having accessibility measures in place to ensure a free, private and informed vote. Voters must be able to understand all aspects of the electoral process and parties’ manifestos and have accessible measures to cast a secret vote.

The manifesto also outlines key demands for the next legislative term – actions that are essential to fully ensure the rights of persons with disabilities, such as:

1. Ensure that all persons with disabilities have the right to vote and the right to stand as candidates in European elections.
2. Ensure strong services focusing on disability rights in EU Institutions: a new **Directorate-General for Equality** and Inclusion in the European Commission under the leadership of the Commissioner for Equality; a **Disability Committee** in the European Parliament; an **Equality Configuration** in the Council.
3. Create a new European agency for accessibility.
4. Adopt an EU-wide Disability Card, which ensures the mutual recognition of disability status across Member States.
5. Introduce stronger legislation to protect the rights of persons with disabilities as passengers, notably the **prohibition of denied boarding to flights** and fair compensation when mobility equipment is lost or damaged during travel.
6. Establish a **Disability Employment and Skills Guarantee** to boost the participation of persons with disabilities in the open labour market.
7. Further protection for women and girls with disabilities, including the prohibition of **forced sterilisation**.
8. Support Ukrainians with disabilities inside and outside Ukraine, and make sure the EU’s contribution to the reconstruction of Ukraine builds a more inclusive country for persons with disabilities.
9. Introduce legislation to guarantee the **availability and affordability of assistive technologies for persons with disabilities**.
10. Ensure the next EU Budget fully supports independent living for persons with disabilities and ensures disability inclusion in the Green and Digital transition.

The comprehensive list of proposals outlined by the Manifesto focuses on realising a Union of Equality; becoming a more social Europe; embracing accessibility; protecting persons with disabilities.

EDF's President **Yannis Vardakastanis** added:

Persons with disabilities want to be full citizens of the European Union – and the participation in this landmark event showed that. The will of the movement is clear: EU institutions must ensure we can participate in the democratic process and in the policies shaping our Union, and they need to build an inclusive Europe together with us.

EDF's Vice President **Gunta Anca** stated:

One of the mottos of the European Union is "United in Diversity". Persons with disabilities are united and are part of this diversity – we should be included and have the freedom to live and move that the European Union allows to its citizens.

EDF's chair of the Women's Committee, **Pirkko Mahlamäki**, commented:

The European Union – and specifically the European Parliament – has taken significant steps in improving women's rights. This event was also a reminder that we need to advance further the specific issues of women with disabilities, who still are subject to practices contrary to the CRPD, such as forced sterilisation and are many times more likely to be victims of violence.

EDF's chair of the Youth Committee, **Elias Tebibel**, shared the importance of the European disability movement for youth with disabilities:

The theme of this event was building an inclusive future – a future which youth will be the leaders of. Policymakers need to ensure we have the chance to do that – and that we need inclusive education, accessible physical and digital societies and, yes, more chances to be involved in the political process.

Source: <https://www.edf-feph.org/700-disability-advocates-call-on-the-eu-to-ensure-nothing-about-them-without-them/> (Press Release after the event)

Related documents

- [5th European Parliament of Persons with Disabilities](#)
- [EDF Manifesto on the European Elections 2024](#)

Addendum by Macrina Clancy, Polio Survivors Ireland, EPU Board Director:

25. 11. 2023

The press release and photo sums up very well what the meeting was about, the two links assist any of our member organisations if they want to look into it further. There is one aspect not reflected in the press release - further action. The idea was that each disability organisation would work out how best to target MEPs going forward for election to the European Parliament next June in their country. Following on from the event last May in Brussels, the Irish delegates, of which I was honoured to be included, are holding meetings to see how best to approach our Irish MEPs. We also have local elections on the same day so there is a great opportunity to make an impact.

I would like this discussed at our next board meeting. I think that there is a good opportunity for the EPU to both do something and to put it up to our member organisations to be proactive in targeting their MEPs on issues within the Manifesto that are relevant to polio survivors. This would address the issue of "what is the EPU actually doing" for member organisations and raise the profile of the EPU and member organisations..

COMMISSION PROPOSES EUROPEAN DISABILITY AND PARKING CARD VALID IN ALL MEMBER STATES

Today, the Commission has proposed the introduction of a European Disability Card as well as the enhancement of the current European Parking Card for persons with disabilities. Both cards will be recognised all across the EU and make it easier for persons with disabilities to travel across the European Union.



The Commission's proposal **introduces a standardised European Disability Card** and **enhances the current European Parking Card** for persons with disabilities.

Both cards will facilitate persons with disabilities to access right to free movement, by making sure they can, on an equal basis, access special conditions, preferential treatment, and parking rights when visiting another Member State.

A European Disability Card

When people's disability status is not recognised abroad, they cannot access the special conditions and preferential treatment, such as free and/or priority access, reduced fees or personal assistance, while visiting other Member States.

To address this issue, the Commission proposes the creation of a standardised European Disability Card.

The European Disability Card will serve as **recognised proof of disability throughout the EU**, granting equal access to special conditions and preferential treatment in public and private services, including for instance:

- transport
- cultural events
- museums
- leisure and sport centres or amusement parks

It will be issued by the national competent authorities and complement existing national cards or certificates.

Improving the European Parking Card

For many persons with disabilities, private car transport remains the best or only possibility for travel and getting around independently, ensuring their autonomy.

The proposed improvements to the current European Parking Card will allow persons with disabilities to **access the same parking rights available in another Member State**.

It will have a binding common format that will replace national parking cards for persons with disabilities and be recognised throughout the EU.

Ensuring accessibility of the cards

To promote ease of use and reduce administrative burden, the proposed Directive will require Member States to:

- Provide the cards in both **physical and digital versions**.
- Make **conditions and rules** for issuing or withdrawing the cards publicly available in **accessible** formats.
- Ensure **service providers offer information** on special conditions and preferential treatment for persons with disabilities **in accessible formats**.

To guarantee compliance, Member States must ensure persons with disabilities, their representative organisations and relevant public bodies can take action under national law if needed.

After adoption of the Directive into national law, Member States are asked to impose fines and corrective measures in case of violations.

Next steps

The Commission's proposal will now be discussed by the European Parliament and the Council. The proposal foresees that once adopted, Member States will have 18 months to incorporate the provisions of the Directive into national law.

Background

The proposed Directive establishing the European Disability Card and the European Parking Card for persons with disabilities was announced in the [EU Strategy for the rights of persons with disabilities 2021-2030](#).

The proposal contributes the implementation by the EU of the United Nations Convention on the rights of persons with disabilities, to which the EU and all its Member States are party (UNCRPD).

The UNCRPD contains obligations for States Parties to recognise the rights of persons with disabilities to liberty of movement on an equal basis with others.

States Parties are also requested to take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities, including by facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost.

The proposal also aligns with the principles of equal opportunities and of inclusion of people with disabilities from the [European Pillar of Social Rights](#).

This initiative builds [on the outcomes of the EU Disability Card pilot project](#) conducted in Belgium, Cyprus, Estonia, Finland, Italy, Malta, Romania, and Slovenia between 2016 and 2018.

In addition, it integrates insights from a recent public consultation, which collected over 3,300 replies, of which 78% from persons with disabilities.

Source: <https://ec.europa.eu/social/> (06/09/2023)

For more information see, e. g.:

https://ec.europa.eu/commission/presscorner/detail/en/qanda_23_4332

PRESENTATION OF THE CHAIR FOR THE STUDY OF PEOPLE AFFECTED BY POLIO AND POST-POLIO SYNDROME



The Polio Chair of the University of Burgos is an academic platform that aspires to coordinate, unite, channel and centralize all the efforts and initiatives that arise to respond, at the health, social and academic levels, to the requirements of those affected. of poliomyelitis and post-polio syndrome in Spain and even internationally. The Chair is a reference and forum for knowledge of this type of pathologies associated with the consequences of polio and post-polio syndrome. Likewise, the Chair must aspire to become a reference for Rotary, which has always fought for the eradication of Polio in the world, and can now also champion support for those affected by poliomyelitis and post-polio syndrome.

Those affected by Poliomyelitis and Post-Polio Syndrome are a forgotten group and Spanish society is indebted to them since now, with the comorbidities associated with age, they maintain a high degree of disability, as scientists in other countries also reflect. Being able to develop epidemiological research studies, clinical and social situation, is a duty that the Spanish scientific society has towards them for their visualization. The battle against Polio will not be won until the global community can ensure that the needs of people living with the disabling consequences of Polio can be met.

JUSTIFICATION OF THE POLIO CHAIR

On November 24, 2022, the specific collaboration agreement was signed between the Rotary Club of Burgos and the University of Burgos to carry out studies on poliomyelitis in the 21st century, and the preparation of the Report on the creation of a chair for the study of those affected by Poliomyelitis and Post-Polio Syndrome, which took place at the Council of the University of Burgos on December 14, 2022.

Rotary International is one of the founding members of the Global Polio Eradication Initiative (GPEI) in which it has been working for more than 35 years, promoting vaccination campaigns, collaborations and very advanced studies on the disease.

The recent Law 20/2022 of October 19, on Democratic Memory (BOE 10-20-2022), in its eleventh additional provision, establishes that *"In recognition of the suffering suffered by people who were affected by the poliovirus during the pandemic that devastated Spain starting in the 1950s, the Government will promote research and studies that clarify the truth of what happened regarding the*

expansion of the epidemic during the Franco dictatorship, as well as health and social measures in favor of people affected by polio, late effects of polio and post-polio, which enable their quality of life, with the participation of representative entities of the affected polio survivors . We cannot yet know how this commitment will be substantiated in practice, but the Law already requires promoting health and social measures for people affected by the disease.

This legal obligation is very relevant. Firstly, for those affected, who currently lack even the most basic instruments of social protection. Secondly, compliance with the aforementioned legal provision should lead to an increase in funds towards research into the disease and its consequences. For these reasons, we think that the creation of the Chair precisely at this time is a great opportunity and will improve the visibility of those affected by polio and post-polio syndrome to gain a thorough understanding of their current clinical and healthcare situation, as well as of the University of Burgos in the biomedical field.

ACADEMIC OBJECTIVES

Objectives of the Chair for the Study of Polio Survivors and Post-Polio Syndrome

In accordance with the provisions of the Eleventh Additional Provision of Law 20/2022 of October 19, on Democratic Memory, the Chair seeks to achieve the following objectives:

1. To advance research and knowledge pertaining to polio and the impacts of post-polio syndrome from both medical and social perspectives.
2. To provide coverage to those affected by encouraging the associative movement.

Furthermore, the Chair aspires to enhance the visibility of the University of Burgos as a leading institution in the biomedical field within Spain.

Activities promoted by the Chair

To attain the objectives outlined in the previous section, and with the support and collaboration of a committee of experts in Poliomyelitis, the Chair will endorse any activity aimed at achieving them. Specifically, these activities include:

1. Encouraging and funding research by professors, professionals, and/or students in the fields of polio and post-polio syndrome through direct grants and/or competitive calls for scholarships and research projects.
2. Rewarding the best research papers in the subject matter, as well as the best social initiatives in support of those affected by polio and post-polio syndrome.
3. Organizing and participating in forums, congresses, seminars, workshops, conferences, talks, or exhibitions related to the aforementioned subjects.
4. Editing or collaborating on publications related to the indicated subjects.
5. Conducting training courses and outreach activities on poliomyelitis and its consequences.
6. Undertaking any other activity dedicated to research, study, knowledge, dissemination, or education on topics related to Post-Polio Syndrome and the determination of the sequelae of Poliomyelitis.
7. Supporting the establishment of the creation of a website for disseminating the objectives, purposes, and activities of the Chair.
8. Supporting the establishment of a Poliomyelitis Survivors Association in Castilla y León.

INFORMATION AND CONTACT

Chair for the Study of People Affected by Polio and Post-Polio Syndrome

Director: Mr. Mateo Díez López. Academic Director: Mr. Jerónimo González-Bernal

University of Burgos, Hospital del Rey s/n. Rectorate Building

09001 Burgos (Burgos)

Spain

catedrapolio@ubu.es

For more information see: <https://www.ubu.es/catedra-para-el-estudio-de-los-afectados-de-la-polio-y-sindrome-postpolio>

(Downloaded from the quoted source on November 22, 2023 by Stefan Grajcar; translation from Spanish by google translator)



THE FIRST “POLIO DAY” AT THE UNIVERSITY OF BURGOS

The Polio Chair at the University of Burgos (Spain) is an academic platform that aims to coordinate, unite, channel, and centralize all efforts and initiatives arising to address the health, social, and academic needs of those affected by polio and post-polio syndrome (PPS) in Spain and even internationally. The Chair serves as a reference and knowledge forum for these types of pathologies associated with the aftermath of polio and PPS.

This Chair began its journey in December 2022, with the aim of providing solid support to those affected by polio from both academic and health care perspectives. It is integrated into the University of Burgos through the University Foundation, and its members are primarily neurologists and university professors who have a special interest in polio and its consequences. Funding comes from contributions from solidarity funds.

The objectives of the Chair include promoting research and knowledge about polio and the effects of PPS, as well as providing support to those affected through the promotion of associative movements.

In light of these goals, the first "Polio Day" at the University of Burgos was held on October 20, 2023, featuring contributions from various specialists. The event was attended by a large number of participants affected by polio, including students and professionals, both in-person and online. The presentations were summarized in four colloquia:

In the first colloquium, the theme was "Polio sequelae and therapeutic approaches":

Dr. García-Güemes, in his presentation "*Polio, orthopaedic and traumatological considerations*", discussed available surgical treatments to alleviate functional sequelae in polio-affected individuals.

Dr. Teruel-González, with the presentation "*Foot with polio, how can we help?*" showcased specialized surgical alternatives in managing the complex treatment of polio-affected feet.

Mr. González-Vicente, presenting "*Rehabilitation of polio users, orthoses*", illustrated various alternatives in neurorehabilitation for patients with polio sequelae and PPS.

The second colloquium, titled "Polio Today and Yesterday", featured the following speakers:

Dr. Santos, with the presentation "*Polio in the world today*", provided an updated view of the current global polio situation.

In this presentation, "*The oral polio vaccine, a means of international collaboration during the Cold War*" Dr. Marco-Igual explained the vaccine's development and complex dissemination.

Dr. Tuells, in the presentation "*The controversial introduction of polio vaccines in Spain (1958-1965)*", uncovered the complexity of introducing the vaccine and the historical development of events.

The third colloquium, "Polio and PPS", began with a presentation by Dr. Gutiérrez-Rivas, titled "*Clinical symptomatology of polio*", followed by Dr. Trejo-Gabriel and Galán's intervention with the presentation "*Post-Polio syndrome*". They explained the pathophysiology and clinical aspects of the disease, as well as its symptomatic management. The third presentation in this block, titled "*Pathophysiology of motor neuron diseases*", was given by Dr. Esteban-Pérez, explaining the complexity of pathologies affecting the lower motor neuron, along with their similarities and differences.

The fourth and final colloquium, "Support for polio-affected individuals", featured contributions from Dr. Del Barrio del Campo, discussing "*Polio and quality of life*", and sharing his personal story of coping with the disease bravely and optimistically.

Mr. Feijoo-Anakabe, in the talk "*Strength in Unity*", presented the current situation of associations for those affected by polio, expressing the desire to work together to achieve common goals.

Dr. Fontcuberta, in his session "*Creation of the rotary committee to support polio-affected individuals*", explained ongoing solidarity initiatives offering support to those affected by polio and PPS.

Finally, Dr. Gil-Polo, in the talk "*Polio units, a shared wish*", proposed the ideal approach to managing patients with polio and PPS sequelae in multidisciplinary units involving different specialists.

These sessions are accessible virtually at the following links:

<https://www.youtube.com/watch?v=Sn6JqAEQ2sU>, and

<https://www.youtube.com/watch?v=ew7HXN0vW2Y>

The Polio Chair at the University of Burgos will continue its efforts to ensure that initiatives like this continue to take place and maintain motivation and interest in polio and PPS.

Mateo Diez López

Director

The Polio Chair at the University of Burgos

Burgos, November 28, 2023

(Next page: Photographs from the Conference at the University of Burgos, October 20, 2023)



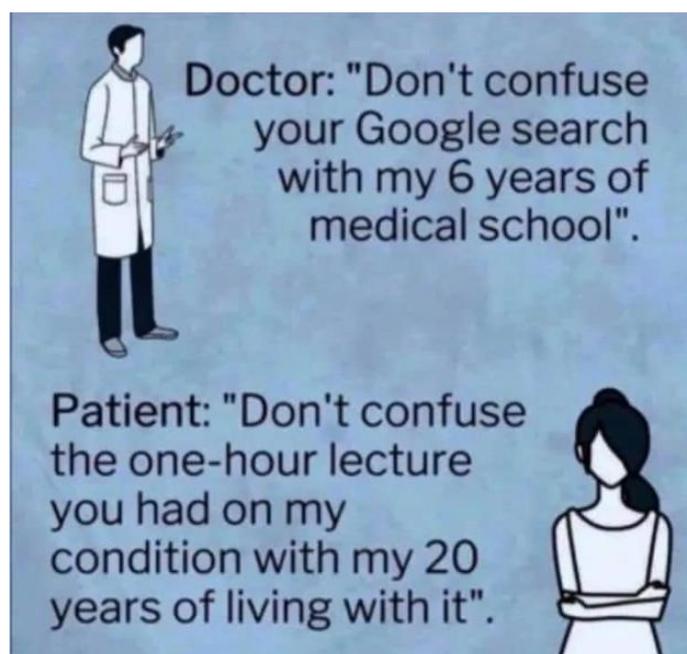
WORLD POLIO DAY 2023 IN SLOVAKIA



Slovak Polio Association (SPA) was invited by the Rotary International, District 2240 for Czech and Slovak Republics to participate on October 18 on an event named **MY JOURNEY TO END POLIO**, the guests of which were Mr. Bashar Asfour, Rotarian and polio survivor from Jordan, and Štefan Grajcár, Past Chair of SPA (2010-2020). B. Asfour presented his life story and the key idea of his [journey](#) – to support the [END POLIO NOW](#) campaign. He started his journey at the end of August in Berlin, and planned to accomplish it in Chemnitz, Germany, on October 20, 2023 – on his route there were nearly 40 stops in 16 European countries. Š. Grajcár presented some facts about polio in Slovakia and the national polio support organisation. After the presentations, the participants watched the Czech film [I Can Jump Puddles](#), based on the novel by Australian writer Alan Marshall, also a polio survivor.

This event, initiated and organised by Rotary International, District 2240, with participants from various Rotary Clubs in Slovakia and polio survivors living in Slovakia themselves, was a good example of successful communication between Rotarians and polio survivors, and might be a positive incentive for more intensive cooperation in the future.

Štefan Grajcár
Slovak Polio Association



Source: <https://www.facebook.com/groups/postpoliosyndromeadvocacygroup/> (26. 11. 2023)



THE ECHO OF THE EPIDEMIC

On May 12, 2023, Niels Frandsen sent us an email:

“Dear friends,

I am a film director and polioramant. I was infected in 1952 during the great polio epidemic in Copenhagen. I have made the film The Echo of the Epidemic, which I would like to show film at your very exciting conference. Here is a link to the film:

<https://vimeo.com/462612831>

I hope you can find a slot in your program for a screening.

I am looking forward to hear from you.

Best regards

Niels Frandsen

Film director”

Unfortunately, it was not possible to present the film directly to participants of the European Polio Conference in Nancy in May, mainly because the whole conference programme was condensed in one day only and there was no free time slot during the whole day when it would be suitable and appropriate. It was therefore decided to present the film of Niels Frandsen in the Autumn 2023 edition of our Newsletter.

Stefan Grajcar, editor

Niels Frandsen is a Danish film director and polio survivor.

He did not notice it, but she was deeply involved in his life throughout his childhood. Now the roles have changed.

The Echo of the Epidemic is a moving story about the sibling couple Niels and Lisbet, who grew up in the shadow of the great polio epidemic in 1952. One marked for life by disabling limitations. The other apparently healthy, but... A deeply personal documentary with and by the award-winning film director Niels Frandsen. A film about repression and concealment, body trauma and cultural history. The Echo of the Epidemic is touching and artistic storytelling of great human interest

Festivals:

The IndieFEST Film Awards USA / Award winner 2021

ReelAbilities Film Festival: New York / 2022

We Care Film Festival UN India / 2021

Over-the-Rhine International Film Festival USA / 2022

Broadcasted at the National DR TV 2020

INTERESTING READING

GLOBAL POLIO ERADICATION EFFORT STRUGGLES WITH END GAME

By Jon Cohen, 18. 9. 2023

Science, Volume 381 (6664); DOI: 10.1126/science.adk9444

View the article online <https://www.science.org/doi/10.1126/science.adk9444>

INDEPENDENT MONITORING BOARD / GLOBAL POLIO ERADICATION INITIATIVE

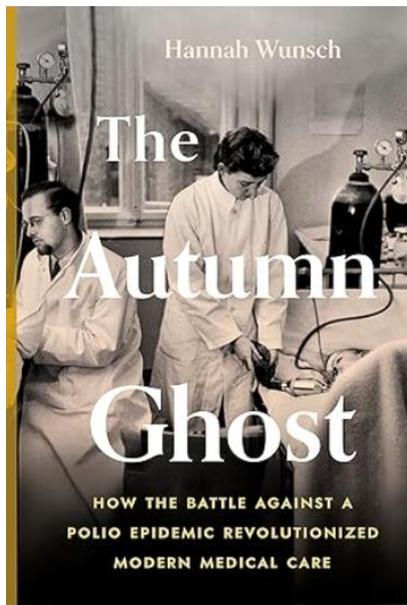
[Closing in on Zero. Adapting to Complexity and Risk on the Path to End Polio. Twenty Second Report, September 2023](#)

FOR SOME SURVIVORS, POLIO CASTS A LONG SHADOW

By Frieda Klotz, 1. 2. 2023

<https://undark.org/2023/01/02/for-some-survivors-polio-casts-a-long-shadow/>

THE AUTUMN GHOST: HOW THE BATTLE AGAINST A POLIO EPIDEMIC REVOLUTIONIZED MODERN MEDICAL CARE BY HANNAH WUNSCH



"A perfectly pitched medical mystery that will captivate you from page one."—Wes Ely, MD, MPH, author of *Every Deep-Drawn Breath*, winner of the 2022 Christopher Award for Literature.

A suspenseful, authoritative account of how the battle against a mid-century polio epidemic sparked a revolution in medical care.

Americans knew polio as the "summer plague." In countries further North, however, the virus arrived later in the year, slipping into the homes of healthy children as the summer waned and the equinox approached. It was described by one writer as "the autumn ghost."

Intensive care units and mechanical ventilation are the crucial foundation of modern medical care: without them, the appalling death toll of the COVID-19 pandemic would be even higher. In *The Autumn Ghost*, Dr. Hannah Wunsch traces the origins of these two innovations back to a polio epidemic in the autumn of 1952. Drawing together compelling testimony from doctors, nurses, medical students, and patients, Wunsch relates a gripping tale of an epidemic that changed the world.

In vivid, captivating chapters, Wunsch tells the dramatic true story of how insiders and iconoclasts came together in one overwhelmed hospital in Copenhagen to save the lives of many polio patients dying of respiratory failure. Their radical advances in care marked a turning point in the treatment of patients around the world—from the rise of life support and the creation of intensive care units to the evolution of rehabilitation medicine.

Moving and informative, *The Autumn Ghost* will leave readers in awe of the courage of those who battled the polio epidemic, and grateful for the modern medical care they pioneered.

Source: amazon.com

Read also the Book excerpt from UNDARK magazine: <https://undark.org/2023/05/19/book-excerpt-how-the-iron-lung-transformed-polio-care>

HOW TO BE A SELF-ADVOCATE FOR POLIO SURVIVORS AND THOSE WITH POST-POLIO SYNDROME / LATE EFFECTS OF POLIO.

John McFarlane
PPS AG Expert

Self-advocacy is the act of speaking up for yourself and your rights. It is an important skill for people with disabilities to have, as it allows them to have more control over their lives.

Here are some tips on how to be a self-advocate:

Know your rights. It is important to know what your rights are as a person with a disability. This includes knowing about the law in your own country, i. e. in the USA - Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act, in the UK - Disability Discrimination Act 2005, and in the EU the various Directives governing anti-discrimination and other laws that protect your rights. Know your law in your country is a basic starting point. If there is now anti-discrimination laws in your country be an advocate to rectify that situation!

Be assertive. When advocating for yourself, it is important to be assertive. This means being able to clearly and confidently express your needs and wants.

Be prepared. Before you advocate for yourself, it is important to be prepared. This means knowing what you want to say, who you need to talk to, and what documentation you may need.

Be persistent. It is important to be persistent when advocating for yourself. This means not giving up if you don't get what you want the first time.

Ask for help. If you need help advocating for yourself, there are many resources available. These resources can include family and friends, disability rights organizations, and legal advocates.

Self-advocacy can be a challenge, but it is an important skill for people with disabilities to have. By following these tips, you can learn how to be a more effective self-advocate.

Here are some additional tips for self-advocates:

Be positive. When talking to others about your needs, it is important to be positive and upbeat. This will help to create a more productive and cooperative atmosphere.

Be open to feedback. It is important to be open to feedback from others. This feedback can help you to improve your communication skills and to better understand your rights.

Be willing to compromise. In some cases, you may not be able to get everything you want. In these cases, it is important to be willing to compromise. This will help you to reach a mutually agreeable solution.

Self-advocacy is an important skill that can help people with disabilities to live more independent and fulfilling lives. By following these tips, you can learn how to be a more effective self-advocate.

Here are some examples of self-advocacy:

A student with a disability asks for a note-taker in class.

A person with a disability requests a wheelchair-accessible vehicle from their health insurance provider, governmental source or local dealer (and funding where needed).

A person with a disability speaks up at a meeting about the need for more accessible parking.

Here are some illustrations of self-advocacy:

A person with a disability who is unable to speak for themselves may use a communication device or an advocate to speak on their behalf.

A person with a disability who is shy or introverted may find it helpful to advocate for themselves in writing.

A person with a disability who is visually impaired may use a screen reader or other assistive technology to help them advocate for themselves.

There are many different ways to advocate for yourself. Find a method that works for you and don't be afraid to ask for help.

<https://www.facebook.com/groups/postpoliosyndromeadvocacygroup>

Published on June 5, 2023 by JMCF

THE GOALS AND OBJECTIVES OF ADVOCACY

Ken Mason

Post Polio Syndrome Advocacy Group

The *goals* and *objectives* of advocacy are to facilitate change and the development of new areas of policy, in order to tackle unmet health needs or deal with emerging health needs in a given community.

A *goal* is the desired result of any advocacy activity. An advocacy goal will usually be a long-term result, and it may take three to five years of advocacy work to bring about the desired result. It is unlikely that your advocacy network can achieve a goal on its own; it will probably require other allies to bring about the required change. It is vital to know what you are trying to do before you start your advocacy work. This involves developing a goal that applies to the situation that needs to change.

Important points to note about **goals** are as follows:

- A goal is the overall purpose of a project. It is a broad statement of what you are trying to do.
- A goal often refers to the benefit that will be felt by those affected by an issue.
- A goal is long term and gives direction — it helps you know where you are going. It needs an accompanying route map or strategy to show you how to get there.
- Without a goal, it is possible to lose sight of what you are trying to do.
- A goal needs to be linked to the mission and vision of your organization.

Source: <https://www.facebook.com/groups/postpoliosyndromeadvocacygroup/>; 20. 11. 2023



*Merry Christmas and
Happy New Year
2024!*



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.

© European Polio Union, Autumn 2023

Authors (in order of appearance; where not clearly indicated, articles are based on online sources and were prepared by the editor):

David Mitchell
Kripen Dhrona
Robert Cordier
Els Symons
Prof. Frans Nollet
Tine Tournicourt
Polio Australia
Cathleen Davies & N E Groce
Andre Felix
Mateo Diez López
Stefan Grajcar
Niels Frandsen
John McFarlane
Ken Mason

Editor & layout: Stefan Grajcar, stefan.grajcar@gmail.com