



# **EUROPEAN POLIO UNION**

## **Newsletter No. 1**

**June 2019**

## EPU MISSION

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

Our objectives are:

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

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

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## EDITORIAL

**Dear Members and Friends,**

Our first edition of the EPU Newsletter 2019 will give you a summary of EPU activities during 2018. The Newsletter will also give you a summary of some of the activities carried out by member organizations. We hope you will find inspiration when reading the Newsletter. At our AGM 2018 in Rheinsberg we urged you to contribute with articles for the Newsletter. It is very important that we get inputs from you.

The AGM 2018 was my first AGM as President of EPU, and I was very excited to meet representatives from our member organizations. It was a great pleasure for me to see so many of our members, and I was very impressed by the commitment. There is no doubt that the AGM gives us a unique opportunity to meet and share our experience so that we can learn from each other. Networking is very important both nationally and internationally. A lot of good people do a great job in spreading the knowledge of polio and postpolio syndrome, and it is necessary. In many countries they know little or nothing about it. We hope to meet many of you at our AGM 2019 in July in Lobbach so that we can learn more about your work, activities, and experience.

Gurli Nielsen

EPU President

## **INVITATION TO THE EPU ANNUAL GENERAL MEETING 2019 IN LOBBACH, GERMANY**

Dear Members and Friends,

Our 2019 Annual General Meeting will take place in Lobbach near Heidelberg, Germany, from 5<sup>th</sup> to 7<sup>th</sup> July 2019. Due to unforeseen circumstances we had to change date and location of this year's AGM from what had been announced in the last year's AGM Minutes.

Based on previous experiences and in order to be able to welcome many associations or countries delegates, the EPU board has decided to accept maximum 2 delegates per association at the AGM and the official dinner. Additional persons are welcomed of course, but they'll have to pay individually the cost of the expenses paid by EPU like e. g. official dinner, coffee breaks, etc.

Transport from and to Frankfurt Airport will be arranged similarly as we did in 2017 and the same applies for simultaneous interpretation.

We are pleased to announce that we will have three guest speakers – Dr. Peter Brauer, Prof. Pierre van Damme, and Prof. Frans Nollet.

We are looking forward to seeing you again in Lobbach.

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**ANNUAL REPORT PRESENTED AT THE ANNUAL GENERAL MEETING  
IN RHEINSBERG, GERMANY, ON June 16, 2018**

*by EPU President Gurli Nielsen*



After having considered it carefully I decided to be nominated to the Board of Directors at EPU's AGM 24<sup>th</sup> June 2017. I was elected together with Paul Neuhaus, Germany, and David Mitchell, UK. At the same time Philip Rendtorff stood down from the board as the Danish representative. He remains in the Board as a special advisor. At the Board meeting the next day the Board elected me as the new President of EPU. The other Board members are John McFarlane, Ireland, Daniel Peltzer, Belgium, Margret Embry, France, Erika Gehrig, Switzerland, and Stefan Grajcar, Slovakia.

As EPU was quite new to me I have spent the past year to be acquainted with the procedures, contacts etc. The Board members have been very supportive, and I really appreciate the cooperation with them. They are fantastic people, and they work very hard for EPU and the polio survivors. They are extremely committed and competent, and they have taken upon them a lot of tasks. I am very grateful to know that I can rely on their assistance whenever I need it.

It is very important that EPU continues spreading the knowledge of polio and post polio syndrome. The knowledge must not disappear. It is therefore necessary that the EPU is visible as an active organization with an agenda which is relevant to politicians, health professionals as well as for our members and all polio survivors. Polio is almost eradicated, but what about the millions of polio survivors who are facing problems with post polio syndrome. Who will take care of them and will they get the necessary medical treatment? I know that EPU's Board members work very hard both nationally and internationally to raise awareness. They participate in many meetings in order to make EPU known as an organization dealing with polio and post polio issues. However, EPU member organizations must also help to spread the knowledge. We know that Central and Eastern Europe countries need to be supported, but how can we do it? We have sent an invitation letter to join the EPU to organizations in Croatia, Estonia, Bulgaria, Macedonia, Albania and Bosnia and Herzegovina. Regrettably only Croatia has responded so far, but that will not prevent us from trying again. The more organizations and countries we are, the stronger we will be. Right now EPU has 31 member organizations from 20 countries, and that is quite impressive numbers.

The AGM gives us a unique opportunity to meet and share our experience. I have been looking forward to meeting you all. I am sure that we can learn from each other, and the EPU needs input from all our member organizations. It is important that we are networking. Cross-border cooperation is a good idea. It makes it possible for us to take advantage of each other's experience. The problems with post polio syndrome are the same wherever in Europe or any other place you live. Post polio syndrome must be recognized everywhere.

We have had two Board meetings, one on 25<sup>th</sup> of June 2017 in Lobbach and one on 2<sup>nd</sup> of February 2018 in Paris. Moreover we have had ten telephone conferences. In Paris we discussed the future of EPU. The organization has some challenges to deal with. One challenge is the ageing and progressively reduced mobility of polio survivors. Another challenge is the lack of funds to support EPU's activities.

At the AGM in Lobbach John told us about the PoPSyCLE project. It is a fantastic project, and it will change everything for the polio survivors. We do not know yet what time will bring, but EPU will be very positive and supportive to the project.

Early this year EPU issued Newsletter No 1. 2018. Margret had worked very hard with gathering materials for the Newsletter. We are very grateful to Margret for all her efforts. If you have anything for the future Newsletters, you are very welcome to contact Margret. She will appreciate receiving stuff from you.

It has been a very interesting year with a lot of good discussions in the Board, and I look forward to the coming year. One of the important issues is to continue our discussions about the future of EPU, but it is also necessary to discuss a Social Media strategy. We can assure you that we will work very hard. However, we will need inputs from you, our member organizations. Together we can make a difference.

### EPU Honorary membership awarded to Dr. Peter Brauer

As it was already mentioned in the Minutes of the EPU Annual General Meeting in Rheinsberg, Germany, in June 2018, we were impressed by Dr. Peter Brauer's lecture on PPS Pain Therapy "Pharmacological Aspect of an Urgent Problem".

In recognition of his outstanding and long-term efforts to raising awareness of the needs and health care for poliosurvivors in Europe EPU decided to award Dr. Peter Brauer the **HONORARY MEMBERSHIP OF THE EUROPEAN POLIO UNION**. The award was warmly applauded by the audience.

Let us say little bit more about him.



Dr. Brauer has always been a great supporter of the European polio idea. In 2003 he attended a meeting at the EU in Brussels where a first attempt was made to unite all European polio support groups into a Union, the name European Polio Union – short EPU – was chosen upon his suggestion. It took until 2007 for this European Polio Union to materialize. In a meeting in Luxemburg in October 2007 with some of the EPU members Dr. Brauer put down his ideas of a framework of points and actions for the EPU to work on.

It has taken many years for some of his suggestions to materialize, others haven't for the very reason of lack of money.

Dr. Brauer also was the initiator of the medical emergency card, he designed it and advocated that it be issued by all polio support groups in all languages, Germany was the first to make it available to their members, now it can be printed off the EPU home page in nearly all languages.

Dr. Brauer had polio at the age of 8 and polio really played a decisive role in his choice of a professional career. After qualifying as a medical doctor he specialized in transfusion medicine and worked in this field until his retirement in 2003. In spite of all the difficulties due to polio, he managed to combine his medical career with the responsibility of raising a family.

In the mid-nineteenth – 50 years after the acute polio infection – the symptoms of the post-polio syndrome made itself felt and due to this he had to take early retirement in 2003. He felt as if the disease had taken hold of him once again. He did voluntary work in polio support groups and realizing the medical profession's failures in providing proper medical care and treatment of polio survivors he spent all his time to research medical literature on the subject. He read every article and book on polio and post-polio syndrome that he could get his hands on. He wrote and published a great number of articles on the various aspects of the post polio syndrome and finally compiled all these articles in his book 'Aspects of Post-Polio Syndrome' which by now has appeared in its third edition. He dissipated all his knowledge amongst medical circles and polio patients. His research and the information he collected made him conclude that poliomyelitis actually is polio encephalomyelitis and that not only in the post-polio syndrome but also in the initial infection. A special role he attributes to the polio-damaged brain which contributes to the development and the characterization of the post-polio syndrome and he bases the post-polio syndrome on a wear and tear effect.

He has fought a never-ending battle against the medical ignorance about the post-polio-syndrome.

In 2014 Dr. Brauer has been honored with the 'Bundesverdienstkreuz am Bande' – a special award given by the German Federal Republic for his work and services in the field of Post-Polio Syndrome.

The European Polio Union recognizes his outstanding achievements and has honored these by appointing him an Honorary Member of the EPU. Thank you very much Dr. Brauer for all your work.

## REPORTING PAST EVENTS

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### EUROPEAN REFERENCE NETWORK

A positive step for Patients and Medical Professionals in Europe

EURORDIS, a European umbrella organization for rare diseases, organized their 2018 annual general meeting in Vienna from 10<sup>th</sup> - 12<sup>th</sup> May. An exhibition of rare diseases?

Not really, but for anybody interested in obtaining an idea of this type of diseases, in particular about the European cross border efforts in this field, the congress was quite conclusive. EURORDIS represents more than 800 rare diseases and is instrumental in networking between medical and therapeutic professionals, hospitals and patient representatives. Not a subject for us polio survivors? Well, in total there are about 700.000 polio survivors in Europe. As per statistics, about one third to one half of them develop the post-polio syndrome up to 50 years after the original infection and as such it qualifies as a rare disease.

Consequently, advocacy and networking are a matter of great importance.

Side meetings at this event provided opportunities for polio survivors from Germany, Slovakia, Poland, Czechia and Rumania to exchange experience.



Paul Neuhaus, Board Member of the EPU and of the German Bundesverband Poliomyelitis e. V., and Stefan Grajcar, chairman of the Slovak Polio Association and EPU Board Member, attended the annual congress ECRD in Vienna.

The congress covered a wide range of subjects, such as THE EUROPEAN REFERENCE NETWORK (ERN) which has been developed over several years with the support of the European Union. ERNs are medical and therapeutic centres of excellence set up in the individual member countries and oriented towards interdisciplinary and transnational efforts aimed

at a faster diagnosis, thus avoiding months of searching to find the cause of the symptoms. The exchange of cross-border know-how is to help achieve effective treatments for the people concerned. The involvement of patient representatives is necessary and is promoted. So far 24 ERNs exist in Europe, more will be set up. EURORDIS regularly organises seminars (summer schools) to train medical doctors and European patient organisations representatives by bringing them into contact with specialists all over Europe. Over and above the basic know-how the seminars provide an interdisciplinary exchange of special aspects in the diagnosis and treatment of rare diseases.

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## THE GENERAL ASSEMBLY OF THE EUROPEAN DISABILITY FORUM

Vilnius, Lithuania, May 26-27, 2018

### A EUROPE FOR ALL ITS PEOPLE

The European Disability Movement gathers in Lithuania to demand a decent standard of living for all persons with disabilities in Europe. European disability movement demands that “nothing about us without us” becomes reality.

The General Assembly of the European Disability Forum took place in Vilnius, Lithuania on May 26th and 27th, co-organised and co-hosted by EDF and the Lithuanian Disability Forum. The Assembly brought together over 150 delegates from across Europe in Vilnius, Lithuania. The conclusion was clear: European and national authorities need to do more to meaningfully involve persons with disabilities and the organisations that represent them.

The Assembly opened with a strong call for political participation of persons with disabilities in the European elections. All persons with disabilities should have the right to vote and should be able to vote. Persons with disabilities should stand for election, and be elected, to ensure that their issues are central to the political decision-making process in Europe.

Yannis Vardakastanis, President of the European Disability Forum proclaimed that “We need to vote. We need to keep the European project in our hands. Persons with disabilities and their families must vote. Candidates with disabilities must stand for election.”

The General Assembly included a meeting between the European Disability Forum, Lithuanian Disability Forum and the national authorities; a conference on the implementation of the Web Accessibility Directive” and discussions on disability assessment, the European Pillar of Social Rights, the future of EU structural funds and the European Accessibility Act.

EDF members also had the opportunity to discuss with the CRPD Committee rapporteur Stig Langvad on the drafting of the general comment no. 7, and stressed the need for organisations of persons with disabilities to be fully involved and closely consulted in all spaces of public decision making on an equal basis of others.

### **Time to make sure that the Web Accessibility Directive becomes a reality**

Delegates discussed the web accessibility directive with Marco Marsella, Head of Unit G3 in the Directorate-General for Communications Networks, Content and Technology of the European Commission, and Shadi Abou-Zahra, Strategy and Technology Specialist Web Accessibility Initiative at the World Wide Web Consortium.

The meeting was preceded by a statement from the Commissioner Mariya Gabriel, EU Commissioner for Digital Economy and Society, which highlighted the importance of this directive on creating inclusive digital technologies.

Marco Marsella insisted on the importance of involving all stakeholders in the transposition of the Directive to national law. He assured Delegates that the European Commission will closely review the national laws and challenge them if they are not according to the spirit and letter of the Directive.

Shadi Abou-Zahra underlined that not only the websites need to be accessible – the tools that are used to create them have to be accessible as well.

Alejandro Moledo concluded that “organisations of persons with disabilities have to act now to ensure that the Directive is correctly transposed. We have to contact our governments and demand to be fully involved.”

Case studies from Denmark, Slovenia, Spain and Lithuania highlighted that involvement of organisations of persons with disabilities is necessary to make the process of transposition easier, better and more cost-efficient for national governments. They also explained their advocacy actions so far to ensure that the Directive was transposed in the most ambitious way possible, including the widest scope, and no loopholes. Delegates appreciated the recommendations for transposition in the EDF toolkit for the Web Directive.

### **“If we need to, we will protest on the streets of the EU Capitals for Inclusive Structural Funds” declares EDF president**

We are deeply concerned with the current proposal for Cohesion Policy 2021-2027. We call for the budget to be increased and to ensure that the needs of persons with disabilities are always taken into account in all projects that are funded by the EU.

It is also essential that structural funds support accessibility for persons with disabilities and the implementation of the European Pillar of Social Rights.

Yannis Vardakastanis, President of the European Disability Forum declared that: “The budget of the European Union must not produce anymore exclusion. The European disability movement will take to the streets to guarantee this, if we have to!”

The General Assembly approved a resolution on the future of the Cohesion Policy 2021-2027. Disability Assessment should never be a tool to cut disability benefits. Worrying trends on disability assessment across Europe were displayed during presentations of case studies from Lithuania, Portugal and Croatia. Lack of proper support, lack of individual assessment and focus on a medical model of disability, among others, lead to discrimination, increased risk of poverty, and health issues due to stress and anxiety.

“It is clear that the European disability movement has to be more involved in the process of disability assessment” said Yannis Vardakastanis. Rodolfo Cattani, Executive Committee member added that “Disability Assessment is a priority for EDF. We have to ensure that changes are made in accordance with the UN Convention on the Rights of Persons with Disabilities and the full protection of disability benefits.”

Disability assessment should be as objective as possible, ensuring the respect and dignity of persons with disabilities.

### **It is urgent to adopt a strong, meaningful European Accessibility Act**

The European Disability Forum adopted an emergency resolution on the European Accessibility Act. We demand the Act to:

- Support the accessibility provisions of other Union acts, such as the Public Procurement Directive or the EU Funds Regulations,
- include a compulsory clause on the accessibility of the built environment,
- cover emergency services fully,
- cover all microenterprises,
- to cover transport services broadly,
- not to limit the scope for self-service terminals,

- ensure that audio-visual media services and the access to the latter can benefit from common accessibility requirements.

The resolution also includes the demand to adopt a horizontal principle on promotion of equality between men and women, accessibility for persons with disabilities and non-discrimination in the Structural and Investment Funds Common Provisions Regulation 2021-2027.

The General Assembly concluded with an intervention of Kamil Goungor the new chair of the European Disability Forum's Youth Committee. In it he stressed that young persons with disabilities face double discrimination.

He stated "It is difficult for a person with a disability to be employed. But it is twice as difficult if you are young and disabled."

EDF has committed to greatly increase the visibility and the impact of youth within its work.

Source: <http://www.edf-feph.org>;  
Media release, May 27, 2018 (shortened, amended)

Note: I attended the General Assembly of the European Disability Forum in Vilnius, Lithuania, on May 26-27, 2018, representing there the Slovak Disability Council

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### SCANDINAVIAN POLIO SEMINAR IN COPENHAGEN, SEPTEMBER 2018

Friday the 7<sup>th</sup> of September 2018 Polio Denmark hosted a Polio Seminar together with other Scandinavian polio organizations. The main subjects were polio, postpolio, recent research, pain, fatigue and how to live a good life with polio. More than 220 polio survivors from Norway, Finland, Sweden, and Denmark participated in the event. The seminar was primarily for polio survivors and it made it possible for the participants to obtain knowledge and to share experiences. There were several interesting speeches by doctors, physiotherapists and psychologists, some of the speeches are mentioned below:

**IVIG treatment:** Doctor Peter Sjøborg, a specialist from Rigshospitalet, spoke about the IVIG treatment and gave the participants a status of the on-going international research project regarding IVIG. Experts expect the project to be finished within 3-4 years.

**Fatigue:** Doctor Michael Felding made a speech of sleeping and respiration problems, which are well-known symptoms with postpolio. Sleeping problems and respiration problems often walk hand in hand. It is therefore important to consult a doctor when noticing the problems.

**Pain:** Doctor Ole Bo Hansen, a specialist from the Pain Clinic at Holbæk Hospital, spoke about pains and how to treat pains. He emphasized that it could be very complex and time-consuming to treat pains. The longer you feel pain the harder it is to treat it. His recommendation was that pain should be treated with several different actions. Sometimes the best treatment might be physical therapy, and sometimes medicine treatment is helpful. However, not all pains can be relieved by medicine.

**Psychological aspects:** Psychologist Mette Nyrup made a speech of identity crisis that might occur when you no longer are able to do what you used to. Many polio survivors experience that their physique gets worse and they feel that they have been cheated of good years. It is necessary to accept the impermanence of the physique and adjust activities to the ability of the body.

Thursday the 6<sup>th</sup> of September the participants who were interested had the opportunity to visit the Special Hospital for polio and accident victims in Rødovre.

The Scandinavian Polio Seminar was a big success and hopefully more seminars will be arranged because the consequences of polio go across national borders. It is very important to draw attention to the fact that we are still here and together we are much stronger.

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**ROYAL VISITS TO BELGIAN ASSOCIATIONS**

ABP and GES - La Famille welcomed Queen Mathilde in September 2018



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Welcome to Queen Mathilde



© EPA



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Special welcome by one of ABP « campers », nicely accepted by the Queen!

The ABP summer camp was happy to welcome Queen Mathilde last September on the Belgian seaside.

One specificity of this camp - organised each year since nearly 70 years - is to welcome 50 physically handicapped people coming mainly from institutions where they live; those heavy disabled persons need to be helped by personal assistant during meals, activities and for health care. Boys and girls, between 18 and 23 mainly, stay with their “camper” all the day long during the 8 days stay. The relationship established between them is really exceptional and creates a particular atmosphere and a tremendous ambience.

During her short visit, Queen Mathilde has been deeply impressed by the various types of activities organised for the campers (painting, paper flowers creation, pictionary, etc.) with an active participation of everyone.



The Queen left after a photo souvenir with the whole group

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Two weeks later, we were delighted and honoured to welcome the Queen, once again, to celebrate the 50th anniversary of a school for physically disabled boys and girls, from 2 to 12 years, named « La Famille ». Being the vice-president of this organisation, I had the privilege to welcome the Queen with local authorities, President and staff of the school.



The Queen listening to the Staff introduction



Chatting with children in the kindergarten class

The first part of the visit was dedicated to the school where 60 children are welcomed and taught every day. They were all extremely impressed by this royal visit they will never forget. Queen Mathilde indeed was extremely simple and natural, listening to all, asking questions and having private discussions with many children.



The Queen receiving a souvenir from her visit to the school

During the second part of her visit, the Queen had the opportunity to meet the 17 adults coming every day at the disabled day center to have occupational activities.

On top, she met a man who celebrated his 50 years anniversary with the Center where he arrived, as a child, when he was 5 years old.



Queen Mathilde having decorated this gentleman who is at La Famille **since 50 years!**



As one can see, the ambiance between the Queen and the disabled persons was very friendly and far from the protocol.

Thank you for your visit, Madame, and come again. (Daniel Peltzer)

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EVENT "CARE FOR LIVING WITH POLIO" IN THE NETHERLANDS



On the evening of October 23, 2018, an event took place in theatre De Flint in Amersfoort with the theme 'Care for living with polio'. It was the evening before World Polio Day, which is held annually on October 24th.

The organizers were Rotary Netherlands, Muscle Diseases Netherlands, the RIVM (National Institute of Health), the Princess Beatrix Spierfonds and the Post-polio Expertise Centre of the AMC (Academic Medical Centre Amsterdam).

The meeting consisted of a mix of presentations, short films, and entertainment.

The aim of the evening was to draw public attention to the worldwide campaign End Polio Now. Another important goal was to focus more attention on the late consequences of polio and post-polio syndrome.

The evening was the kick-off for a national campaign to collect money to enable research into improving the treatment and quality of life of (post) polio patients. For the meeting were invited: people with (post) polio, members of the Rotary and other interested parties, including health care professionals.

The efforts involved in the final eradication of polio turned out to be more difficult than expected. In addition, in our own country we are confronted with a shocking decrease in vaccination coverage among the population on the basis of some irrational arguments.

For the first time, Rotary International mentioned at the International Convention in Toronto that, in addition to controlling polio as an infectious disease, they will be confronted with the late effects of the disease and post-polio syndrome for decades to come. It was Dr. Tedros Adhanom Ghebreyesus, Director General of the WHO, who made a passionate plea to focus attention on post-polio syndrome in addition to the effective rehabilitation of polio patients.

We are very pleased with the fact that Rotary has spoken about supporting people who suffer from the late consequences of polio and post-polio syndrome. We can use that attention and support very well!

### ***The program of the event "Care for living with polio"***

The program was presented by two chairmen, Bauke Boersma, District Governor of Rotary, and Aldith Hunkar, journalist.

It started with a very nice video message from our Dutch comedian Paul Haenen. As his famous character, Reverend Gremdaat, he gave a passionate and humorous presentation about vaccination against polio, the eradication of the poliovirus, and the horrors of post-polio syndrome. Funny was the message he gave to the religious people from the Bible belt: "To believe is ok, but do it in moderation ....."

A video was shown by the RIVM, about polio and vaccines.

Albertine Perre of the Rotary spoke about the Rotary's struggle to eradicate polio and about the many vaccination rounds in which she and many members of the Rotary participated.

Erwin Duizer of the National Polio Laboratory of the RIVM gave a presentation about what is still needed to eradicate the virus: 'Polio eradication 4.0: the endgame'.

Then a film was shown about post-polio syndrome. This film was specially made for this evening and the follow-up. In this film three people talk about their life with PPS. Frans Nollet also featured in the film and a paediatrician advocating vaccination.

As an intermezzo there was a very impressive performance by dancers from Codarts. It was beautiful.



This was followed by a presentation by Aadjie de Groot. She told us about her life with polio and post-polio. She did that in a fantastic and often humorous way. Everyone was impressed by her story. She was for many the star of the evening!

The title of Frans Nollet's talk was: The post-polio syndrome; the second epidemic. He told about PPS, indicated what the PPSers have to deal with and what research he would like to do to improve

treatment and care for people with PPS. He made it clear that this is necessary for people in the Netherlands but also for people in, for example, Asia and Africa, where the 'epidemic' of PPS will also strike. He also indicated that money was needed for this and made an appeal to take action for this.

The PPS campaign Internet page of the Princes Beatrix Spierfonds was presented. It keeps track of how much money comes in through donations and from campaigns. There is also information about PPS on this site and a video can be viewed.

After a performance of the AMC big band, the three people who were starring in the video we saw earlier in the evening, made an appeal to raise money.

The evening was continued in the foyer. Polio tulip bulbs could be bought at the Rotary stand and information material could be obtained from Spierziekten Nederland. There were delicious snacks and the glass raised for the thirtieth anniversary of the diagnostic workgroup (post)-polio.

The evening was a great success and we are looking forward to working together with all the organizations involved.

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**CONFERENCE “POSTPOLIO SYNDROME. POLIOMYELITIS. POLIO SURVIVORS’ EXPERIENCES”**

PRAGUE, CZECH REPUBLIC, OCTOBER 24<sup>TH</sup>, 2018

The National Institute of Public Health (NIPH) in cooperation with the Polio Association and with support from the Office of Government of the Czech Republic organised in its own premises already the second conference “*Postpolio Syndrome. Poliomyelitis. Polio Survivors’ Experiences*”. The event was organised on October 24, 2018, exactly on the day when the World Day for the Eradication of Polio, announced by the United Nations, is celebrated.

There were more than 110 participants at the conference from various fields of medicine, and also with a strong group of polio survivors, members of the Czech Polio Association (CPA) and one international representative from the Polio Association Slovakia, Štefan Grajčár. All ten presentations were recorded on video and are available (in Czech or Slovak languages) on the NIPH website: <http://www.szu.cz/tema/prevence/odborna-konference-postpoliomyeliticky-syndrom-prenosna-1>

The opening speech by MUDr. Kateřina Fabiánová, coordinator of the whole event, was followed by presentation of MUDr. Pavel Březovský, MBA, Director of the NIPH, who mentioned his own personal experience with polio in his family and who pointed out the importance of vaccination as a protection of the whole population. Mrs. Marcela Stránská, Chair of the Czech Polio Association reminded that thanks to the health care and prevention programmes polio was pushed into the past and nearly forgotten. Nevertheless, the very last generation of people affected by polio associated in the CPA is still striving that polio itself, but mainly polio survivors, those affected by polio decades ago and are now struggling with its sequels including PPS, should not be forgotten. The last speaker in this introductory part was MUDr. Barbora Macková, Head of the NIPH Epidemiology and Microbiology Centre.

The conference programme continued by following presentations – here let me just briefly introduce all of them:

- *Poliomyelitis – Current Epidemiological Situation* (MUDr. J. Částková, NIPH): it was mentioned that there is still a risk that polio will transfer from countries where polio is not under control yet. According to Regional Certification Commission there is a threat of exposure to polio virus even in Europe, mainly due to low vaccination, migration and import of the disease. It was stressed that the only prevention against polio is still vaccination.
- *National Programme of Polio Surveillance in External Environment* (MUDr. P. Reinertová, NIPH): an important part of polio surveillance, environmental surveillance, was described. This is the monitoring of waste water for the presence of enteroviruses from the main municipal sewers and the drainage of waste water from refugee camps. Waste water discharges are provided by healthcare staff in cooperation with regional hygiene stations once a month, and tests are performed by the National Reference Laboratory for Enteroviruses.
- *Current Experiences from Polio Advisory Centre and Citizens with Polio* (Prof. MUDr. Olga Švestková, Ph.D., Head of Rehabilitation Medicine Clinic, 1<sup>st</sup> Faculty of Medicine, Charles University, and the General University Hospital, Prague): poliomyelitis and its late effects, together with activities of the Polio Advisory Centre were presented in detail. The immense importance of Janské Lázně in subsequent rehabilitation, as well as the contribution of Prof. Slonim to the prevention of polio were mentioned.

Unfortunately, just few weeks later I learned that the professor suddenly died on December 13, 2018. She was the head of the last and currently the only Polio Clinic in the Czech Republic and for many years she was closely associated with the Polio Association. The professor was convinced that just rehabilitation could give polio survivors hope for a better life despite health complications.

- *Causes and Diagnostics of PPS* (Associate Prof. MUDr. Miluše Havlová, 1<sup>st</sup> Faculty of Medicine, Charles University, Prague): a comprehensive overview of etiology, clinical symptoms of PPS, diagnostics and differential diagnostics were presented.
- *Quality of Life of Polio Survivors in Slovakia – Introductory Exploration* (Štefan Grajcár, Polio Association Slovakia): preliminary results of a short survey (using a modified version of the SF-36 questionnaire) of quality of life with a small sample of polio survivors were presented; selected aspects of their lives were also reviewed. Interesting but bad finding among other things is that about 52 % of general practitioners and medical specialists do not distinguish polio from cerebral palsy (Note: in Slovak and Czech languages for polio the term “detska obrna”, and for cerebral palsy “detska mozgová obrna“ are used; as can be seen, these terms are very similar to each other).
- *Treatment of Polio and PPS in Janské Lázně* (MUDr. Ivana Uiberlayová, Head of the Adult Department, Medical Spa Janské Lázně): principles of polio and PPS treatment were presented. Sister Kenny (Elisabeth Kenny, Australia) and her specially developed physiotherapeutic methodology for polio treatment as well as the proprioceptive neuromuscular facilitation method developed by the American physician and neurophysiologist Herman Kabat, together with physiotherapists Margaret Knott and Dorothy Voss – all these important people from the history of polio treatment were mentioned. The presentation was finished by a series of photographs from rehabilitation stays in Janské Lázně, several decades old, where many of the conference participants could recognise themselves.
- *Pharmacology of PPS* (MUDr. Miluše Havlová): brief and comprehensive summary of the symptomatic therapy including the pain treatment in PPS and the possibility of causal therapy, for example intravenous application of immunoglobulins was provided.
- *My Personal Story* (MUDr. Eliška Běbrová; Marika Mruzková; Vladimír Vondřejš): the last three presentations were offered by polio survivors themselves when each of them shared their own unique personal story, highly appreciated by the audience.

And finally let me say that in spite of huge problems caused by the disease, polio survivors are great life optimists, and it is a pleasure to be with them.

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### **POLIO CONFERENCE IN PARIS, NOVEMBER 22-23, 2018**

At the initiative of “Fondation de Garches” a two day conference has been organized in Paris last November to cover the subject “La Poliomyélite”.

It is important to know that the hospital Raymond Pointcaré located at Garches, near Versailles, was THE hospital who welcomed a large number of boys and girls who were attacked by polio during the polio epidemics in the years 1940 – 1960. On top, Paris region counts a wide number of surgical skills, physical medicine, etc.



Those professors, doctors, physical therapists and other representatives of polio survivors have covered the following subjects with talent and several positive tips. A large group of students in physiotherapy was attending the conference and asked many questions. A promising future for French polio survivors.

The first day was devoted to the following subjects:

- a. History of polio eradication in the world with contribution of MSF expert about vaccination programs.
- b. Aging polio and Post-polio syndrome
- c. Orthopedic surgery and polio
- d. Orthopedic equipment and polio

The second day was dedicated to aging polios: sleeping troubles, pain, respiratory disorders, risk of weight gain. In a second part of the day, the speakers covered the remedies and the possible and existing re-education programs.

Since 30 years, the “Fondation de Garches” is organizing each year similar conference. Believe me or not but despite their long history linked with polio, they realized that they had never before organized such a conference on the polio subject. Now, it is done!

Videos of the presentations will be available by year-end on their website: [www.handicap.org](http://www.handicap.org)

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### ACTIVITY REPORT 2018 BY SIPS, SWISS MEMBER OF EPU

Schweizerische Interessengemeinschaft für das Post-Polio-Syndrom (2018)

Communauté suisse d'Intérêts pour le Syndrome Post-Polio CISP

#### 1. POLIO TULIPS in support of polio eradication

On April 2, 2018, we attended a meeting with Oliver Rosenbauer of the WHO / Rotary Geneva, in Neuchâtel. We also met some members of SIPS and the central board of directors of ASPr-SVG/Polio. Neuchâtel commune officials took us to see the wonderful tulip beds at Lake Neuenburg. After this visit we had lunch together and a very interesting exchange of thoughts.

Edy Bucher was already looking forward to launch together with Oliver Rosenbauer this year's orders for tulip bulbs. In the German part of Switzerland great number of tulip bulbs were ordered in 2018, e. g. In Solothurn, Rappenwil Jona, etc., also in Morges and other communes in the Welsh country.



#### 2. Chocolates / Eradication of Polio / End Polio Now

As usual, we started a few months before Christmas placing orders for chocolates at the Laederach Chocolatier. My husband accompanied me to Lausanne early in December to collect two huge cartons with chocolates which we delivered to the members in and around Zurich, who had placed orders. A short time after delivery we heard the Swiss Television Channel announce the Laederach chocolates to have won first prize in Paris.

SIPS and ASPr SVG have bought 100 boxes of chocolates and according to Oliver Rosenbauer this action has had a total profit of CHF 105,000 (including the contribution from Bill and Melinda Gates) to be used for vaccinations worldwide. This corresponds to a total of 2500 boxes of chocolates.

### 3. Transfer of Knowledge 2018

Polio Survivors all over Europe are aging and the medical professionals' knowledge is limited or non-existent. A polio survivor has great problems finding a doctor or physiotherapist who has any knowledge about polio or PPS. For this very reason we have set up a detailed questionnaire in spring 2018 and distributed it to all our members. In July we spent a whole day with two SIPS members, one an oncologist, the other a child psychiatrist, to check and evaluate the information and questions received. The strategic team is now dealing with the problem and will present the evaluations at the 2019 Annual General Assembly.

### 4. SIPS Meetings

Like every year the SIPS Annual General Meetings were held in Zurich and in Hinterkappelen near Berne and in Yverdon-es-Bains, the subject being physiotherapeutic treatment for polio and post-polio syndrome. We were looking for qualified neurological therapists. In Zurich and in Berne we had a very efficient therapist who had been working on the polio ward in Bern for many years. She has meanwhile specialized in geriatric physiotherapy and has concentrated on treating PPS patients at their homes.

In Yverdon-les-Bains a therapist who treats polio survivors presented some very interesting treatments. A great number of participants were at these meetings. New approaches in physiotherapy have made us look for different therapists. These are described in our Faire Face magazine. Last year we presented methods such as Feldenkrais and Trager methods. Trager is very positive for polio and PPS patients and is applied at the Schinznach rehabilitation clinic. For German and French speakers it is worthwhile to download the Faire Face magazines [www.polio.ch](http://www.polio.ch). (Faire Face Publications 6 per annum).

### 5. World Polio Day 2018

At last year's EPU Annual General Meeting Dr. Peter Brauer asked us to ensure that our members know about the 10 errors concerning post-polio syndrome. Shortly after my return from Rheinsberg / Berlin our media guy had the brochure translated into French and we gave a copy to each of our polio/PPS member as a present on the World Polio Day. We were pleased to find that our members were extremely happy about this brochure and on this occasion we would like to say 'a big thank you to you, Dr Brauer'.

### 6. International Medical Cannabis Day (19<sup>th</sup> January 2019)

Mario Corpataux and I attended a one day's conference at the University Hospital. It was a pleasure for us to see also Dr Thomas Lehmann participating in the morning. The conference took place at the Inselspital of the University Berne. The medical professionals participating came from Switzerland, Canada, USA, England, Germany, Netherlands, Israel, Austria, Italy, Czechia, etc. The conference was held in English with simultaneous interpretation.

The Swiss Bundesrat (Federal Council) is considering dropping the strict regulations concerning medical cannabis. A proposal has been submitted to the Bundesrat and will be debated during the summer session. The National Council has supported this proposal.

### **New Regulations for therapeutic treatment**

The Federal Department for Health is in favour of changing the regulations as proposed by the Bundesrat. A respective draft proposal will be presented by the middle of the year.

This measure is urgently needed – according to a remark by Rudolf Brenneisen, the professor in charge for pharmacy and founder of the Swiss Task Force for Cannabinoids for medical use (SACM) ‘Many patients suffering chronic diseases need to buy this medication in the streets’ because medical professionals dread the red tape or don’t know any better.

Medical cannabis will in future be available at pharmacies on a medical drug prescription, without exceptional agreement of the Bundesamt for Health, such is the proposal made by the Federal Council.

Some people complained about how they suffered from the effect of opiates, morphine and other strong medication. With Cannabidiol etc. they could sleep again. We at SIPs have been advocating for a long time to alleviate the strict regulations for the sale of this medication.

**For more information on this subject please refer to our internet platform [www.polio.ch](http://www.polio.ch), under Post-Polio Syndrome ‘Therapies / Cannabis.**

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## EPU News

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### **FRENCH VERSION OF BOOKLET 'A BETTER UNDERSTANDING OF POLIOMYELITIS AND PPS'**

For the French speakers who want to know more about polio and post-polio syndrome we are pleased to inform you that a French version of the Polio booklet mentioned above, written by Thomas House and Professor Kai Paschen MD (†) is already available through AMAZON.

Since the announcement of this French version at the Piešťany AGM in 2016 a lot of work has been done by many volunteers.

Let me try to summarize this very long – too long – story!

Indeed, the first translation was done but more driven by “Google Translate” application than by real translator capacities. So the text needed to be improved and corrected. Polio France and Polio Belgium proposed to share the workload 50/50.

Believe me or not, none of us could imagine then that it was a tremendous work for not professional translators. This type of activity needs translating and medical skills, none of the volunteers had. But translation by professionals is extremely expensive and EPU cannot afford it.

Today, we are close to the end and you'll see in the booklet the list of people having contributed to its finalization.

This book needs to be advertised and promoted because it summarizes what you – and your doctor and your physiotherapist and your family or friends, must know about polio and post polio syndrome.

Feel free to tell us via an email the quantities your country and your organizations would need in order to print enough copies from the beginning. The selling price is not fixed yet but should be similar to the German and English versions, i.e. about 10-12 €.

Author: Daniel Peltzer  
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EPU board member

### **EPU WEBSITE UNDER RECONSTRUCTION – NEW VERSION COMING SOON!**

The European Polio Union has had a website for nearly 10 years, packed with information for both polio Survivors, families, friends and those in the caring medical professions. However, just like everything else it has aged in format, content and presence on the world-wide web. So, the Board thought an update was needed and that process is now underway and the new site will incorporate the work of Tom House-Arno with content from Polio Echo. There will be new information from many new sources, links to point to other sites from sister organisations such as Polio Health International, Polio Australia and many others.

Caring medical professionals will be able to utilise its resources so that they can provide them most up to date care possible through following links to well established per reviewed medical articles and journals. Plus all the usual information and news from around not just the EPU but the world.

Finally, just for fun there will be a quiz to see just how much you really do know about polio and PPS, sorry no prizes! Our partner in this work is European, as befits an organisation named the EUROPEAN Polio Union, and they and we hope to have a partial demo for all to see at the AGM in Lobbach in June - so until then watch out for more news.”

### IMPORTANT INFORMATION FROM THE TREASURER

Our EPU international organisation receives no subsidies except some financial support from EURORDIS (European Rare Disease Organisation) to help us in our AGM organisation.

As your country associations are sometimes beneficial of some fiscal advantage for your local donors, very soon, our European Polio Union could also receive the same advantage.

Indeed, there is, based in Brussels, a Transnational Giving Europe – TGE organisation authorizing tax effective cross-border cash donations.

If you know, in your country, donors who would / could generously give a financial support to EPU, please inform me, as soon as possible, in order to have you country officially recognized as a partner of TGE and the donor able to receive tax deductibility for his / her donation.

The first countries we'll ask to be recognized are as partners: France, Belgium, Switzerland, Germany, Spain, and Italy. This list could be increased if appropriate.

**Remark:** one must wait the official “GO” from the TGE network before motivating the donors to financially support EPU. This information will be communicated via our EPU website ([www.europeanpolio.eu](http://www.europeanpolio.eu))

Many thanks in advance for your kind attention,

Daniel Peltzer, EPU treasurer

**VARIA**

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Issued on behalf of The British Polio Fellowship



**DO TRAVEL PROVIDERS WANT OUR MONEY?**

*By David Mitchell, Chairman of Trustees of The British Polio Fellowship*

Like many of you in the EPU, I do not drive and rely 100 percent on public transport. As National Chairman of The British Polio Fellowship, I travel up to four days a week sometimes, and a fast, reliable bus/rail service is essential. I am not bothered about coloured trains and buses, not wanting stunning décor, or lavish buffet cars. Along with many (more disabled than I am) I just want to go from A to B in reasonable comfort, with heating where needed, good access and most of all, a reliable timetable, which does not leave me and others stranded. Planes are not too bad but some recent terrible stories of lost wheelchairs, inaccessible toilets and patronising behaviour are not acceptable.

A recent High Court ruling now means that wheelchairs/scooters have priority over baby buggies and shopping trolleys on service buses. I use a bus possibly eight times every week and with the help of the driver, a compromise is often reached with buggy/baby users. Most buses now have seats at the front with large notices proclaiming, 'Priority seats for disabled'.

Train travel, however, is another matter. Since the UK railway network was privatised, the needs of the disabled have taken a back seat. The railways are now run by up to 20 different companies, some fairly good, but most are shocking! There is minimal integration of services. No holding of trains at mainline junctions/railheads when feeder trains have a problem or are late running. Despite a massive increase of new train sets, many are very difficult to use for the disabled. Narrow aisles, small toilets (many often out of use), only one wheelchair space in each carriage (and that's the mainline services), difficult station access (especially on the London Underground) and believe it or not, many small stations where wheelchair passengers are pushed across the track itself. Some small, rural stations do not have this facility/service, as they are unstaffed.

A very recent and absolutely shocking email was sent to the staff on one of the southern English operators that caused outrage. It instructed staff that if it was obvious that to get a disabled passenger onto a train would delay the service, then they were to be left behind on the platform!

Fortunately, an outraged Union employee went public on this and the press and public forced the train company to withdraw this order. It's sending however, showed that despite all the fancy words and promises, they count for nothing when profits are concerned.

There is a major enquiry about to start into the rail industry in Great Britain. In common with many other charities for those with disabilities, The British Polio Fellowship will be fighting for our members. We are not second class citizens, we are normal members of society with some special needs. Catering for us should not be difficult in this age of engineering and technology.

### **About the British Polio Fellowship**

The British Polio Fellowship is a charity dedicated to helping, supporting and empowering those in the UK living with the late effects of Polio and Post Polio Syndrome (PPS). It provides information, advocacy, welfare and support to enable its members to live full independent and integrated lives and works to develop worldwide alliances with other Polio and Post Polio groups for the mutual benefit of its members. Further information about the British Polio Fellowship and details on how to make a donation can be found at [www.britishpolio.org.uk](http://www.britishpolio.org.uk) or by calling 0800 043 1935.

### **About Post Polio Syndrome (PPS)**

Post Polio Syndrome (PPS) is a neurological condition which can occur in up to 80% of those who have had Polio. It is estimated that around 120,000 people in the UK are living with PPS today. After an interval of several years of stability, individuals can develop increasing weakness, fatigue and pain in previously affected or unaffected muscles, a general reduction in stamina, breathing, sleeping and/or swallowing problems and cold intolerance. PPS usually begins very slowly, although it can appear suddenly and often following triggers such as falls, surgery or immobility. There is no specific cure for PPS, but properly managed it may stabilise or only progress slowly and lessen the cost on the NHS whilst increasing the quality of life of those affected. Much can be done to retain independence, including self-management strategies such as pacing and energy management, appropriate use of adaptive equipment, looking after your general health, and social and emotional support.

### **Media contact**

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# En el Camino

## A PILGRIMAGE BY WHEELCHAIR AND SCOOTER TO SANTIAGO – PART II

by Paul Neuhaus

**Sunday, Sept 24<sup>th</sup>, Burgos**



The first day, the 10 of us came together in Burgos as our starting point.



After the Sunday mass in the Cathedral we asked the celebrating priest to give us a special blessing for our journey. He was delighted to do so.

Having visited the touristic highlights of Burgos with its famous buildings and nice alleyways and squares we mentally prepared ourselves for our first walking tour on the next day.

**It is really an adventure!** But a pilgrimage should have also a spiritual dimension. Days of pilgrimage always include a chance to detect some corner of our life we did not know well before. It is also a chance to meet people whom we otherwise never

would have met. And besides that we might experience some sort of strength we never thought we would have.

Certainly, it is not easy for an abled person to go that way and of course, it is much more difficult for a disabled person, be he or she in a wheelchair or not, with one or two legs paralysed.

But we “polios” are used to take some risks and afterwards become a little bit proud of having taken a risk.



For our walk on the CAMINO we tried to choose the itineraries the roads or paths with less ascending slopes. But nevertheless some of them were difficult to overcome with my wheelchair-hand bike or the scooter.

To have more grip on the road I decided to put heavy bike-bags on the front of the hand bike. So my assistants sometimes had to push a 200 kg vehicle.





We were lucky to have some “abled assistants” with us. It was not easy for them staying behind us and being aware of the stumbling blocks we had to tackle.

**Monday, Sept. 25<sup>th</sup>, from Hontanas to Boadilla.**

From Burgos we went to Hontanas by car and bicycle, where we arrived at 11 a. m. From Hontanas we walked to Castrojeiz and arrived in Boadilla in the late afternoon.



It is Monday evening. The first of a ten days’ pilgrimage is done! No accident, no uneasiness! Excellent meal! No rain! New acquaintances! All with good humour! Thanks to God, for this good beginning! What will You prepare for us for the following days?

Arrived at Boadilla we found a very well equipped pilgrim house “en el camino”.



We had our first pilgrim’s night dinner in an international and meanwhile very familiar atmosphere. We met with 15 or 20 other Caminantes of various nations. Some of them we would meet again later.

Since I am able to speak a little bit of Spanish, I had a drink with the former Mayor of Boadilla and now Senior Chef of the hostel. He told me about his grandfather having had polio in the time between the two world wars and then struggling his whole life with its consequences, surely not having the possibilities for mobility as we have nowadays. On my question he affirmed that also today on the Camino it is still quite unusual to meet a pilgrim in a wheelchair or with a rollator.

So in the evening despite the relatively small daily distance of 8 to 12 km we were tired and always happy to have reached our living quarters without any severe accident. At night I appreciated the simple but good and clean twin-bed-rooms on the first floor, all accessible by a lift. Regardless of the fact that the bathrooms were difficult to use for a wheelchair person I managed by moving forward with two shower-chairs sliding from one chair to the other/ it was a good advise by my cousin Heiner who knew the location from former trips.

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