

EUROPEAN POLIO UNION NEWSLETTER MAY 2017

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President's Message

It seems rather strange to realise that this is the last time I will be addressing you in writing as President of the EPU. As you may remember last December I sent out a statement saying that I would be standing down from the position at the next AGM, as you will see later in this edition the time of that AGM is approaching fast – about 9 weeks to go.

Since I took over the Presidency in 2011 at the Copenhagen conference the EPU has grown in stature and confidence, both internally and the respect that it enjoys in the world wide "polio family". This has been brought about to a great degree by the membership as with expansion, both to date, and projected the polio Survivor groups around Europe and further afield have started to actively network. The EPU has done its part by inviting non-member organisations to participate in its events such as the AGM in Piestany last year and in Lobbach, Germany this year. In its efforts to reach out to the wider polio community it has been assisted by grants from EURODIS, the European organisation representing groups and individuals with rare diseases, for this the EPU thanks EURODIS for helping us to help others.

The participation of the organisation in the two European PPS conferences, and lending assistance to the one held in Sydney 2016, has greatly strengthened and confirmed the EPU's standing not just with polio Survivor support groups but medical personnel around the world. I know with things that are planned for just over the horizon the EPU is set for another expansion, both in activity and reputation. But I will leave the person who succeeds me as President to tell you all about that in time to come!

As for me, well although I am stepping down as President I intend to remain active as a Board member if the EPU will have me. I shall continue in my own way to strive to make PPS better understood in the community, ensuring medical personnel are appropriately trained to look after polio Survivors, and agencies so that we may all live lives of quality and independence.

It has been my privilege to serve you and the EPU over the past 6 years.

My best wishes to you all. John R. McFarlane 26 April 2017

Dear Members and Friends,

Time flies and it's hard to believe we are heading into May and are fast approaching the EPU Annual General Meeting in Lobbach near Heidelberg scheduled to take place on the 24th June . Many registrations have been received, in fact more than ever before, and we are looking forward to extending a warm welcome to all participants at this event. Transport arrangements will be made for all delegates arriving at Frankfurt Airport. The hotel is entirely wheelchair accessible, including all rooms and bathrooms. It also has facilities such as a swimming pool, physiotherapy department, fitness centre and a boutique which sells fashion clothes for wheelchair users. We hope you will have a great time and enjoy your stay.



Heidelberg

Just a few words about Heidelberg for those of you who want to visit this city - located about 78 km south of Frankfurt, it is the fifth-largest city in the German state of Baden-Württemberg. Founded in 1386, Heidelberg University is Germany's oldest and one of Europe's most reputable universities and as a scientific hub Heidelberg is the home to several internationally renowned research facilities.



The EPU has reached another turning point in its development and evolution. We are very sad and sorry to say that John McFarlane will announce his resignation from the EPU presidency and that we will have to vote in a new president. We owe a lot to John, he has given the EPU a voice that is heard not just in Europe but also worldwide. Thank you very much John, for all you have done for the EPU and all the polio survivors.

We are lucky to have been able to get Dr. Axel Ruetz MD as a speaker at this year's AGM. Some of you might have met him in Copenhagen or Amsterdam. For those who don't know him you will find his profile in this Newsletter. Dr. Ruetz is the head of the Polio Centre in the German city of Koblenz , you may remember that we reported about this treatment centre in our last Newsletter.

We understand that the Australasian International Conference in Sydney on 'Life Stage Matters' was a great success and you can click on the link below which will give you the possibility to listen in to some of the presentations that had been recorded by Post-Polio Health International. : https://www.poliohealth.org.au/phi-videos-sydney-2016/ The article about pain management is particularly interesting as most of us suffer from chronic pain and medication is not really a solution in the long run. Physiotherapy, pacing, rest, spirituality, are ways and means, whilst not curing, of helping manage chronic pain.

Sylvie Tararbit, board member of G.L.I.P. – the French polio organisation – gave us a short report about the Montpelier Talks on the 17th March 2017 – outlining the polio situation in the Mediterranean countries. Daniel Peltzer, the EPU Treasurer, and Sylvie Tararbit, attended the 6th Congress on Post-Polio Syndrome in Paris and they have written a joint report about this congress which is included in this Newsletter. Daniel has also made a presentation about the 10 years of existence of the European Polio Union, an overview is included herewith as well.

Stefan Grajcar, chairman of Polio Slovakia, has given us an idea about their polio organisation which will be celebrating their 25th anniversary this year.

Polio Australia put together a flyer on the late effects of polio and about how to recognise the signs. They have given permission to pass this on to our members. So you will find a summary of signs that point to LEOP and other features that are not typical for it. All of you most probably have a flyer, but in case you haven't it might be a good thing to copy it and hand it to your doctor.

John McFarlane has given us a review of the book 'A Piece of the World' - by Christina Baker Kline, a beautifully written and very moving nearly biographic story about the polio survivor Christine Olsen whose painting by Andrew Wyeth is one of the most viewed in the New York Museum of Art.

Australia located their oldest polio survivor of 102 years of age and wondered whether there is any polio survivor in the world older than that? Yes, indeed Germany reported of their oldest survivor who is 111 years old and you find a short life story of this polio lady in this Newsletter . British Polio Fellowship and Polio Finland also reported that they had members who were older than 100. So polio and its late effects doesn't mean polio survivors can't reach a ripe old age!

Finally let's go to Switzerland and their polio tulip show. We reported about the tulip called 'Polio' in our previous Newsletter. These tulips are now on show in the tulip festival city of Morges, Switzerland.

Wishing you a wonderful summer season The Editors

PROFILE Dr. Axel Ruetz, M.D.





Dr. Axel Ruetz, M.D.

*31.07.1958

Head of Polio Centre Bruederhaus Koblenz
Head of the Sports-Medical Examination Facilities of the Regional Sports
Association Rhineland-Palatinate
Chief Consultant of the Clinic for Conservative Orthopaedics
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Consultant for Orthopaedics and Accident Surgery
Physical Therapy, Sports Medicine, Chirotherapy, and Social Medicine
Since 20/11/2009 – Speaker of the Medical Scientific Committee
of the Bundesverband Poliomyelitis e.V.
Since 01/07/2010 – Member of the Medical Committee of the Orthopaedic
Association Region South-West

Since 01/05/2012 – Medical Consultant of the German Paralympic Sitting Volley
Ball Committee, Paralympic classifier level 1

Author of 'Diagnostics and Therapy Guide for patients with the late effect of polio and with post-polio syndrome.

SUMMARY OF THE 45th PHYSICAL AND REHABILITATION MEDICINE TALKS MONTPELLIER – FRANCE - MARCH 17TH 2017

(report by Sylvie Tararbit – G.L.I.P. France)

HOW ABOUT POLIO IN MEDITERRANEAN COUNTRIES IN 2017?

In Tunisia, polio has been eradicated n 1993 after great epidemics in the 60's/70's and a national vaccination campaign. The Tunisian Pasteur Institute is a reference for north Africa and physical and rehabilitation doctors have a good knowledge of the pathology.

In Algeria, vaccination has been mandatory since 1969. Cooperation with surgeons is important. There is still much to do to help polio survivors: technical aids, transport, family and social life.

In Morocco, the first vaccinations took place in 1964/67 and polio was eradicated in 2001. There are about ten orthopaedic device centres in the country .

Professor Isabelle Laffont underlined the fact that medical research owes much to polio:

- swallowing re-education
- tiltable beds
- first resuscitation (iron lungs)
- first emergency paramedics (in Necker hospital)
- first physiotherapists (specialised nurses at the very beginning)
- first muscles testing
- first occupational therapists (specialised physiotherapists at the very beginning)
- development of balneotherapy, hydrotherapy...
- development of technical aids, orthopaedic devices
- treatment of scoliosis
- improvements in neurosurgery
- development of rehabilitation

Polio patients come to see Doctor Rania Belmahfoud whether just after a cancer surgery, a neurological deterioration, an autonomy decrease (over-use, fear of falls) or for orthopaedic devices (then, a multi-disciplinary visit) but hardly for a preventive testing. The important point is to respect the compensations organized by the patient.

According to Professor Alain Yelnik, 200 million people, 700 000 in Europe and about 50 000 in France suffer from polio after effects. 20% of neuronal loss is needed to reveal a clinical condition.

Orthopaedic devices must offer the following qualities: – lightness – comfort – durability – easiness of use – respect of compensation strategies – adaptation to the patient's specific body. Otherwise, they will spend their lives in the cupboard !!

6th Polio Congress in Paris on 6th April 2017

by Daniel Peltzer (President Association Belges des Paralysées and EPU Treasurer) and by Sylvie Tararbit (board member of G.L.I.P. France)

1. Epidemiology in the world

- Extracts of the film 'Every last child' was shown which is targeting the vaccination and eradication of polio in Pakistan.
- An updated action plan was presented by Dr. Michael O-Connor OMS
- Discussion about the types of vaccines: discontinue the oral vaccine in favour of an injected vaccine
- Necessity to continue immunisation and continue concentrating on risk areas such as Nigeria, Afghanistan, Pakistan.

2. Eradication of Polio: Dr. Emmanuel Maron, Dr Claire Magone, MSF

- Fatalities of the epidemics in Congo Brazza in 2010 (180 out of 434 cases registered)
- Difficult to administer a polio vaccination programme as measles and malaria are still causing terrible health problems in the African countries.
- A great gap still exists between government priorities (such as vaccinations) and the actual need of the people (starvation and other diseases).

3. EPU – 10 Years of Existence – Why and what to do? (see separate presentation)

4. Polio Research: Prof François Genet, Garches

- Based on 292 participants: 173 females and 119 males, 81% still active (a detailed report has been requested)
- Studies in progress: the message that it conveys is 'we are not forgotten yet'
 - polio and insomnia
 - Bone loss
 - Aids and back support
- Treatment of PPS (on a European level)

5. Polio Quiz: some proves / reminders:

- Muscle performance: not more protein but a balanced diet
- Statine: acts like a toxin on the muscles
- Strengthening of muscles: no, BUT keep muscle strength and endurance
- Attention with anaesthesia: always inform the medical professional before an operation, take a photograph to ensure that 'repair' is as before!
- www.aphp.fr/handicap

6. Pain Treatment: without medication

1. Hypnosis

- to disconnect from the pain
- to have a pleasant experience
- to have a new perspective for the future: a very convincing presentation
- audience was under the hypnotic charm of Dr. Chabroche!

2. Therapy of pain acceptance and management (Dr. Peignard)

- acceptance of pain and integration of it
- meditation exercises: close eyes, let the thoughts wander / controlled breathing /
 Sensations
- meditation with full consciousness: let thoughts come and go

3. Acupuncture (Dr Patrick Sautreuil, Hop. Rotschild)

experience in the U.S.: results been proved encouraging

4. Hydrotherapy:

positive effect of the water on mobility / temperature / physiology

hydrotherapyin comparison tothalassotherapyLess painDuration 18 daysMobilisationRestMaintain muscle strengthMud bathsRegular treatment during the yearDaily massage

Conclusions

Very good participation and positive exchange of experience Positive messages:

- Polio near eradication
- Research programmes
- French competence in these areas
- Treatment of pain without medication

Very good contacts, have been established with the medical professionals, the organisers, and the speakers.

European Polio Union – 10 years after its foundation

Summary of Daniel Peltzer's presentation



First initiative by EPU founder Johan Bijttebier, a lawyer from Antwerp advocating polio

- Evolution of his polio status, falls, etc.
- Trying to find explanations, solutions
- Founded Dutch-speaking "Post-Polio Belgium" association in 1997
- Started internet networking with Netherlands and Germany
- Participation / get-togethers / meetings about PPS

What was the situation in the beginning of the years 2000?

- Spread information and knowledge and other resources
- Each country had their own individual approach and attitude / North South
- Differences: problems, means, languages
- <u>But</u> there was the necessity and the good will to form a federation.

Joining of various national polio organisations: B / IT / F / IRL / DK / NL / SP /CH /UK/ D

- First action that happened was in October 2007 in Brussels
- Petition was sent to European Parliament Members which were signed by 75 members of the EU-Parliament.
- Manifestation outside the European Parliament





• Get-together in the European Parliament: presentation of PPS and the necessity to join up in order to be heard.



- Newsletter / AGM / Contacts via Internet
- Contacts with Canada / USA / Australia / Africa / Asia.
- In August 2009, the EPU got her official status as an international charity.
- Annual general meetings were held in Berlin, Lille, Malcesine (Italy), Copenhagen, Janske Lazne (Cz), Tullamore (Irl), Amsterdam, London, Piestany (Slovakia), Lobbach-Heidelberg (D).
- Progressive building of networking between member countries medical professionals authorities

Important achievements

1st Congress Post-Polio Syndrome Copenhagen (09/2011)

- In Europe, there are around 700.000 people affected by polio
- European research activities on PPS: what are the treatments?
- Participation 300 people / from 5 continents
- 50% professionals / 50% polio survivors and families
- Website: https://www.poliohealth.org/au/conference-copenhagen-2011

2nd Congress: Amsterdam 06/2014

- Presentations about research, medication, conserve to preserve, orthopaedic and psychological aids, rehabilitation centres
- Participants about 250
- Presentations made by Europe, Australia, USA, Turkey, India, Africa
- http://www.informed-scientist.org/congress/2nd-european-polio-conference
- 15 to 20 Mio polio survivors are supposed to exist world-wide.
- Partnerships that have been created are Rotary International, Australia...

What else has been done?

- Cooperation: assistance with Sydney conference (September 2016)
- Awareness of the needs of the third world (see film on polio in Pakistan)
- Transfer the knowledge on treatment, technical aids and means to these countries
- Project PoPSyCLE (which is impeded by Brexit) / Polio world alliance/ consolidated knowledge / data base/ exchange of experience and networking.
- Centre of competence in London (to be finalised)
- Questions: financial resources / Bill and Melinda Gates Foundation.

And what is the future?

- 3rd Polio International conference is scheduled to take place in Stockholm in 2018
- Networking with new EPU arrivals from central Europe (AGM Piestany 2016)
- Strengthen networking (next AGM Lobbach 2017)
- Links with Rotary, Gates, EDF, etc
- Short-term needs: structure, secretariat, interpreters, funds, website dynamics, newsletters.
- www.europeanpolio.eu

Slovak Polio Association is celebrating its 25th anniversary

written by Stefan Grajcar, Chairman of the Slovak Polio Organisation

In the summer of 1992 a group of enthusiastic polio survivors in the western part of Slovakia decided to establish an official organisation which would be active in supporting polio survivors in the whole country. The group was very probably inspired by polio survivors in the Czech Republic (which at the time was together with the Slovak Republic one state – the Czech and Slovak Federal Republic which a few months later was split into two independent countries) where a



similar association was established in 1991. The Slovak Polio Association is sheltered by the Slovak Union of People with Physical Disabilities but has a legal entity and in many ways, may act independently. The essential aim of the new association was get together polio survivors in the country and try to provide them with support in their individual efforts to live decent lives with the help of appropriate health care and social security. Besides that the association had from the very beginning an ambition to be a place for meeting and sharing knowledge and experience of all polio survivors in Slovakia. The Slovak Polio Association (SPA) has been organising regular national meetings of members at least twice a year where about 50 polio survivors from the whole Slovakia meet for a few days in one place. Two of these meetings became most popular during the last few years: a three or four-day weekend meeting in some easy-to-access and barrier free hotel in some part of Slovakia (but most often in Piešťany) usually at the beginning of May, and a whole week meeting in some Slovak spa town usually in the second half of August, the latter combined with some rehabilitation, physical exercise, and swimming. But what is most appreciated by all participants of these meeting, they are full of fun, music, dancing, discussions, sunbathing, shopping, and also – why not mentioning it – with having a few pints of beer or some good wine.

As you may already know, Czechoslovakia was declared by the WHO as one of the first polio-free counties in the world – it was in 1960. Similarly, as in all other countries in Europe, North America or Australia, the number of polio survivors is gradually diminishing, it is reflected also in the number of our members. Currently the Slovakian polio group SPA has nearly 150 active and registered members, and it is estimated that it is about 10 % of all polio survivors in Slovakia. Our Association is trying to cooperate also with similar organisations in other countries, mainly in those neighbouring with Slovakia. Traditionally the best

cooperation we have with the Czech Polio Association, but we have also close links to our polio friends in Hungary and Austria. With great enthusiasm and pleasure we became the member of the European Polio Union in 2012 and participated since then in nearly all annual general meetings (2012, 2014, and 2015). Moreover, in June 2016 we had the privilege to organise the AGM in Piešťany with participation of 35 polio survivors representing national polio organisations from 13 European countries. It was an excellent opportunity to present to our guests from abroad not only our polio association but also Piešťany as the world-famous spa town, and also Slovakia as a country, which for most AGM 2016 participants was visited for the first time.

In years to come we would certainly like to continue in everything that has been proved as successful and useful for the benefit of polio survivors in Slovakia, but also in other countries. There is still too much to do for us all, so let's hope we will have a chance to achieve what we promised to ourselves and to our members and polio survivors.

Late Effects of Polio: Do you know the signs? Pathophysiology of the Late Effects of Polio (LEoP)

FLYER made available by Polio Australia

Acute poliomyelitis (polio, also known as 'infantile paralysis') is a viral infection affecting the nervous system. It can infect both the central and the peripheral nervous system, but the most common infection is in the anterior motor horn cells, resulting in flaccid paresis of the muscles. This can present as a widely variable distribution of weakness in skeletal and bulbar musculature, with residual impairment and paralysis ranging from minor muscle weakness to total paralysis requiring intervention such as ventilation. After motor-neuron destruction during the acute polio phase, surviving motor units sprout axons to reinnervate the de-enervated or 'orphaned' muscle fibres. This process of denervation and re-innervation is ongoing over the muscle lifespan. As a consequence, polio-affected muscles have oversized motor units and increased muscle-fibre density. It is thought that these large motor units result in increased weakness as they 'drop out' due to ageing and/or overuse. Due to this process, people with LEoP may have experienced a prolonged period of stability of physical symptoms such as weakness and pain, often lasting several decades, before presenting to their primary care provider with what can feel like a resurgence of polio-like symptoms. LEOP can present as a unique cluster of biomechanical and/or neurologic features in each individual, which can be moderated if properly assessed and managed. The LEOP are essentially a 'diagnosis of exclusion', but should be considered for clients/patients who are known to have had polio themselves — or other members of their family (which may indicate undiagnosed sub-clinical damage). The LEoP refer to any of the following features.

Musculoskeletal features

- Decreased muscle endurance and muscle fatigue
- Overuse of compensatory muscle groups
- Muscle pain and/or spasms
- Joint pain and/or degeneration such as arthritis
- Biomechanical deformity such as kypho-scoliosis
- Muscle contracture
- Osteopenia or osteoporosis

Neurological features

- New muscle weakness
- Muscle atrophy
- Preservation of sensation irrespective of muscle loss
- Muscle twitching/fasciculation
- Compression neuropathy

Respiratory features

- Shortness of breath due to chest deformities
- Respiratory insufficiency due to sleep apnoea
- Weakening respiratory muscles
- Hypoventilation due to early damage to the respiratory system

Bulbar features

- •Impaired thermoregulation
- Dysphagia/swallowing problems
- Dysphonia/vocal dysfunction
- Dysarthria/unclear speech
- Chronic fatigue, headaches, poor concentration

Additional considerations

- Biomechanical problems
- Bladder dysfunction
- · Weight gain due to decreased mobility
- Oedema
- Psychosocial concerns due to increasing disability
- Pr- and post-planning for surgical procedures

Comorbidities

- Cardiovascular disease
- Endocrine and metabolic diseases
- Chronic pulmonary disease
- Hip and limb fractures due to falls

Supporting factors

- Actual or suspected history of poliomyelitis
- A period of partial or complete functional recovery after acute infection, followed by an interval of stable neurologic function
- Symptoms persist for at least a year
- Exclusion of other neurologic, medical and orthopaedic problems

Factors NOT supportive of the LEoP condition

- Resting tremor of limbs or head
- Worsening peripheral neuropathy
- Dizziness or vertigo
- Numbness
- Problems with sensory organs
- Primary altered sensation

LEoP Health Team

- Rehabilitation Specialist
- Neurologist
- Physiotherapist / Occupational Therapist
- Orthotist / Podiatrist
- Respiratory / Sleep Specialist
- Speech Pathologist
- Dietitian / Nutritionist
- Osteopath / Massage Therapist
- Psychologist / Social Worker

Polio Australia's www.poliohealth.org.au website contains resources for health professionals including clinical practice publications, post-polio research papers, and the Health Professionals Register for referral or further consultation. Contact Polio Australia: PO Box 500, Kew East, Victoria, 3102 Email: office@polioaustralia.org.au, or your national or regional polio group.

"A Piece of the World" by Christine Baker Kline

Review of the book by John McFarlane



One of the paintings most viewed in the New York Museum of Modern Art is by Andrew Wyeth, and entitled "Christina's World". It shows a young woman in the middle of a field, legs behind her looking at clapperboard farm buildings on the skyline. This is perhaps the most enigmatic and moving piece of art ever created about a polio Survivor, her name Christina Olson. Her story has been told, although not fully biographically but accurately in the book "A Piece of the World" by Christina Baker Kline, the American author of "Orphan Train" – itself a best seller.

Christina Olson, of Scandinavian seafaring descent lived out her life on the windswept rocky coast of Maine on the eastern seaboard of the USA, where her family settled down after escaping from the notorious and now infamous Salem witch hunts. The challenges of living out her life in an isolated setting with mostly just her brother for company was challenging enough, but throw in the fact that she struggled through paralysis with just everyday living made it even more so. Little or no allowance was made for her, she had to pull her weight and do her bit on the farm and in the house. Slighted by the man whom she loved, and thought would be her salvation she withdrew into herself until a young struggling artist, Andrew Wyeth, came on the scene and became obsessed with her, the isolated farm house and their way of living. This is not a story of romance but rather how two lost souls found a purpose through art, for Wyeth had his own wife and house. That isolated farmhouse became his studio and escape point, and Christina, whilst his senior, became his muse. Over the years he painted Christina, her brother and the farm house many time,. Some of these pictures of Christina are intimate but all hold an air of mystery and thoughtfulness – the most famous "Christina's World" says more than a thousand words ever can.

The book is wonderfully written and without being sentimental, conversations are imagined but are based on writings and recollections. It tells the back story of that painting and anyone interested in human nature and interactions will find it riveting. It's a story that allows the reader to marvel at Andrew Wyeth's iconic painting from the other side of the canvas.

"A Piece of the World" by Christina Baker Kline, published by Harper Collins 2017

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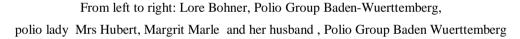
German Bundesverband Poliomyelitis Team visits 110 year old polio survivor on her birthday

On the occasion of her 110th birthday in February last year a team of the Germany Polio organisation Bundesverband Poliomyelitis visited Mrs. Huber to congratulate her. Mrs Huber still lives in her own apartment with a carer and she was described as a mentally alert lady in a wheelchair who extended a very warm welcome to the team and told them her life story. At the age of 22 she woke up one morning and could not get up or stand any more. The doctor treated her at her home, she was not diagnosed with polio until 20 years later..

After her recovery she started studying chemistry at the university of Heidelberg but the distances between lecture halls and laboratories proved too difficult for her to walk, she discontinued her chemistry study and started to study law in Munich and Berlin.. After graduation, she worked as a lawyer for a bank. At the age of 60 her state of health deteriorated to a point where she needed to use a wheelchair to remain active and mobile.

She met her husband at the age of 14 and she said he had always been very supportive. Two of his marriage proposals she refused with the reason that she didn't want him to be tied to a disabled wife. However, he insisted and she accepted his third proposal on the very day Hitler and Mussolini met for the first time. The marriage worked out very well.

As to the question what would she advise polio survivors her reply was 'just live as if polio doesn't exist'





A TULIP CALLED 'POLIO'



In our previous Newsletter we reported about the tulip that is grown in Holland and had the name 'polio', its colour RED and YELLOW just like those of 'End Polio Now'. Edy Bucher, a Swiss polio survivor had the bright idea to buy the bulbs, sell them at a small profit which goes to the 'End Polio Now' efforts. At this year's tulip festival in Morges which started on the 1st April and will lasts to the 15th May the polio tulip has been displayed in massive splendour at a location where most people had to pass and where attention was drawn to polio and the efforts to eradicate it. What a fantastic way of creating awareness of the polio issue and it couldn't be done better than saying it with flowers.
