

# EUROPEAN POST POLIO NEWS

The Official Newsletter of  
**European Polio Union**



Newsletter 1/2014

[www.europeanpolio.eu](http://www.europeanpolio.eu)

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In this newsletter:

<b>MESSAGE FROM THE EPU PRESIDENT</b>	<b>2</b>
<b>HOLGER KALLEHAUGE - 40 Years of Service</b>	<b>3</b>
<b>THE EUROPEAN POLIO UNION GOES TO IRELAND</b>	<b>7</b>
<b>EPU ATTENDS EFNA 2013 CONGRESS IN VIENNA</b>	<b>9</b>
<b>EU DIRECTIVE 2011/24</b>	<b>9</b>
<b>SYRIA REGION WHERE POLIO FOUND</b>	<b>10</b>
<b>BOOK REVIEWS</b>	<b>12</b>
<b>MEMBER NEWS</b>	<b>14</b>
<b>NOTICE OF THE EPU AGM – JUNE 2014</b>	<b>17</b>
<b>CALL FOR VOLUNTEER DIRECTORS</b>	<b>17</b>
<b>BOARD UPDATE</b>	<b>17</b>
<b>EPU NOTICES, BOARD MEMBERS &amp; DISCLAIMERS</b>	<b>18</b>



## MESSAGE FROM THE EPU PRESIDENT

I trust that by the time you receive this you will have enjoyed a wonderful festive season with family and friends and are now looking forward to the challenges that face us all in 2014. Many countries have been suffering from austerity measures following the economic crash, some countries being hit with draconian cut backs. All these cut backs have affected society in general but have impinged on the elderly and disabled in a disproportionate manner.

May 2014 sees EU wide elections for the European Parliament and this is where we all can express, or indeed vent, feelings both about this and other matters that politicians have affected. Remember the successful MEPs are your representatives and are at least supposed to represent you regardless of how you vote. The EPU has prepared a political manifesto and I would urge all member organisations to adapt and adopt it to their own national circumstances and then to get it out to all the parties putting up candidates for the EU elections. The manifesto is specific to disabled persons and makes particular reference to PPS and calls upon the EU Parliament and indeed national Parliaments and Assemblies to recognise polio Survivors in their own right as a specific group as well as the desperately needed recognition of PPS by all governments as a medical reality.

It was my pleasure to welcome the 2013 AGM to my adopted home town and I think all who attended enjoyed themselves, a report on the event is carried elsewhere in this edition. Also included is the notice announcing the date and venue of the 2014 AGM. Together with a call for AGM Agenda items as well as people who might volunteer to act as Directors, timescale and terms and conditions are also included. In the event that more information is need please email me, my details as well as those of the other Directors are included at the end of the Newsletter.

Through the first Post Polio Syndrome conference held in 2011 the EPU became a senior player in the field of influence and as a point of reference for a growing body of knowledge on PPS. The second conference being held between 25-27 June 2014 in Amsterdam ([www.poliocconference.com](http://www.poliocconference.com)) will see that role reinforced. As we all know Rotary International has been involved in the struggle to rid the world of poliomyelitis, but it is now beginning to look beyond that goal and the EPU is working with Rotary Great Britain & Ireland on a pilot project where Rotary will engage with polio Survivors in the community - watch this space!

On a personal note in September of this year I stood down as the Chair and a Director of the Irish Group. I had served as an officer or in a position of executive responsibly for nearly 10 years, and as a researcher for the Group before then, it was time to move on and allows me to bring the knowledge and experience gained into a bigger arena - namely the EPU. I am looking forward to being able to concentrate my efforts into making the EPU into the polio Survivor and PPS member led organisation of Europe - ensuring it can work on behalf of all not just in the EU but across the whole of Europe - that's nearly a million in number!

Well that's about it for this first edition 2014, it is hoped that we shall be able to have 3 or 4 editions a year but part of that depends on you and your organisations. A Newsletter cannot be produced without news and events being sent in - no input, no output. There is only so much that that can be sourced and written centrally. So comment, letters, opinions and news of your organisation flow through. On the other side anything that is contained in this edition can be reproduced in your own publications, we just ask that the source is acknowledged.

It is my intent to try to see as many people and organisations in the year as possible, I hope to renew friendships and make new ones at the Amsterdam conference. Apart from that Mary and I intend to get in our camper van and travel - so if you see a big camper with Irish plates in your town or outside office or home you have two choices - put on the kettle or run for the hills!

Every best wish to you all  
John

**HOLGER KALLEHAUGE**  
**President PTU, Denmark**  
**40 Years of Service**



The EPU sent heartfelt congratulations to Holger KALLEHAUGE at the beginning of December 2013, the date marked the 40th anniversary of service to PTU in the position as the organisation's President. It marks a remarkable achievement in the devotion he has shown to the well being of polio survivors, not just in Denmark but all over Europe.

He replied "Thank you for your kind granulations with my 40 year jubilee as president of PTU. It has been a good experience and many good results for our members have been a consequence of my work. Our members have been very loyal and have re-elected me 20 times for which I am most grateful. I step down as president in May 2014, but I shall continue to be involved in the work of PTU.

I am looking forward to meeting you again in Amsterdam in June at the Polio conference."

The following address was given Holger Kallehauge to the Copenhagen 2011 conference and it has just as much resonance today as then, if not even more so with the upcoming European Parliamentary elections to be held in May 2014. Read it in conjunction with the political manifesto prepared by the EPU and previously distributed to all member organisations. Then challenge every political party in your EU country who are putting up candidates for the EU elections. **YOU CAN MAKE A DIFFERENCE BY CHALLENGING POLITICIANS CURRENT & ASPIRATIONAL.**

**Post Polio Policy in the EU**

Holger Kallehauge, retired Danish High Court Judge  
President of PTU

The conference in Copenhagen has more than one goal. The primary goal is of course to share knowledge and information about the Post Polio Syndrome, and the diagnosis, the symptoms, treatment and how to live with and if possible how to overcome some of the symptoms. This is equally important for the health professionals as for the Polio survivors.

My subject is however another and more general:

How shall we in The European Polio Union (EPU) enhance and work for:

- Research in Post Polio
- Adequate rehabilitation, training and treatment to all Polio Survivors
- Development aid to Polio survivors in poor countries in the third world

How shall we make best use of the UN Convention of December 13<sup>th</sup> 2006 about the rights of persons with disabilities (CRPD) to forward the three above mentioned goals at a national, European and global level?

## **1. The UN Convention on the Rights of Persons with Disabilities**

The UN Convention about our human and fundamental rights is a most useful instrument in all disability matters, also when it comes to health issues as the Post Polio Syndrome.

The convention does not deal directly with Polio survivors nor with Post Polio as we all know, but is a general set of legally binding rules dealing with all aspects of disability affairs. Therefore the convention is - as I shall try to demonstrate in my intervention - also both applicable and instrumental for us in our efforts to formulate an EU Polio policy if we read, understand and interpret the convention correctly.

As an opening I shall point to article 3 in the convention about general principles covering rules as respect for our human dignity, autonomy and freedom to make our own choices.

But also fundamental rights as

- non-discrimination
- full and effective inclusion in society
- equality of opportunities, and
- accessibility

Respect for these fundamental rights is now an universal obligation as it is also confirmed by the EU ratification of the convention as well as by a majority of the EU member states.

The purpose of the UN Convention is as it is stated in article 1 to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms for all persons with disabilities.

Without awareness-raising as prescribed in article 8 of the convention no Post Polio policy in the EU shall have any chance of being realized. Issue number one after having formulated such a policy is to spread the message and thus making it clear primarily to the EU decision makers, parliamentarians, ministers in the EU Council and members of the Commission what our goals are. Such a campaign has at the same time to be duplicated at the national level by EPU member organizations viz a viz the national ministers of health and other health authorities.

The convention articles number 25 about health and 26 about rehabilitation are our rights and terms of reference in support of our Post Polio policy. The walls around Jericho are of course not tumbling down just by quoting these articles but they provide us with arguments for justification of our policy which cannot easily be put aside. More arguments of medical, social and statistical nature are also needed, but the UN Convention gives us a legally speaking sound case.

So we don't have to invent all arguments and to start from scratch. On the contrary we can base our Post Polio policy legally on the UN Convention and medically, socially and by means of rehabilitation on the good experiences developed especially in the Nordic countries, in the Netherlands and elsewhere in Europe.

We need to agree on an EPU strategy for developing a programme leading to a fulfilment of the above mentioned goals; research, rehabilitation, training and a development aid programme.

## **2. A research programme**

A scientific Post Polio committee has to be established in the EU. This committee shall be a coordinator for research activities in the field of Post Polio. The committee shall act as a center, where all medical knowledge about Post Polio shall be registered in a database at disposal for all doctors and other health personal and to the public as well.

The committee shall also act as an information centre spreading news about the latest research results and initiatives sending out newsletters to members and subscribers.

For interested health professionals one might also host regular telephone conferences taking up questions and themes which the committee considers to be of special interest.

The committee shall also try to make the centre part of other similar networks in the US and elsewhere aiming at establishing a global Post Polio network.

One of the first challenges shall be to give a valid description of the Post Polio diagnosis, prognosis and best practice for rehabilitation and recommended life style for Polio survivors.

## **3. A Post Polio rehabilitation programme**

EPU shall adopt a plan of action leading to developing of a standard rehabilitation programme for Polio survivors.

When it comes to rehabilitation a close cooperation between doctors and physiotherapists is absolutely needed.

The goal is to secure, that such a rehabilitation programme primarily is made well known and accepted by doctors, physiotherapists and other health personal in all EU member states but also realized in practice so that all Polio survivors have access to such a rehabilitation programme

It is also needed to identify at least one national rehabilitation center for Polio survivors in each member state hopefully as a special clinic or unit at a major university hospital.

An initial step is to find doctors and other health professionals with various relevant backgrounds, who are interested in working with Polio victims in each member state and making them form a network with the mission to develop the above mentioned Poliocenters.

## **4. An international development aid programme for Polio survivors in the third world**

In the UN Disability Convention CRPD article 32 one find a rule about international cooperation. Implementation of this rule for Polio survivors ought to be an important goal for the EU. EPU should take this up lobbying for our brothers and sisters with Polio impairment in developing countries giving them better and more equal opportunities in their home countries. Obviously they need support much more than we do in the EU.

EU is one of the major global international donors. The resources are available, but EPU has to influence the distribution, so that Polio survivors are given the priority and share they need of EU-development aid.

The Scandinavian development agencies, Danida, Sida and Norad are also possible donors, which might contribute.

So far vaccination against Polio with good reason has been given top priority aiming at Ending Polio Now as the Rotary programme is called. The goal to eradicate Polio has almost been achieved and seems to be within reach in a few years from now. But millions of Polio survivors so far have been left to fight for themselves. Few if any have cared for them. Is that not now a worthy challenge to take up for the EPU?

## **5. Conclusion**

EPU cannot expect to be seen and recognized as an important NGO if we don't make EPU visible as an active disability organization with an agenda which is relevant to politicians and to the public as well as for our members.

EPU therefore has to consider the above mentioned proposals carefully and to elaborate a plan of action in which they need to be the pillars on which the future work of our organization shall be founded.

We have to establish a working group, which shall draw up a programme for each of the main goals answering the questions who, how and when:

- Who shall draft and run each of the programmes?  
A small dedicated hard working drafting committee is needed
- How shall we raise funding for the programmes?  
The EPU board has to adopt a fund raising programme
- When are we ready to act – a timetable is needed?  
Also that issue is a job for the EPU board

Each of the three goals might be achieved separately and might also be worth working for uncoordinated, but united they become a strategy, which takes care of all Polio Survivors both within and outside of the EU. EPU should not be seen only as an egoistic NGO looking after its own members, but also as an idealistic organization demonstrating solidarity with Polio survivors at a global level.

If we act accordingly EPU shall have a good common cause to fight for and in that way prove to be worthy of respect from the public as well as from possible donors without whom EPU cannot achieve any of the goals which I have focused on in this short intervention.

Thank you for your kind attention.  
H. Kallehauge

## THE EUROPEAN POLIO UNION GOES TO IRELAND

Friday, 18 October 2013, dawned bright and clear over the midlands of Ireland as the Tullamore Court Hotel, prepared to welcome delegates converging from all over Europe for the AGM & Conference 2013 of the EPU. It might have been bright and clear in Ireland but the weather over the rest of Europe tested the patience and stamina of many as flights were cancelled or delayed due to fog and then to top it all an air traffic control strike over Italian airspace. The last delegates from Italy eventually were brought to Tullamore by the special shuttle bus service arriving at 10.45 p.m.



After a leisurely but hearty Irish breakfast 30 delegates gathered in the hotel's Conference Centre, which was devoted to EPU and polio business all weekend, gathered to deal with the statutory and legal work that any company limited by guarantee must conduct each year. The Treasurer, Margret EMBRY from Belgium, reported that for the first time in its history the EPU had a year on year surplus. Delegates considered recommendations from the

Board regarding changes to the "Statuten", the legal instruments of the company registered in Belgium and they considered whether the minor changes that had arisen from the previous year's meeting could not be covered by the use of other rules already in place.

The real work of the meeting started in the afternoon when member organisations were challenged to say how they saw the future of the EPU and what it could do for them in their own countries. All agreed that the EPU is and will be needed in the future to oversee matters in an increasingly legalistic and federal Europe and the many challenges that this brings on its coat tails. An example of this was the lack of knowledge regarding EU Directive 2011/24 on the access to cross border medical treatment within the EU. The matter was raised by the Italian delegation and the EPU was charged with contacting the EU Commission to clarify the position of how many and which states had signed the Directive into their own national laws by the due date - 23 October 2013. An update as of 31st December 2013 is covered elsewhere in this edition of the Newsletter.

That evening the EPU held its annual delegates' dinner and to celebrate the 20th anniversary of the formation of the Post Polio Support Group of Ireland it invited three of the founder and early members, Joan Bradley, Jim Costello and Ciáran Nicholson, to join them. Also as a guest was John Dolan, CEO of the Disability Federation of Ireland, John is himself a polio Survivor and a member of PPSG.



At the 2011 Copenhagen conference a paper had been presented on the importance on peer support and since then organisations had been requested more information on how it worked in practice. The original paper had been given by a polio Survivor as well as an employee of PPSG so it fell to the new chair, Susan Dowling, of the Irish Group to give an informative talk that concentrated delegate's minds and gave food for thought as to how they could adapt the examples given to set up PhoneChat and RingRing services within their own organisations. The hand out give was well received and the principles it encompassed are actively under consideration by the Boards of at least two European organisations as to how quickly they can implement and are seeking sponsors.

The final part of the formal proceedings was a presentation by Hilary Boone, of the Polio Survivors' Network in the UK on her personal journey and experiences as a polio Survivor right through from her school days, into the police to her present condition. Most present were able to identify with her experiences, they welcomed someone who said what so many had thought over the years but had been too afraid or cautious to voice. The meeting was then formally adjourned with the next AGM to be held on the afternoon of Tuesday 24 June, 2014 in Amsterdam - this is the day before the the second pan European conference entitled "Post Polio Syndrome - a condition without boundaries" commences and brings together an estimated 600 delegates drawn from polio Survivors and leading medical professionals from all over the world. (The EPU is one of the lead organisers of the event.)



The EPU delegates then joined 100 PPSG members for a luncheon celebrating the 20th anniversary of their organisation, apart from the meal there was music, mirth and merriment that went on late into the Sunday evening. All too soon it was Monday morning and for some a very early 7 a.m. Start as the shuttle bus service started on its way back to Dublin Airport. Friendships had been renewed, experiences exchanged, ideas talked through, Guinness and other local amber liquids consumed and all enjoyed their interaction with the Irish members they

met. In the end regardless of language, nationality etc. all are polio Survivors and joined as one "family".

The only down side, the sun shone on the Friday when delegates were travelling to Ireland after that it poured with rain but as one person said "the welcome more than made up for the weather - warm, friendly and unconditional" - enough said!



## **EPU ATTENDS EFNA 2013 CONGRESS IN VIENNA**

For the first time, EFNA hosted a Patient Corner in the Exhibition Centre where Member Groups and Partners were invited to distribute information and network with the health professional and industry delegates from across the world. Stands were taken by European Headache Alliance, European Huntington's Association, **European Polio Union**, International Brain Tumor Alliance, Danish Trigeminal Neuralgia Association, ADHD Europe, Pain Alliance Europe, Euro-Ataxia, European Multiple Sclerosis Association and European Alliance for Restless Legs Syndrome.



EFNA used this opportunity to promote its work and garner support for their Pledge to Protect Neuroscience Research and Neurology Patients. At the same time and in the same venue the World Congress of Neurology was taking place. Els Symons represented the EPU and reported to the 2013 conference that trade at the desk was brisk but that she was shocked to discover the lack of knowledge about PPS amongst those neurological medical fraternity. It emphasised the work that the EPU has to undertake in education of medical professionals.

Next year the EFNA meeting and World Congress of Neurology will be held in Istanbul and as EPU is a member of EFNA it pays for the travelling expenses and hotel for one representative from each EFNA member organisation so we shall be there. The EPU is due to take part in a working group discussion aimed at neurological professionals to discuss complaints such as PPS.

Els Symons was asked whether it was worthwhile attending, her answer "Not just useful but imperative if we are to get over the message about PPS and polio Survivors to so many who are still in ignorance".

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### **EU DIRECTIVE 2011/24**

#### **Seeking Healthcare in another European member state**

In March 2011 the European Directive 2011/24 was published with a date for it to be enforced and signed (transposed) into EU member states national statutes by 5 p.m. local time on 23 October 2013.

It can fairly be said that national governments, apart possibly for Italy, have not exactly advertised the fact the citizens can access healthcare in another other members states.

As of 12 December 2013, it is understood from the European Commission that six member states have fully transposed the directive, seven member states, including the United Kingdom, have provided a partial notification of transposition, and a further four member states will transpose by the end of 2013. It is understood from national sources that Finland will transpose in January 2014. The EPU President asked the Irish Government for their position and the Minister of Health stated that the matter was still under consideration but that a National Contact point had been established where further information can be sought. In

total under the Directive member states have to establish contact points, 27 member states have complied with no information being available for Croatia.

The national contact points can be found by clicking at the bottom of the following web page link:

[http://ec.europa.eu/health/cross\\_border\\_care/policy/index\\_en.htm](http://ec.europa.eu/health/cross_border_care/policy/index_en.htm)

For a leaflet explaining the Directive go to:-

[www.europa.eu/youreurope](http://www.europa.eu/youreurope)

As and when more information becomes available EPU member organisations will be informed accordingly. However, it is recommended that member organisations ask their respective National Contact Point regarding the EU Directive being transposed into national law. In the event that your national Government has not complied with Article 21.1 of the Directive pressure should be exerted on your national Minister responsible for Health as well as the Minister responsible for European affairs.

The EPU asked the EU Directorate responsible for monitoring and implementation of 2011/24 for a statement as to which countries had transposed but it was refused on the grounds that legal action was being prepared against non compliant member states.

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## **SYRIA REGION WHERE POLIO FOUND EXCLUDED FROM 2012 VACCINATION DRIVE**

By Oliver Holmes, Reuters

BEIRUT (Reuters) - The Syrian government excluded the largely rebel-held province of Deir al-Zor - where polio broke out this year - from a 2012 vaccination campaign, arguing that most residents had fled although hundreds of thousands were still there, a Reuters investigation shows.

Public health researchers say missing out the Syrian province contributed to the reemergence there of polio, a highly infectious, incurable disease that can paralyze a child within hours but has been wiped out in many parts of the world.

In November, the World Health Organisation (WHO) said 13 cases had been found in the province. Two more have since been recorded there and the virus has surfaced in Aleppo city and near Damascus, the first outbreak since 1999 in Syria, where civil war has raged since a crackdown on protests in 2011. A Dec 6, 2012, WHO statement said it, in conjunction with the Syrian Ministry of Health and the United Nations Children's Fund, had launched a campaign to vaccinate "all children below the age of five against polio". It said the campaign, involving 4,000 health workers and volunteers, would cover roughly 2.5 million children in 13 of Syria's 14 governorates except for Deir al-Zor as "the majority of its residents have relocated to other areas in the country".

It was not possible to contact the Syrian government for comment on its reported decision to leave out Deir al-Zor, a region of roughly 1.2 million people, where more than 600,000 under 15s were living in 2012, according to WHO data.

By December of that year, rebels had taken territory in other provinces as well.

While international agencies support such vaccination campaigns, designed to fill gaps left when emergencies prevent routine vaccinations, it is a country's government which decides when and where they will take place. Asked to comment on researchers' allegations aid groups should have raised the

alarm earlier and prepared better, Chris Maher, who is coordinating the regional polio response for the WHO, said it had warned vaccination rates were falling.

The Dec 2012 and the Oct-Nov 2013 campaigns were planned and organized in response to that, he said. "In a complex emergency setting, it is not that easy to continue routine campaigns." Maher said it was reported that 67,000 children under the age of five were subsequently vaccinated in Deir al-Zor in January 2013.

Public health researchers say that is a coverage rate of around 50 percent, insufficient to prevent polio from spreading, based on census data. The actual population is hard to establish; some residents fled while other people fled into Deir al-Zor from elsewhere.

Repeated vaccinations and high coverage levels are needed to interrupt transmission of the virus and prevent outbreaks. "There was a lack of a proper campaign to vaccinate children across the country over the past two years," said Dr Adam Coutts, a Lebanon-based public health researcher who has been studying the humanitarian response in Syria.

"With the breakdown of the health system, sanitation and nutrition, the exclusion of Deir al-Zour from the vaccination campaign provided the ideal conditions for an outbreak to occur."

It was not clear why the remote province near Syria's border with Iraq was singled out. The city of Deir al-Zor is partially controlled by Syrian government forces while the countryside around it is in the hands of rebels fighting to remove President Bashar al-Assad. Maher did not say whether there were other vaccination campaigns in Deir al-Zor during 2012 but confirmed that there was one in October this year, around the same time that polio cases were found in Deir al-Zor.

Asked if he thought leaving a gap in the 2012 campaign allowed polio to take hold in Deir al Zor, Maher said: "There are unimmunized kids all over Syria. I have no information that that particular area was higher risk than anywhere else given the general deterioration of immunization rates during the conflict." He said polio vaccination coverage had dropped across Syria from more than 90 percent in 2010 to below 70 percent in 2012.

United Nations humanitarian agencies work in Syria with the permission of the Syrian government, which has blocked aid convoys to some areas of the country. Opposition fighters and clashes have also hampered access for aid work. Despite dramatic progress many parts of the world thanks to a 25-year-old campaign to eradicate the disease, Polio is still endemic in Pakistan, Afghanistan and Nigeria. There is no cure and it can only be prevented through immunization, usually three doses. The WHO's long-standing and repeated warning on the disease is that as long as any child remains infected, children everywhere are at risk.

"Questions remain as to why WHO did not better prepare for this, given their own recognition about the risk of outbreaks," said Coutts, whose colleague Dr Fouad Fouad shares his concern. The WHO says the largest-ever immunization response in the Middle East is under way, aiming to vaccinate more than 23 million children against polio in Syria and neighboring countries.

"Inside Syria, the campaign aims to reach 2.2 million children, including those who live in contested areas and those who were missed in an earlier campaign. Many children in Syria remain inaccessible, particularly those trapped in sealed off areas or living in areas where conflict is ongoing," it said.

The WHO says almost 2 million children in Syria have already been vaccinated, including 600,000 in contested areas of the country, in the first of several rounds. Coutts says public health professionals in the region are concerned that this response is "too little too late and is exposing a deeper failure of regional health agencies and systems to respond to a very predictable health crisis".

©Thomson Reuters

## **BOOK REVIEWS**

### **THE POLIO SURVIVOR'S HANDBOOK by Dr. Richard L. Bruno**

The post-polio Institute's Polio Survivors Handbook is given to all their patients and contains the research-based and time-tested protocol that has proved successful over the years in treating Post-Polio Sequelae. This edition it's the "home version" of the handbook that has been written in a way to educate the polio Survivor, their caring medical practitioner and therapists so that they can deliver to the Polio Survivor the same level, or as near as possible, of care that they would receive if attending the Post-Polio Institute in the USA. The handbook explains the causes of PPS, symptoms, fatigue, muscle weakness, pain, sleep disorder, cold intolerance and heightened sensitivity to pain and anaesthesia.

It then goes into the "ways" to help the Polio Survivor to identify and avoid PPS symptom triggers, and describes a combination of energy conservation, stress, pain management and stress - but not to exercise - that addresses the physical and psychological aspects of PPS, helping the polio Survivor to substitute the old adage "Use it or Lose it" mantra to a new "Conserve to Preserve" lifestyle that reduces fatigue, muscle weakness, pain and stress.

This is an important book for the polio Survivor who does not have the opportunity to go to the PPI in the USA. If nothing else it offers another look and choices for the polio Survivor to manage their condition and lifestyle.

Published by Random House eBook

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### **BITTERSWEET: a novel by Thomas Moon**

He is sixteen, and, Tim McClellan a Scottish émigré, is Utah's Junior Tennis Champion and a remarkably gifted trumpet player. The year is 1953.

However, he doesn't want as could be imagined to become a tennis professional, but rather to become a trumpet player in one of the world's finest symphony orchestras. But firstly he dreams of fulfilling a childhood dream by becoming one. Of the two fanfare players at the world famous Edinburgh Festival Military Tattoo held every August on the esplanade of the city's historic castle.

His plans are shattered by a servers case of polio, that leaves him with more to overcome than just physical paralysis. The McClellan family, and extended clan, have their doubts whether he can overcome a far more deep seated disabling nemesis - that of anger and bitterness.

The novel is based on the author's own experience, "Bittersweet" is a warm detailed study of facing down an intractable foe with the help and support of caring friends, family, a father's wisdom and the unconditional love of a young woman.

Published by Random House eBook

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### **THE END OF PLAGUES by John Rhodes**

The defeat of polio, when it happens, will be the second global eradication of a deadly disease afflicting humans. At the turn of the 20th century smallpox killed more than 2 million people a

year. In 1979 the disease was declared eradicated and the victory of science over disease was celebrated across the whole world

But the story of smallpox remains the exception rather than the rule. In the 21<sup>st</sup> century there are still a host of contagious diseases affecting mankind, including AIDS and polio, despite years of research and millions being invested by companies and trusts in funding the search for their eradication.

"The End of Plagues" spans three centuries of fascinating history that stitched together the discovery of vaccination (Edward Jenner 1796), the birth of immunology and its growth, on to the background of the fight to rid the world of its most feared diseases. It looks at the early 19<sup>th</sup> century foundling voyages in which countless orphans, vaccinated one by one, were sent to colonies all over the world, to the discovery of the polio vaccine and the stockpiling of smallpox to be used as a biological agent in that era known as the Cold War.

The author, John Rhodes, himself a distinguished immunologist, describes the fight against these diseases that strike fear into the heart of humanity and shows how vaccination gave us the upper hand.

The Bill & Melinda Gates Foundation, World Health Organisation and Rotary International have made the eradication of polio their top priority, and the author takes the reader behind the scenes to witness how, hopefully in this decade, the world may be celebrating that second world wide eradication of a disease and which one might be on the target list next.

Published by Palgrave MacMillan - ISBN 978-1-137-27852-4

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***TO BE AMONGST THOSE REVIEWED IN THE NEXT EDITION OF THE EPU NEWSLETTER:***

**"Travelling without a Spare" by Dr. Wendell A. Left.**

Decades after overcoming polio many are grappling with an emergence of new pain, weakness and fatigue. This unforeseen symphony of symptoms is a central fact of polio Survivors' lives. This book, admittedly written for an American audience but with resonance to all polio Survivors look at every aspect of life. The title of this sympathetically written book refers to when Survivors begin to lose cells both through PPS and ageing and they find they are truly "travelling without a spare".

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## **ONLY IN IRELAND!**

A tourist from Spain was visiting Cork, in Southern Ireland recently and was intrigued to see two local authority workers, one was digging a hole and the other was filling it in. The tourist watched this for some time. After they had dug and filled in a number of holes he could contain himself any longer and asked what they were doing.

"Ah well, there are normally three of us" said Paddy "there's me and this is Sean and Michael. We plant trees. I dig the hole, Michael plants the tree and Sean fills it in."

"But where are the trees?" The tourist asked.

" Ah well, Michael is out sick today" Paddy replied.

## **MEMBER NEWS**

**Groupe de Liaison et d'Information Post-Polio** has moved offices to:-

GLIP - Groupe de Liaison et d'Information Post-Polio, 34 rue des coutures, 51100  
Reims, France

Tel: +33 3 51 00 13 58

Email: [asso.postpolio@lapost.net](mailto:asso.postpolio@lapost.net)

At their General Assembly on 5 October 2013 a new Board was elected as follows:-

Président: Lionel Meuret  
Vice-Président: Bernadette Cauldron-Praud  
Secrétaire: Bernadette Cauldron-Praud  
Treasurer: Guy Leprétaire

Brigitte Bonnin stays as administrator.

### **Post Polio Support Group - Ireland**

The following have been elected as the new senior officers and representatives of the Group:

Chairperson: Susan Dowling  
Vice Chairperson: Jim Barratt  
Secretary: Jim Costello

In addition Ruth Barror the CEO during 2013 has not renewed her contract and her replacement is Fran Brennan. Office contact telephone numbers and emails remain unaffected.

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### **A 2012 PARALYMPIC EXPERIENCE The Belgian Association for Paralysed People**

On 5<sup>th</sup> September 2012 a very long day for more than a hundred participants at the BAPP camp in Oostduikinkerke began with waking up before 5 am. Their objective was to attend the 7 a side football competition at the Paralympics. So what exactly did this entail?

The group was made up of forty 'campers', nearly all in wheelchairs, and sixty helpers and organisers, in all 100 people. These young, and not so young, people were spending a week on holiday at the Ter Helme Hotel in Oostduikinkerke.

The volunteers, a bit sleepy but as enthusiastic as ever, got on with waking, washing, dressing and pampering their campers and, once that was done, everyone assembled for a good solid breakfast at 6 am. Shortly afterwards two coaches arrived and loading by means of a wheelchair lift was able to begin.



Embarkation for the Paralympics

Departure was at 7.15 precisely, because a fixed reservation had been made for crossing the Channel through the tunnel. The journey as far as Calais was through a typically Belgian drizzle, which dampened everyone's spirits below their usual happy level, the weather having been particularly fine since the first day of their stay.

There was a happy surprise when they reached England: the weather was super. Clouds were barely visible and the sun was to stay with us throughout the long day. With the route well sign posted all the way to the Olympic Park, our convoy reached its destination around noon local time.



Disembarking over a hundred people, of whom forty were in wheelchairs, must have been beyond the normal experience of the numerous police officers and stewards in the parking area. They expected everyone to be off the coaches in just a few minutes... an impossible task! We narrowly avoided an incident when a breakdown crew arrived threatening to remove one of our three accompanying cars. Eventually they agreed to let us finish unloading and marshalling all our travellers into the Paralympic venue.

Serious security checks followed, with the contents of everyone's pockets, bags and bottles being searched – like they do at the airport – before allowing us in to our first port of call: MacDonald's, that temple of fast and junk food.

### **Arrival at the Olympic Park**

The Park and its venues, seen so many times on the TV, were most impressive with, in some cases, magnificent architecture. But what impressed us the most was the crowd: so dense, spreading everywhere, able bodied and the less able, policemen on horseback, families, English, foreigners, white and black faces, children; in short every continent was represented on a grand scale.

At 2 pm our group arrived at the venue for the event, the Riverbank Arena. Then we had a moment of doubt: would it be fully accessible or not? After yet another check of our tickets we were directed towards the entrance to the stadium where an incline led us up to a spectator area right next to but 1.5 metres above the playing field. We had a superb view, with plenty of wheelchair spaces, and folding seats for the helpers readily available. **Perfect happiness!**

The first match was a warm up: Brazil v Ukraine. Who was the favourite: Brazil, but, thanks to a no score draw, Ukraine were top of their group.

### ***The stadium was ready for THE MATCH: USA v Great Britain.***

There was frenzy among the crowd as the teams entered. National pride - everyone rose to their feet for the national anthems which all the English people there sang with gusto (and we Belgians joined in).

Sadly we had to leave the stadium at half-time to get back on our busses and head to Folkestone, Calais and then back to Oostduinkerke, where we arrived at 1.00 a.m. the following morning. Not to lose anyone in the crowded Olympic park had been a major concern of the organisers, with the need for everyone to be assembled back at the busses by 6 pm.



As a phalanx we advanced, four wheelchairs abreast, ten ranks deep, with all our helpers pushing and guiding the chairs, under the leadership of Pily, who managed his troupe with all the authority of an English Major. The crowd were sympathetic, parting to give us space and we advanced with a minimum of difficulty. A “**BAPP battalion**”, most impressive !

Back at the coach park we counted heads. Everyone was present. Our visit to the Paralympics had been accompanied by warm hospitality from the many stewards posted at the entries and exits to the site. Before embarking on our coaches it only remained for all the participants to do justice to the picnic prepared for us that same afternoon by our organisers. Just imagine: more than 400 sandwiches (cheese, ham, ham and cheese, and crab salad), apple juice, orange juice, bottles of water, apples, bananas and little biscuits. Something to satisfy every appetite.

And then we were back on the road, tanned by the day long sun, heads and eyes filled with memories of remarkable athletes, of an enthusiastic crowd, of impressive venues and of a huge and appreciative audience. It has been an experience that none of the participants is ready to forget and that will remain in their memories for the rest of their lives.

A big thank you to all those who brought this project to fruition.

With sponsorship from CERA

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### **BRITISH POLIO FELLOWSHIP – AGM GLASGOW SEPTEMBER 2013**

When members of The British Polio Fellowship met in Glasgow recently, it was a chance to hold their AGM alongside an Information Day, plus an important opportunity to mark the 60<sup>th</sup> Anniversary of the Scottish Region by forging links with Polio and Post Polio Syndrome (PPS) groups throughout Europe.



The charity was delighted to give a warm Scottish Polio Fellowship welcome to John R McFarlane, who is based in southern Ireland and as President of the European Polio Union (EPU) took the opportunity to meet with The British Polio Fellowship CEO Ted Hill.

“It was a pleasure to welcome John along to our AGM and Information Day in Glasgow,” said Ted Hill, MBE, CEO of The British Polio Fellowship. “John is well-connected in both Ireland and Europe we are looking forward to joining forces where we can and working together in various partnership arrangements to the mutual advantage of all our members.”

McFarlane is the current President of the European Polio Union (EPU), a group of Polio and PPS support groups similar to The British Polio Fellowship, found throughout Europe but not exclusively the European Union. John is currently working on arranging a session in the European Parliament in Strasbourg to discuss Post Polio Syndrome (PPS) which the Fellowship is very keen to support on behalf of its members.

“PPS is an important issue for our members and joining forces with John and other Polio groups throughout Europe enables us to see that the concerns of our members are on the



political agenda when it comes to health issues not just in Britain but in Europe too,” added Ted. “We are all working towards the same goals, so joining forces makes a lot of sense.”

“The British Polio Fellowship’s event in Scotland was an important event and I was delighted to be asked to come along,” said John McFarlane, President of the EPU. “I will be using my presidency of the EPU to move the debate on issues like PPS forward and the support of the Fellowship will prove invaluable in enabling me to do so.”

The forging of these European links comes as the charity makes the final preparations for ambitious plans for its 75th Anniversary celebrations in 2014 and marks the start of a re-alignment of the charity’s work and objectives over the next five years.

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**NOTICE OF THE ANNUAL GENERAL MEETING**  
**of the EUROPEAN POLIO UNION**  
**AMSTERDAM 24 June 2014**

Notice is hereby given that the Annual General Meeting for 2014 of the European Polio Union will be held in the NH Grand Hotel Krasnapolsky, Amsterdam on the afternoon of 24 June 2014. Exact time to be advised. Papers will be issued no less than 8 weeks prior to date of meeting. Organisations wishing items to be included on the Agenda must submit these, by email to the President of the European Polio Union ([jmcfarlane1@iolfree.ie](mailto:jmcfarlane1@iolfree.ie)) by no later than 22nd April 2014.

**CALL FOR VOLUNTEER DIRECTORS**

At the AGM of 2014 there will be an opportunity for nominations submitted by organisations for volunteer Directors to be considered. Such nominations must be sent to the President of the European Polio Union by no later than 22 April 2014 by email ([jmcfarlane1@iolfree.ie](mailto:jmcfarlane1@iolfree.ie)) and must include formal permission of the candidate for the nomination, a note saying that the nomination is endorsed by the Board of the submitting member organisation, and the "Curriculum Vitae" of the nominee, together with photo. These details will form part of AGM papers to be sent to member organisations not less than 8 weeks prior to the due date of the AGM.

**BOARD UPDATE**

The next Board meeting of Trustees & Directors of the European Polio Union will be held on Thursday 13th March in Ghent, Belgium courtesy of Post Polio België. Location will be advised to Board members and invited guests in due course.

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**Internationale Vereniging, Zonder Winstoogmerk**

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**URL: [www.europeanpolio.eu](http://www.europeanpolio.eu). Twitter: @polioeurope**

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The views expressed in this Newsletter are not necessarily their views or the views of the  
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