



EUROPEAN POLIO UNION

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EDITORIAL



Dear Members of EPU,

This year will soon come to an end, and a new one will begin. I would like to take this opportunity to thank you all for a good cooperation throughout the year. A special thank to you who attended the AGM last June in Lobbach. It is always such a pleasure meeting you all. The most important outcome of our AGM is the sharing of our experience and the good inputs from you.

A lot of new tasks are waiting for us in 2020. A new website will be launched in the beginning of the year. We are cooperating with the German company JSD to issue a new brochure, in which the member organizations are offered space for a description of themselves in national language and English. The brochure will be of no cost for the membership and EPU as JSD will try to get the costs covered by advertisers. GDPR is a big challenge for all, and that goes for EPU, too. John McFarlane is in lead of GDPR issue concerning EPU.

In 2020 the 3rd Post Polio Conference will take place from 10th to 12th of June in Vitoria, Spain. It has been decided to hold EPU's AGM 2020 in connection with the conference – most likely on 11th of June. The AGM 2020 will contain only the formal part – i. e. that the AGM will last about 1½ hours.

I wish you all a peaceful, happy New Year. I hope seeing you in Vitoria in June 2020.

Gurli Bechmann Nielsen
President of EPU

ANNUAL GENERAL MEETING OF THE EUROPEAN POLIO UNION IN LOBBACH, GERMANY, JULY 6, 2019

We started our trip to the Annual General Meeting of the EPU to Lobbach, a small town in Germany, just a few kilometres from Heidelberg, on Friday, July 5, and for us, my wife Gizka and me, it was already quite a well-known itinerary as we experienced the same route and for the same reason (AGM of the EPU) two years ago. Less than 800 kilometres from Bratislava via Sankt Polten – Linz – Passau – Regensburg – Schwabach – Lobbach, with half an hour's break somewhere halfway we took in less than nine hours without problems, mainly because Austrian and German highways provide comfortable driving conditions, but also due to the fact that long queues of cars from Bavaria were moving in the opposite direction to holiday resorts by the Mediterranean Sea as school holidays had just started.

Immediately after arriving at the Seminar Hotel Manfred Sauer Stiftung in Lobbach I rushed into the EPU Board meeting where only John McFarlane was missing due to his persisting health problems. We were all pleased to meet with Robert Cordier, a new candidate for the EPU Board, representing the French polio organisation (www.polio-france.org). The key point of the agenda was the organisation and practicalities of the AGM the next day.

The AGM itself started on Saturday morning, July 6, with representatives of 35 EPU member organisations and three guest speakers – Dr. med. Peter Brauer from Germany, Prof. Pierre van Damme from Belgium, and Prof. Frans Nollet from the Netherlands.

Official programme of the AGM was as usual – welcome speeches, activity report, treasurer's and auditor's reports, some news, election of a new EPU Board member (Robert Cordier, France) and re-election of another one (Stefan Grajcar, Slovakia). Though worth mentioning are all presented and/or discussed issues, let me mention those few of them with major or wider importance:

- "TGE – Transnational Giving Europe", a potential tool for EPU fundraising was introduced to us by Paul Neuhaus, Germany, EPU Board member (if you wish to have more information about it, see <https://www.transnationalgiving.eu/>);
- EPU website (<http://www.europeanpolio.eu/>) is under reconstruction, though it would be more accurate to say that a new website is being prepared; what progress had been achieved up to date was reported by Daniel Peltzer, Belgium, EPU Board member;
- Daniel Peltzer introduced also the French edition of the booklet "Better Understanding of Poliomyelitis and PPS" with a title "Mieux comprendre la polio et le SPP" written by Tom House and Professor Kai Paschen (†), few copies were available even on the spot; the booklet may be ordered via Amazon (<https://www.amazon.fr/Mieux-comprendre-Poliomy%C3%A9lite-Syndrome-Post-Polio/dp/1098970772>).

The final point on the official agenda of the AGM was the information that the next AGM 2020 would take place in Vitoria-Gasteiz, Spain, during the 3rd European Congress on Polio and PPS on June 10-12 – for more information about this unique international event see the article below in this issue.

After the official part of the AGM the meeting continued with three presentations of our guest speakers – Dr med Peter Brauer, Prof Pierre van Damme, and Prof Frans Nollet:

- Dr med Peter Brauer: "*Ventilation and Post-Polio Syndrome*"

- Prof Pierre van Damme: *“Quarantine vaccine study to assess safety, immunogenicity and shedding of novel polio vaccines”*
- Prof Frans Nollet: *“Results achieved up to this date of a Study B-Fit – A guideline to individualized exercise in Post-Polio Syndrome”* and *“Vitoria Congress 2020”*.

(Note: Presentations of all three guest speakers can be sent to you on request.)

The special moment came at the very end of our meeting – EPU Honorary Memberships were ceremoniously awarded to three well-known experts with high reputation not only in Europe but worldwide who are devoted to polio and PPS issues for many years; the EPU Honorary members became:

Dr. med. Thomas Lehmann, Switzerland – “In recognition of his outstanding PPS studies and his great efforts to raising awareness of the needs and health care for polio survivors in Europe”;

Thomas House, Germany – „In recognition of his outstanding work in the search, research, and collection of information on polio and PPS, its integration into the new EPU website and summarised in a booklet *“Better Understanding of Polio and PPS”* in English, German, and French for polio survivors in Europe”;

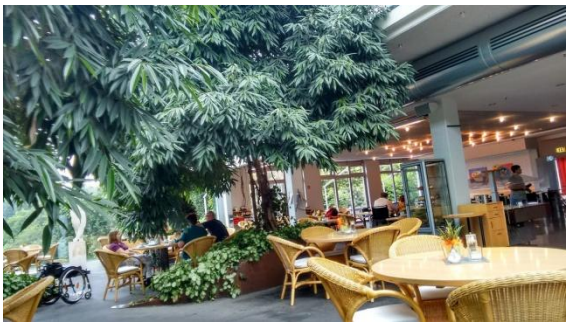
Prof. Frans Nollet, MD, PhD – „Prof. Frans Nollet’s work has advanced the understanding of Postpoliomyelitic Syndrome, its diagnosis and treatment. His work at the Amsterdam Medical Centre, in medical publications, and with conferences he has organised has improved the lives of polio survivors not just in Europe but worldwide both medically and socially. This certificate and honorary membership of the European Polio Union is in recognition of his outstanding work and achievements to better the lives of polio survivors”.

On Sunday morning, shortly after breakfast we set out on a journey home – the same route, but the conditions were a bit worse, as we had – at least for a time – to join the stream of German holidaymakers stretching to the southernmost holiday destinations. We managed to make our way back, and on Sunday night we were quite happy to say that the 1,550 kilometres had gone without any problems. We could just resume that it was an interesting and inspiring meeting, and that we were looking forward to meet again in Spain in June 2020...

Štefan Grajčár
Slovak Polio Association
EPU Board Member

And here are some photos to remind the atmosphere of this year’s AGM in Lobbach:





LAUDATIO OF TOM HOUSE

(presented at the AGM 2019 in Lobbach on July 6, by Margret Embry, EPU Board Member)



Tom – a multi-talented polio survivor – born in Scotland, had polio at the age of 6, is a writer, a painter and a musician.

Tom entered the army at a young age, later changed into the Intelligence Corps and operated during the Cold War in Central Europe in counter-espionage, counter-intelligence, and counter-sabotage. The late effects of polio made him leave the Services and after computer studies worked 25 years with American and German computer companies as system programmer and analyst until he founded his own computer company in Southern Germany.

His deteriorating physical condition which he felt was linked to his childhood polio infection made him search for answers and he joined the German polio self-help group but was disappointed about the lack of information that was available about the late effects of polio at that time. He started out on years of search, research, collecting information, translating it, finding and defining the correct medical terminology which was understandable by lay people and this not just about polio but also about the human body and the nervous system.

Through his translation work he got acquainted with Prof Dr med Kai Paschen and together they founded the charity 'Polio Echo'. Tom was instrumental in setting up the website of the same name including all the information he had collected and which was supervised for medical correctness by Kai Paschen. Unfortunately the charity had to close down in December 2017 following Kai Paschen's death and Tom falling seriously ill.

All the information Tom had collected in years of laborious search and research mostly at his own financial expenses he has generously put at the disposal of the EPU to be integrated into the new EPU website.

Last but not least we need to mention Tom as the author of the booklet 'A better Understanding of Polio and Post-Polio Syndrome (PPS)' (German version 'Polio and Post-Polio Besser Verstehen), this booklet has just come off the press in a French version "Mieux Comprendre La Poliomyélite et Le Syndrome Post Polio (PPS)".

The booklet is available via Amazon, fr, de, org.uk.

To show Tom our great appreciation and gratitude for all his work we have awarded him the Honorary Membership of the EPU.

Unfortunately Tom was unable to attend the 2019 AGM in Lobbach, so Lore Bohner of the Bundesverband Poliomyelitis who attended the AGM was so kind as to hand the certificate over to Tom at one of their local polio meetings.

LAUDATIO OF DR. THOMAS LEHMANN

(presented at the AGM 2019 in Lobbach on July 6, by Erika Gehrig, EPU Board Member)

I would like to give you a short summary of Thomas Lehmann's efforts regarding the foundation of the Union of Polio survivors in Europe.

Thomas Lehmann has been involved right from the year 1989 in polio and PPS issues and was one of the first to be in contact with Polio Health International USA.

In 1994 he met with Rolf Kiessig, then Vicepresident of the European Disability Forum, discussing ideas about how to structure European Polio self-help organisations and what tasks they should set themselves - Europäische (Post-) Polio Network (EU (P)Pon).

In 1999 – at a meeting in Hanover / Frankfurt the Polio Network (Europe (PNE) was founded: Bundesverband Poliomyelitis e. v., H. J. Woebeking / H. Bernback (CH).

In 2000 – in Kassel, Germany, Thomas met with Johan Bijettebier and others. In 2007 – Foundation of the European Polio Union in Erba, Lake of Como / Italy.

Some personal information

Date of birth: 1949; 4 siblings

Polio hit Thomas in 1957 as bulbar symptomatic polio (swallowing, speech, mimic) two of his siblings had apparalytical polio, they are now both suffering from PPS.

After Thomas had promised his polio Doctor and predecessor at the Berne Polio Station (University Hospital) to study medicine he visited the University, qualified as a medical Doctor. He then worked as an assistant Doctor while continuing his medical education until 1981 when he started work at the Berne Polio Clinic.

After having succeeded this he took over the work of his Polio Doctor and started taking care of all polio survivors in Switzerland, especially of those with breathing problems.

After 1988 he attended various PPS Congresses in Europe and USA.

1989/1990 he contacted an author of Reader's Letter concerning PPS. This gave him the idea to exchange experience with other polio survivors. Special members of ASPr-SVG like Ernst Gerber supported the foundation of the Swiss polio group, a self -help group, which later became SIPS. Most members came from ASPr-SVG which was originally founded by polio survivors.

1990 the SIPS was founded.

"I would like to point out, that we are more than grateful that we have Thomas Lehmann – he has such an empathy like no one else for polio survivors. Even now – being pensioned I can count on his advice and support. Therefore, SIPS is a great success. We at the EPU board thank you so much for your valuable medical help for the new French brochure "Mieux comprendre la Poliomyélite et le Syndrome Post-Polio. Therefore, a big THANK YOU from all of us from the EPU board."

LAUDATIO OF PROF. FRANS NOLLET

(presented at the AGM 2019 in Lobbach on July 6, by Els Symons and Aadje de Groot)

STUDY: Medical Doctor, Specialisation: Rehabilitation Medicine

2002: He obtained his **PhD** on his thesis, entitled: Perceived Health and Physical Performance in Post-Polio Syndrome

2003: Professor of Rehabilitation Medicine and chair of the department of Rehabilitation Medicine of the Amsterdam Medical Hospital

2015: **Also** Scientific director of **MOVE** research institute: Movement Sciences (researchers on movement work together)

Main research interests: Neurological Muscular Diseases, especially Post Polio Syndrome

His research ranges from prognostic studies with long follow-up, to a broad range of therapeutical studies, including pharmacological and rehabilitation interventions, such as physical training, psychological interventions and orthoses.

He **published** more than 150 indexed peer reviewed papers of which one third on PPS.

2014: He published a book on lower extremity orthotic devices, following a national guideline project he chaired.

He supervised 24 **PhD theses:** of which 7 on PPS. And at the moment 7 more are running: on orthotics and walking efficiency, falls and training and training interventions.

FORCE Trial: Study of the Efficacy and Safety of Immune Globulin in PPS. Frans was involved in the development of the protocol and is a member of the trial steering committee.

Awards: for his research achievements:

2006: AMC Principal Investigator

2011: Danish PTU Research Award

2016: VRA-Ipsen Innovation Award for patient care (union of rehabilitation medics).

2018: PHI Research Award

Congresses and workshops

He gave lots of invited lectures and workshops in all sorts of congresses all over the world. Not only for medical specialists but also for patient organisations.

European Polio Conference

2011 Copenhagen: chair of the scientific committee

2014 Amsterdam: chair of the organizing committee and co-chair of the scientific committee

2020: Vitoria: chair of the scientific committee

He is a member of the Medical Advisory Board of PHI.

He is Medical advisor of VSN (Dutch Postpolio patient organisation) and EPU.

In his research and work the most important things are: it must lead to a better understanding and better care.

We all benefit from that.

Els has told you about the impressive curriculum vitae of Frans Nollet and... you would not believe it, he is also a real doctor with a white coat!

And a very special kind of doctor indeed. In the last, let me say thirty years, he has seen/treated more than a thousand poliosurvivors in his clinic in Amsterdam. Not only patients from The Netherlands but also many poliosurvivors from abroad. They know how to reach/find this expert on Post Polio Syndrome. And yes, I am one of them for more than twenty-five years.

He is a no-nonsense doctor, he is really involved with his patients, clear in his advice and treatment. He is always beside the patient, trying to find the best solution for the problem together, a real 'shared decision' maker. He is able to put the misery of PPS in perspective and last but not least, he is just a nice guy with a good sense of humour.

So, it's clear for us, that he really, really deserves this Honorary Membership of the EPU.

“The following article by Dr Peter Brauer, MD, is his opinion and garnered from his clinical experiences and previously published papers. In the opinion of the EPU Medical & Scientific Committee the views expressed are not compliant with established and peer reviewed medical opinion and the reader should take this into account when forming their own opinion.”

COMMON MISCONCEPTIONS CONCERNING THE POST-POLIO SYNDROME

Peter Brauer, MD

“Someone once said that everyone has the right to their own opinion but not to those based on their own facts.”

John Robbins

Currently, over 99% of physicians do not possess the knowledge required to treat polio survivors for a polio-encephalic-myelitis and the Post-polio syndrome (PPS). The general level of knowledge ranges from strongly predominant ignorance to superficial perceptions and half-truths masked with misjudgement, even though the poliomyelitis disease, also known as infantile paralysis, is one of the best studied infections in the world. Due to professional ignorance, the state of recognition and the state of knowledge differ catastrophically. This is clearly at the expense of the affected patients, most of whom are misdiagnosed and subsequently wrongly treated.

For PPS patients, a misdiagnosis rate of more than 99 percent must be assumed, including asymptomatic and abortive infection courses with their sequelae. Even under the exclusive consideration of paralytic illness cases, the polio survivors still have approximately the same magnitude of misdiagnosis.

With a few exceptions, the condition PPS exceeds the imagination of those who are not affected to a point of complete incomprehension. This lack of understanding ranges from family members, friends, acquaintances, work colleagues, doctors, health insurance companies, medical services, physiotherapists, health and social services, expert ascertainment services, right up to the social courts. The patient affected has to explain countless everywhere, whereby encountering unbelief and ignorance and is accused of being a know-all if he is a disease related informed patient and also not infrequently discredited even to the extent of being regarded as psychosomatic, depressive or even as a simulant.

Just a few errors or opinions offered as facts repeatedly in everyday practice prevent an adequate PPS diagnosis. These are referred to below:

*** Poliomyelitis is a disease of the anterior horns of the spinal cord**

This statement consists of several half-truths.

1. Poliomyelitis is not just an illness, but already disease-worthy as an infection, since as such, it leaves permanent damage to the central nervous system (CNS), under which the spinal cord and brain are to be understood.

2. On infection, the spinal cord is mostly affected. The brain on the contrary is always affected. So it is strictly speaking, a polio-encephalic-myelitis disease.
3. Infection and illness lead to damage in the CNS. It usually occurs in the spinal cord, but always causes consequential damage to the brain. Strictly speaking, the brain is "preferentially" infested, which means that during the incubation phase it is reached the fastest through the blood stream by the most massive of the polio viruses.
4. Not only the anterior horns of the spinal cord, but also the side horns and hind horns, as well as the dorsal root ganglia, may be affected.

*** Poliomyelitis is a disease of the alpha motor neuron**

This statement is imperfect.

1. It is strictly speaking a polio-encephalic-myelitis (see above)
2. Not only alpha motor neurons, but nerve cells, which innervate the muscular fibers of voluntary movement and nearly all neuro-regulatory brain areas such as brain activation, motor skills, pain regulation, the temperature regulation, respiratory regulation, stress regulation, sensitivity, cardiac circulatory regulation, hormone regulation and emotion regulation, can be affected.

*** The bulbopontine and the encephalitic form of polio infection are extreme rare**

This statement is incorrect in its incompleteness.

All polio infections are encephalitic and can damage the whole brain, mostly functional depending on the functional load for a more or less long period, as a result of the ability of the brain to compensate (equalization = neurogenic plasticity), which remains hidden (subclinical) to the outside. About 5 - 10% of course forms with visible (clinical) symptoms show involvement of the central nervous system (CNS). Thus, according to general understanding, the abortive, the aparytic and paralytic forms are meant, of which the paralytic form in about 1% of cases of infection can be found. With regard to the Post-polio syndrome, the subclinical bulbopontine and encephalitic infectious history are virtually always given, only the clinical proportion is relatively rare.

*** The polio disease follows a stable phase after recovery**

This statement is imperfect.

It is not a real stable phase, but a clinically stable phase with a subclinical unstable background. The losses of destroyed nerve cells are compensated through previously damaged and / or healthy nerve cells. The functional and structural compensation process is subject to constant re-construction and decomposition with a limited durational magnitude. This is only clinically visible after a loss of about 50% of the nerve cells in a functional area due to functional impairment or functional failure. Even before this limit is exceeded, a subclinical PPS degenerative process may exist, which always emanates from the brain.

*** The stable phase lasts at least 10, 15 or even 20 years**

This statement is incorrect.

PPS is a degenerative disease of the overburdened balancing nerve cells of the brain and spinal cord. Transient processes in the musculature are also affected. The period up to their overload failure

depends on the magnitude of the previous damage and the duration and extent of the relative or absolute load / overload. This can last from a few years, rarely months, up to several decades, without an upper time limit.

*** A polio illness must be known for a PPS diagnosis**

This statement is incorrect.

98% of polio infections go unnoticed without disease or are uncharacteristic but also carry a PPS risk. On clinically and / or epidemiologically probable infections on diagnosis, is also at least a possible post viral late effect to be taken into consideration.

*** A PPS after an aparalytic polio is not credibly proven**

This statement is incorrect.

A PPS can be expected with the aparalytic, the abortive and the inapparent (asymptomatic) infection course. A credible verification being the same as a proof of claim does not exist for the paralytic course of infection. Clinical and para-clinical findings are generally unspecific with PPS, or otherwise even mainly inconspicuous. Decisive is a compulsory thorough medical case history. This applies for all infection courses of polio-encephalic-myelitis. Polio-related damage to the central nervous system (CNS) is proven in all infections of the asymptomatic, the abortive, aparalytic and paralytic courses. In any case, this results with the risk of a later PPS.

*** For a PPS diagnosis disease consequences must be apparent**

This statement is incorrect.

Visible sequelae such as muscle paralysis and muscle atrophy need not exist. 99% of polio infections occur without paralysis and their consequences such as muscular dystrophy, however not without a PPS risk. Also, paralysis may have regressed in the recovery phase after the disease.

*** A preserved sensitivity is required for a PPS diagnosis**

This statement is incorrect.

During the polio infection, areas of sensitivity such as in the dorsal root ganglia or in the brain can also be damaged and later lead to PPS symptoms.

*** At least two or more characteristic symptoms must exist for a PPS diagnosis**

This statement is incorrect.

The requirement for at least two or more existing symptoms is par excellence medical nonsense. Any indicative symptom of over 100 possibilities may or may not be required to exist. The virus infestation of nerve cells is irregular in location and extent, therefore also the late effects. In addition, weak symptoms are often not perceived or not registered as disease worthy. One mostly initially unique indicative symptom is sufficient for the suspected diagnosis. Proofing symptoms do not exist. All possible indicative symptoms may be single or in different combinational occurrence. They may or may not be constantly present. Their occurrence can be timely, vary locally and in strength.

*** The symptoms must have persisted for at least 1 year for a PPS diagnosis**

This statement is incorrect.

The PPS usually begins insidiously creeping, but can also be suddenly noticeable. A diagnosis is obligatory on its beginning. The probability of a different causative disease with the same symptoms or additionally causative disease is always possible. However, the PPS diagnosis never excludes parallel diseases as indicative symptoms. Consequently, the diagnosis PPS is not limited in time tied to a minimum duration of its symptoms. It is also mandatory with changing symptoms.

*** Other diseases must be excluded for a PPS diagnosis**

This statement is incorrect.

The exclusion of other diseases serves to prevent their treatment not to be missed out and not just purely a PPS confirmation. Their presence does not exclude the PPS, because an exclusion diagnosis cannot be excludable as such. Parallel diseases are possible. In the presence of corresponding symptoms, the PPS diagnosis has to be kept independent from other illnesses. The suspected diagnosis thus remains.

*** A new increasing muscle weakness must be present for a PPS diagnosis**

This statement is incorrect.

Although new muscle weaknesses are common, they are not a condition for a PPS diagnosis. Predominantly the first, most frequent and main symptoms are states of fatigue, which often register very late as disease-grade with slow onset and progression. In addition to exhaustion, for example, pain, as an indicative symptom, occurs without evidence of apparent muscle weakness.

*** Clinically ill conditions with polio survivors should not automatically suggest a PPS**

This statement is misleading.

Without exception and in addition to other illnesses with polio survivors, PPS should always be considered automatically.

*** The causes of the PPS are still unknown**

This statement is incorrect.

PPS is the result of a chronic relative as well as absolute overload, caused by a polio infection with or without disease of previously damaged and diminished healthy nerve cells, which depending on the strength and duration and result of overloading, after a more or less long period of time, die-off. It is therefore as in sports medicine defined described as an overtraining syndrome. Only the molecular sequence of event processes are not yet known, which do not matter for the diagnosis and the required symptomatic treatment,

*** The Post-polio syndrome is very rare**

This statement is incorrect.

When only 1% to 1‰ of polio infections have a paralysis, but all the infection courses have the risk of a later PPS, the reported cases of paralysis are multiplied by 100 to 1,000 to reach the approximate real number of polio-infected. According to the official risk profile gained from the

proportion of the population, this results in the fact that there are actually always more PPS patients as defined under the definition for rare disease. A rare disease is considered to be less than 1 patient in 2,000 inhabitants.

*** Post-polio syndrome is not a disease**

This statement is incorrect.

The term syndrome is used to describe "*... the simultaneous presence of various symptoms, so-called symptoms*" (Wikipedia) with known cause and unknown development. Only with known cause and known development is the term syndrome usually avoided and generally described as clinical picture. In that sense, it is an unfortunate choice of the consensus to call the polio late-effects term a *Post-polio syndrome*, as this is a disease where cause and development - with the exception of molecular biology processes - are known. On the other hand, this term refers to the characteristic variety of possible symptoms and the complexity of the disease, which is quite an advantage for primary diagnostic understanding. This is also followed by the WHO in their classification of diseases ICD 10 with the code G 14 Post-polio syndrome as a name for an independent disease.

*** Post-polio syndrome is an immunological disorder**

This statement is incorrect.

With PPS, nerve cells die-off as a result of chronic overload. The cellular decomposition process leads to the release of cell components, some of which are protein molecules that activate the immune system. This has a local inflammatory reaction resulting in the framework of cell debris removal. In some cases it can also release poliovirus fragments from cell-inactivated and fragmented polio viruses, which lead to this nonspecific reaction. Freed virus genetic material (RNA) in the form of fragments can therefore also directly trigger an immune response. This is secondary non-causative to the PPS immune process. Immunological inflammatory processes can also be primarily triggered through chronic stress without structural degenerative processes. Chronic stress is one of the main causes of the Post-polio syndrome. The brain is also affected by this process.

Conclusion

As long as the polio-encephalic-myelitis is considered just to be polio-myelitis with almost exclusive limitation to the consequences of the body motor system in the form of pitiable paralysis and skeletal deformities, whereby other consequences of the infection to the spinal cord and especially to the brain, are not considered, then the late effects, the Post-polio syndrome cannot be understood and thus not properly diagnosed and treated. As long as clinical proof and para-clinical symptoms or finding requirements for a diagnosis are continuously being sought, where in any exclusion diagnosis, as even in this case only naturally indicative, which do not exclude such a disease and parallel diseases from the outset, misdiagnosis and mistreatment are inevitable.

The basis for the detection of a Post-polio syndrome is the medical case history.

No diagnosis in the case of a suspected Post-polio syndrome is already a misdiagnosis!

Peter Brauer MD



Updated version of an article in the German publication:

" Supplement zu Aspekte des Post-Polio-Syndroms" pages. 22-27

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Translation:

German to English by:

Thomas House-Arno (*Tom House*) on the 23/7/2019

OVERTRAINING – POST-POLIO SYNDROME

Peter Brauer, MD

The polio survivor as a competitive athlete

A polio survivor is often compared with a competitive athlete. This is not an over-statement. It is all the more astonishing that so far sports medicinal findings have not been thoroughly examined concerning a possible connection with the development process of the post-polio syndrome (PPS).

The rehabilitative power-survival- marathon alone during the recovery phase following the polio disease justifies this approach. Even after a treatment period of three to six months, states of exhaustion and fatigue often occurred, which required treatment pauses of up to half a year (GRÜNINGER). This was and is considered to be a challenge. A warning against a therapeutic "over dosage" is also suggested. (CHRISTOFFEL in DORRER p. 234)

Looking at it from today's point of view a continuation of the training without a break in those days would inevitably have been seen as overtraining and would have led to PPS after a relatively short time. From a physical as well as a psychological point of view, this poses for the polio survivor in all areas of life relatively and / or absolutely above average requirements with very often completely inadequate recovery periods from the early phase of the convalescence after the illness.

A disease-related diminished load-bearing capacity based on duration and / or strength relative to absolute chronic over-training without adjusted recovery, ultimately resulted in stages of recreational fatigue and exhaustion, as developmental stages of a post-polio syndrome to end-stage post-polio syndrome, which ultimately led to a progressive, non-recoverable performance and compensation failure of the affected neuromuscular, neurological, and dependent functions and structures. The overstraining genesis of PPS as a result of lifelong "aggressive activity" (PERRY et al.) is undeniable and by no means limited to the neuro-motor domain.

Overload of athletes and polio survivors in comparison

The general rule is that any burden must be adjusted for performance and recoverability in the long run in order to avoid permanent functional and structural damage. Such an adjustment includes sufficient rest periods to maintain the balance between stress and recovery sensitive to disturbances (GRIMM). This applies for any healthy- and even more so for any weakened biological structure.

According to sports medicine, the overreaching (OR, short-term overtraining, overload condition) is regarded as overload weakness and the overtraining syndrome (OTS, long-term overtraining) as a disease-related overtraining syndrome with systemic fatigue (VOGEL), often present as a mixed type (URHAUSEN et.al.). Although molecular biology and neurological interactions have not yet been clearly clarified, there already exists data and causal hypotheses in this area that permit a pathogenetic orientation.

In the absence of a comparable polio-related research, the findings obtained in sports medicine for comparative evaluation are appropriate for the post-polio syndrome corresponding to the overtraining syndrome.

However, the risk expectancy for the latter is to be set much higher, as the load and over-burdening on a randomly distributed already pre-damaged and thus overall weakened structure for the normal daily load, right up to the central nervous system, is usually already overloaded.

Overload weakness and fatigue syndrome trigger reactive changes in the body in all functional areas (BUDGETT), (MEEUSEN et al.) and (MOOSBURGER), whereby general stress factors often play a key role (URHAUSEN et al.). Overtraining is based on a two-phase reaction (GRIMM) and (MOOSBURGER).

At the beginning (early phase) peripheral reduced neuro-modulatory excitability is indicated and a breakdown of type 2 muscle fibers - also found in PPS with cellular metabolic disorders and reduced cortisol formation. As a consequence, central (late phase) an inhibition of hypothalamic and pituitary body hormone production and inhibition of sympathetic activity occurs (GRIMM). The involved brain areas with OTS are the hypothalamus, basal ganglia, limbic system, hippocampus, striatum and various brain cores (MEEUSEN et al.), areas that may also be affected by the underlying disease PPS (BRAUER).

An OTS is also discussed as the result of overburdened brain plasticity as a performance-limiting reorganization response of the brain (HOLLMANN et al.) where it can also be assumed with PPS. The normal function can also be overburdened as such and lead to a regulatory limiting performance restriction as a failure protection (HOLLMANN et al.), (ADERHOLD) and (UNIVERSITY OF ZURICH). Similarities to burnout syndrome, chronic fatigue syndrome, myalgia encephalomyelitis, and post-viral syndrome are also under discussion (VOGEL) and (BUDGETT). With the post-polio syndrome, which is a post-viral syndrome, a shift or overlap or reversal of phase or phaselessness due to central pre-damage, depending on where the lesion is located as well as function and structure that are overloaded, is to be expected.

The variety of the often unstable or changeable disturbing influences usually cause a highly usually individual symptom picture with OR, OTS and PPS (VOGEL), (KASPRAK), (UHRHAUSEN et al.), (HOLLMANN et al.) and (BRAUER) and not always applicable in every single case. OR and OTS are exclusion diagnoses that cannot be clinically and para-clinically established (URHAUSEN et al.) as with PPS.

An evaluation of disease-worthy phenomena must always be carried out on an individualized, mainly anamnesis manner (KASPRAK) and (BUDGETT), which limit standardized studies and make them, if at all, meaningful for the individual case.

On the efforts to compare OTS with PPS, the genesis here is only intended to elucidate the comparable multifactorial model concepts of previously not finally defined pathophysiological processes of overloads with their effects, since identical points of attack and sequelae are to be assumed.

What is needed is a departure from the exclusive neuro-motor approach to PPS, which is also considered misleading in OTS due to the systemic effect (VOGEL). Both the OTS and the PPS currently have the best chance of gaining insights with non-standardized casuistic presentations.

** Common features of OTS and PPS:*

- *An overload is relative depending on individual performance and recovery ability.*
- *Performance and recovery ability are individually different.*
- *Physical- and psychological weak points cause a lower performance as well as a greater need for recreation and therefore react initially with overload.*
- *Based on the initial situation and depending on the stage of development, OTS and PPS are recoverable on a relative overload.*
- *OTS and PPS are essentially influenced by mental factors.*

- *OTS and PPS overload have the same physiological structures with comparable reaction patterns.*
- *It is to be assumed that OTS and PPS are peripheral and central factors.*
- *The most common and serious symptom of OTS and PPS is fatigue.*
- *The symptoms often creep in slowly and gradually, rarely suddenly and abruptly.*
- *A progressive disorder parallel to the magnitude of the burden.*
- *A secured practice-relevant standardized diagnostic is not given.*
- *No specific pharmacological therapy exists.*
- *The only causally effective influence lies in the reduction of stress and an adjusted regeneration period.*
- *OTS and PPS require a high degree of individual approach.*

** Differences between OTS and PPS:*

- *The development of PPS is primarily dependent on the least localizable weaknesses or respective previous polio-related damage.*
- *The PPS is in contrast to the OTS the result of a not quite avoidable chronic overload associated with a fatal decompensation development.*
- *The risk of systemic consequence is due to a lack of a general load control possibility for PPS, which is much higher than for OTS.*
- *OTS is usually curable, that is to say reversible but PPS never. There is no natural targeted avoidance strategy for PPS.*
- *In contrast to PPS, OTS is patho-physiologically relatively more extensive in the focus of interest.*
- *In any case PPS results in the expense of substance.*

A distinction between OR and OTS is difficult due to flowing transitions (BUDGETT) and (GRIMM). Molecular transgressions can be assumed here as with PPS. Diagnostic demarcations are arbitrary and lack a scientific basis to this day.

Symptoms of OR and OTS include:

- Poor performance
- Endurance restriction
- Impairment of the maximum force
- Coordination disorders
- Delayed recovery
- Increased excitability, moods of disapproval
- Sleep disorders
- Muscle-, joint- and bone pains
- Exhaustion

It is striking that despite occasional evidence of their diversity throughout literature a relatively small number of OTS symptoms is mentioned. This amounts to more than a hundred symptoms for PPS, which can be easily explained by the variety of all possible polio-related neurological damage with all its side effects in the very strongly networked structure of the nervous system and healthy areas.

There are various hypotheses about the causes and origin of an OTS. However, the exact development on the molecular level is still unknown. The localization of individual structural and functional areas is hardly possible due to the close networking of all control circuits (VOGEL). There only appears to be a relative as well as absolute mismatch between load and recovery.

As is common with PPS and also similar with OTS, there is also an attempt with OTS to brush this off into the psychopathological field because of causal diagnostical non-specific difficulty. That the significance of medical diagnostic procedures is extremely limited and is usually considerably overrated is not considered. At the same time the absence of physio-pathological findings does not mean there is an absence of somatic disorders or damage. A mental overload due to PPS on the other hand, is more likely to be of greater importance than with a healthy athlete due to the polio-related pre-damage problem involving the neuro-endocrine and the limbic system. Furthermore, an excessive demand on the autonomic nervous system is discussed concerning both the sympathetic and the parasympathetic nervous system. We know about possible damage in both areas, including its subsequent effects in connection with a polio infection.

Peripheral and central fatigue processes are also causally blamed. However, both are so closely linked with each other regulatory that the attribution of a priority appears presumptuous. With PPS a mixed form is to be assumed, even if the peripheral component appears superficial. Brain defects, especially subclinical, can never be ruled out and are more widespread than generally assumed.

The hypothesis of an OTS-favourable glycogen deficiency as an energy supplier should also be transcribed to PPS as a metabolic challenge of overloaded neurons and muscles. Other substrate hypotheses do not seem worthy of discussion for the PPS. More important is the assumption of central protection inhibition. Peripheral fatigue triggers central inhibition with just such a reaction thereafter. Within the somatic hierarchy, the brain in its supreme controlling and commanding power has an ego-centric setting focused on its own survival. All body functions are subordinated to this goal in the sense of a self-protective feedback mechanism (URHAUSEN et.al.). That is to say, the clinical as well as para-clinical patho-physiological findings of an overload can be the result of both an absolute failure state and that of a central nervous regulation.

A neuro-endocrine involvement with hypothalamic origin in the overall process of the OTS is considered (VOGEL). This in turn, suggests absolute comparability with the PPS due to the proven polio damage in the hypothalamus.

Overstraining in sports leads to a secondary differentiated immune response (GMÜNDER). The secondary immunological sequelae in the neuro-degenerative process is comparable with the post-polio syndrome. According to a study by the British Columbia University in Vancouver, the inflammatory markers in the blood are increased during sports stress (APOTHEKEN UMSCHAU). A chronic stress situation inhibits the normal re-regulation of the pro-inflammatory effect (BRAUER).

OTS and PPS require a systemic approach. Neither individual causes can be identified assuredly as the sole cause, nor can causes and effects be strictly separated (VOGEL) and (BRAUER). Combinations must be expected in a more or less wide-spread range. An individual appearance and developmental pattern is diagnostically more crucial for OTS and PPS than generally defined criteria. Ethical unobjectionable experimental studies under standardized conditions with unrestricted generalizable results are to be regarded as far from reality in both cases.

Whether more or less minor performance improvements are reached through moderate training in OR and OTS by some probands, super-compensation occasionally observed in PPS studies correspond to the observed is conceivable but remains hypothetical. One thing is certain: the renewed overloading is bound to a difficult to estimate narrow window of time, which is highly individualized and empirically calculated from the pre-burden on strength, duration and recovery interval dosed load size, so that a slip into the syndrome is avoided – a very difficult and in the long run rather ineffective undertaking. Super-compensation is an over-exertional increase in exercise

performance during the process of recovery, but can be sustained even by a healthy organism for a limited period of time.

The deliberate or unknowing application of the super-compensation principle for polio survivors in the form of a study is not only prohibitive for reasons of individuality, but also because of the predominantly unknown polio-related neurological damage and its heterogeneity, which generally prohibits a strength and endurance training in this group of patients. This way of creating a "stock of temporary performance" is subject to healthy functions and structures that are not assured and presupposed when dealing with a polio survivor. In addition, the functional systems involved in this process require extremely different recovery times (hetero-chronism) called restoration, which cannot be considered in a study group without leading the rest of an already un-given comparability ad absurdum.

Training in the true sense is also a departure from the comfort zone of everyday exercise – a dosed load to increase performance. But this exceeds the unpredictable and uncontrollable capacity of an organism that has been pre-damaged by polio. This is primarily about preserving performance and inhibiting its decline. According to current knowledge, for everyday burdens, polio survivors require per se prolonged recovery periods comparable to the requirements of the OR. On the appearance of the PPS, the control rule of two (2) applies, which means a doubling of the recovery time.

As with sport polio survivors have mostly unknown weak points, which are of primary importance for the onset and further development of a disease-causing overload syndrome and will increasingly involve the aid of healthy structures. The key difference with the PPS is, in addition to the clinically visible, the random multitude of undetectable possible subclinical pre-damage. The physiological weak points of the athlete as a whole are compared with the pathological weak points of the polio survivor. Due to the usually creeping development of the PPS from the predominantly subclinical polio-related damage and its irreversibility as well as its extensive effects on the entire organism it relates to a potentiated overtraining syndrome.

Finding the causes at levels other than the load of function and structure for the PPS seems utterly absurd. This assumption is supported by the sports medical data.

Conclusion

In terms of causality, the PPS is quite comparable to the OTS as an overload syndrome. The molecular biological processes are to-date still unclear for both. Finding the causes at levels other than the overload sector of function and structure for the PPS seems absurd. This assumption is supported by the sports medical data.

There are no symptoms of proof for the OTS or the PPS. If there are any indicative symptoms, the diagnosis should always be an overload syndrome, which never rules out parallel causes.

A major treatment measure for the OTS and the PPS is a physical and mental load reduction, especially in terms of stress as well as maintaining sufficient rest periods.

This is not always met with enthusiasm by athletes and polio survivors and does not always create insightful behaviour. Load reduction also includes the early preventive use of help aids and, last but not least, the effective treatment of concomitant diseases. In addition, a relatively lack of understanding from the social environment exists concerning the polio late effects regarding the limitation of performance and its many symptoms, if the disease is accepted as such at all. All this together still requires extensive individual and public information activity.

The body usually signals its weaknesses in time. Polio patients are required to listen to their body and follow its warnings.

"Listen to the whisper of your body before it cries!"

Honorary translation - German to English by:

Thomas House-Arno (Tom House) on 8th November 2019

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05/2019

SIPS PROJECTS DURING THE LAST SIX MONTHS

1. Answer by Thomas Lehmann after receiving the Award Honorary Member of EPU

Thomas Lehmann

“I’d like to precede my thanks for this honour with the following quote by German poet, Christian Morgenstern: “Your home isn’t where your house is, but where you are understood.”

I’d like to thank you all for giving me the privilege of Honorary Member. I’d also like to thank all the people that have made it possible for me to go about my honoured work: my parents who have passed away, my siblings who have supported me during my struggles with Polio, my wife, Madeleine, my five children, and my grandchildren, but most of all I’d like to thank my friend, mentor and predecessor, Dr. Paul Walther.

He had already observed signs of the Post-Polio Syndrome by his patients, who later on became my patients, around 60 years ago. Today’s ruling guidelines for Post-Polio were already set up by Dr. Walther during those days.

I’d like to thank all those mentioned that I was capable of putting in such an effort for the cause of the European Polio Union.

It had become more and more important to me during the supervision of my patients to minimize the lack of knowledge and misunderstanding towards Post-Polio Syndrome, to burn out those errors and also to kindle the knowledge and understanding with the help of personal, communal and international scientific experience, to shine a light, so that those suffering from PPS might once again feel at home.”

Translated into English by Erika Gehrig



Foto Dr. Thomas Lehmann and Dr. Brauer

2. Worldpolioday in Geneva, 24th October 2019

One of our members from the French speaking part who is very active selling tulip bulbs for Rotary and I were invited to take part at the special event at WHO. The celebrations were organized for WPV3 eradication and WPV 3 certificate by WHO.

The exhibition regarding polio eradication and the demonstration of the two iron lungs from Basle were very interesting and had many visitors.

The discussions with the participants from many countries all over the world were very interesting and we could make valuable contacts.

In the afternoon of the World Polio Day 1000 polio tulip bulbs were planted at the Parc et Promenade in Morges. One of our polio survivors who will be pensioned at the end of the year sponsored 500 tulip bulbs. The other 500 bulbs were sponsored by Rotary in the French speaking area around the Lake of Geneva. Many members of SIPS ordered tulip bulbs as well.

Swiss Rotary Chocolate

The SIPS Board has ordered around 70 boxes of Läderach Chocolate for Eradication of Polio. Every box sold at CHF 30.-- , CHF 10.-- per box go to Rotary for eradication of polio. The sales of the boxes are still going on.



Just before Christmas we were informed by WHO that the sales of these chocolate boxes were impressive compared to previous years. Orders for next year are already on the way!

The result means that 367'878 children can be vaccinated through the sale of these chocolates by Rotary, WHO and SIPS. These figures include the contribution of Bill and Melinda Gates.

Rotary Concert next year March 15th 2020

A great beneficiary Concert, Sunday 15th March 2020 at 17.00 hour will take place at KKL Lucerne. We will be welcomed by Mark D. Maloney, President of Rotary International. Most tickets are sold, no disabled seats left. For more information see: www.rotarykonzert.ch.

Erika Gehrig
EPU Board Member

SOME NEWS FROM THE BRITISH POLIO FELLOWSHIP

To start with an update from my article in the "Newsletter No 1" which focused on one of the four main objectives of The British Polio Fellowship--- a campaigner to promote accessibility for our members, in conjunction with other similar organisations disability has for a long time been to the forefront of national political and media activity. Unfortunately "Climate Change" and the long Brexit saga have taken over the agenda. We now (as I write) have a General Election and so nothing is moving forward!! As I explained last time the railway system is so fragmented, that the government has ordered a major review of the current "broken Franchise model". I suspect that even if good things come from this review, disabled travel care will be low priority. This is very wrong as here in Great Britain (and I suspect in you countries) we are all living longer, and the number of disabled persons is rising fast!

As regards access to buildings I was shocked and saddened when investigating the possibility of bringing our EPU AGM to London (Heathrow). I found that after three visits even with hotels up to 1,000 bedrooms the percentage of fully disabled access rooms was nearly zero!!. This statistic flies in the face of the fact that nearly 14 million people (22% of our population) have a Disability, 45% are of pension age (65 years in GB) and that we have an estimated spending power of £249 billion! So why do they not cater for us?

The average age of our members is 77 years (my age) and so here in the UK we must look to the ethnic immigrant community for new and younger members. Leicester is a large city with an active BPF branch, and also we are told Polio groups for Indian survivors, Pakistani, and Bangladeshi. We are committed to reaching out to Polios from the Black and multi ethnic communities for co-operation and mutual support. The BPF has been accused of ignoring these groups of people, but I must point out that in our Head Office we employ three Indian Hindus, and a Sri Lankan Hindu. One of our Ambassadors is from Kenya, and a good friend and supporter is a very well known TV Star called Ade Adepitan, a wheelchair Polio survivor from Nigeria. He is very influential but is always described as disabled, never Polio disabled!! which highlights our low priority. We note however the large number of non Danish polios in that country and so this is the strength of the EPU that we can learn from each other. I would guess that countries such as Holland, Germany, France Italy and the Baltic states also have a good amount of younger polios who for many reasons have left their birth countries. If we can reach out to them then all the better for both sides involved, a challenge but a worthwhile effort.

Can I close by repeating that if Great Britain does leave the European Union we will not leave the EPU and will continue to support our fantastic fellow members, and the ideals and objectives of our Union.

Wishing you all the best in 2020.

David Mitchell
National Chairman BPF
EPU Board Member

EPU NEWSLETTER PIECES

All prepared by John McFarlane, EPU Board Member

European Polio Union – 2020 Annual General Meeting

Notice is hereby given that **the Annual General Meeting of the European Polio Union will be held on 11th June 2020 in the Armentia meeting room of Europa Congress Palace, Vitoria Gasteiz, Spain at 16.00 Hrs.** The meeting will receive reports from officers of the European Polio Union and conduct matters as required by law and rules of the European Polio Union. Further details, agenda and supporting papers will be issued not less than 5 weeks prior to the given date. Any person, being a paid up member of the European Polio Union or representing a paid up member organisation of the European Polio Union should contact europeanpolio@eircom.net for further details.

European Polio Union Brochure

It has been some years since the EPU had a brochure for distribution, the last update was in 2011 for the conference in Copenhagen and a revision is long overdue. So it has been decided to take the plunge but in a rather novel way. The one thing the EPU has not got much of is € (or whatever your currency might be) and brochures cost a lot, especially in full colour and roughly 24 pages of A4.

So how will it be afforded? The answer to some extent lies in the hands and knowledge of EPU Members and member organisations. Previously two members of the EPU have used a company in Bonn, Germany called JS Deutschland to produce brochures for them at no cost. The EPU has entered into a relationship with them on a no fee basis. We have already sent out a letter from the President of the EPU to all members, affiliates and associates asking for a piece of roughly 200/250 in the members own language, and the same in English as well as English describing their organisation and work. The letter also asked for a couple of photos. It is your words and photos that will form the core and most important part of the brochure. At the same time the letter also asked for names of companies who might like to buy advertising space in the brochure. This is the key to the project, as no advertisers – no brochure!

Centrally the EPU has put together a list of just under 100 potential companies that JS Deutschland are going to approach and try to sell advertising space. Some might think 100 is enough, but we need more to guarantee getting the brochure produced and in print. Alongside the brochure we shall also be producing a video about the work, ethos and how the EPU can help polio Survivors not just in Europe but all over the world.

So, to a large extent whether this brochure ever sees the light of day is down to you, your words, your photos and names of those who might buy advertising. We are not asking you to sell the advertising space that is the work of JS Deutschland, and how they get the money to produce the brochure at no cost to the EPU.

This is YOUR Chance to tell others what you do and show that where the EPU leads others follow.

Renewed & Revitalised Website

Elsewhere in this Newsletter you will have read about the plans we have for a brochure highlighting and demonstrating not just what is the European Polio Union but also **YOUR** organisations. Brochures are great for exhibitions and presentations but in the digital age what is needed is a good website and social media presence.

The current EPU website is outdated, and it was created on a shoe string using the framework of Polio Ireland's website www.polioireland.ie (Post Polio Support Group as it was known then). It has served us well over the years but can no longer be supported in its current format so showing we are truly European we searched for a developer who could not just help us develop the concept, but also implement it – and at a price we could afford – a tall order. Thanks to one of our Board members, we identified a concern in Slovakia who were willing to undertake the work. Language barriers have been overcome and development work is well under way with a Beta test version having been delivered. This is undergoing scrutiny and debugging before we subject it to a wider test audience for opinion. In other words, not just do they approve but can they also beak or find fault with it. The EPU does not want to be in the business of some many banks over the past couple of years in having its website crash – or even worse be hacked – and that has been attempted but thwarted on the current site.

The new site will be ready as soon as we can be confident of it, and certainly well in time to give further information as well as cover the proceedings of the 3rd Post Polio Congress that is being held between 10 – 12 June 2020. Also, the brochure mentioned earlier will be available in digital format as will the accompanying video.

Changing demographics of polio Survivors in Europe

A few short years ago nearly all the polio support groups in Western Europe, at least, were forecasting their demise by 2030 – 2035. How the world has changed since then, we have had ongoing conflict in the Middle and Far East and a whole raft of refugee movements across the Mediterranean, some with tragic consequences.

Many of those seeking asylum and shelter in Europe from the terrors of war and hunger are young, and it is becoming increasingly obvious that included in their number are young polio Survivors. The vast majority of polio Survivors in member groups of the EPU are over the age of 60, in some countries such as UK and Ireland the demographic age profile is even higher.

These younger polio Survivors from the immigrant and refugee communities are setting up their own polio support groups, often in total isolation from the mainstream organisations that are EPU members. Traditional and long established polio support groups, and the EPU, face a challenge in the next few years – how to help these new groups and integrate them in “the polio family” without swamping them with preconceived notions of how they should operate. These new groups often operate within the bounds of very different cultural, and indeed religious traditions.

The first obstacle is to identify these new groups and offer a helping hand, both difficult to achieve. The EPU has already discussed this challenge at Board level and is determined that the EPU will do all it can to help those in need. We would strongly urge all member organisations and polio Survivors to offer the hand of friendship and help to our younger colleagues wherever they may come from.

Book Review

In 2016 the New York Times took a bold step for a mainstream newspaper by launching a weekly column called “Disability”. Each week a different contributor would tackle an issue that has touched them or their disability community. The topics covered have now been gathered together in a book under the title “ABOUT US” that reflects the refrain of disability movements worldwide “Nothing About Us Without Us”, and under this heading it tackles all disabilities and issues.

The pieces within the book tell stories of first romance, childhood shame and isolation, segregation, professional ambition, having children, the challenges faced by a parent with a disability to old age and beyond.

It reflects conversations that many of us will have had from the “I don’t think of you as disabled” from a friend to the frustrated father who shouts at his CP child with athetoid spasms “Stop it, stop it, what’s wrong with you”.

One writer in particular recounts something pretty unique in that she went through medical school and her hospital training in a wheelchair – it allowed her to form a special bridge between patients with a disability and their doctors. Despite notes of triumph throughout the essays that make up this work there are many stories of frustration and anger about social attitudes, access to medical care and the right equipment, the social stigma that some feel or perceive due to their disability

Although as its source implies American in tone there is enough in this book for anyone with a disability to recognise themselves and the triumphs, challenges and frustrations we can and do all feel from time to time. Edited by Peter Catapano of the New York Times and Rosemarie Garland Thomson, Professor of English and Bioethics at Emory University it is a worthwhile and easy read as none of the contributions are over 3-4 pages long. They may be short but the thoughts and discussions that result from them will last a great deal longer and offer much food for thought.

Available from Amazon and other leading suppliers.

“About Us”. ISBN 978-1-63149-585-4

Wheelchairs and Airlines

Have you ever had your wheelchair damaged while travelling by air, well I most certainly have. When I was going from home to the EU Commission in Brussels, quite often twice a week I used to have an average of 3 totally wrecked each year. Alright they were not the complex power chair I have to use these days due to PPS but Quickie RS chairs at an average price of £1 400 each. Only problem was that due to the still unchanged Montreal Convention the compensation from the airline was roughly 70% of the cost. For the rest you either had to rely on your own pocket or on travel insurance – but the insurers get fed up with multiple claims and have the option to refuse claim.

These days in the EU the airlines are no longer responsible for looking after people with a disability but rather it’s the airport that has that responsibility. However the airline still looks after luggage loading and that’s includes what amounts to peoples’ mobility – their wheelchair, scooter, rollator and other aids and appliances. I once was sitting in my window seat right above the bage handlers unloading point, first out came my wheelchair flying through the air to land with a crash on their cart, next came a hold container down the conveyor belt that landed straight on top of my chair. I

was reunited at arrivals in O'Hare, Chicago with the now badly damaged wheelchair that had been so badly twisted that it would only go around in circles.

The size of the problem in the USA has just been revealed. Since the beginning of 2019 to September, American registered airlines have damaged a staggering 7 747 mobility aids, that's 29 a day!

According to USA Today "the actual number of mishandled wheelchairs is likely to be higher, according to disability advocates, who claim many passengers don't formally report damage to airlines or are not immediately aware that damage has been done. It follows US Senator Tammy Duckworth, herself an amputee who uses a wheelchair, including a provision in last year's reauthorisation of the Federal Aviation Administration that requires airlines to track damage to wheelchairs and scooters that are in their care."

"These medical devices are essentially a part of a disabled person's body," Senator Duckworth told USA Today. "Imagine if in a single year (that many) people had their legs broken by an airline as a result of flying. The effect is the same."

While figures are reported in the USA to federal authorities under FAA regulations no such provision exists in EU or EEA countries, nor is the provision included in any EU Commission directive either in force or proposed. So what is the size of the problem here, no one knows. Occasionally something hits the newspaper like the paralympian who had to drag himself across the floor of a UK airport as his wheelchair had been left behind at the departure airport in Spain, perhaps even worse than it being damaged. Other reported have centred on budget airlines who see wheelchairs and their users as an impediment to fast turn around and maximised revenue.

So how can you avoid getting your mobility aid damaged, here's a few tips:

If it's a manual chair insist you stay in your chair right to the aircraft door and insist its brought back to the door when you land. It still must carry a baggage strip but will also get a priority on loading and unloading so it's on its own, and take off things like footplates, armrests and cushions and get them put in a cabin overhead locker. Same thing for rollators.

If it's a scooter things are a little more complex. It's batteries must be IATA Class 3 specification, in plain terms gel sealed batteries not the old wet lead acid type. Airlines tell you the batteries must be removed – not so as long as you have a flight safety isolator such as "Airsafe Power Inhibit Plug" – see illustration.



When your power chair or scooter is plugged to charge the mobility aid cannot be mobilised, this plug effectively does the same thing and it's recognised by countless airlines across the world.

If you can with scooters try not to allow the airline to take them apart but keep in one piece. If you have a complex power chair such as a Permobil, Meyra or Balder type I have one piece of advice DON'T take them on air travel unless you are rich enough to have it palletised and carried as cargo – and that costs big time. One polio Survivor in Ireland took his top of range Invacare J55 over to Paris where he was to be honoured with an award at the Pasteur Institute. Due to his disability it is fitted with foot and attendant controls. Got there alright on the way back it suffered €15 000 of damage, well outside the Montreal Convention, and he was without it for 3 months whilst getting it repaired and fighting for compensation.

This piece just seems to be a tale of woe but even those appalling figures from the USA only represent 3.6% of mobility aids and appliances carried. So if you go flying just be aware of the pitfalls, do all you can to ensure the safety of what is effectively your legs – and just in case before you fly research where at your final destination you can hire equipment – just in case.

Enjoy your flight!

**INVITATION TO THE 3RD INTERNATIONAL CONGRESS ON POST-POLIO SYNDROME
IN VITORIA-GASTEIX, SPAIN, 10th - 12th JUNE 2020**

Dear Members,

We have the pleasure of inviting you to the 3rd European Congress on Post-Polio Syndrome concentrating on *'Improving the Care for Polio Survivors'*. This congress is being organized by Rotary, EPU, PTU Denmark and the University Medical Centre of Amsterdam. It will take place in Vitoria-Gasteix, Basque country, Spain, from the 10th - 12th June 2020.

For details as far as they are available at this moment in time please refer to the attached leaflet, and the link <https://postpoliocongress.com> which gives a list of hotels in the vicinity of the Congress Center. Registration has started and we recommend early booking of accommodation. For this purpose please use the form on the conference website and give precise details of your needs as far as room and bathroom facilities are concerned.

As you might have seen in the 2019 AGM Lobbach Minutes, the Annual General Meeting 2020 will be integrated into the congress timetable, possibly in the morning of the 10th June, details will follow in due time.

Scientific program

The Scientific Committee is made up from more than 30 health professionals from different countries working side by side to be able to deliver a program that Congress deserves, with the aim to improve care for polio Survivors who are confronted with Post-polio Syndrome, in Europe and worldwide.

This Congress will bring together an international audience of polio survivors, health care professionals from multiple disciplines, together with researchers to exchange knowledge and experiences.

The main topics of the Congress are:

- Diagnosis and Therapy
- Symptom Management
- Multidisciplinary Rehabilitation
- Orthotic Devices
- Best Practices
- Latest Research Results

EUROPEAN POLIO UNION Board



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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