



EUROPEAN POLIO UNION

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English version

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Editorial

According to the Chinese horoscope, 2020 is the year of the rat, but I do not know if another living / inanimate organism, the corona virus SARS-CoV-2, by the World Health Organization and almost all national health authorities called COVID-19, has decided to usurp it.

COVID-19 interfered quite dramatically in the lives of all of us as individuals in all the roles we have honestly performed – as parents, grandparents, partners, friends, neighbours, casual acquaintances, tourists, athletes, people sitting in restaurants, cafes or at beers, lone runners roaming the country among other lone runners, visitors to theatres, cinemas, exhibitions, museums, castles and chateaux scattered on hills or surrounded by cliffs or castle parks, travellers in buses, trains, planes, co-patients in rehabilitation institutions, hospitals, health resorts, vacationers on reconditioning stays ... If you have not found all your roles among the listed, which is more than likely, feel free to add them to the list.

We as polio survivors know quite a lot about viruses. No one will tell us how innocent they are and that they are actually only helping us raise the threshold of our sensitivity to the various ailments of this world and ultimately doing us good by boosting our immunity. Nothing like that in this case, this polio virus, so well-known to us, that visited us decades ago, left such a storm in our lives that we haven't recuperated from it to these days, and it will probably remain so forever. In its insidiousness, "our" poliovirus even went so far that when it chose us as its host (because viruses always need someone to go crazy on, without us as hosts it would be just a tiny, nearly invisible mini-cluster of molecules without its own metabolism, which neither science nor history would bother about), we were mostly so small and young that we don't even remember those pre-viral times. (And it's good, at least we're not sorry about those times, we wouldn't do anything about it anyway.)

COVID-19 – and it's a weak consolation that not only to us but absolutely to everyone – took care of this year's program, where the main and quite simple motto is "Stay at home!". The events we had planned for this year, which we were very much looking forward to, remained mostly only on paper and in the form of our plans.

COVID-19's influence has reflected also on the international polio scene. At the beginning of June 2020 (June 10-12), the 3rd International Conference on Polio and PPS, as well as the regular annual general meeting of the European Union polio were supposed to be held in Vitoria-Gasteiz, Spain - the conference was postponed, and this year's Annual General Meeting was cancelled.

And finally, one more remark – the polio virus was the most successful in the child population, we all witness it, with a few exceptions. And as on purpose, the COVID-19, which came 70 years after the greatest polio epidemic, thought that the best host for its multiplication and spreading further would be the elderly of us. So let's not offer the virus the joy of going crazy on us for the second time, let's be careful and do not underestimate anything!

Štefan Grajčár
EPU Board member

EPU President's Address



Dear friends,

What strange times we live in – the COVID-19 has turned the world upside down. Many countries have been affected very hard and a huge number of people have died. All our sympathy goes to those who have lost their loved ones. We know that all our member organizations try very hard to support polio survivors in the best possible way, however the restrictions make it very difficult. All activities of the organizations have been cancelled. The 3rd European Conference on Post-Polio Syndrome: “Improving care for Polio survivors” has been cancelled, too, but hopefully the conference can take place when it is safe to get together again. Many of us have looked forward to the conference and the opportunity of meeting polio survivors and health care professionals from many countries. We know that a lot of effort has been put into the conference so it is a great disappointment both to the organizers, the polio survivors, and the health care professionals.

As you know, EPU planned to hold our AGM 2020 in connection with the conference, but unfortunately we have to cancel our AGM this year. Due to the COVID-19 situation it is impossible to hold an ordinary AGM for many months to come. Our members are considered to be a vulnerable group and in a particular risk of severe complications if they are affected by COVID-19. The Board of Directors has therefore decided to cancel the AGM 2020. The legal consequence is that the Board of Directors continues for another year despite of the requirements in the Rules regarding election. However, an approval of the financial statements will probably be necessary. Philip Rendtorff has consulted Johan Bijttebier, who confirms that also according to Belgian law the situation is extraordinary (force majeure) and that it will be legitimate to cancel the AGM as described. With regard to the financial statements it will probably be acceptable to approve by mail. Johan will consult a colleague for precise confirmation. He mentioned that the Belgian government most likely will state guidelines in this matter for all associations in Belgium in September 2020. We will keep you informed about the procedures.

Personally, I have looked forward to the AGM 2020. It is always a great pleasure to meet you. The AGM gives us a unique opportunity to meet and share our experience. We can learn from and be inspired by each other. We can bring inspiration and information from the AGMs back to our organizations.

Hopefully, the COVID-19 will not prevent us from meeting at the AGM 2021. Until then take good care of yourself and your family. Have a nice summer.

I send you my warmest greetings.

Gurli Nielsen – President of EPU

The 3rd European Congress on Post Polio Syndrome postponed



Important announcement

Dear Sir, Madam,

Due to the global COVID-19 virus situation we announce the cancellation of the 3rd European Conference on Post-Polio Syndrome: 'Improving care for Polio survivors' June 10 - 12, 2020, Vitoria-Gasteiz, Spain.

Per Tuesday March 10, the World Health Organisation (WHO) has increased the assessment of the risk of spread and the risk of impact of COVID-19 to very high at global level. In many countries health care workers are forbidden to attend (international) conferences and meetings. We consider the well-being and security of all the conference attendees and exhibitors our top priority. Therefore, we have decided to cancel the 3rd European Conference on Post-Polio Syndrome.

We have decided to freeze all preparations of the conference. We intend to reschedule the meeting at a later stage based on the current program. As soon as it is safe again to organize international meetings, we will reschedule the meeting and inform you.

In connection with the cancellation, the organizers will inform you at a later moment about the refund policy. We apologize for any inconveniences this decision causes.

We thank you for your enthusiasm and contribution to the preparation of the conference. We hope for your understanding and continued enthusiasm to contribute to the conference at a later date.

With kind regards,

Pablo Cervantes, Frans Nollet, Merete Bertelsen

Source: <https://postpoliocongress.com/en/the-congress/>

The Post-Polio Syndrome during the Corona Crisis

Peter Brauer MD

The Covid-19 (= Corona Virus Disease 2019) is a Sars-Cov-2 virus (= Severe acute respiratory syndrome-Corona virus-2,) which in individual cases has caused a very serious infectious disease of the respiratory tract, primarily the lungs, but mostly to other body organs.

The course of infection in approximately 14% of those infected is similar to that of a severe influenza. According to the WHO, a mild course, more like a slight cold, is found in about 80 percent of those infected. In around 5 percent of cases, the effects of the disease in the form of respiratory arrest, septic shock or multi-organ failure are life-threatening. This information is to be regarded as provisional with regard to the course of infection, since it only relates to the recognized course of the disease. There are also reports of some patients who show no symptoms of illness after a confirmed infection. Figures for these inapparent (asymptomatic, subclinical) infection courses require further environmental studies regarding the immunity development of the population in the pandemic areas.

According to the WHO, patients with the mild course of the disease recover within 2 weeks, those with the severe course in 3 to 7 weeks. Even with mild courses, direct long-term damage to the lungs and heart, for example, cannot be excluded. The development of late effects remains to be seen. This possibility is to be assumed.

Older people from 60 to 65 years of age upwards are particularly at risk of an infection and severe life-threatening courses. In some cases the age limit of 50 years is also given and those with disabilities for various reasons or with medically significant pre-existing illnesses, i.e.: chronic respiratory diseases, chronic liver diseases and high blood pressure, diseases of the cardiovascular system, diabetes mellitus, cancer and immunodeficiency. Smokers are also included in this group.

It is misleading that the disease was declared as a respiratory disease, based on the site of the most striking emergence of the disease, whereby insufficient knowledge of the overall infection especially the lungs, was available. In the meantime, even the more or less questioned observations of a clinical and pathological anatomical nature are increasing and indicate that other organs such as the brain, heart, liver, kidneys, intestine, spleen and possibly muscles are also affected. The cause is the conflict between a systemic infection by the corona viruses and a reactive immunologically excessive inflammation by cytokines (protein messengers of the body) such as chemokines (signal protein substances of the body, although virus genetic material for example already exists in the kidneys, viruses in the nerve water (cerebrospinal fluid), as well as of the heart, intestine, liver, blood and lesions in various brain areas, primarily in the brain stem. Accordingly, the corona virus is not just a lung virus, but a multi-organ virus.

This raises the overall question of the importance of a corona virus infection for polio survivors with or without the post-polio syndrome (PPS). Since most polio survival patients have reached the age of sixty, they are predestined at risk for a serious course of infection with Covid-19. Due to the polio-related primary, secondary and ultimately tertiary polio after-effects with function-weakening effects on the whole organism, including the immune system as a pre-existing disease, they are also

high-risk patients. However, if they already suffer from the severely incurable chronic progressive PPS, they should be considered as high-risk patients.

With polio survivors, the Sars-Cov-2 viruses always encounter a patient with previous polio damage of a drastic form to their nervous system. This proves to be particularly critical because Covid-19 itself can affect the spinal cord and brain, verifiably the brain stem with vital regulatory functions, but also in other areas. Even with mild corona infection courses brain damage is found. As a consequence, a corona infection can trigger the PPS and accelerate its progression. Yes, it can be extremely life-threatening.

Taking the PPS risks on type and dosage into account, the survival-critical intensive care requirements must be given therapeutic priority. Under these circumstances, if necessary, the artificial ventilation, which is not designed to be permanent, is carried out according to the applicable rules, especially since in such cases the corona infection offers almost no scope for other criteria. About 60% of PPS patients have breathing problems, often without even knowing it. Therefore they are extremely vulnerable to the most severe Covid-19 courses. Polio survivors who had to be ventilated by means of the so-called iron lung during their initial polio illness or those who are already dependent on home ventilation (NIV) due to PPS, should be considered here in particular. Far-reaching weaknesses of the respiratory pump and previous brain damage, especially to the respiratory regulation center, must be expected with such patients.

Pneumologists, intensive care physicians and other specialists who are involved in the treatment of a corona infection cannot be expected to have a basic knowledge of the PPS and its characteristics. Polio survivors are therefore recommended, as on a doctor's visit, to have a written summary of no more than one A4 page covering their personal PPS problems ready for presentation, in this case preferably as a copy included with the patient documents file.

Under the corona infection, artificial respiration can cause permanent damage to the lungs due to the necessarily relatively high overpressure and oxygen supplied. In addition, organ damage to the heart, kidney, stomach or liver and the nervous system can also occur as a result of ventilation. However, there is no alternative to these measures and not every ventilation leads to such consequences. However, the patient can refuse artificial respiration at their own responsibility and risk with a greatly reduced chance of survival, and if possible, just continue their NIV with the addition of oxygen.

If there is reasonable suspicion of a corona infection, priority should be given by calling the medical hotline, which is available around the clock every day, including weekends and public holidays. From there, medical advice is given on how to proceed, including the test procedure and decision on whether a hospital admission is necessary. PPS patients should indicate their status as a high-risk patient.

PPS patients are strongly advised to adhere to the generally recommended corona protective measures in a disciplined manner. This also includes extensive avoidance of external contacts and the acceptance or organization of offers of help for everyday errands. Face masks and especially hand hygiene is essential in any case. Operations that can be postponed without significant health disadvantages must be postponed during the current infection risk phase. Regardless of the medical corona crisis, existing respiratory problems with polio survivors should be clarified as soon as possible and taken care of. In this context, technical problems regarding breathing apparatus and mask-systems must also be solved.

Given the observation time, which has been far too short, the question of immunity after surviving a Covid-19 infection cannot be answered with certainty. This requires longer follow-up studies. A renewed illness within the same and following season can be more than likely excluded. The estimates for the possible immunity period are between one and three years. As soon as a vaccine becomes available, such vaccinations can be carried out in accordance with the rules for vaccination suitability and contraindications, whereby existing illnesses, particularly of an immunological type, will certainly be taken into account in the considerations.

Note: As the findings on Covid-19 are still very much under investigation, this information, as of May 2020, may be subject to correction and future update.

Translation: 4th June 2020 German -> English

By: Tom House (Thomas House-Arno)

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Some views on COVID-19 and Polio

There were thousands articles about COVID-19 in various media published during last months, and few of them were of some relevance also for us as polio survivors. Let us present here just few of them.

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Corona-Live-Blog: University medical professionals: COVID-19 may also lead to temporary paraplegia

A Live blog by *M. Schnippert and M. Fieber*

updated 19th May 2020, 15h58

The German Federal Minister of Research Anja Karliezek (CDU) and well-known university medical professionals have warned about underestimating the danger of a COVID-19 infection. On Tuesday representatives of several university hospitals have drawn some interim conclusions – two months after having created a network of German University Medicines to exchange methods of treatment and patient data in the Corona pandemic. At the end of March the university hospitals had agreed on a reciprocate exchange.

The COVID-19 infection is not a classic pneumonia such as occurs with influenza, said Michael Albrecht, Medical Chairman of the University Clinic Carl Gustav Carus in Dresden. The disease is quite special and „extremely complex“.

This has become evident in many cases of seriously infected patients in hospitals during the past weeks. In patients showing particularly severe disease progression, it was observed that the central

nervous system, the spine and the blood vessels were affected and even a temporary paraplegia or total failure of kidneys and liver were evident.

During the last weeks measures have been organised and planned so well that attention about the ghastly consequences and effects of this disease not only escaped the attention of the individuals but also of great parts of society, says Albrecht with a view to the criticism received about the anti corona measures.

The pandemic is not an imaginary phenomenon but a real and serious hazard, says Research Minister Aja Karliczek (CDU), “and is definitely not to be taken lightly and the more we find out about it the clearer this becomes“. She stressed the importance of continuing social distance and the measures of hygiene.

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"The British Prime Minister, Boris Johnson caught the Coronavirus, and nearly died. Upon his recovery he praised two Doctors in particular for saving his life, Dr Nicholas Price, and Professor Nicholas Hart. Boris was so thankful to these men that he gave his newborn son the name, Nicholas. They both work at St. Thomas Hospital in central London, where you will find the famous " Lane Fox Polio Clinic", and Professor Hart is a good friend of the British Polio Fellowship, and has supported us in many ways. The two Doctors then wrote an article for the "Daily Mail"(Britain’s best selling newspaper) titled "[This \(Coronavirus\) is our generation's Polio!](#)" pointing out great similarities between our experiences, and current happenings. They also warned that just as with Polio the new illness will require long term care management, and that all countries must plan ahead. On a personal note I am alarmed that many people are expecting an instant vaccine!! . Once the medical profession sprung into action to find the vaccine for Polio it took six years of trial and error before Dr Salks success.

David Mitchell, National Chairman
British Polio Fellowship
EPU Board Member

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One of the most relevant and significant articles for us was published on the Post-Polio Health International website – its title is “**PHI Statement on COVID-19. What do polio survivors need to know about coronavirus? PHI offers advice on staying safe amid the pandemic.**”, the full article you can find here: <https://post-polio.org/2020/05/16/1683/>

Introduction to Tom's article by Margret Embry



In our previous edition of the EPU Newsletter No. 2-2019 we reported on the 2019 EPU Lobbach AGM on which occasion we awarded Honorary Membership to three personalities whom we honoured for their outstanding work on polio and PPS. One of these personalities was Thomas House who was unable to be present at the award ceremony and who was presented with the award certificate at a local meeting of the German Bundesverband Poliomyelitis e. V.

In reply to the award Tom sent us the following article which is highly interesting and gives a short resume of his life as a polio survivor and his devotion and determination for the cause of polio and PPS and it may be of importance for some survivors who may find help, reassurance and the courage they need to carry on.

We owe Tom great appreciation, gratitude and admiration for his selfless work.

Thomas House-Arno – alias Tom House: How I got involved in work for the interests of polio survivors!

First of all I'd like to mention that I've been socially engaged most of my life. My first engagement was during my time as a boy soldier in Dover, Kent where I joined a formation dancing team in 1960 and took part in venues for *Save the Children Fund*. There was a major pause until I was fully integrated back into civilian life.

In 1975 I grounded an Anglo German Club in Villingen, South Germany and was chairman for a number of years. During that time we had venues with other clubs and carried out folk song nights where I took part with others playing my guitar and singing evergreens and ballads. I also gave English lessons for free. During my time as chair, six couples who met in the club married.

Later on I helped to ground a pipe band in 1986 that we named the Caverhill Guardians where I was piper and band master for a number of years. I played the pipes even though I had double blowing effort due to lung volume deficits. The pipe band is now well known in Germany, Switzerland and Scotland. Some pipers have been extremely successful in German and international competitions.

I enjoy singing and as I'm able to sing over more than one octave, bass or tenor suits fine. I have sung with a number of mixed or male choirs and a male a-cappella quartette, sometimes for charity purposes, until too much standing around on stage became difficult and painful.

I went into early retirement in 2004 at the age of 60. I'd started research for my first book in 1996 and had it ready for publishing in 2007. It's a modern spy and murder thriller with other underlying sub-plots involving the Vatican Secret Service, British and international intelligence organizations

and G8 governments called *Spies and Sacred Lies* by Tom House – ISBN 978-1-4389-7718-8, 532 pages, available from *authorHOUSE*, UK.

I'll have to go back to my polio recuperation days to explain how I came to write a book so late in life:

The only leisure open to me after the polio illness was reading books and when I was 9 years old my head teacher sent in three of the best essays for a school essay competition run by the County of Angus, Scotland – mine was one of the three. Well, what do you know, my essay was accepted and I won the competition. That was when I said to myself: "One day I'm going to write a book!" Nowadays, this school prize is on the list of the major UK literature prizes, including the Booker prize.

From 2006 onwards I sang in duo with a soprano, Gerlinde, the friend of my wife. We've sung many venues together, mostly for charity purposes.

Gerlinde and I, together with a mixed choir, made a CD especially for polio charity funding in Germany in 2010. I help out in the local church choir now and again but am not able to stand around for long and I guess I'm not one for fixed structures and rules – I had enough of that during my time in the forces.

As you may find out when you've read between the lines, I'm not the sort of person to hang around for long until someone else decides to do something about it when things are needy. I go ahead and do it. I trust that explains my frustration at the lack of and slowness of the general information flow regarding polio and the late effects that I found here in Germany in the late 1990's and my decision to do something about it. After all, most polio survivors caught the disease in the 1950's, or before and their numbers were rapidly decreasing.

I first realized that my main health problems during adult life reflected from the poliomyelitis infection that put me down as a cripple in 1950 at the age of 6, when my doctor Frank Spiegl, a naturopathic doctor who had travelled the world attending various medical meetings/congresses, first mentioned the possibility of polio late effects in 1978. Stuck to my job in the research and development of computer systems, I only gave in reluctantly for treatment when I really had to go into hospital over the following years for multiple operations.

During the years that followed I kept an eye out for information regarding polio survivor treatments, mostly in English, which were extremely sparse, until I finally decided to do something about the information deficit, especially regarding the lack of knowledge of GP's and medical specialists by gathering the information myself for future purposes should I ever need it.

I became aware of a local branch of a German polio self-help organization called the "*Bundesverband Poliomyelitis e. V. – BVP*" in 1997 from the local press and contacted them for information. It was a bit disappointing, as there seemed to be no real news that would have helped me further. However, I joined the organization in the hope that things would change. Other than a few meetings in a pub where small talk, mostly about the general problems involving other polio survivors and no real progress towards new information, I gave up going to the meetings.

In 2006 a new branch, which was nearer to my house, was being grounded, so I joined it and became a committee member. The members of the new group were eager to understand how the infection came about, how it affected the body and general information concerning our nervous system. This was the beginning of my real information gathering (mostly English), collating and translating it first of all into German and then modifying the medical language used into common language

understandable to laymen/laywomen. I produced many man-sized charts and MS-PowerPoint Presentations, films, animations, etc., and carried-out our own venues for polio survivors and their relatives/families or others who were interested. We also began inviting medical experts to hold venues. Prof. Kai Paschen MD was one of them, so that we were able to show and reassure our members that the information we were presenting to them was correct and state-of-the-art.

Why wasn't this already general practice or more information flowing from the top one would ask in a self-help organization with over 3000 members?

Well, the impression that I gained was that the main board committee and especially the chair of the BVP had their hands tied with the running of the organization. However they also had the typical German attitude that I've often experienced in R&D with German computer companies regarding new operating systems. Outside (foreign) information seemed not to be generally accepted (world-wide) on poliomyelitis unless it had been verified by German doctors or their own board doctors, whereby they then prepared their own interpretation (*or, as I used to call it with a particular computer company that I worked for: the re-invention of the cartwheel, whereby new computer operating systems were bought and re-made. By the time they then hit the market, they were out-of-date*).

The general BVP practice was inexplicitly conveyed to me by the BVP. I was given the impression that only information from them would be deemed correct. They seemed to have ignored the fact that a lot of the other regional groups had started doing exactly what we were doing. Fortunately, the chair of our local organization was not of the same opinion. The problem with the main BVP board committee members was/is that apart from one member, no-one was/is capable of, or wants to understand English or seems to be really interested in other foreign polio self-help organizations and their information. I trust this explains why I decided to go it alone.

One of my hobbies is oil painting. In 2007 I was asked if I'd like to join a small number of polio survivors organized by Anita Diener, the chair of the BVP main board group in the German state of Thuringen, to help instigate a wander exhibition of paintings done by polio survivors. I gladly offered my assistance and created an oil painting trilogy, which, with paintings from 10 other polio survivors from various parts of Germany has since accompanied many exhibitions throughout Germany and bordering countries over the last 13 years. The subject of my paintings is my own polio infection as a six-year-old and the long-term consequences displayed individually in stages on each painting of the trilogy. I wrote three short stories for each of these paintings. The response to the presentation of the paintings and recited stories at a regional vernissage in Rottweil on the 9th September, 2007 was enormous and encouraging. Siegfried Spliesgart (†), chair of the regional BVP main board Baden-Württemberg, inspired me to publish my story in book form, which I did. "*Jimmy McCall*" (in German) by Tom House, a *memoir*, was published in 2008 through the Litera Verlag Rottweil, 208 pages, ISBN 978-3-00-024418-6. I am currently processing the publication of "*Jimmy McCall*" through Amazon, which should be available by the end of February, as the Litera Verlag no longer exists. I wrote the same *memoir*, which includes the stages of my illness in English (much longer with more info) and is called "*Green Fields on a Dusty Road*" by Tom House, available through Amazon, 440 pages, ISBN-13: 978-1505899634.

Over the last couple of years I've been contacted by a number of people who recognized themselves in the references, or I'd mentioned under their real names in my book *Green Fields...* We are now in steady contact and Bobby Post, my best friend from my days as a boy soldier, who now lives in Texas, USA, came over the pond to visit me last August for a few days. It was a great reunion – Bob is

a wonderful person, always cheerful and full of fun. The last time I'd seen him was 56 years ago. I've never seen my wife Erika, laugh so much. Jeananne Marner, a distant cousin also mentioned in *Green Fields...*, wrote to me four weeks after it was published, quote: *"I am the girl that was lying with you on the sofa on page 312."*

I hadn't seen or had contact with her since 1956. She is now a retired teacher living in N. Ireland. She and her husband Tom now run a sheep farm. I published one of the plays for her that she'd written for her school children, called *"The Children of Lir"*, which they staged at the yearly *"Feis"* in Newry, also available through Amazon under ISBN-13: 978-1541028036. I am in the process of making a compendium of all her plays, which I hope to publish for her in due course, God sparing.

Late 2007 I was approached by Professor Kai Paschen MD, who requested some translations – German to English, which I speedily carried out for him. That was the start of a great friendship.

Kai experienced similar problems regarding the distribution of polio-info for the treatment of polio survivors gained from outside sources, even though he was a member of the main BVP committee medical group, whereby only infrequent meetings were held. The controversial medical opinions regarding PPS, overall polio-info and treatment, were the general tenor of the meetings. The impression I gained from Kai was that some of the doctors in the BVP committee were also representing various rehabilitation clinics and thus had their own specific interpretations of how to treat polio survivors. Kai was extremely annoyed about some of his fellow physicians, as some of the treatments in his mind were possibly harmful for polio survivors – he dropped out of that medical commission.

In closer contact over the years Kai invited me to join him in grounding an internet website: www.polio-echo.eu, which was to contain all the information available on poliomyelitis and its late effects, PPS. Our main reason being: the progress and distribution of the information gained by existing self-help organizations were so tied down by regulations contained in their statutes that we thought we'd probably never have seen them in our lifetime – Kai's health at the time was also a key problem. The other problem – the information available was mainly in medical jargon not generally understandable to most laymen/laywomen.

Our organization Polio-Echo consisted of 12 members, mostly academic friends of Kai from Kaiserslautern. Unfortunately the cast didn't lie under a good star and didn't last long. Kai was continuously ill, Karen, Kai's wife who acted as secretary, had her hands tied looking after him and Hans Clemm the treasurer became seriously ill. Fortunately Bärbel Fisher from EIKA took over from Hans and did a great job – my wife Erika took over from Karen. Lothar Epe from EIKA helped out with the text proofing of the German booklet *Polio & PPS Besser Verstehen* and generally with some of the website texts. Kai's and Hans's conditions were additionally plagued with a blood cancerous illness, which sadly led to their passing away within a few months of each other in 2015. Lothar Epe had previously opted out. My health suffered considerably under the additional strain of reorganizing and finishing the website www.polio-echo.eu in two languages. I was able to complete it before Kai passed away. I managed to persuade Dr. Gisela Ilgenfritz from the BVP to take over as vice chair and I became chair. However, there was no hope of help from Kai's friends – we were on our own. This was a devastating situation for me, as my own health continued to decline.

Let's go back to the website part for a short explanation:

Fortunately, I was able to obtain help from the son of a friend, Thomas Schmidt, who was experienced in the website programming language HTML, as it was unknown territory for me. Kai

and I subsidized him initially with substantial monetary funds from our private resources. Through time I managed to adapt to the new computer language and was able to do the necessary changes that kept on cropping-up.

During site processing, Kai's condition gradually worsened, so much that the next project was brought forward: to publish a booklet with a shortened version of our website information in English and German. I decided to produce the German version first and Kai managed to check it once it was finished and add a chapter "PPS Research". Lothar Epe did the German text proofing. I did all the writing and illustrations myself. I published the booklet in December 2014 through Amazon: "Polio & PPS Besser Verstehen", ISBN-13: 978-1508404156, 96 pages. I carried on with the site and the English booklet, which I published in July 2015 through Amazon: "A Better Understanding of Poliomyelitis and PPS", ISBN-13: 978-1515249665, 96 pages, and sent Kai a copy. I was extremely thankful to John McFarlane who helped out by doing the English proofing and adding a few words concerning the quality of the contents. I spoke to Kai on the phone a week before he passed away in 2015.

The following is a reference to the contents of "A Better Understanding of Poliomyelitis and PPS" displayed on the Amazon bookshelf written by John McFarlane:

"This publication demonstrates and illustrates best practice that allows poliomyelitis survivors to live with dignity and independence. It shows impressively how poliomyelitis and the long-term late effects have evolved over the past number of decades and how personal counselling, the development of self-help groups and a targeted reduction of information deficits in the population continues. The majority of information regarding poliomyelitis and the Post-polio-myelitis Syndrome available on the world market is quite often expensive and sometimes difficult for the uninitiated to fully understand. The main reason for this is that it is mostly initiated and written by members of the medical profession and their usage of general professional medical scientific terminology in their explanations. The main goal of the authors was to present this documentation using plain common language where possible, especially with the aim of making it understandable for an uninitiated poliomyelitis clientele within the wide range of existing information deficits, and further, to make this booklet obtainable at a reasonable price, therefore making it available for a wider public.

In June 2016 I had a stroke. It took me several months to recover somewhat. I am still enduring occasional memory blockages and dizziness. By the end of 2016 there was no more hope of help forthcoming, so that we decided to unregister our organization *Polio-Echo e. V.* This was fulfilled. The homepage part of our website is therefore no longer available. The main information parts however will be available for perusal in English and German for a few more years to come.

I've been subjected to the fraught of many who seem to be horrified that we managed to produce such a vast amount of information in such a short period of time, only to let it be and not carry on.

However, I've sent the complete data-bases, MS-PowerPoint presentations, English and German source texts, audio-files, animations, films, etc., in other words: the complete Polio-Echo English and German web platform to the EPU and the BVP, free of charge, to be implemented or published as they see fit for their own information purposes, so at least some of it will hopefully find its way to those who may be thankful for the information.

Due to insufficient help over so many years, my health has suffered too much and my own writing has been put aside. I have not been able to pursue the marketing of my books and the sales have

therefore sunk to an extremely low level, causing difficulties keeping them on the market with the publishers and problems with the tax office.

Besides, I am getting older (in my mind I still feel relatively young), have had Polio as an infant, regained control of my body at the age of 13 – joined the army as a boy soldier (Junior Leaders Regiment Royal Engineers, Dover) at the age of 15 – spent a number of years in the British Army Intelligence Corps on counter-espionage and counter-intelligence work in central Europe during the cold war – gone through extensive physical commando training and even took part in high performance sports. I left to study computer science and worked for various English and German computer companies.

During those years I underwent many surgical operations for bone cancer, with chemo therapy and ray treatment, had a heart attack and three heart operations, after which I was diagnosed with PPS and put in a wheelchair (my legs were all putty and I couldn't walk at the time). Fortunately I decided that it was not my thing and since using a Moto-Med daily (passive leg and arm training) I am able to walk about a little and go very short distances. Fortunately my sick insurance company the *Siemens Betriebs Krankenkasse* supplied me with the Moto-Med, a manual wheelchair and an e-wheelchair. I am so grateful for being a member of such a terrific sick insurance company as they have supported me all the way.

The last couple of years I have been recuperating from the stroke that cost me large chunks of memory, initial speech and swallowing problems, which slowed me down considerably. I guess the stroke is my main answer for finally giving-up further support to polio self-help orgs and my wife Erika is in agreement that I have done enough!

I would like to make a last humble request to the medical profession:

It is extremely important for doctors (world-wide) to come to an agreement on treatment matters for polio patients and polio survivors. This is a necessitation for the benefit of the patient. There are so many different opinions making the rounds and too many doctors who proclaim to be moguls of knowledge on Polio-Encephalo-Myelitis and the late effects: the Post-Polio-Syndrome.

My special thanks to Margret Embry, John McFarlane, Erika Gehrig, Lothar Epe, Bärbel Fisher, Gisela Ilgenfritz, Thomas Schmidt and all the others who have helped or delved in the unrelenting pursuit for the benefit of polio survivors, also many thanks to Daniel Pelzer for being so patient with me during the transition of the booklet from English to French.

I remember words of strength that my mother passed on to me when I returned home from hospital as a cripple shortly before my seventh birthday. Some of the children I used to play with were now taunting and either throwing stones, hitting me or calling names. Her words for me to think about: *“Sticks and stones may break my bones but names can never harm me”*, it was that bad!

Only one friend still cared. – Roy Woodford, a Jewish boy who moved house later with his family after the kids tormented them so much due to the catholic priest at our school (a right bastard) who kept taunting about the Jews being responsible for crucifying Jesus.

I don't care what others say or think about me, it's what I think that matters! I feel chuffed about what I have achieved in life and hopefully will enjoy many more years in this beautiful part of Germany, the Black Forest with my dearest wife Erika.

One of my wishes was to meet you – so many of whom I have read your articles, been in email-, or phone contact, over the years, or those of you who are working for the benefit of other polio survivors. If any of you are in the vicinity of my home please don't hesitate to pop in, it's never too late.

My contact details:

Thomas House-Arno & Erika Arno, Weberweg 4, D-78q126 Königsfeld-Buchenberg. Tel.: +49(0)7725-917604, www.thomas.house@gmx.de

I wish you all good luck and God's blessing. Keep well and bear in mind – polio survivors are stubborn, have gained a survival nature over the years and are extremely hard in persuading to slow down and not to overdo things. Keep some energy in reserve, because if you don't you'll end up in bed forever one day! I have learned to accept my body and condition and my motto is: *Your life is what you make of it yourself no matter what illness or ailments you have or are experiencing. Don't bother what other people think or say, it's you that matters.*

Yours Aye
Tom House
(Thomas House-Arno)



SIPS Information regarding "End Polio Now"

For the last few years we have always bought polio tulip bulbs "End Polio Now" and sold them to friends, neighbours, communities, etc. When Edy and I took part in Geneva at WHO to celebrate the eradication of polio Virus WPV3 on the World Polio Day on October 24th, the 1000 bulbs were planted at Morges.

Rotary International arranged to have this wonderful tulip "End Polio Now" cultivated a few years ago. It is a wonderful tulip which changes the colour during the time of blooming.

As this year the Flower show would have celebrated the 50th birthday, we wanted a big flower bed with polio tulips. 500 bulbs were paid by Rotary International and the other 500 bulbs were paid by our former SIPS member Edy Bucher. We arranged to visit the flower show on April 14th 2020 in Morges on the lake of Geneva together with board members of SIPS.

The community of Morges organized a big event with a special tent, Restaurant and other events.

A Flyer was put in front of the tent with information about polio. Visitors were informed that they could order beautiful cards with the polio tulips. The polio tulips were painted by a Dutch artist Miek Verdegaal. Last year some of our members went to visit a gallery of the community Morges where Miek Verdegaal exhibited wonderful pictures. The daughter of Miek Verdegaal who lives in Geneva has close contacts to Oliver Rosenbauer. They decided to give this picture for auction to all the Rotarians of the region. It was also decided to print cards and sell them to Rotarians, SIPS etc. I bought 65 cards to take to Vitoria. They sell so well and also make wonderful presents. In case Vitoria should take place in the near future I will definitely bring some cards for our EPU board members.

On the back of the card "End Polio Now Tulip" (2019). By Dutch artist Miek Verdegaal. Commissioned by Rotary Switzerland/Lichtenstein.

Through the purchase of this card, 12 children will be vaccinated against polio.

The sad news reached us that the flower show could not be opened officially, the tent was closed etc. because of the Corona Pandemic. Single visitors could watch the flowers from outside during the most beautiful time. Edy Bucher went almost daily to take photos from outside the fence and sent us reports and photos, towards the end even videos. Beginning of May the park was partially opened. He already started saving for next year. He could buy many bulbs a few days ago when the officials of Morges took them out of the earth. He has placed them on to special pallets in his cellar to dry them. He will give them away in fall. The community will celebrate next year 50 + flower show.

At the present time he is asking us to order new tulip bulbs. Apparently the Dutch and Swiss government have allowed these bulbs to export to Switzerland. We are collecting the orders from our members. As the news are rather sad by GPEI - Global Eradication of Polio International that children may not be vaccinated against polio due to the Corona epidemics. Therefore, our fight for eradication of polio goes on.

We had other hard times, i.e. the Polio concert in Lucerne on March 15th was cancelled one week before. Rotarians and many other sponsors, i.e. SIPS could not take part as all the concerts were

cancelled due to the Corona pandemic. We were looking forward to the speech of Daniel Maloney, President, Rotary International.

In May another cancellation of a meeting with Prof. Schefer at the University of Basle, i. e. **Behindertengleichstellungsrecht May 15th 2020**. Prof. Schefer has been elected to the UN Board as advocate for disabled. We have attended this occasion at the University in Basle in the past years with many interesting speakers from all over Europe – always concerning laws and fights for disabled people.

Erika Gehrig
EPU Board Member



And here is the CardFlyer – inspire yourself ☺:



Send a greeting card to a friend and save children from lifelong polio paralysis

Rotary International, partner in the global polio eradication effort, have cultivated a unique tulip, the 'End Polio Now' tulip. It has been exhibited at various international tulip festivals, including at the yearly world-renowned 'Morges Tulip Festival', in Morges, Switzerland (on Lake Geneva). The tulip is known for its beauty and that it changes colour as it blooms... but what makes this tulip all the more beautiful is that its purchase saves children from lifelong polio paralysis!

A wonderful painting by renowned Dutch artist Miek Verdegaal

This Dutch artist has immortalised these beautiful tulips in a marvelous painting, which is now also featured on a commemorative greeting card. These cards make for wonderful greetings for family, friends, colleagues, to mark birthdays, holidays, 'get-well' greetings or for all other occasions worth marking.

Each card (with envelope) is sold for CHF3, and through the purchase of a single card, 12 children will be vaccinated against polio.

To order, please contact:

Oliver Rosenbauer, rosenbauero@who.int, tel +41 (0)79 500 6536
(For free delivery within Switzerland, a minimum order of 10 cards is required)

For additional donations:

Account name and Address: Verein Rotary Distriktskasse 1980, c/o Confiducia AG, Postfach 212,
4127 Birsfelden, Switzerland

Reference: 'End Polio Now' card

IBAN: CH68 8077 4000 0018 7151 6

Bank name and address: Raiffeisenbank Birsig, 4104 Oberwil, Switzerland



Presenting EPU Members – national polio organizations and support groups

It is our pleasure as editors of the EPU Newsletter to start with introducing EPU member organisations. We'll try to present short profiles of all national polio organisations and support groups throughout Europe, and we hope that through this it will be easier for our readers to be acquainted with these organisations and even get to direct contact with them. Information provided may also be an inspiration for other polio support groups to broaden their own activities in case they wish so.

Profiles of presented polio organisations and support groups are not strictly structured, we however hope the information might be quite valuable. In most cases for more detailed information it is possible to visit the polio organisation's website, the address of which you can find at the end.

Polio organisations will be presented randomly, not in alphabetical order or according to some other criterion. The first two polio organisations to be presented here are the British Polio Fellowship and Postpolio Belgium VZW.

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The British Polio Fellowship was started in 1939 by Patricia Carey, and Frederic Moreno, and last year we proudly celebrated our 80th anniversary.

Major polio outbreaks hit the British Isles from the 1920 s onwards, with particular virulence in the 40s, and 50s (hence the average age of our members is now 76 years). It is estimated that there are still between 110,000 and 120,000 polio survivors in the Country now. Most of our current members were disease victims, but unfortunately we do have some vaccine damaged younger members. We are very proud of 20 year old Peter, and 21 year old Hamish. Despite huge problems both these young men have gone on to great achievement, leading full and worthwhile lives with huge support from their families.

The Fellowship has in common with many small Charities in G.B. gone through troubled times with much reduced funding, and we have had to downsize and relocate. We are kept going by our magnificent members and their families and friends. We have 50 branches and groups and are split into 9 regions. These wonderful bodies meet frequently, and offer support and friendship to their fellow Polios. At National level we offer a Holiday grant, a Heating payment, support for the purchase of Mobility Aids, and a member advice line for Benefit and medical problems (and a million other questions!!!). We employ 6 fantastic Staff, and use interns for specific projects. We have a Board of 8 Trustees/Directors and have an Expert Panel to advise on medical matters, mainly PPS. One of our long standing annual member events is the National Indoor Games where the Regions join in "Friendly" competition.

Can I assure readers that whatever happens with Brexit that the B.P.F. intends to remain an active member of the EPU, fully committed to its aims and objectives, particularly with support for PPS victims, and to monitor the recent growing cases worldwide of Polio. We have two mottos in the BPF, "Polio may be dead, but we are not" , and "Broken body does not mean broken brain".

Thank you,

David Mitchell, National Chairman

B.P.F. website: <https://www.britishpolio.org.uk/>

POSTPOLIO BELGIUM VZW

Postpolio Belgium VZW was founded in 1996 by Johan Bijttebier, also the founder of EPU. In Belgium, the number of people who have previously had polio is estimated at 8,000 to 15,000. A number of them suffer from 30 to 40 years after their initial infection with post-polio syndrome (PPS). The association aims to provide these people with the necessary support. On the other hand, we want to raise awareness of this disease. We notice that the effects of polio are still not known or recognized by too many doctors.

What are we doing?

We are a self-help group, which is mainly focused on helping fellow sufferers through our own experience. Postpolio Belgium organizes support groups in every province where members can tell their story and mutual tips are exchanged. It is also a tradition to organize a festive annual and happy gathering with food, drinks and a speaker on a certain topic.

Belgium has a solid social security. Members often get lost in the offer and information to the right counter is not easy. The priorities of our organization are information and referral. Neuromuscular centers for muscle diseases are housed in 6 university hospitals.

Three times a year we send a newsletter to all our members. This is especially important for those who are unable to attend the activities.

In Belgium there is a compulsory vaccination, but more and more people are voting to question vaccination. We must ensure that we do not forget the terrible consequences that polio can have.

Johan Bijttebier

Postpolio België V.Z.W, Chairman

Website: <http://www.postpolio.be/home>



REPORT: EU COUNTRIES FAIL TO REDUCE POVERTY OF PERSONS WITH DISABILITIES

20 April 2020

“We launched the fourth edition of our Human Rights Report which looks at poverty and social exclusion of persons with disabilities in the EU.

We found that 28.7% of persons with disabilities living in the EU are at risk of poverty. This number will likely grow in the aftermath of the pandemic. It highlights how EU countries have largely failed at reducing poverty faced by persons with disabilities, especially in the wake of the financial crisis.

The situation has worsened since 2010 in Estonia, Luxembourg, Germany, Sweden, Ireland, Czechia, Lithuania, Italy, Netherlands, Malta and Spain.

In all EU countries, persons with disabilities are more likely to be poor and unemployed than persons without disabilities. They also face extra costs from living in a society that is not adapted to them: disability-related costs estimated at 23,012 euros/year in Sweden or 14,550 euros/year in Belgium.

We urge EU and national decision-makers to follow our recommendations, presented in full at the end of the report.

- Fully implement the EU Pillar of Social Rights by establishing an action plan that includes proposals for the inclusion of persons with disabilities.
- Follow-up the European Disability Strategy 2010-2020 for the coming decade including measures to address poverty and social exclusion of persons with disabilities and their families.
- Adopt legislation that will protect persons with disabilities against discrimination in all areas of their lives beyond employment.
- Foster job creation by establishing a Disability Rights Guarantee ensuring an offer of employment, apprenticeships, training or life-long-learning. This can be further supported by person-centred and flexible support to persons with disabilities seeking work, helping them not lose disability allocations when taking up work, as well as setting standards for reasonable accommodation in the workplace and necessary support or assistance.
- Favour the use of disability assessment methods that follow a CRPD-compliant and holistic approach, looking at a person-centred approach and using a combination of impairment and functional considerations.
- Invest in the accessibility of all support structures and services provided to the general public to enable persons with disabilities to make use of them, reducing the need to resort to costly, specialised services, thus minimising extra disability-related costs to individuals.

Read all recommendations and deeper analysis in the [full report \(PDF\)](#) or in the [Easy to read Report “European Human Rights Report - issue 4” \(Word\)](#).”

Source: <http://www.edf-feph.org/newsroom/news/report-eu-countries-fail-reduce-poverty-persons-disabilities>

HISTORY OF POLIO IN FRANCE

At a conference of the 'Fondation Garches' in Paris in November 2018 **Prof Dr Alain YELNIK** made a very interesting presentation about the history of Polio in France. Our member Polio.France-Glip summarised this speech in their Newsletter and Polio France's President Robert Cordier and Glip board member Syvlie Tarabit were so kind to translate this speech from French into English.

Historical overview of Poliomyelitis in France

Prof Dr Alain YELNIK

As an introduction to these 2 days entirely dedicated to Polio, Professor Alain Yelnik proposed a non-exhaustive, though as well documented as possible presentation of this disease.

Etymological recall

The word poliomyelitis derives from Greek: Polios grey – meolos marrow.

The poliovirus strikes the grey substance of the spinal cord. Polio was also named Infant paralysis, and more precisely infant spinal paralysis to stress the difference between peripheral paralysis, of which polio is the prototype, and all other neonatal disorders that are of central origin.

Main landmarks in Polio history

The very first scientific studies dealing with polio are rather recent since they date back to 1789 when British Doctor Michael Underwood wrote his treaty on "A debility of the lower extremities". Doctor Underwood is said to have studied the case of paralysis of writer Walter Scott.

Though, Egyptian bas-reliefs as "Ruma gatekeeper" (Ishtar goddess's temple employee) or Peter Bruegel's paintings in 1559 representing people with amyotrophies of the lower limbs clearly suggest a polio-related disease.

However, the medical science will have to wait until the mid-nineteenth century, and the creation and development of infectious diseases specialties to have a more accurate knowledge of the disease.

- 1840: Md Jakob Von Heine (German orthopaedic physician) makes out the specific characteristics of Infant paralysis from other paralytic nervous disorders. These are the first systematic studies on polio and convey the idea that polio is a catching disease.

-1865: In France, Prévost, Vulpian and Cornil describe specific damages in the anterior horn of the spinal cord.

- 1887: During an epidemic in Stockholm, Karl Oskar (Swedish pediatrician) draws attention to the infectious nature; localization of the infection is under discussion which, he believes, can extend to the whole cerebrospinal axis (later it will be discovered that the presence of the virus in the whole nervous system does not mean its pathogenicity).

Spinal Infant Paralysis (polio) will then be called Heine and Medin disease until 1960-70. It was considered as the most frequent form even if some spasmodic forms of Heine-Medin disease had

been described (misinterpretation with ALS in particular), as well as some bulbo-protuberant damages (probably bulbar polio).

However, Heine-Medin disease was considered as essentially spinal.

Le Pr YELNIK s'est interrogé : «Pourquoi la polio n'a-t-elle pas été décrite plutôt alors qu'elle sévissait depuis de longues décennies?».

Professor Yelnik wondered why polio had not been described earlier as it had been rampant during so many decades.

And he found 3 possible explanations:

- Children's death rate was then generally very high and most of those with polio died, as did those suffering from other serious illnesses.
- At that time, people didn't pay much attention to children.
- And above all, polio was mistaken for other paralysis syndromes. The first classification of the various types of paralysis only appears during the 19th century.

Discovering the virus and the vaccine

1908: Karl Landsteiner and Ervin Popper proved polio could be transmitted by injecting an emulsion of the spinal cord taken from a dead child to two monkeys.

1910: LEVADITI and LANDSTEINER demonstrate that polio virus causes lysis (destruction of the cell membrane by osmotic shock) of the spinal cord motor cells.

1931: Sir MacFARLANE BURNET and Dame Annie Jean MacNamara identify 3 types of virus 1,2,3.

1948: Thomas WELKER and Frederick ROBBINS grow polio virus in living cells and win the Nobel Prize as a Doctor in 1954.

1955: Jonas SALK develops the first inactivated polio injection vaccine.

1957: shortly followed at the Pasteur Institute in Paris by Jean LEPINE who is also developing an inactivated vaccine.

In 1958, the « Salk-Lépine » vaccine is developed.

1957-1961: Albert SABIN develops the first live (attenuated) oral vaccine, which by its ease of production but also of administration, will be, from 1962, the major vector of vaccination in the world. It is still the most used.

The big epidemics

The very first testimonies of great epidemics are not written before the 19th century, in the USA and in Europe as well. The first epidemic in France is reported in 1885 in Ste Foy l'Argentière and may be at the origin of the establishment of a center in this city.

In 1916 the severe epidemic that strikes the US acts as a worldwide bombshell and it arouses awareness of the dangers of this disease and leads to a strong mobilization of public authorities

Wave confirmed in 1921 by Franklin Delano ROOSEVELT who created the « National Foundation for Infantile Paralysis » after having been infected himself with poliovirus.

Very huge epidemics occurred in Europe, US and Latin America, during the fifties.

See the book by Philippe ROTH «Nemesis» on the 1944 epidemic in Newark.

In France, the last very important epidemics happened during 1957 and 1959 and vaccination became compulsory in 1964 (Sweden got it 'till 1957, we were not pioneers!...).

Care institutions

Healthcare is mainly structured from the fifties although it should be noted that the first center for the treatment of polios opened in 1919 in St FARGEAU in *Seine et Marne* French department (more or less pilot structure). Ellen POIDATZ, herself polio survivor, offers there some education and mechanotherapy to polios kids.

RENNES 1948: An infectious disease clinic for polio patients, global treatment called « From bed to workshop » with Prof. Denis LEROY and in 1953 a real medical center for poliomyelitics.

In 1949, Ministry requires mandatory reporting of poliovirus contamination and recommends its diagnosis on lumbar puncture. That will enlighten polio non-paralytics forms (only 1/200 presents clinical manifestations).

GARCHES 1949, Raymond POINCARÉ Hospital : opening of the National Center of poliomyelitis sequelae treatment with Prof. André GROSSIORD ; taken over by Jean Pierre HELD in 1979, then time of traumatic paralysis epidemic that fills Garches' services.

Limoges and Nancy (1952) will also open facilities dedicated to the treatment of polio patients.

The teaching of Polio

Polio has been the perfect model for learning and developing Physical and Rehabilitation Medicine as well as orthopedic surgery because of the consequences of paralysis on growth, on different motor functions, on activity and participation in society but also by its consequences in aging.

Poliomyelitis was taught and was part of the internship programs until 1984 (one hour question exam); from then on, polio has totally disappeared from official medicine teaching programs.

Prof. YELNIK quotes the book of Annie DANIEL, Md, «Fléau Moderne: La Poliomyélite» (1950) [Poliomyelitis: Modern Plague] and commented on her excellent book.

Recent developments of Polio in the world and Polio today – The Post-Polio Syndrome (PPS).

In 1988, the WHO launched the global poliomyelitis eradication program. A program that has paid off and has allowed WHO to certify whole polio-free areas over the years: 1994 both Americas, 2000 western Pacific, 2002 Europe, 2014 South East Asia.

We went from 380 000 wild poliovirus cases in 1988 to 25 cases in 2018 (November the 4th).

Now, “polio survivors” are the main issue with an estimate of 50,000 in France. This problem arose around 1979 and the following years.

In the USA, Gini LAURIA, publisher of the medical gazette « Rehabilitation », received more and more testimonies that echo the one received in 1979 from Laury SCHNEIDER. Infected by polio, she observed and described 30 years after its attack symptoms that could evoke, in a less severe way, those of an acute impairment: « **recent outbreak of pain, abnormal fatigue and a feeling of progressive weakness** ».

Her publications alert, question and lead to the venue of a **first international conference on late effects of poliomyelitis**, Chicago 1981.

Then at Warm Springs, Georgia (USA) in 1984 the **first international conference took place on the Post-Polio Syndrome (PPS)**.

1985, HALSTEAD criteria publication.

Of course, it is appropriate to distinguish the PPS from all the late effects of poliomyelitis on the osteo-articular apparatus, muscles and cardiac system...

Patients' organizations also tell this story:

- USA, 1938, creation of the « National Foundation for Infantile Paralysis » which becomes the « March of Dimes ».
- 1933, creation of the **Association des Paralysés de France (APF)** [French Paralytics Association] by André TRANNOY, polio himself.
- 1953, creation of the **Fédération Nationale des malades infirmes et paralysés** [National Federation of disabled and Paralyzed Sick].
- 2001, creation of the Ile de France network (réseau IdF) with Prof. Olivier DIZIEN and Philippe DENORMANDIE Md, surgeon, still an active network.
- 2002 the **Groupe de liaison et d'information Post-Polio GLIP** [Post-Polio Liaison and Information Group] constitutes itself on French territory. (since 2018 : **Polio-France-Glip**).
- Europe 2006, the « **European Polio Union** » (**EPU**) unites national organizations, such as the GLIP for France.

The history of treatments

The history of treatments could be the subject of a separate communication of its own.

Prof. YELNIK recalls the main points: namely that **the ineffectiveness of antibiotics** is quickly established and, at the same time, that **the effectiveness of integrated treatment centers** is equally clear.

They are able to treat at the same time respiratory problems with «iron **lungs**» which provide artificial breathing but also to implement **rehabilitation treatments** for orthopaedic complications.

Then the **functional rehabilitation will include balneotherapy**. Finally, in many institutions that will host young polios, **schooling will be integrated** into medical care.

Polio was also a model for **essential advances in orthopaedic surgery** that may have subsequently been applied to other pathologies.

1944, Prof. Marcel BOPPE publishes « Le Traitement Orthopédique de la Paralyse Infantile » [Orthopaedic Treatment of Infantile Paralysis] real introduction to neuro-orthopaedics.

During the sixties, **Pol LE CŒUR, Md, surgeon, is THE great polios surgeon** and for spinal surgery **Jean DUBOUSSET and Michel GUILLAUMAT**.

We also have to name **Marie Ann KEEMAN** in USA.

The challenges of this orthopaedic neurosurgery:

- Avoid long standstills.
- Allow the most stable sitting position possible.
- Improve respiratory function, regain walking.

Objectives included: rebalancing muscle forces around a joint, stabilizing an unstable joint or spine, correcting orthopaedic deformities, promoting growth.

The major techniques: arthrodesis, musculo-tendinous transfers and osteotomies.

Prof. YELNIK then recalls the essential role of **Prof. Olivier DIZIEN** during several decades in medical treatment of polio patients, the contributions of **Ginette DUVAL-BEAUPERE, Md**, in analysis and treatment of paralytic scoliosis with polio, but not only...

Prof. YELNIK also recalls that after being discouraged or even prohibited, **physical activity** is now promoted **in the treatment of this pathology**.

Polio tomorrow? Challenges of ageing

- Don't forget « Polios Survivors »
- Don't forget the surgical and rehabilitation techniques that are useful, not only for polios
- Improve equipment
- Is it conceivable to prevent PPS?

Writing assume by Arlette BOURON

Polio - France – Glip Association's Secretary

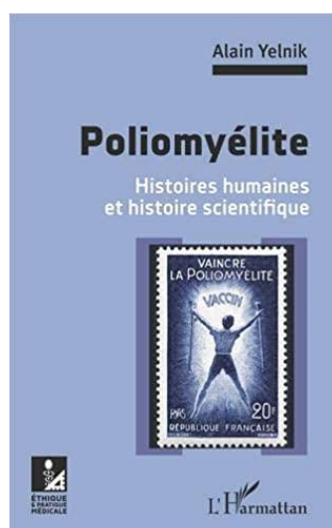
Proofreading Prof. Alain YELNIK

October 2019

Translation: Sylvie Tararbit, Robert Cordier (Polio-France), March 2020

www.polio-france.org

Book by Prof. Alain Yelnik



«**Poliomyélite, Histoires humaines et histoire scientifique**»

Pr Alain Yelnik; L'Harmattan editions, Coll. «*Éthique et pratique médicale*». March 2020.

Poliomyelitis, Human stories and scientific history. Only available in French at the moment.

Summary:

“POLIO”. It is nearly forgotten. And yet, what fear it raised during the years 1950-1960! Parents dreaded that terrible disease which conveyed an image of suffering, paralysis and death. Finally the vaccine came. But the children – it was them mostly affected by this disease – “the polios” as they were called, grew up and became old, with their bundle of pain and disability with which they had to live. There are still about 50.000 polio survivors in France and 2 Million all over the world.

This book describes the battle of the polio survivors – the medical professionals, nursing personnel, physiotherapists, surgeons and orthopaedists – and those children who became adults, and their testimonials of their lives and their willpower speak for themselves. The book traces back the history of this unusual disease, the great epidemics at the end of the nineteenth and twentieth centuries, the research in trying to understand the cause to the point of finding a vaccine. Finally the battle that the WHO is fighting to eradicate it from the world.

The book is written with understanding and great compassion for those who survived the disease and who are still battling with the late effects of it.

Professor Alain Yelnik specialises in physical and rehabilitation medicine and is in charge of MPR (Medecine Physique et Readaptation) at the Lariboisière Hospital in Paris. His speciality centers around the consequences of neurological diseases of vascular, traumatic or infectious origin in adults.



Professor Alain Yelnik, MD, PhD

Hospital Group Saint-Louis Lariboisiere and Fernand-Widal, Paris, France

Not Without a Trace

Dedicated to all polio survivors!

*You were young?
An infant
perhaps,
or even an adult;
weak
and torn from life
with a limbless feeling.
Stretched out,
almost motionless
and helpless,
you were lying
in a hospital bed
without even a pillow,
isolated
from the outside world.
A period
of lonely days, weeks,
and frightening nights;
left with your own day-dreams
and nightmares;
an unconscious presence
with no vision of the
future outcome.
Despite the ups and downs
of rehabilitation efforts,
a different world
awaited you
on the day you left.
In this other world,
even after recovery,
an everlasting trace remained,
a stain,
with which you were forced
to live with and accept.
This stain;
a remnant influential trace;
became a life's companion.
Inwardly and
invisible to the outside;
you had become
an idiosyncratic person
quite often miss-understood.*

*Constantly left
to self-decision making,
with countless setbacks;
you had to make
it on your own.*

*Normality
required more strength
that you just didn't have any more.
Nobody else saw it that way,
other than yourself.*

*Sometimes,
on the verge of hopelessness,
thoughts of an end
to your misery
may have come to mind.
You have lived your life
on the threshold
of limits
to your reserves.*

*Now,
many years,
possibly decades later,
you face the consequences,
the big bill!*

*Sadly, you pay it
with the loss of life's quality,
living with the discrepancy
between wanting to
and not being able to.*

*I bow in humility
to your life's achievements,
as I too have walked
along this path.*

Peter Brauer, MD

Modified lyrical translation: German to English by Tom House



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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