



EUROPEAN POLIO UNION

Newsletter No. 1

2018

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Dear Members and Friends,

Our first edition of the EPU Newsletter 2018 will give you a summary of EPU activities during the first six months of 2017 while the EPU was still under the presidency of John McFarlane. Following his report is an introduction by our new president Mrs Gurli Bechmann Nielsen and her plans for the future of EPU under her presidency.

It was a great pleasure to see so many of our members attend the Lobbach AGM last year and we feel that all participants had great pleasure in renewing old friendships, networking with new participants and enjoying each other's company.



ANNUAL GENERAL MEETING 2018

We are looking forward to this year's AGM held at the Seehotel in Rheinsberg on the 16th June 2018. Rheinsberg is situated 75 km north-east of Berlin in the Lake District of Mecklenburg. This is the location where the first EPU Annual General Meeting took place, in 2008. The hotel which you can see in the background on the picture below is entirely wheelchair accessible, so is the entire area around it.



Rheinsberg, a small picturesque town at Lake Griesenick, is a well-known holiday and recreational centre in Germany. Its waterways of lakes and canals connect this town right to Berlin and to the Baltic Sea.

View and pleasure boats are easily accessible by wheelchair and trips are available from 1 to several hours with a restaurant service on board.

<https://www.youtube.com/watch?v=fvlwNjK2wYo>

The cultural centre of this town is the Chateau Rheinsberg which in the middle ages was a moated castle converted into a roccoco-style chateau in 1734 under crown prince Frederic, the later king of Prussia, known as Frederic the Great. A charming park adjoining the chateau is open to the public and can be explored by wheelchair users due to a multitude of paths.



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At the beginning John McFarlane, our Ex-President, and Gurli Nielsen, our current President, are providing us with Annual Reports – John is covering the first part of the last year, Gurli the second one; pages 5-8.

Polio Slovakia was very successful with their petition to make spa care free for polio survivors, details on pages 8-9. They also submitted an article about rare diseases and whether or not polio is a rare disease, pages 10-11.

Polio Switzerland's (SiPS) celebrated their 25th anniversary of existence last year, they report about their very successful 'polio' tulip show under the slogan 'end polio now' as referred to in our previous Newsletter. This polio tulip action had been so successful that the same event will be repeated this year. SiPS also sold chocolates with labels 'end polio now'. A good way of creating awareness of polio still being around and the continuing efforts 'to end polio'; pages 12-13.

In May last year the University of Antwerp started a test with a new polio vaccine inundating 30 participants who were quarantined in a container village for 28 days to prevent the virus getting into the environment. An interview with the supervising professor Pierre van Damme is included in this edition of the Newsletter – see pages 14-20.

Pakistan – one of the last strongholds of the polio virus – only registered 8 polio cases in 2017. Blood samples showed the highest immunity ever, yet sewerage samples showed the existence of the polio virus still all over Pakistan. Scientists say what the hell is going on. Details on pages 21-22.

The G20 leaders who met in Hamburg last July 2017 DECIDED to tackle common health threats to the global community, one of which being polio. The paragraph dealing with this issue in the G20 Declaration is reprinted on page 23.

Diane Chamberlain's book 'The Stolen Marriage' as well as Marc O'Brian's Film 'Breathing' is reviewed in this issue of the Newsletter, pages 23-25. An obituary: Sir Bert Massie – a leading disability rights campaigner – died on 15/10/17 aged 68 – page 26-27.

Some links will lead you to subjects and articles that you might be interested in, page 27.

At the end of this Newsletter (pages 28-30) we start a series on a wheelchair journey to Santiago de Compostela. Every year hundreds and thousands of people – young and old – from all over the world walk the 'camino', the 'way of St James'. Why do they? What are they trying or hoping to find? Will the experience provide some sort of value in their lives? Or are they looking for God? Will they find him? Let's wait and see what the author of this pilgrimage has to say.

And a piece of poetry – a poem by Max Ehrmann – you can find at the very end, on page 31.

The Editors
March 2018

ANNUAL REPORT FROM JANUARY 2017 TO JUNE 2017

by Ex-President John R. McFarlane



It was always known that 2017 would be a year of change for the EPU as the then President, John McFarlane had informed the board that he intended to step down at the AGM in June of that year – so the hunt started for someone to take over as President and to lead the EPU in its next phase of development.

It was always realised that eventually the EPU would have to establish a permanent base with a secretariat and somewhere which it could always call home. Since its inception and registration as a legal charity in 2009 it had depended totally upon volunteers to both carry out and publicise its functions as well as deal with all the legal matters and constraints of being a company and charity registered under Belgian Law.

Another issue that needed urgent attention was that of membership criteria and how to allow small groups of polio Survivors to join the EPU as full members. The core membership from 2009 had paid substantial accession fees that had sustained its operation for some years. The time had now come to go out and help the smaller and less fortunate groups both in the EPU's traditional areas of operation as well as new countries. This led to protracted debate not just amongst the Board but also the general membership.

The ground work for resolving both of these difficult issues, that of the presidency and membership had been laid at the Board meeting in October 2016 held in Dublin. Early in 2017 it was announced to the general membership that John McFarlane would not be continuing as President beyond June 2017 but would be remaining on the Board for at least the rest of his tenure as a Director. At the same time the Board appealed to member organisations for nominations to the Board as well as those who may be willing to take on the presidency. Simultaneously a revision to Article 5 of the EPU Constitution was circulated which would have the effect of expanding the membership to both organisations and individuals in countries where there is no established Polio Survivor Group. Additionally, it was proposed to expand the geographical area of coverage from just those countries in the EU and EEA to all the countries covered by the Council of Europe Membership, in other words taking eligible countries from 30 to 48.

Whilst all this was happening the day to day work of promoting the care, treatment and management in primary care of the symptoms and effects of Polio Sequelae a Post-Polio Syndrome carried on unabated through contacts with other groups and concerned organisations around the world. By the time the AGM occurred in June the EPU was in regular contact with over 60 organisations around the globe and was seen as a leading player in the fight to get polio Survivors true recognition for both medical treatment and social security benefits. This will be an ongoing task for the EPU not just in the next few years but for decades to come.

The high prominence given to “End Polio Now” has led to many thinking that Polio is truly a thing of the past, and we all wish it were so. The hard fact is that there are over 30 million polio Survivors around the world according to estimates by the World Health Organisation. The last person to be infected with the virus, if a child, will need care and help for decades to come. That is the reason why the slogan “WE ARE STILL HERE” is so appropriate and is at the core of the EPU’s work.

The largest number of representatives, for some years, of member organisations and invited guests gathered in Lobbach, a little south of the old university city of Heidelberg, Germany, for the 2017 Annual General Meeting of the EPU. As always it saw renewal of old friendships and the formation of new ones but the one common theme in all the conversations and discussions was Post-Polio Syndrome and how things could be made better for polio Survivors everywhere. The guest speaker Dr Axel Rütz, Orthopaedic surgeon in Koblenz, Germany, described the work of his hospital and the increasing demand on their services by polio Survivors. He reported that the demand and number of patients had grown over 50% in the last few years against expectations of many who thought that as the age profile increased the demand would decrease – the opposite has proved to be true.

We were also fortunate to be joined by Professor Arzu On of the University Hospital of Izmir (Neurology), Turkey, who had just established the first polio Survivor Group in that country. She also reported on the increased demands being placed upon the Turkish Health System by an ever-increasing number of Polio Survivors fleeing war torn Syria. This led to Dr Rütz saying they were experiencing a similar upturn in Germany by the influx of refugees not just from Syria but also from the Indian Sub-Continent and Sub-Saharan Africa.

Preceding the guest speakers came the formal part of the AGM and all the legal necessities that are called for to comply with company and charity law in Belgium. This saw the accounts for the previous 12 months being presented and approved as well as the budget for the next 12 months. It also saw Mrs Gurli Nielsen (Polio Denmark), David Mitchell (British Polio Fellowship) and Paul Neuhaus (Independent) being elected to the Board of Directors. The alterations to Article 5 of the Constitution were approved for both membership criteria, accession and annual membership fees. This immediately meant that application for membership was received from 3 countries with representatives in attendance that had been previously ineligible.

The outgoing President gave the meeting welcome news regarding a new organisation designed to train Doctors in the primary care of Polio Survivors as well as giving advice and website access to the Survivors themselves, their carers, family and friends. PoPSyCLE (Post-Polio Centre for Learning Excellence) is to be initially established on the treatment centres at St Thomas Hospital in London and Beaumont Hospital, Dublin. Its funding will be coming from an anonymous benefactor, himself a polio Survivor, but it had to be acknowledged that the setup of the organisation, infrastructure and legal requirements would mean that operational results would not be seen until well into 2018. PoPSyCLE is a direct result of the demands of polio Survivors around the world and its formation points to a brighter future for all.

The next day the Board of the European Polio Union met in formal session and elected Mrs Gurli Nielsen of Polio Denmark as the new President of the organisation. At the meeting, she acknowledged the task that faced her and knew that she could rely on Board members to give her all the assistance needed to take the EPU to the next level. At the same time Phillip Rendtorff stood down from the Board as the Danish representative and received the thanks of Board members for all his advice and efforts over the years. He will be remaining as a special advisor to Mrs Nielsen in his capacity as the CEO of Polio Denmark.

With my best wishes to you all

John R. McFarlane

ANNUAL REPORT FROM JUNE TO DECEMBER 2017 by EPU President Gurli Bechmann Nielsen

As mentioned above, John R. McFarlane stood down as President of EPU last June and he was succeeded by Gurli Bechmann Nielsen, Vice Chairman of Polio Denmark. Gurli was only eight months old when she contracted polio in 1952. She was hospitalised for two years. After the hospitalisation she went through a long and hard rehabilitation. Since then she got an education as a correspondent, got married and had three sons. She is now a grandmother of eight grandchildren. Post-polio syndrome forced Gurli to stop working in 1996. Then she got involved in the disability policy on a local and national level. She has been a member of the main Board of Polio Denmark for more than 12 years, vice chairman since June 2016. Since 1995 she has been chairman of a local branch of Polio Denmark.



Gurli Nielsen has extensive experience working internationally with polio across national borders. She has worked with projects in Vietnam and the Philippines. She has also worked in cooperation with the polio associations in the Nordic countries.

In the EPU Gurli will work in close cooperation with the various polio associations and groups. The problems with post-polio syndrome are the same wherever you live in Europe. Cross-border cooperation gives us a great opportunity to take advantage of each other's experience. Another core issue is the eradication of polio worldwide. The world community is very close to eradicating this disease and together we can make it happen. It is also very important that we encourage vaccination of our children and grandchildren.

In Denmark there are about 10,000 polio survivors and it is estimated that about half of them have developed post-polio syndrome. Denmark has vaccinated against polio since 1955, and the last polio case in Denmark was in 1976.

Polio Denmark operates a special hospital for polio and accident patients. Here the patients can obtain both maintenance training and rehabilitation. Physiotherapists, occupational therapists, social workers, psychologists and doctors are employed in the hospital.

Since the AGM last June, the Board has had 5 telephone conferences to discuss various issues. In October Gurli visited John R. McFarlane in Ireland to be briefed about EPU and to discuss the future of EPU. One of the priorities is the renewal of the website and all supporting and information materials. It is very important that EPU is visible as an active organization with an agenda which is relevant to politicians, health professionals as well as for our members and all polio survivors. The knowledge of post-polio syndrome must be spread so that polio survivors can get the best possible treatment.

The last Board meeting was held on the 2nd of February 2018 in Paris. Detailed discussion was on EPU priorities.

With my best wishes to you all,

Gurli Bechmann Nielsen
President – EUROPEAN POLIO UNION

BETTER ACCESS TO SPA CARE FOR POLIO SURVIVORS IN SLOVAKIA

by Stefan Grajcar, Slovak Polio Association

The Slovak Polio Association (SPA) has been introduced to EPU Newsletter readers just recently, in May 2017, briefly describing our organisation and its 25 years of existence. What we have not mentioned in the May article is the problem of very poor access to spa care we were facing for almost fourteen years.

Background

Czechoslovakia was affected by polio quite seriously by several epidemics during 1930's, 1940's, and 1950's, with about five year's intervals between each of them. In the period 1939-1956 nearly 13 thousand new cases occurred (with mortality rate 9 %). In 1957 mass vaccination of all children started, and at the beginning of 1960 94 % of all children up to 15 years of age went through this huge vaccination programme, hardly comparable to any other country. Since August 1960, there has been no case of uncontrolled paralytic poliomyelitis in Czechoslovakia. No wild poliovirus has been isolated from clinical materials, faeces of healthy children or sewage samples since then.

Thousands of children and young people, later adult polio survivors were successfully treated during the next few decades in some of spas around the country, but most often in Janske Lazne in the north of the Czech Republic (which some of EPU members may remember as the place where AGM was organised in 2012). There are not many polio survivors of our generation (60+) who were never in Janske Lazne during our childhood,

teenage age or adulthood, thousands of us, including the author of this article, are thankful for what had been done there for us and for the improvement of our health condition.

For decades, before 1989 and even later when political, economic and social situation in Czechoslovakia has dramatically changed, services for health care in spas, including costs for accommodation and food were fully covered from the compulsory health insurance. The substantial and very negative change for polio survivors in Slovakia came in January 2004 when new legislation came into force – spa care of patients with poliomyelitis sequelae was put into a category where only health care was covered from public health insurance, but associated services (accommodation and food) were not and polio patients had to pay them themselves. The result was that suddenly spa care for vast majority of polio survivors became hardly accessible or even inaccessible, mainly due to low pensions of most of them.

A Victory Day on October 10, 2017

Ten years later, in summer 2014, Slovak Polio Association initiated a petition the aim of which was to support a proposal to change the current legislation and allow the ageing population of polio survivors to get back to category of spa care where all costs are covered from the public health insurance. During four months, from June to October 2014, we managed to collect more than 7,300 signatures supporting our proposal – hundreds of them were also from our friends and supporters from the Czech Republic, few of them we have found also in some other countries (e. g. Hungary or Spain). Several hundreds of petition sheets together with a letter for the national Minister of Health we delivered to the ministerial office symbolically on October 24, 2014, on the World Polio Day. After three years of intensive communication with the Ministry of Health, with the biggest (and public) insurance company, other supporters in the country, and finally with members of the national parliament and its Health Committee, we have reached our goal: on October 10, 2017, the National Council of the Slovak Republic passed the proposal of the law according to which all services associated with spa care for patients with polio sequelae and PPS are covered from the public health insurance. Good news for us is also the fact that arguments we used to support our proposal – that regular, repeating rehabilitation and spa care of polio survivors is according to newest scientific knowledge and recommendations the only verified way how to slow down the deterioration process of their health – were fully accepted both by the ministry, and by the parliament.

Since 2018, polio survivors in Slovakia will in October each year remind themselves not only the World Polio Day, but also the day when we accomplished our efforts for better access to the spa care.



Slovak Polio Association

November 2017

IS POLIO AND/OR PPS A RARE DISEASE?

This is a question where in most cases we can say YES, but in some specific contexts the answer might be NO.

According to EURORDIS¹ – Rare Diseases Europe, a non-governmental patient-driven alliance of patient organisations representing 792 rare disease patient organisations in 69 countries in Europe, a disease or disorder is defined as rare in Europe when it affects less than 1 in 2,000 citizens. This definition is based on the Orphan Drug Regulation No. 141/2000 (*“a prevalence of not more than five affected persons per 10 thousand is generally regarded as the appropriate threshold”*). It should be noted that in some countries a rare disease is defined differently – e. g., in the U. S. A. it is *“any disease or condition that affects fewer than 200,000 people in the United States”*, or about 1 in 1,500 people; the legal definition of a rare disease in Japan is *“one that affects fewer than 50,000 patients, or about 1 in 2,500 people”*, etc.)².

List of rare diseases or disorders that comply with this definition is very long – currently it contains more than 6,000 items. The document *“List of rare diseases and synonyms: Listed in alphabetical order”*, published in January 2018 by Orphanet, has 181 pages, and this document is the key source for answer to our question mentioned above. We can find there these polio-related diseases:

- Orpha number 2912: Poliomyelitis;
- Orpha number 330009: Poliomyelitis in patients with immunodeficiencies deemed at risk;
- Orpha number 2942: Postpolio syndrome (synonyms: Postpoliomyelitic syndrome, Postpoliomyelitis syndrome, Postpolio sequelae, Postpoliomyelitis sequelae).

Orphanet allows to use a search engine through which it is possible to find any rare disease from the directory with a description (Disease definition; Orpha number; Summary: Epidemiology – Clinical description – Etiology – Differential diagnosis – Management and treatment; Detailed information; Additional information), basically a huge amount of relevant and up-to-date information.

For us as Europeans the key reference point is the EURORDIS, and we can proudly say that EPU is a full member of this European organisation, what is also a clear proof that polio and PPS are rare diseases.

EURORDIS has about 700 member organisations from all over Europe, list of them you can find on this page:

<http://download.eurordis.org.s3.amazonaws.com/membership/members.pdf>.

Important point here is that besides rare diseases patient organisations from nearly all European countries, and even some from outside of Europe, also national patient organisations with rare diseases can be found there.

¹ EURORDIS stands for **E**uropean **O**rganisation for **R**are **D**iseases

² Source: Wikipedia.

As can be seen what was mentioned up to now, the answer to our question from the title is YES, polio and PPS are rare diseases. There is no doubt that this is very good news for people all over the world. Let's hope that polio will be eradicated within next few years, and also that by 2150 there will be no polio survivors at all (☺/☹).

Nevertheless, it may happen that in some countries the prevalence of polio disease with all its forms is still higher than the threshold less than 1 on 2,000 citizens, and the answer to our question is NO, polio and PPS are not rare diseases in these countries. There are very few countries in the world (if any) where official statistics of polio survivors' numbers are available, it is therefore difficult to say here in how many countries polio and PPS are unfortunately still not rare diseases.

And finally, let me add that the Slovak Polio Association became the member of the Slovak Alliance of Rare Diseases in September 2017, and the main reason for this step was that we want to make hear the voice of Slovak polio survivors through this Alliance, a respected partner of the Ministry of Health, stronger than uttered only by ourselves.

Since 2008 the EURORDIS is organising the Rare Disease Day, which takes place on the last day of February each year. "The main objective of Rare Disease Day is to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients' lives. The campaign targets primarily the general public and also seeks to raise awareness amongst policy makers, public authorities, industry representatives, researchers, health professionals and anyone who has a genuine interest in rare diseases." Slovak Polio Association will for the first time participate at the national Rare Diseases Day 2018, and we hope that it will help to "raise awareness amongst the general public and decision-makers" about polio and PPS also in our country.

And this is something that might be interesting also for other EPU members, national polio and PPS organisations and polio support groups. It is worth considering joining a national association, union, or alliance of patients with rare diseases. The Rare Disease Day 2019 might be also YOUR DAY.

Stefan Grajcar
Slovak Polio Association

References:

<http://www.eurordis.org>

<https://www.rarediseaseday.org>

<http://www.orpha.net>

<https://rarediseases.org>

ACTIVITY REPORT 2017 PROVIDED BY OUR SWISS MEMBER SIPS

Schweizerische Interessengemeinschaft für das Post-Polio-Syndrom (2017)

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

Author: Erika Gehrig

1. Prof. Dr. med. Dirk Fischer - Studies with use of L-Citrulline.

In the first days of 2018 we received an email from the Secretary of Prof. Fischer informing us that the PPS Study has come to a close. Prof. Fischer will send us his study (See Newsletter May 2017) as soon as he has reached a conclusion. As you know Hans Peter Käsermann was one of the participants. We look forward to informing you accordingly at our next AGM meeting in Rheinsberg.

2. Polio Tulips for further eradication of Polio

As written in our last newsletter our SIPS board member, Edy Bucher, of Préverenges near Lausanne has dealt with the polio tulips and the French speaking communities. During last autumn, he went from village to village including Zermatt, Montana, Neuchâtel, Bienne and many other places in the French speaking part. For about four days, he and his wife distributed the boxes with the tulip bulbs to the various villages.

In April 2017, we celebrated 25 years of SIPS. The SIPS board members and the secretary and two further members of the office in Fribourg attended our first board meeting of 2017 and visited the tulip show at the Morges flower show. The tulip bed was placed very close to the restaurant. Members of the community of Morges invited us to an "apéro riche" the next day. We had a wonderful exchange regarding eradication of polio.

As Dr. Urs Herzog retired from Polio Plus Switzerland and Liechtenstein last year, Oliver Rosenbauer of WHO has taken over with the following task Rotary - End Polio Now and Rotaract Club.

We at SIPS have a great cooperation with WHO and support them as much as we can with the eradication of polio / End Polio Now.

Presently we are in touch with the communities to find out how many bulbs they would like to order for 2018. The sale of tulip bulbs will continue this year in order to further eradicate polio / End Polio Now.

Unfortunately, we received a phone call from Brig, Canton Valais this week informing us that their whole flowerbed, which should have bloomed in the city centre, has been flooded due to the heavy rainfalls we had during the previous days in Switzerland.

3. Chocolates / Eradicate Polio / End Polio Now

A few months before Christmas, we started ordering boxes of chocolates, which were made by the Läderach Chocolatier, offering pralinés to Rotary PolioPlus at a special price. Each box sold at CHF 30.-, respectively CHF 35.-. The Rotary Special box contained 24 Pralinés, of

which 8 pralinés were branded with the Rotary logo. The standard box without Rotary logo sold at CHF 30.-. From every box sold CHF 10.- respectively CHF 15.- went to PolioPlus. The Bill & Melinda Gates Foundation tripled the amount. Therefore, with every box sold 75 children could be vaccinated four times and be protected lifelong against Polio.

In autumn 2018, there is again the possibility to buy these boxes of pralinés, branded with, or without the Rotary logo.

4. 25 Year Anniversary of SIPS/CISP

Our SIPS board members worked hard to get information on the past 25 years. A part-time employee of SIPS went to the archive to find old papers on how SIPS was founded. One of the founders was our retired Polio Doctor, Thomas Lehmann. We had quite a few meetings and discussions on how to make this brochure special. Our communication deputy in charge of the Faire Face magazine went several times to the graphic designer to talk about all the special requirements. Every member of SIPS as well as hospitals, some doctors and the press received one of these beautiful brochures. The feedback was very pleasing.

5. World Polio Day in October 2018

We provide our SIPS members every year with a small present for the World Polio Day. One year, we sent them a medical card with their name. Last year, we had pink coloured stickers made with the following lettering:

Hier	Gestern
Polio	Polio
Aujourd'hui	Heute
Post-Polio	Post-Polio
www.post-polio.ch	www.post-polio.ch

We asked our members to send photos of the stickers from where ever they are presented like shops, cars, travel bags, suitcases, scooters, wheelchairs, etc. We will try to make a collage for an appearance in our Faire Face magazine.

POLIOPOLIS IN ANTWERP (BELGIUM): WHAT IS THIS?

On 15/02/2018, Chantal Pirlot de Corbion from ABP, Johan Bijttebier from Post Polio België, and Daniel Peltzer, EPU treasurer, interviewed Prof. Pierre Van Damme, MD, PhD, who is conducting a Vaccine Polio trial at the University in Antwerp under the sponsorship of the Bill & Melinda Gates Foundation.



Pierre Van Damme is full professor at the University of Antwerp, Faculty of Medicine and Health Sciences. He chairs the Vaccine & Infectious Disease Institute (VAXINFECTIO, University of Antwerp); VAXINFECTIO is a consortium of three research units within the university: The Laboratory of Medical Microbiology (LMM), the Laboratory of Experimental Hematology (LEH), and the Centre for the Evaluation of Vaccination (CEV). It is recognized as 'Centre of Excellence' of the University of Antwerp and functions as WHO Collaborating Centre for the WHO European Region for the control and prevention of infectious diseases.

Introduction: Trial summary

The polio disease is close to a complete eradication in the world but 22 new wild type cases have been declared in 2017 plus around 90 vaccine-derived ones with origin from Syria and Congo. Those last cases are due to vaccine-derived mutant polio viruses.

Therefore, international health authorities have asked the Antwerp University to conduct a project to test newly developed vaccines. The purpose of our meeting with Prof. Pierre Van Damme was to understand what has been done up to now and what can be expected in the next future.

Globally, the world saw the fewest number of children ever paralyzed by poliovirus in 2017, with the virus restricted to a few areas of Pakistan, Afghanistan and Nigeria. As the global polio program nears eradication, measures are being taken to ensure the world both achieves polio eradication and take the necessary steps to keep it polio-free.

In extremely rare cases, the live, weakened virus originally contained in the current oral polio vaccine used today can mutate and spread in under-immunized populations. As part of the eradication effort, researchers have developed new vaccine candidates. If successful, these new vaccine candidates will not carry the same risk of mutation and could play an important role in keeping the world polio-free after we achieve eradication.

The University of Antwerp has conducted a Phase 1 clinical trial to assess the safety and immunogenicity of two novel oral polio vaccines against type 2 polio (nOPV2). This trial is a single centre, blinded study in 30 healthy adults who have received in the past inactivated polio vaccine (IPV). The study was conducted at one temporary containment facility of the University of Antwerp in Belgium (called "Poliopolis"). Volunteers remained within the containment facility for a maximum of 28 days.

There are stringent safeguards surrounding research activities for the attenuated (weakened) type 2 vaccine strains because of the global withdrawal of type 2 oral polio vaccine from routine use. As such, this trial is using a containment facility to safeguard against potential environmental contamination with the attenuated strains in nOPV2 (for example, through stools in the sewage system). The clinical trial participants are protected due to their previous vaccination with IPV and were closely monitored throughout the study.



Questions & answers about the vaccine test:

What is polio?

- Polio can invade the nervous system, which can cause permanent limb paralysis.
- There are three types of wild polioviruses: serotype 1, 2, and 3.
 - The poliovirus serotype 2 has been eradicated globally.
 - Type 3 virus has not been detected since late 2012.
 - Type 1 is the only strain still circulating and paralyzed less than 40 children in 2016, and 22 in 2017.

How is polio spread?

- Poliomyelitis (polio) is a highly infectious viral disease typically transmitted by contaminated water and sewage.
- Polio is a virus that is spread through the fecal-oral route (by ingesting contaminated water and sewage).

How can disease from polio be prevented?

- Improvements in hygiene and sanitation have helped minimize exposure to the polio virus and thus the number of polio cases, but the only way to prevent the disease is through vaccination.
- The world is very close to eradicating polio. Over 2.5 billion children have been vaccinated since 1988 and the number of polio cases per year is down by more than 99 percent.
 - In 2017, fewer children were paralyzed by polio than in any other year, with the virus now restricted to just small areas of three countries – Afghanistan, Pakistan, and Nigeria.

What is the status of vaccines against polio?

- There are two types of vaccines currently used against polio – a live attenuated oral polio vaccine (OPV) delivered as oral drops, and inactivated polio vaccine (IPV) delivered via injection.
- IPV has primarily been used in wealthier, low-risk countries because of the cost and type of immunity it provides. OPV is primarily used in high-risk settings because it is more affordable, is easier for untrained health workers to deliver, and reduces the risk of person-to-person transmission (unlike IPV, which confers high individual immunity but has limited impact in preventing transmission). Because of this, it is the vaccine deployed to control outbreaks.
- While OPV has been very effective in protecting children from polio, on very rare occasions, in under-immunized populations, the live attenuated vaccine virus can mutate and circulate in a community – what’s known as circulating vaccine-derived poliovirus (cVDPV).
- Because the majority of circulating vaccine-derived polio cases come from the type 2 component in OPV, and because type 2 wild poliovirus is considered eradicated, countries around the world switched the type of OPV they use last April 2016.
 - Countries stopped using the trivalent oral polio vaccine (tOPV), which protects against all three strains of wild poliovirus, and replaced it with bivalent OPV (bOPV), which protects against the remaining two wild polio strains, types 1 and 3. This lowered the risk of vaccine-derived polio cases and enhanced immunity to the remaining two types.
 - To maintain immunity levels to type 2 polio, high-risk countries also introduced IPV into routine immunization schedules prior to the removal of OPV2.
 - Once all wild polio transmission has been stopped, all countries will stop using OPV entirely and only protect children with IPV.

Why is it important to develop new oral polio vaccines (nOPV)?

- In order to ensure the world stays polio-free, new OPVs could be used to halt disease transmission should there be future outbreaks, *without* carrying the same risk of new vaccine-derived polio cases as with the current OPV.
- Although the wild type 2 polio strain is considered eradicated, and types 1 and 3 are on the cusp of eradication, the World Health Organization – WHO will maintain vaccine stockpiles for use during outbreaks for several years to come.

What is the goal of the nOPV program?

- The goal of the nOPV program is to develop new oral polio vaccines against type 1, type 2, and type 3, respectively, that are safer than the currently available OPVs (that is, the attenuated virus is less prone to reverting back to its virulent state).
- If successful, the nOPVs will replace the current OPV stockpile set aside to respond to outbreaks.

What is the current status of the nOPV vaccine candidates?

- A Phase 1 clinical trial was undertaken to assess the safety and immunogenicity of two novel oral polio vaccines against type 2 polio (nOPV2).
- Partners have selected and are generating storage banks called “working virus seeds” for nOPV1 and nOPV3 in preparation for forthcoming clinical trials.

Who is funding and conducting the nOPV program?

- The Bill & Melinda Gates Foundation is funding the nOPV program and related clinical trials.
- Clinical candidates were created by scientists at the US Centers for Disease Control and Prevention (CDC), the National Institute for Biological Standards and Controls (UK) and the University of California at San Francisco (UCSF) with a collaborator at the US Food and Drug Administration.
- The University of Antwerp in Belgium conducted the first in human nOPV2 clinical trial.
- PATH, an international non-profit organization, is providing project management for the nOPV program.

How is the trial being conducted?

- This trial is a single centre, blinded study in 30 healthy IPV-only vaccinated adults: 15 participants per vaccine candidate. The study has been conducted during summer 2017 at one temporary containment facility of the Antwerp University, Belgium. Volunteers remained within the containment facility for a maximum of 28 days.

How did the two phases in the containers go?

These were two very exciting phases, as this was also the first time that the Centre for the Evaluation of Vaccination implemented this new way of working. The team spent many months, working day and night, and it was all hands on deck during the two phases of the project this past summer. But all partners were happy that the project was a success from start to end.

Everything went according to plan in the containers. The collaboration with the technical service, with the decontamination team, the food supplies... everything happened as planned. We had to make some minor adjustments here and there but our thorough preparations and extensive problem-solving skills ultimately proved very effective.

Did anybody leave? Did anybody express the desire to opt out?

The two groups of fifteen volunteers spent the scheduled time in Poliopolis. Nobody left the containers. Some of the participants did however indicate that they wanted to leave after some time. At those times, the presence of a psychologist, an assistant and the medical team proved crucial. The participants were nonetheless convinced to stay, with the team lending a listening ear, engaging in a dialogue with them, reminding them of the goal of the study and providing them with regular updates about the progress we made in the study.

If anyone had wanted to really leave Poliopolis, they could have done this, albeit that they would have to commit to observe a number of biosafety measures. Every individual participant in a clinical study has the right to opt out of the study at any time. This naturally has some special implications: the individual would have been asked to install a chemical toilet in his place of residence, to prevent the polio virus from entering the environment after the individual relieved himself. The individual would also be required to stay in a Belgian place of residence or hotel.

What was the atmosphere like among the participants?

It was nice to see how a group dynamic soon developed during both phases. Naturally not all the participants became good friends, but there were never any real quarrels. They spoke with each other a lot and sometimes vented their grievances or questions to us, or spoke with the supervisor or the psychologist. Maintaining daily communication between the supervisor, the medical team and the psychologist was vital in this context. Where possible, we took the participants' requests into account. They requested a ping pong table for example, a request we obviously granted. This only served to enhance the group dynamic, providing them with a form of relaxation and an occupation and the ability to organise small tournaments with the entire group.

How did the participants keep busy? Did you organise many activities?

The first days passed very quickly for all the participants, but after two weeks it was vital that they could participate in the activities we scheduled. We offered an hour of exercise every day, under the supervision of a gym instructor. Every week, the volunteers were also

treated to a mystery phone call, with Rik de Leeuw and Marcel Vanthilt (two Flemish TV personalities) among others. We also organised a beer sampling evening with Belgian beers (albeit in very small quantities), a BBQ course, a poker evening, remote yoga lessons and much more.

Did anyone fall ill during the study?

The incidence of so-called serious adverse events is very important in a phase 1 study. Fortunately, there were none. All the participants tolerated the vaccine very well. Over a period of 28 days, the 15 participants did exhibit some medical complaints, i.e., a meal that did not sit well or a sprained ankle or an ingrown toe nail. But none of these events were related to the intake of the oral vaccine.

What was it like to work in the container village?

It was quite a unique experience and even a real challenge for the Centre for the Evaluation of Vaccination. After their “shift”, the medical employees could go home. When entering or exiting the container village, however, they always had to observe the safety measures, including the stringent dressing and undressing procedures. The team of eleven medical employees conducted a huge amount of work in just three months: there was always a doctor on hand from morning until evening and on the weekends, there were on-call doctors on evenings and nights for a study that took place in July and August. While you can develop a good script, based on the experience and input of experts, you soon come to realise that you and your team must have excellent problem-solving skills and creativity to deal with every new problem, situation or question as soon as it arises and in the right manner. This may include dealing with a clogged toilet drain, or the ripped white overall of a gym instructor. Hurricane Irma also interfered with our study. The CDC lab in Atlanta where all the stool samples were analysed was forced to close for several days.

What about the waste and the sewage?

We could not afford to run the risk of the polio virus in the vaccine leaking into the environment. That is why all the waste was collected and processed by a specialised firm. All the water used in the container village (kitchen, shower, toilets) was transferred to large storage tanks, to which we regularly added chlorine dioxide. A specialised company drained the contents of the tank every four to five days.

Is it safe to enter the container units now?

The entire complex was decontaminated immediately after every phase of the vaccine study. This was done by an external firm and was a rather expensive undertaking. The belongings of the volunteers and the employees were first decontaminated before they could use them again in the “real” world. This did not just apply to clothing and bed linens, but also to mobile phones, computers and other personal belongings, which were all adequately decontaminated.

When do you expect the initial results?

The safety data are already very reassuring. We are currently working on the first analyses, but the results regarding virus concentrations in the stool samples and the genetic stability of the respective vaccine virus strains are expected by early 2017. We will then quickly finalise the scientific publications and launch the next phases of this vaccine study.

What are the next steps for the candidate polio vaccines?

As soon as we have all the results, the files for launching the next phase can be submitted to the regulatory institutions (FAGG), the biosafety committee, the WHO, and the ethical committee. The idea is to administer both candidate vaccines to more than 200 volunteers, to further document the vaccine's safety profile and immunogenic capacity.

What will happen to the containers?

We received a two-year permit for the container units. We hope to conduct other clinical studies in these containers, where necessary with people who must remain in quarantine. We are already in discussions about new studies with polio vaccines, but also about new future vaccines, which must be tested in quarantine.

Key dates

- Spring 2017: installation of containers on the parking of the Medical University Antwerp to become "Poliopolis"
- May - June 2017: 2 groups of 15 adult volunteers were totally isolated during 28 days after injection of a vaccine
- September 2017 – March 2018: control and measure process of all steps before conclusions
- End of 2018: expected communication of test results
- 2019: second test to be launched with 300 candidates, including teenagers and adults.

Conclusions after Prof. Van Damme's interview

As mentioned at the beginning, there are still a lot of controls and verification to be done before publication of the polio test vaccine results.

The final report is expected in the 2nd half of 2018. More on the subject in the Fall version of the EPU newsletter.

We want to thank Prof. Pierre Van Damme very much for his time and his availability to explain us the objectives and the detailed process of this polio vaccine test that we are proud and happy to share with our EPU friends.

Authors:

Daniel Peltzer
EPU treasurer

Chantal Pirlot de Corbion
Association Belge des Paralysés – ABP

Johan Bijttebier
Postpolio België



Extensive sampling shows that poliovirus lurks in many open sewers.

‘WHAT THE HELL IS GOING ON?’ POLIO CASES ARE VANISHING IN PAKISTAN, YET THE VIRUS WON’T GO AWAY

By [Leslie Roberts](#), January 11, 2018

Just a year ago, poliovirus seemed on its last legs in Pakistan, one of its final strongholds. Polio cases were steadily falling, from 306 in 2014 to 54 in 2015, 20 in 2016, and, by last count, eight in 2017. Blood tests showed that, overall, immunity to the virus had never been higher, even among children aged 6 to 11 months, thanks to years of tireless vaccination campaigns. Surely, there were not enough susceptible kids to sustain transmission, and the virus would burn itself out within a year.

Unsettling new findings, however, show it is far from gone. In the most extensive effort in any country to scour the environment for traces of the virus, polio workers are finding it widely across Pakistan, in places they thought it had disappeared. They are wondering “just what the hell is going on” and how worried they should be, says epidemiologist Chris Maher of the World Health Organization (WHO) in Geneva, Switzerland, who runs polio operations in the eastern Mediterranean region. Does this mean the virus is more entrenched than anyone realized and is poised to resurge? Or is this how a virus behaves in its final days – persisting in the environment but not causing disease until it fades out?

“We have never had this level of environmental sampling anywhere else. We have nothing to compare it to,” Maher says. “We don’t understand the dynamic,” agrees Michel Zaffran, who leads the Global Polio Eradication Initiative at WHO. “But we take it very seriously.” In response to the sampling data, he and his colleagues are already changing their tactics – and their definition of success.

Along with Afghanistan and Nigeria, Pakistan is one of just three endemic countries – places where indigenous wild poliovirus has never been vanquished. With its dysfunctional government, unceasing violence, poverty, and huge numbers of people on the move, it may well be the toughest challenge for eradication. The border with Afghanistan is so porous that the two countries are considered one epidemiologic block in which the virus circulates freely. Conventional wisdom is that if Pakistan defeats polio, Afghanistan will soon follow.

That could be the key to global eradication, as no virus has been detected in Nigeria for the past 15 months.

Since the eradication effort began in 1988, the gold standard for detecting poliovirus has been surveillance for acute flaccid paralysis (AFP) – finding and testing every child with a sudden weakness or floppiness in the arms or legs. The yearly case count has been the benchmark for success: After 12 months without a polio case, WHO has historically removed a country from the endemic list.

But as case numbers fell to today's low levels, **AFP surveillance is no longer the only meaningful indicator. Only about one in 200 or 300 people infected with the virus becomes paralyzed; the rest show no symptoms but can still shed the virus in their stool and infect others. Environmental surveillance can detect that hidden virus.**

Polio workers collect sewage samples, usually from open drainage ditches, and test them for virus. If the test is positive, that means someone in the catchment area is infected and actively excreting it. Pakistan now has 53 sampling sites, more than any other country. And at a time when cases are the lowest on record, 16 % of samples from across the country are testing positive.

“It is extraordinary to have so much virus in sewage and so few cases,” Zaffran says.

What makes the environmental samples so hard to interpret is that a catchment area may contain the combined feces of 50,000 or 100,000 people. “If you isolate a virus from a child, you know who is infected. When you find it in an environmental sample, you don't know if three people are infected or 3000,” Maher explains.

One possible explanation for the disconnect is that AFP surveillance is missing cases. Maher doubts that the number is significant, but others suspect that too many children among the mobile populations, including the marginalized Pashtun minority, still aren't being vaccinated despite ramped up efforts to reach them. “I don't think polio is entrenched across Pakistan, but this last reservoir of ‘people on the move’ is sustaining the virus,” says Steve Cochi, a polio expert at the U.S. Centers for Disease Control and Prevention in Atlanta.

Maher has another view. “My own suspicion is this is part of what we see at the end,” he says. “The lack of cases means immunity is high, but because of the very difficult circumstance in Pakistan,” the virus still has a tenuous hold. Ultimately, he says, “The virus will die out because it is not getting enough purchase.”

The program is not taking any chances. The response to each positive environmental test is now as aggressive as to a case of paralysis. And the program is hammering the virus with repeated vaccination campaigns throughout the “low season,” between December and May, when cold weather makes it tougher for the virus to survive. Whether the strategy works will become clear later this year when the weather turns warm. But one thing is certain: The absence of cases is no longer enough to declare victory over polio. Going forward, a country will not be considered polio-free until 12 months have passed without a case – or a positive.

G20 DECLARATION – HEALTH THREATS

Safeguarding against Health Crises and Strengthening Health Systems: The G20 has a crucial role in advancing preparedness and responsiveness against global health challenges. With reference to the results of the G20 health emergency simulation exercise, we emphasise the value of our ongoing, trust-building, cross-sectoral cooperation. We recall universal health coverage is a goal adopted in the 2030 Agenda and recognize that strong health systems are important to effectively address health crises. We call on the UN to keep global health high on the political agenda and we strive for cooperative action to strengthen health systems worldwide, including through developing the health workforce. We recognise that implementation of and compliance with the International Health Regulations (IHR 2005) is critical for efficient prevention, preparedness and response efforts. We strive to fully eradicate polio. We also acknowledge that mass movement of people can pose significant health challenges and encourage countries and International Organisations to strengthen cooperation on the topic. We support the WHO's central coordinating role, especially for capacity building and response to health emergencies, and we encourage full implementation of its emergency reform. We advocate for sufficient and sustainable funding to strengthen global health capacities, including for rapid financing mechanisms and the WHO's Health Emergencies Programme. Furthermore, we see a need to foster R&D preparedness through globally coordinated models as guided by the WHO R&D Blueprint, such as the Coalition for Epidemic Preparedness Innovations (CEPI).

BOOK REVIEW BY – John McFarlane

“THE STOLEN MARRIAGE” BY DIANE CHAMBERLAIN

One of the unusual advantages of being a polio Survivor and having PPS is the fact that you are also an ardent insomniac. Hence, you seem to have all the time in the world for reading especially in the middle of the night when everyone else is fast asleep and there is no one to divert you from a good book.

One of the other strange things is authors seem to have a fascination with returning to favoured and favourite themes – for example the endless fascination with stories about the Titanic and believe it or not about polio and polio Survivors. Many people do not realise that the arch villain in Dan Browns book “The Da Vinci Code” is a polio Survivor nor that many of the characters in Geraldine O' Neil's books have an association with Polio, probably not unsurprising as Geraldine herself is a polio Survivor. The latest in this long line is Diane Chamberlains book “The Stolen Marriage”.

Although not a genre of book that normally attracts me I was fascinated by the back story which is known as The Miracle of Hickory. When a polio epidemic strikes an area taking the

lives of some children, the townspeople band together to build a polio hospital in less than 3 days. The central character in the book Tess DeMello immediately starts working at the hospital despite the objections of her husband, Henry Kraft, to whom she is bound to in a loveless marriage. She is treated with suspicion by the townspeople who she suspects are talking about her behind her back and undermining her position. At the same time her husband's behaviour becomes more and more baffling and alarming.

Despite all of this she finds new ways to treat and save the lives of her young patients and to gain respect amongst those who treat her as an outright newcomer to the area. At the heart of the book the building of a hospital in Hickory is a true story, it really did happen and many lives were saved because of it. Around this true event Diane Chamberlain has woven a tale of suspicion, human frailty and eventual triumph over adversity. It is a well worth read for those who have an interest in the fight against polio as well as the general population who will find resonance with everyday life.

“The Stolen Marriage” by Diane Chamberlain – published 2017 by Macmillan, London and St Martin's Press New York.

ISBN 978-1-5098-0957-8

FILM REVIEW BY John McFarlane

“Breathing Lessons – The Life and Work of Mark O’ Brien”

The recent release of “Breathe” starring Andrew Garfield and Clair Foy has brought the polio story and those who pioneered the Disability Movement into sharp focus. However, the granddaddy of all these films is Breathing Lessons the Life and Work of Mark O’Brien” a film by Jessica Yu. Made in 1996, it is basically a documentary where Mark from his iron lung explains his philosophy of life, living, religion, belief and love.

Although like so many of his era he is still tied to an iron lung, he demonstrates that his mind and imagination has no boundaries. He challenged convention by going to Berkley and graduating in English, he found independence it is not just something of the body but it is also of the mind. He challenged physical boundaries by having a wheelchair built, complete with respiratory, in which he could lie and take himself not just around the campus, but all over the local built environment.

Although dependent upon attendants (although they are more commonly known as personal assistants these days) his mind explores all facets of his life and he puts these into writing most notably in his book of poetry “Breathing”.

He goes back through his life and eloquently describes the dilemmas his parents faced when he was diagnosed with polio and the options they had and acknowledges that without their

love, determination and courage he would not have achieved as much as he had, and in fact doubts whether he would have even lived for long. Like the majority of people, he not only craves companionship but feels it is a basic human right and he has the courage to even explore the subject of his own sexuality and his solution to discovering what that mysterious thing called “sex” is all about – like so many others he wonders whether it is all it is cracked up to be.

The film which last for just over 30 minutes is not an easy watch as it lays bare the very most innermost thought, feeling and soul of Mark O’Brien. Many who watch it will have resonance and share some or part of his feelings and philosophy. It hit many memories back for me about the struggle of acceptance with a disability in the big bad world of the 60s and 70s and how things in some areas have progress and in other areas still have a long way to go.

Mark's life inspired the Oscar winning drama “The Sessions” that starred William H Macy and Helen Hunt with John Hawke. The film reflects Mark's life right the way down to his mode of transport, the iron lung, and his exploration of both his soul and body. It caused controversy as the portrayal of one of his greatest supporters in the film was a Catholic priest and some of the philosophies go contrary to the churches teaching thus causing it to be boycotted in many areas around the world and on occasion damned from the pulpit. Which one to watch, I have seen both Mark's own story from his own mouth told from his iron lung is the more powerful but the more difficult. Both tell the same basic story in different ways, one the reality, the second the dramatisation. I know which I would rather watch.

“The Breathing Lessons” a documentary by Jessica Yu available to watch online from Snagfilms.com

OBITUARY

Sir Bert Massie obituary – 1949 - 2017: Leading disability rights campaigner

Sir Bert Massie died on 15/10/17 aged 68

After contracting polio at three months old, Sir Bert Massie spent his life fighting for discrimination against disability to be outlawed and making the world a more accessible place for wheelchair users and those with long-term physical or mental impairment.

His drive for change came from both “a personal need and an appreciation of what was wrong”. During the 1960s he explained that he often used to go to restaurants and “people would say: ‘We don’t serve wheelchairs’. “And I would say: ‘Well, that’s okay, I don’t eat wheelchairs’.”

It was a typically humorous response from the fiercely proud Liverpoolian but he was the first to admit life could often be a battle. Sir Bert turned out to be a “great champion of the possible”.

He was a leading light of the Disability Discrimination Act 1995 – now replaced by the Equality Act 2010 – which makes it unlawful to discriminate against people in respect of their disabilities. The son of Herbert and Lucy Massie, young Bert spent the first five years of his life at Liverpool’s Alder Hey

Children’s Hospital. He then moved to the Children’s School of Rest and Recovery and Sandfield Park Special School at the age of 11.

As disabled students were not expected to study for O-levels, he left school without qualifications. His first job was operating a lift but having been told that he was unemployable he was concerned other wheelchair users were facing the same discrimination and joined the Liverpool Association for the

Disabled he was unable to study for A-levels in his home city because none of the night schools had an accessible entrance. Instead, he attended a specialist college in Coventry and returned to take a degree at Liverpool Polytechnic.



After obtaining a postgraduate diploma in social work from Manchester Polytechnic he joined the Royal Association for Disability and Rehabilitation (Radar) in London from 1978 to 1999, becoming chief executive in 1990.

Sir Bert served as chairman of the United Kingdom's Disability Rights Commission from 2000 to 2007 and was founding commissioner of its successor, the Equality and Human Rights Commission.

He was awarded the OBE in 1984, CBE in 2000 and a knighthood for "services to disabled people" in 2007. He is survived by his wife Maureen.

SHORT NEWS

Post-Polio Support Group Ireland has rebranded itself. Although its official legal name will remain as Post Polio Support Group (a company limited by guarantee) its public name by which it will be known, almost like a trading name, is Polio Survivors Ireland. This is a change brought about by consultation with its members. In addition, they have a new logo – all this can be seen on the new website www.polio.ie.



The reasons for the change in name and the meaning of the new logo are on the website, Facebook and Twitter links.

In this connection we would like to draw your attention to the film "BREATHE" by Andy Serkis, the premier was shown in London in October 2017, an inspiring true story of Robin and Diana Cavendish, an adventurous couple who refuse to give up in the face of a devastating disease – polio: <https://www.theguardian.com/film/2017/oct/29/breathe-andy-serkis-andrew-garfield-claire-foy-robin-cavendish-polio-review>.

PLANT-PRODUCED POLIO VACCINES could help eradicate age old disease

A very interesting article dealing with a new method of infiltrating genes that carry information to produce virus-like particles into the plant tissue, causing the host plant to reproduce large quantities of them using its own protein expression mechanism. They have been used to produce a new vaccine against poliovirus in what is hoped to be a major step towards global eradication of the disease. For Details click on the link:

<https://www.jic.ac.uk/news-and-events/news/2017/08/plant-produced-polio-vaccines-could-help-eradicate-age-old-disease/>

En el Camino

A PILGRIMAGE BY WHEELCHAIR AND SCOOTER TO SANTIAGO – PART I

by Paul Neuhaus



For two years one of my dreams had been a pilgrimage to Santiago de Compostela.

The reader might know that Santiago is a famous place for a pilgrimage to the apostle James who was one of the chosen apostles (John, Peter and James) whom Jesus took on the mountain TABOR to reveal his Glory and Divinity to them. James was an early martyr sentenced to death by King Herodes in the year 44. His relics came to Santiago which is situated in the north-west of Spain, some time between 818-834. The name Santiago came from Sant Jago, short for Sant Jaco(bus). King Alfonso III decided in 872 to build a cathedral which was destroyed in the following years by the Saracens. Rebuilding started under Alfons VI in the year 1075. Nearly 1000 years ago the city of Santiago was – together with Rome and Jerusalem – a well known place of



Christian pilgrimage, it is reported that Francis de Assisi pilgrimed to the grave of the Apostle James (from Assise to Santiago it was nearly 2000 km).

What was the motivation to choose this way?

Curiosity? Adventurism or adventure-tourism: or to feel good in going beyond one's strength? Religiosity? Touristic motivation? Yes, it was a bit of everything. But my main motivations were two-fold:

First: I wanted to experience an intense time of prayer and at the same time as is the aim of a pilgrimage trust in God, our good Father, what he had foreseen for me - maybe difficulties and challenges, but also new acquaintances, the company of friends, companions and other pilgrims on the way, all of them having their own personal story and history, all of them with certain expectations and their own

special life's burden that they were carrying with them.

Second: ... helping other people with disabilities to overcome the obstacles which are sometimes only within them. Yes, we can! With the help of God and so many other people! We are not alone! Having travelled this way I can say: my expectations were right. I found something important for my life from that pilgrimage.

I heard someone say: a pilgrimage is just like a little mirror of your life, also spiritually spoken. We experience in a very short period success and failure, expectations and disappointments, discouragement, pain, suffering, joy and happiness. We experience the hand of God on our way, encountering people who sometimes convey some sort of a hidden message with their life-stories, and I found that was true!



Decision...

In September 2017 en el camino!... off to Santiago!

I was really keen to find out whether it would be possible to go to Santiago by wheelchair. Since I heard of Felix Bernhard, a paraplegic investment banker and his journey from the Pyrenees to Santiago, all on his own, in a wheelchair,

the idea didn't leave me. Perhaps we polio survivors wouldn't have that much strength as we are told by the doctors and therefore we should not overstrain ourselves.

So I decided: I would go by wheelchair, sure, but not alone and with assistance. As I need to wear orthotics on both legs and the use of crutches due to PPS the distance I can walk is not more than 100 m. I decided to invite some friends to accompany me and also some other polios to join. I asked a polio affected woman, Elsmarie, whether she would be willing to accompany me with her husband. She instantly agreed. Elsmarie suffered polio from her childhood and was not able to walk more than 200 m in one go. I would use a light and stable aluminium wheelchair adapted for the use of a handbike. Elsmarie, because of a beginning weakness in her arms, would use a scooter instead of a wheelchair. I considered this travel a test to find out whether such a journey could be organised in the future with more polio survivors and people with other disabilities.

When I finally had the confirmation of 8 persons (aged from 39 to 73) we started planning the project. My older brother, Klemens, and my cousin decided to come along with us with their bikes. Having two cars we would be able to bridge those paths that we were told could not be managed by wheelchair.

The two bikers would have to drive the cars to the walkers' points of arrival and park them there.

Then the walkers and their assistants would, in turn, have to drive the cars from there to our hostel in the evening.

But where to start and how long should the pilgrimage last?

As my cousin Heiner (67), an expert in the CAMINO FRANCÉS, advised not to do more than 8 to 12 km per day (i. e. 4-6 hours) and cover the rest of the distance by car. My cousin and my brother would accompany us by bike and would drive the two cars to where we were supposed to arrive. Reaching the destination in the afternoon we would load wheelchairs and scooter into the cars and drive to the hotels or hostales which we would have to book beforehand.



We planned to start our pilgrimage at Burgos in Spain which is about 490 km far from Santiago de Compostela. On the „Camino“ we should be able to “walk“ about 90 km in 10 days , a distance that seemed to be feasible. I would come from Germany to Burgos by car and two bicycles, passing through France, with a stop-over in Tours and another one in San Sebastian. The other part of the group would go by plane from Düsseldorf to Bilbao and rent a car suitable to transport a scooter. The assistants would have to go directly to Burgos which would be the meeting and starting point. How to arrive at Burgos and how to leave Santiago was everyone’s own responsibility.

That was our plan.

(... to be continued)

Max Ehrmann: Desiderata

Go placidly amid the noise and haste,
and remember what peace there may be in silence.
As far as possible without surrender
be on good terms with all persons.
Speak your truth quietly and clearly;
and listen to others,
even the dull and the ignorant;
they too have their story.

Avoid loud and aggressive persons,
they are vexations to the spirit.
If you compare yourself with others,
you may become vain and bitter;
for always there will be greater and lesser persons than yourself.
Enjoy your achievements as well as your plans.

Keep interested in your own career, however humble;
it is a real possession in the changing fortunes of time.
Exercise caution in your business affairs;
for the world is full of trickery.
But let this not blind you to what virtue there is;
many persons strive for high ideals;
and everywhere life is full of heroism.

Be yourself.
Especially, do not feign affection.
Neither be cynical about love;
for in the face of all aridity and disenchantment
it is as perennial as the grass.

Take kindly the counsel of the years,
gracefully surrendering the things of youth.
Nurture strength of spirit to shield you in sudden misfortune.
But do not distress yourself with dark imaginings.
Many fears are born of fatigue and loneliness.
Beyond a wholesome discipline,
be gentle with yourself.

You are a child of the universe,
no less than the trees and the stars;
you have a right to be here.
And whether or not it is clear to you,
no doubt the universe is unfolding as it should.

Therefore be at peace with God,
whatever you conceive Him to be,
and whatever your labors and aspirations,
in the noisy confusion of life keep peace with your soul.

With all its sham, drudgery, and broken dreams,
it is still a beautiful world.

Be cheerful.

Strive to be happy.

Max Ehrmann, Desiderata, Copyright 1952.

(Source: <https://allpoetry.com/Desiderata---Words-for-Life>)

Note: I was lucky to find this poem – in Czech translation – in early seventies, being then a university student, a young man full of doubts and uncertainties about my future... It helped me many times since then to overcome not only troubles of those tempestuous years, but also later. What is more important is that it helps me always when I want to breathe better, with more optimism and enthusiasm...

Stefan Grajcar, Slovakia

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Authors: Margret Embry
John McFarlane
Gurli Nielsen
Stefan Grajcar
Erika Gehrig
Daniel Peltzer – Chantal Pirlot de Corbion - Johan Bijttebier
Leslie Roberts
Paul Neuhaus
Editor: Margret Embry
Layout: Stefan Grajcar