



EUROPEAN POLIO UNION

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English version

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Editorial

Dear Reader,

The winter 2021 or December 2021 edition of our Newsletter brings to you latest news from the European Polio Union and the polio survivors world in EPU's member countries, but we are sure that our scope is even wider and in some way reaches polio survivors in the whole continent.

Since the beginning of 2020 our world is facing the COVID-19 pandemic and after nearly two years it seems that eradication of this virus disease will be a long distance run. Nobody knows at the moment if longer than in the case of polio eradication, which started many decades ago. And as we know, polio eradication in the world has not come to the end yet – in spite of the fact that nearly 99 % of countries of the world are now polio free, there are two where polio in its endemic form is still a threat. We have learned to live with polio, and only we know that this journey was neither easy, nor short for most of us. Now we hear that we will have to learn to live with COVID-19 – and we have no doubt we will manage.

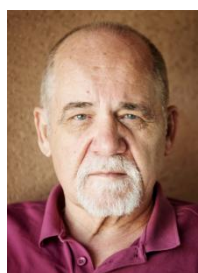
We start the issue with introducing new EPU Board members elected during the Annual General Meeting held online on November 19, 2021. Two weeks later, on December 2, the new, or more precisely renewed EPU Board has elected our new President – David Mitchell from the BPF, and three officials: the Vice-President, Treasurer and Secretary. Profiles of elected and re-elected Board members are followed by Presidents' Addresses prepared by David Mitchell and Gurli B. Nielsen.

We are very happy to announce that the AGM 2022 will be hosted by the Czech Polio Association in June 2022 in Prague, and we all hope that we will be allowed to meet in person, after three years it would be a real relief for all of us.

The next section contains five articles providing us with some useful information on various aspects of polio and PPS prepared by respected experts in the field – Frances Quinn from the BPF, Angela Reddy, from Guy's and St. Thomas' NHS Foundation Trust, London, Peter Brauer, EPU Honorary Member, and Prof. Iris Zöllner from the Baden-Württemberg State Health Office, Germany. We are very grateful to have a chance to share their knowledge and experience with our readers all over Europe.

Last pages bring news from polio world around us – in the world (David Mitchell), in Switzerland (Erika Gehrig), with few pictures from the World Polio Day 2021 (Belgium, Czech Republic, France, UK), and also a review of the new edition of the book "Polio & Us" from Ireland. We finish with a poem by Pat Ingoldsby, which reminds us what wonderful and happy lives we live in spite of or thanks to polio 😊...

We are polio survivors, and we hope we will be only survivors of the COVID-19 era, not of the COVID-19 disease itself. The burden we already have could be then too big. Let's be optimistic, stay safe and healthy.



Stefan Grajcar, Editor,
on behalf of EPU Board

Introducing the new EPU President and the new EPU Board members

As was already mentioned in the Editorial, during the Annual General Assembly held online on November 19, 2021, five new Board Directors were elected (in alphabetical order): Macrina Clancy, Michal Haindl, Pat McGillion, Frances Quinn and Tine Tournicourt; two Board Directors were re-elected: David Mitchell and Paul Neuhaus. All Directors were elected unanimously. The EPU Board of Directors has now 9 Directors, two more than in the previous period – here are their names: Macrina Clancy, Robert Cordier (Polio France), Štefan Grajcár (Slovak Polio Association), Michal Haindl, Pat McGillion, David Mitchell, Paul Neuhaus, Frances Quinn, Tine Tournicourt.

At the first meeting of the newly elected and re-elected Board it was in a secret ballot decided that these Directors for the period of the next three years would serve in these positions:

David Mitchell	President of the EPU
Pat McGillion	Vice-President of the EPU
Tine Tournicourt	EPU Treasurer
Štefan Grajcár	EPU Secretary

We all have to say GREAT THANK YOU to three ladies who were Board Directors in previous years and who decided not to candidate for re-election and stepped down: **Margret Embry** – Board Director since 2015, **Erika Gehrig** – Board Director since 2015, **Gurli B. Nielsen** – Board Director and EPU President since 2017.

Below you can find detailed profiles of five newly elected and two re-elected Board Directors.



Macrina Clancy, Polio Survivors Ireland

Occupation: I have been a Teacher, banker, entrepreneur, administrator and a Director of Iconic Jewellery Ltd.

Board Directorship Experience: I was previously a Director of Ogham Design. I am a Board Director of Polio Survivors Ireland since 2016 and served as Treasurer from 2017 to 2021. After joining the Board of PSI I took a three month Certificate Course on Charity Law, Trusteeship & Governance at the Law Society of Ireland. This year I was elected Chair of the Board.

Financial Experience: Worked with Standard Chartered Bank for 11 years where I was made head of the Cash Department. While there I obtained a Diploma in Banking from the Institute of Bankers of Ireland.

Community/Voluntary Sector Experience: I worked for over nine years with Ballyogan Family Resource Centre as Administrator. I had responsibility for compiling and submitting financial returns to Irish Statutory funding bodies. I have also been a Convenor of Bray Social Support Group of Polio Survivors Ireland.

Why I believe I should be elected to the Board of the EPU: I am a polio survivor with a good understanding of financial best practice and I also have some understanding of the requirements of corporate governance. I would be an active and conscientious member of the board of the EPU on behalf of my fellow polio survivors.



Michal Haindl, Czech Polio Association

Michal Haindl graduated from the Czech Technical University (1979), Prague, received his Ph.D. from the Czechoslovak Academy of Sciences (1983), and subsequently earned the ScD degree (2001). He is the IAPR and AAIA fellow, IEEE senior member, and Professor. Since 1983 he has worked on various image analysis and pattern recognition topics in the Institute of Information Theory and Automation (UTIA) of the Czechoslovak Academy of Sciences, Prague; University of Newcastle; Rutherford Appleton Laboratory; CWI, Amsterdam, and INRIA, Rocquencourt. In 1995 he rejoined UTIA, where he is the Pattern Recognition Department head. His current research interests include random fields applications in pattern recognition and image processing.

In 1957 he got polio, and since 2020 he has been the vice-chair of the Czech Polio Association responsible for its international relations.



Pat McGillion, Polio Survivors Ireland

Occupation: I am a retired Engineering Manager with Ireland's Electricity Supply Board (ESB).

Board Directorship Experience: I have held directorships of a property management company and Training & Development Company. I have also served as Company Secretary of ESOT Ltd, a subsidiary of ESB.

I have been a Board Director of Polio Survivors Ireland since 2014 and served as Treasurer from 2014 to 2017 and Chair of the Board from 2017 – 2021.

Other Governance Experience: I have also completed a course in corporate governance.

Financial Experience: As General Manager of several Business Units within ESB, I had all responsibility for their financial management.

Other Non-Profit Sector Experience: I have been a volunteer with the Irish Charity, St. Vincent De Paul for 20 years.

HR Experience: One of my roles in ESB was manager of Strategic HR Planning. Other relevant roles included responsibility for industrial relations, recruitment and selection and succession planning.

Why I believe I should be elected to the Board of the EPU: I am a polio survivor and with my corporate and voluntary sector experience, I believe I can contribute to the EPU for the benefit of people affected by polio in Europe.

David Mitchell, British Polio Fellowship

I have been involved with the EPU since the GM/Conference in Piestany (Slovakia) in 2016 where I was given a wonderful welcome, typifying the ethos of the members. I became a Director in 2017 for a 3 year period, this being extended for an extra year due to Covid. I have found the work involved to be most interesting, hard, but of value to us Polios. Having the heartfelt respect and gratitude for our founding members, and their



enormous effort and vision which has given us our current reputation. Things change however, and we have reached a level which possibly reflects a plateau from which to operate, possibly as a "Head Office" working with our 19 member Countries, and our 27 Polio Associations. Giving them more of a voice, concentrating more on medical matters and advice EG the links between PPS and Long Covid, and looking to hold our AGMs in member countries. More links with our Eastern European neighbours. Our priority must be to have a data base of medical, physical, and financial benefits available to all Polios in member Countries, and lobby for a PanEuropean standard.



Paul Neuhaus, Bundesverband-Polio e.V, Germany

Professional background: working for more than 30 years in an international bank, from 2001 to 2012 as Senior Vice President in Mergers & Acquisitions. Board Directorship Experience: From 2011 to 2020 I was a board member of the Bundesverband-Polio e.V (Germany) society with more than 3000 members. From 2017 to 2021, board member of the European Polio Union. Financial Experience: working at Dresdner Bank and at Landesbank BW for more than 30 years in finance and risk analysis. Most recently as head of the risk department with 60 employees. Community / Voluntary Sector Experience: since 2011 strategic development in fundraising for selected self-help

groups and charities. Why I believe I should be elected to the Board of the EPU: I am a polio survivor, mobile, with good communication skills and speak several languages (English, Italian, German, Spanish, French). I have a good understanding of the needs of people affected by polio. I have expertise in finance, fundraising and business management. I believe that EPU, as an umbrella organization, should take into account the specific needs of national associations and also give them a voice in a European political environment. I am convinced that a regular interregional exchange between the various polio survivor groups and medical experts in an intraregional European context could facilitate the transfer of know-how across national borders.



Frances Quinn, British Polio Fellowship

I contracted polio in 1957 in Northern Ireland, in hospital for about 2 years; I have muscle loss in both legs and arms though I can walk with sticks. I was a member of the Northern Ireland Polio Fellowship and benefited from swimming sessions and Christmas parties, but didn't keep the membership up as an adult. Like many people, when trying to understand PPS in my 40's, I rejoined the UK British Polio Fellowship.

In 2009, after retiring from a 30 year career in physics research, I took the opportunity to pursue my interest in health and wellbeing, especially for polio. I did an MSc in Exercise and Nutrition and a research project on polio and weight. This led me to joining the BPF expert panel in 2012 and also to attending the recent polio conferences in Australia and Amsterdam. On the BPF expert panel, I co-ordinated the review and production of PPS factsheets and the development of the UK guidelines, 'PPS: A guide to management for healthcare professionals'. I also became a volunteer tutor and assessor for the UK Expert Patient 'Self management for Long Term Conditions', delivering courses to a wide range of people, not just polio survivors.

I applied to be a BPF trustee as there is vital work to do for polio survivors, providing information and support, raising awareness of this often neglected community. There has been huge change in the past few years, and a lot of change still to come and I want to help promote the cause of polio survivors as widely as possible - which is needed now as much as ever.

I am strongly interested in collaboration as we are a relatively small community and I believe we should work together globally to improve the situation of polio survivors. This is my motivation in applying to join the EPU work and helping to build forward again after COVID and Brexit.



Tine Tournicourt, Post-Polio Belgium

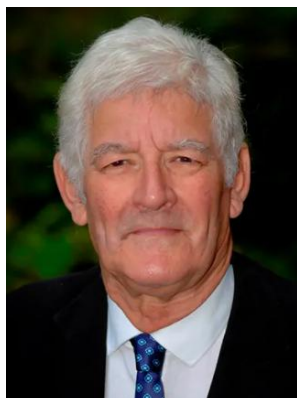
I am a Belgian national, was born in 1954 and had polio when I was 6 months old.

I am the Treasurer of 'POST-POLIO BELGIUM', an association looking after polio survivors in Belgium, and I have been a member of this group since 1996.

As the European Polio Union is an international organisation registered in Belgium according to Belgian law accounts and reporting to the fiscal authorities have to comply with Belgian law and any change in the board of directors have to be reported to the respective Belgian authorities in the language of the country. Being a Belgian and a qualified book-keeper I know the Belgian accounting law and I think I can serve the European Polio Union with their accounts and their reporting to the Belgian authorities.

I am retired and live with my husband in the Flemish part of Belgium, the so-called Westhoek which is close to the French border.

EPU Presidents' Addresses



THE SHORT TERM FUTURE OF THE EPU

If we are fortunate enough to receive the 'tacit' support of our 19 member countries and gain up to 7/9 willing directors then I propose we look at a plan to take us forward for the next six years (2 x 3 year terms for a Board up to the end of 2027). The Statutes/Mems and Arts to remain in place and also the subscription and voting criteria. (I expect that the new Board will discuss and consult on the level and amount of subscription fees.) We have already proposed a 'physical' AGM (2022) in Prague and hope to join the expected 'Polio France' mini conference in 2023, holding our own AGM in tandem. Unfortunately gone are the days when we, the EPU, arranged large and excellent conferences always with a medical theme. So what could our role be?

To be an umbrella organisation with a united voice for European polio survivors giving each member group the opportunity to tell how they operate, aims and objectives.

- To try, again, to ask the Eastern European countries to join us.
- To propose 2/3 newsletters each year.
- To try to revamp and revitalise our website
- To work very closely alongside our medical experts and disseminate new information quickly.
- To continue to hold Board Meetings by 'zoom' or telecom.
- To make Rotary International, Eurordis (The Rare Diseases Group) and other bodies aware of us.
- To ask member organisations if they would co-host our AGM (as is proposed in France in 2023).
- To monitor (with great care) if catching Covid is having a detrimental effect on polio survivors.
- To monitor 'long Covid' and compare any similarities with PPS/LEP and take part in national discussions as to how our experiences can help others.
- To add our voice to any vaccination campaigns – wherever the country.
- To ensure that polio survivors receive their rightful disability/medical benefits. There is great disparity between member countries. Some offer polio survivors holidays, free transport, adapted vehicles, sanatoria and spa treatment, free equipment, free orthotics etc. We need a definitive list of resources/help available and hope to inspire our colleagues in their respective countries to use this information to bargain for better rights and support.

SUMMARY

The superb hard work and vision of those directors who founded and then grew the EPU must not go to waste. We have reached what I consider is our proper level and our new role should be that of a 'head office' holding member groups together with advice and intelligence/information/guidance and help with publicity.

David Mitchell, EPU President



**EUROPEAN POLIO UNION
PRESIDENT'S ADDRESS**

By

Gurli Bechmann Nielsen

**Annual General Meeting
19th November 2021**

The COVID-19 pandemic has affected us all in one way or another and has caused much distress in the broad population as well groups and individual. The polio family has lost many loved and treasured members over the past 20 months, and I fear that there will be more to come who will leave us before their time is due. Polio affects many and all parts of the human body, especially the respiratory system, something the dreaded COVID virus looks to attack with gusto.

Most polio Survivors in Europe have taken every precaution they can to isolate or shield from the general population, hence helping to ensure their safety as far as possible. However, this has led many to feel isolated and cut off or worse forgotten. It has had a profound effect on polio Survivors being able to meet, socialise and talk, something I think you will agree we all do very well. The easing of the pandemic is beginning to allow things to open up and some say get back to normal, whatever normal maybe in the future. We, polio Survivors, have endured and survived polio epidemics, let's ensure we get past this pandemic. In fact, it could be argued, and is in many medical and social quarters that we have much to teach COVID Survivors about how our experiences can benefit them.

The one thing that has allowed some polio support organisations to continue functioning is ZOOM. We have all had to learn new techniques and technologies. I would much prefer that we could all meet physically, share a meal, have a good laugh but it was not to be this year. I'm hoping that will all change for next year but more of that later in the proceedings.

ZOOM, and tele-conferencing, has allowed the Board members of the EPU to communicate regularly, and to overcome many problems. We are aware of the difficulties that EPU member organisations were, and still are, experiencing. All Board members are desperate and committed to keeping this European Polio family together, but we have had severe difficulties, some of which we still haven't managed to overcome yet. One of these was the much hyped and needed revamp of the website. Just when we thought we were getting somewhere the pandemic and lockdown hit! The website was being worked on in different countries and when one exited a lockdown, one of the others entered one. Result is that much work, data and commitment were lost. Then, as some may have realised in the middle of all this the old website "disappeared", due to a hitch much like the one that hit Facebook a few weeks ago. Like Facebook normal service was resumed pretty quickly!

When it was hoped that EPU would participate in the polio conference in Vitoria last year, it was intended to produce a new glossy brochure describing the EPU, introducing its members and generally informing what they do for polio Survivors with regard to Post Polio Syndrome. The EPU formed an agreement with a company in Germany who could undertake the work, indeed they produced a brochure for my own organisation, Polio Denmark, a little while ago. Much depended on advertising, and once again COVID got in the way. The EPU will still be producing a new brochure but

not quite as first envisaged. Someone I know when asked why advertising was scarce replied “polio survivors just aren’t sexy enough”. That was his opinion, you and I may have a different one.

We have managed to keep producing newsletters, indeed there will be another coming out after this AGM. I, and others, must give due acknowledgment and thanks to Stefan Grajcar, Margret Embry and Erika Gehrig in gathering copy for the publication, checking that it could be reproduced, reformatting, proof checking and then getting it out to members – and translation cannot be overlooked. Where would the EPU be without these three stalwarts?

This brings me on to look to the EPU’s future, Margret and Erika are retiring from the Board. Margret has been there right from Johann Bijttebier’s conception of the EPU. Many things have changed and are still doing so since 2007. The age of polio Survivors in Europe is now averaging around 69/70 years. They are not as fit as they used to be, so reluctant to travel, often in their own localities let alone nationally or internationally. So, what lies in the future?

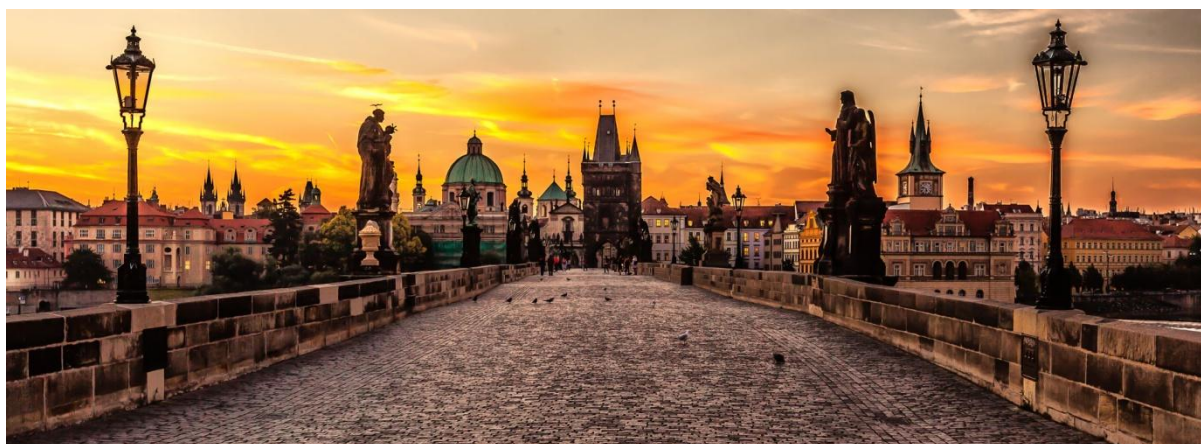
The Polio family in Europe houses a huge body of knowledge about ways of treating PPS, coping mechanism, social effects. All these skills are needed still, not just here but worldwide. There are over 25 million polio Survivors who need that knowledge that reposes in your organisations and communities. It behoves us to ensure it’s not lost. Tragically COVID may provide a lifeline for PPS support groups. Many polio support groups are being approached and asked for advice on how to set up COVID groups. The long-term effects of COVID are unknown and unclear, but the medical professionals are also looking to the polio experience to learn lessons to take the COVID fight forward and not to make the same mistakes they did about polio and PPS. Remember when PPS was denied and all an aberration of our minds!

On the wider polio front it looks as if there will be many fewer polio Survivors in the future with the great news that that dreaded virus that affected us all seems to be near eradication thanks to the Global Polio Eradication Initiative (GPEI). As I write this only one wild case in Pakistan and Afghanistan respectively during 2021. Now perhaps those who funded GPEI, such as Gates Foundation, Warren Buffet, Rotary, WHO and the like will finally wake up and realise there are millions of polio Survivors out there who desperately need help. They may get rid of the virus, but its after-effects will last for decades to come, its time they woke up and listened to our community!

There are so many uncertainties ahead of all of us, your organisations, and the EPU. We, and that means all of us and your wider membership must find a way to drive things forward. The whole polio support movement needs revitalisation from the next generation, my age and physical abilities are against me, hence my decision to retire not just as the President of the EPU but also from its Board. I have seen the toll it has taken on many – we must pass on the baton, the problem is the track in front of me looks very empty. This is the challenge for the new Board and for whomever they elect as the new EPU President.

It has been an absolute privilege to serve as the EPU President and I wish it, all its member organisations and all polio survivors every best wish for the future.

Thank you.



[Source](#)

AGM 2022 in Prague

SAVE THE DATE: JUNE 10th 2022

The 1st announcement of the Annual General Meeting of EPU

The AGM 2022 in Prague will be hosted by the [Czech Polio Association](#). The meeting will be held on **Friday 10th June 2022** in the [hotel Pyramida](#) (Bělohorská 24, 169 00 Praha 6) located in the historical part of Prague just a few minutes' walk from the Prague Castle and 15 minutes drive from the Vaclav Havel Airport. We have reserved a sufficient number of rooms at the hotel for the participants including 4 wheelchair adapted rooms during the workshop period. The fees of hotel reservation should be at the participants' own expenses and we have negotiated with the hotel for the maximum discount.



Please fill in the registration form for the AGM 2022 in the AGM 2022 meeting web <https://www.polio.cz/AGM2022>.

Registration will be open at the beginning of January 2022.

Michal Haindl,
Czech Polio Association

Information for polio survivors

Polio and bone health¹

By Frances Quinn

BPF Expert Panel Member

1. Introduction

As polio survivors, we are very aware of the damage to our motor neurons and the impact that had on our muscles. What may be less well understood is the impact of this on our bones. Due to reduced mobility and weight bearing activity, we have an increased likelihood of lower than average bone mineral density (osteopenia). If the bone mineral density (BMD) is very low, it can lead to very fragile bones which are at risk of fractures, a condition called osteoporosis.

Living our lives with weakened or atrophied muscles also increases the risk of falls. For those with osteoporosis, falls are more likely to result in life-changing fractures.

Best management of these issues is helped by understanding a bit more about the risks, what treatment is available and what changes in our lifestyle can help. These can be simple like looking for and removing trip hazards in our home. Improving the food we eat can support our bone health.

2. Bone growth

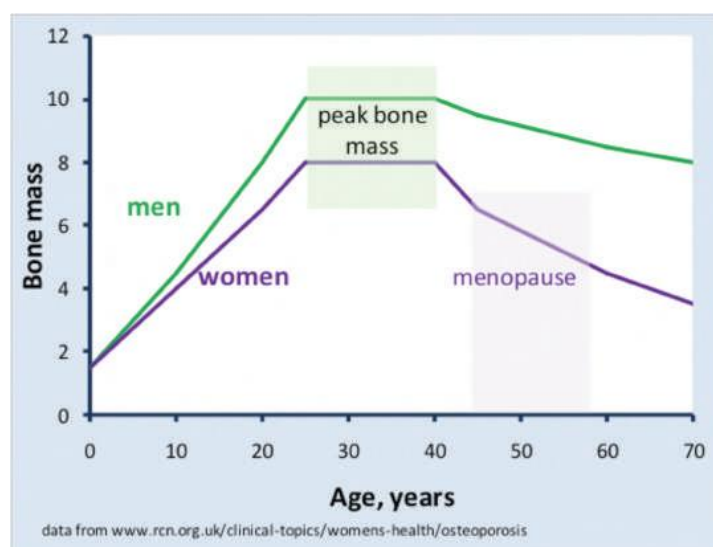
Bones are complex systems made up of compact bone, spongy honeycomb-like bone and are filled with bone marrow. They are living tissue and interact with the rest of the body by a network of blood vessels and nerves, metabolically active and constantly changing. Cells called osteoblasts build new bone and older bone is reabsorbed with the help of cells called osteoclasts. When we are growing, more bone is made than is reabsorbed. Typically, bone mass reaches a peak in the twenties and then reduces from about the forties. Women have lower bone mass than men, and following menopause, this reduces more quickly than for men (see the graph opposite). Weight bearing physical activity stimulates bone formation as does the push and pull of muscle activity.

Bone mass or density that is too low leads to osteoporosis and a risk of 'fragility fractures'. These are defined as fractures following a fall from standing height or less - when normally no damage would be done. In the spine, they may occur as a result of ordinary activities such as bending or lifting.

There are an estimated 3 million people in the UK with osteoporosis, and 300,000 fragility fractures each year. The risk of 'osteoporotic' fractures in the wrist, spine and hip increases strongly after the age of 70, but can occur much younger.

Many things besides low physical activity can affect the health of bones and increase risk. Older age, being female and post menopause, family history, some medicines and some health conditions. Poor nutrition, smoking and alcohol also increase the risk of weakening bones.

¹ Published previously in the BPF Bulletin, Autumn 2021 edition. Permission to publish in the Winter 2021 edition of the EPU Newsletter kindly provided by the BPF and the author.



3. Polio and bone health

People who contracted polio will have had decades of reduced mobility and less weight bearing activity and are thus likely to have lower bone mass than average. The exact effect on bone strength will depend on the degree and location in the body of the motor neuron and muscle loss. It is also possible that areas of the body that are compensating for weaker areas may even have higher bone mass.

A recent study in Ireland looking at bone health in 50 post-polio patients attending outpatients clinics found that 28 (56%) had osteoporosis. This is five times higher than the estimated rate of 10% for the general population of a similar age range. Like other studies in Canada, Turkey and Israel, these show that polio survivors are at increased risk of osteoporosis.

The risk of falls and fractures is also higher than average in polio survivors, and more likely on weaker limbs. Eight out of nine recorded hip fractures in the Irish study were on the weaker leg and resulting from falls from a standing height - fragility fractures. The impact of a fall on daily activities is likely to be greater - it is less likely that another limb can compensate while the injury heals.

The British Polio Fellowship Health Survey carried out in 2013/14 found that 86 (25%) out of 378 members responded that they had either osteoporosis or osteopenia, 70 of whom were women and 16 were men. This number is only those who know they have a low BMD. The published studies suggest many more may be undiagnosed and therefore untreated.

4. Assessment and diagnosis

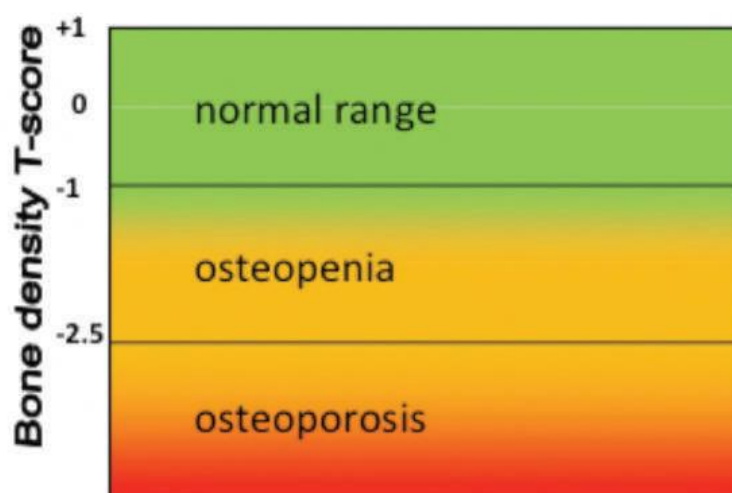
There are rarely any early signs of a problem, or any pain until a fracture occurs. This makes assessment of fracture risk very important. Many factors such as those mentioned earlier will be included in assessing a person's risk.

If you feel you would benefit from a fracture risk assessment, this may be carried out by your GP, or they might refer you to a fracture clinic or a fracture liaison service (FLS: these services are aimed at reducing further fractures in people who have had a fragility fracture). They will ask a series of questions to look at your personal risk of a fracture in the next 10 years. They may use a computer 'tool' to do help with the calculation of risk, such as FRAX or Qfracture. Qfracture includes falls history in its calculation, but FRAX does not, so make sure you tell the health care professional about your falls history and your balance.

As polio survivors have a high risk of falls, a falls risk assessment would also be useful if you haven't already had one.

Following this, you may be referred for a measurement of bone density using DXA (sometimes called DEXA: dual-energy X-ray absorptiometry). This uses low energy X-rays to measure the density of bone – most often in the hip and spine and usually only on one side. People who have had polio should have both sides measured (both hips) as there can be large differences depending on where the muscle loss is greatest. It may also be important to measure other areas such as shoulders and arms. This needs to be discussed with your GP during referral.

For most adults, the results are given as a T score: the difference between your measurement and the average for young healthy adults is calculated as a standard deviation (SD).



Z scores are used for young people who are still growing and is the difference between your measurement and someone of the same age. Above -1 SD is considered normal, below -2.5 SD is defined as osteoporosis.

This score only measures bone density which is related to bone strength, it does not measure the 'quality' of the bone and is only one aspect of assessing risk.

The results will be sent to your doctor who will then advise on any recommended treatments.

5. Non-medical management

Depending on your risk assessment and your preference, you may not be offered a drug treatment. You may be recommended to do a combination of things to reduce your falls risk and/or improve your bone health.

Reducing falls risk

As we know well, and many studies have proved, falls are very common among polio survivors. A recent Swedish survey of people who had polio, average age 69, found that three-quarters had fallen at least once in the previous year, and one quarter had fallen 5 times or more. Two thirds had been injured as a result. 10% who fell had fractures, twice as high as in the general population. They also found that most were afraid of falling, and nearly half had decreased their walking as a result.

Reducing the risk of falls is clearly very important for those with neuromuscular weakness caused by polio. The challenge is to also reduce the fear of falling and to maintain mobility.

A falls prevention assessment and course may help by looking at your home environment, handrails, ensuring well fitting supportive shoes, and checking your eyesight and hearing. Balance training may

also be possible for those who are still mobile and can involve very simple exercises like standing with your eyes closed for short periods. A occupational therapist may be very helpful, especially if they are experienced in supporting people with neurological conditions. Independent Age has a good falls prevention checklist on their website.

Other aspects of post-polio management may help to reduce falls. Managing fatigue by pacing or adapting activities can preserve energy. Addressing any problems that affect sleep such as breathing issues or sleep apnea can improve alertness during the day. Pain management may help ease of mobility.

Keeping muscles warm can help them function at their best. Elsewhere in this Bulletin, the BPF Heating Grants are announced - please apply if you need help to keep warm.

Improving bone health

Look to reduce activities that weaken bones, for example, limiting alcohol consumption and stopping smoking. In the Irish polio study, six out of the seven men who had osteopenia had a history of smoking.

Good nutrition can also help as Angela Reddy describes in the following section.

Physical activity is very important for strong bones. For polio survivors, exercise and physical activity can present great challenges. However, it is important to preserve what activity is possible and reviewing mobility aids and orthotics may help. Any physical activity or exercise programme must be non-fatiguing and pain-free.

Recent studies have investigated whole body vibration therapy to see if it can improve bone health. However, a major US review found very little scientific evidence for benefits or harms. A small 3 month study in Texas (2018) looked at the possibility of using it as a form of weight bearing exercise in polio survivors. While some improvements in walking speed and pain were seen, and no adverse events occurred, this is only a starting point for future study. At present, these machines are not approved for medical use in the US, and are unregulated and with wide variation in design and unclear risks. It may be that after more research, that these might be helpful for polio survivors in the future.

6. Medical Treatment

A wide range of drugs have been shown to increase bone density and reduce fracture risk. These mostly work by reducing the rate of absorption of bone, sometimes called antiresorptive drugs, or by stimulating the growth of bone, called anabolic drugs. Some can do both. The range of drugs and how effective they are is changing all the time - to get the most up to date information it is best to talk to your GP, fracture service or consultant. The Royal Osteoporosis Society has a helpline run by specialist osteoporosis nurses who can provide information.

Bisphosphonates, such as alendronic acid or risedronate, are the most commonly prescribed drugs for treatment of osteoporosis. These slow the rate that bone is broken down. Some are tablets and some have to be injected. The selective oestrogen receptor modulator Raloxifene has a similar effect on bone to oestrogen and helps to maintain BMD. Hormone replacement therapy (HRT) has been shown to keep bones strong, but is rarely used for osteoporosis. Testosterone treatment can be used if the bone loss is caused by low levels of male hormones.

All medications have side effects. These can be quite minor, like irritation of the throat, or more serious. Some have a very rare side effect of causing an atypical fracture of the thigh bone (AFF), or delayed healing of the jaw. These very rare side effects are more common with intravenous drugs and longer term use (greater than 2 to 5 years).

The offered treatment will be based on which one is most appropriate for you, depending on the main cause of the osteoporosis, sex, individual fracture risk assessment without treatment, and previous history. Any drug treatment should be reviewed regularly.

7. Key points

- polio survivors are at increased risk of osteopenia and osteoporosis compared to the general population
- polio survivors have a high incidence of falling and therefore injury and fractures
- Consider talking to your GP about your bone health and fracture risk; include your polio history, your mobility and falls
- A falls risk assessment could be useful – contact your GP surgery to see what they provide
- If referred for a DXA scan, both sides should be measured - measurements should be made where the bones are likely to be weakest; for example both the stronger and weaker hips.
- Look at the simple things you can do to reduce falls risk - use a falls checklist
- Good nutrition can improve bone health and reduce risk
- Stopping smoking and reducing alcohol intake can reduced risk
- Regular review of any recommended management or drug treatment is essential

8. Further information

- NHS website <https://www.nhs.uk/conditions/osteoporosis/treatment/>
- <https://www.nhs.uk/conditions/dexa-scan/>
- Royal Osteoporosis Society <https://theros.org.uk/information-and-support/fact-sheets-andbooklets/> - helpline 0808 800 0035
- The International Osteoporosis Foundation <https://www.osteoporosis.foundation/>
- Independent Age falls prevention checklist <https://www.independentage.org/get-advice/housing-options/how-to-stay-safe-at-home/staying-steady-on-your-feet>
- 'Post-polio Osteoporosis', an article by Dr. Marny Eulberg, with kind permission of the PA Polio Network, USA, <https://www.papolionetwork.org/primary-care-and-pps.html>

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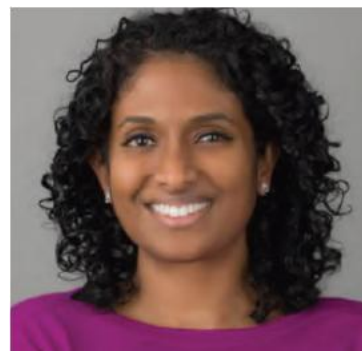
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Nutrition and bone health²

By Angela Reddy

dietician at Guy's and St. Thomas' NHS Foundation Trust, London

Post-polio syndrome (PPS) is strongly associated with an increased risk of osteoporosis. Fifty to eight four percent of adults with PPS experience one or more falls per year. Research shows an increased incidence of osteoporosis and a positive correlation between bone mass and muscle strength in the post-polio population.



Bone is made up of mostly collagen, a protein providing the soft bone framework, and phosphate, a mineral providing the bones hard structure of bone. Ninety-nine percent of the body's calcium is found in bone and teeth, with the resulting 1% found in blood. Bone stores calcium, provides structure, safeguards organs and secures muscle. It is continuously changing with new bone made and old bone broken down. Peak bone mass is reached by the age of 30 with slightly more bone broken down than built after that.

Adequate calcium and vitamin D alongside a healthy balanced diet is required to maintain bone health. The recommended calcium per day is 700-1000 mg for adults in the UK. Vitamin D is vital in bone health as it regulates plasma calcium, promotes calcium absorption from

the bowel, allows bone mineralisation and has a role in muscle function. Low vitamin D status is associated with an increased risk of falls. Vitamin D deficiency therefore promotes bone demineralisation by mobilising calcium from the bone due to the low plasma calcium and phosphate, thereby weakening the bone and leading to osteomalacia/rickets. The recommended vitamin D intake in the UK is 10 micrograms or 400 international units for the general population.

Low oral intakes and nutritional deficiencies, mainly of calcium, vitamin D and phosphorus can lead to fragile, poorly mineralised bones forming. Furthermore a lack of sunlight exposure and adiposity or high body mass index worsens bone health. Nutritional deficiency symptoms include aching bones, fatigue, vague aches and pains, generally feeling unwell, muscle weakness or twitching and light headedness. No symptoms can also describe a nutritional deficiency. Further risk factors of osteoporosis include advanced age, female gender, familial predisposition, smoking, heavy alcohol intake, and reduced physical activity and muscle weakness.

Vitamin D sources include oily fish, liver, meat, eggs, margarine, fortified breakfast cereals and orange juice and our skin, with over 90% of people's vitamin D requirements deriving from sun exposure. Darker skin requires longer exposure to sunlight to make the same amount of vitamin D as those with lighter skin. Moreover, a 70 year old will make a quarter of vitamin D than that of a 20 year old when exposed to the same amount of sunlight. It is best to get calcium from food. Dietary sources include milk, cheese, yoghurts, sardines and pilchards (with bones), tinned salmon,

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whitebait, bread, broccoli and kale and fortified foods. Note that low-fat dairy foods have the same amount of calcium as the fullfat versions.

Regular monitoring of serum vitamin D and adjusted calcium is recommended. At risk groups are advised to take daily vitamin D supplements of not more than 10 micrograms all year round⁴. However first speak to your doctor, dietician or pharmacist if you are concerned about adequate vitamin D, calcium and phosphorus. Furthermore high vitamin supplement intakes can cause toxicity.



The Brain and Post-Polio Syndrome

Peter Brauer MD

Polio-Encephalo-Myelitis manifests itself as an infection and disease causing permanent damage to the central nervous system (CNS), i.e. always in the brain, mostly in the spinal cord and often in the spinal ganglia.

That is why it is considered a **neurological disease**. A polio infection is always associated with brain inflammation, therefore encephalitic (BODIAN). The damage is predominantly subliminal, hidden therefore subclinical – because if up to 50% of nerve cells are lost (destroyed) in a functional area, the remaining healthy and previously damaged nerve cells take over the function of the destroyed ones to compensate the loss.

This means that they are permanently (chronically) overloaded with an up to ten times load compared to normal performance requirement. If equilibrium and recovery are no longer possible, there will be permanent functional failure and structural loss, nerve cell death: the post-polio syndrome as a long-term consequence of a polio infection with and without previous clinical disease.

This process is best researched or rather more explained for the spinal cord in the neuromuscular system. The nerve connections of muscles, which have been destroyed by the polio viruses, are supplied with new supplies of nerve sprouts from neighbouring nerves and thereby retain their muscle functionality. However, the connections are not stable. They are subject to constant dismantling and reconstruction, the capacity of which is finite. The nerves overloaded in this way die depending on the size and duration of the overload as well as the limited ability to compensate for a particular different period of time.

Muscles that are no longer provided recede, they shrink and atrophy. This results in functional weaknesses and functional failures in the form of paralysis. Furthermore, a reduced muscle mass is also overloaded if the performance requirements remain the same. It tries to compensate for the resulting reduction in performance by increasing the muscle tissue through hypertrophy, whereby the metabolic apparatus does not grow to the same extent and is consequently more prone to overload. But even this process is only possible to a limited extent. If the performance limit is continuously exceeded, the result is ultimately a state of muscular failure and muscle dystrophy. The clinically symptomatic post-polio syndrome in the muscular area, which is peripheral in appearance, therefore has a neurological and a muscular root.

The fewest and often the most serious long-term effects are, however, due to pathological changes (alterations) affecting the spinal cord. After a polio infection and a polio disease, nerve cell damage and destruction also occurs in the brain. This raises the question of possible compensation

mechanisms in this area. After surviving a polio illness, it should be noted that there is much less visible permanent consequential damage to the brain than to the spinal cord.

Analogous to the neuromuscular system, a similar compensatory process would be assumed in the case of polio-related destruction of nerve cells. The takeover of functions by neighbouring cell formations within the functional complex via a re-networking by forming new connection points – the synapses as neural interconnection and signal paths, a facilitation is therefore conceivable. Given the enormous number of nerve cells in the brain, around 100 billion in the cerebrum and around 100 billion in the cerebellum, each with 100 billion synapses (contact points), and assuming the compensation limit of a 50% cell loss in a functional area, most of the damage inevitably remains subliminal.

But the performance of the brain also has its limits. An overload with functional weakness up to the rare occurrence of complete loss of function is consequently possible. This opens up a wide range of possible functional disorders with a multitude of possible symptoms for brain-related symptoms of a post-polio syndrome. The pathological-anatomically proven numerous random damage areas caused by polio viruses (BRAUER) in this regard, currently still exceed the imagination of their functional effects and are in stark contrast to the relatively seldom observed and / or acknowledged disorders.

Since there is apparently no interest currently in specific polio-related research in this area, it is important to focus on fundamental findings on the subject of **neuronal and brain plasticity**, the **adaptive and compensatory capacity of the nervous system**, including the brain, of other origins. The idea of including fundamental findings from problem-related areas and examining them for applicable conclusions is by no means new (BOLLENBACH).

As with motor nerve cells in the spinal cord, the nerve cells in the brain also try to functionally compensate for neighbouring defects. (HARSIEBER), (SCHAEFERS). The brain has many more compensatory options, so-called compensation mechanisms, than the peripheral neuromuscular apparatus. The ability to adapt to new requirements of any kind, including the replacement of lost functions even of a larger scale, is referred to as neuronal plasticity or neuroplasticity. This is much greater with children than adults, although the brain can still be restructured at any age (DOIDGE) (HAAS), which also explains the clinically favourable convalescence course.

A distinction must be made between synaptic plasticity, which affects nerve cell contact, and cortical plasticity, which affects the cerebral cortex. Cortical areas on the latter are also not involved. The term **cerebral plasticity**, which affects the whole brain, would therefore be correct. **Synaptic plasticity** is understood to mean anatomical-structural and functional synaptic changes, while **cortical plasticity** is the adaptation, reallocation and expansion of brain areas, as well as the reorganization of neural networks (GRAFMAN in MERGNER), whereby synaptic plasticity can also be found in the complex of cortical plasticity (MAYER), (BECK). On the other hand, a distinction is also made between **functional** and **structural neuroplasticity** (SCHAEFERS).

The peripheral neuromuscular component is a synaptic component: New nerve connections to the successful organ muscle are formed through sprouts from neighbouring nerves – in the narrower sense an axonal neuro genetic regenerative synaptic plasticity based on neural new growth, in contrast to functional synaptic, facilitation plasticity with a change in the synaptic scope of functions (HOLDERBACH), which is associated to a change in the existing structure (SPITZER).

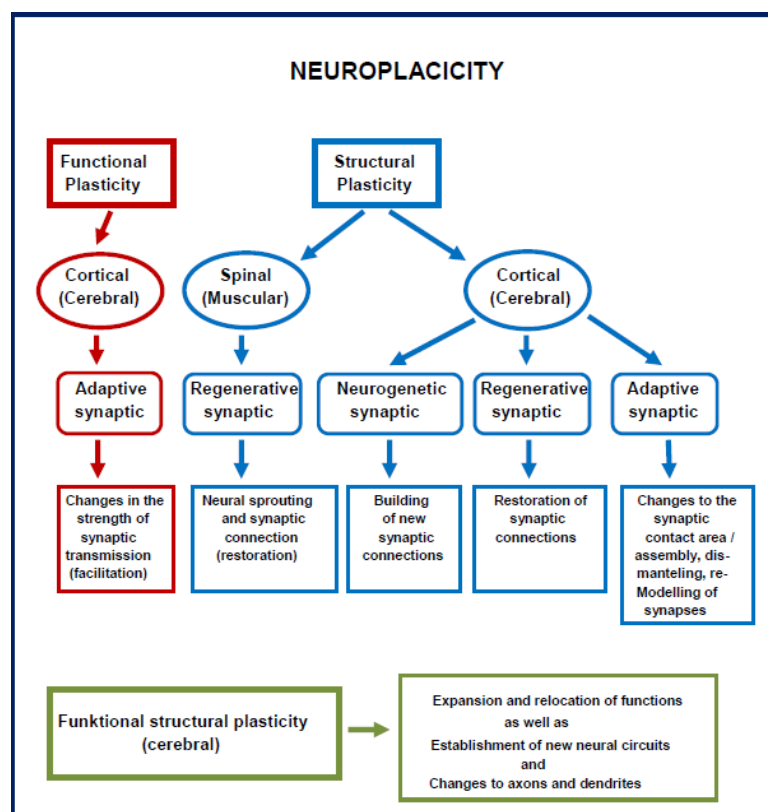
In contrast to this, the compensation process in the brain through regeneration and reshaping (HAAS), is far more diverse. The **brain** has the **ability to repair itself** (GAGE) (DOIDGE). Sprouts forming new synaptic connections are also described here (MAYER), (BECK). Distinctive scar tissue can hinder this process (BECK). Regeneration and restoration of synaptic connections after nerve cell

injuries can also be assumed (BECK). The synaptic changes are of particular importance with regard to their facilitation differentiated conduction capacity, meaning their size and functional scope depending on the amount of repeatedly transmitted signals (SPITZER).

To what extent this could play a role in with functional compensation – functional balance after local neurological damage – is still open. However, such a process per se is conceivable. In addition, a function in the brain can be relocated or expanded locally. (*Wikipedia: Neuronale Plastizität*).

The cerebellum can even take over the tasks of the cerebral cortex (HAAS). New neural circuits establish autonomously (MAYER). Overall though, the formation of new synaptic connections plays an essential role (MAYER). Even the lifelong (probably limited in scope) new formation of nerve cells (several thousand daily) (BLECH), from neural stem cells of the brain, is now being discussed in the meantime on a basis of scientific studies (GAGE), (HARSIEBER), (TREPPEL) and (SCHÄFFERS).

They are localized in the brain areas of the hippocampus and the olfactory bulb and have been detected beyond the age of 70 (BISCHOFBERGER et al.), (ERIKSSON et al.), (KEMPERMANN et al.), (RAY) and (SCHÄFFERS). Accordingly, maturing neural stem cells can even migrate from their place of formation to other brain regions (TREPPEL). However, due to their locally very limited occurrence in the brain they are most likely of subordinate importance for general reconstitution and regeneration processes on a larger scale. It has not yet been clarified whether they also serve as a substitute for neuronal loss (STREPPEL).



(Figure modified from: www.gehirnlernen.de/gehirn/plastizität/)

Information or signals (impulses) are passed on from one nerve cell to the other not only via their nerve cell extensions, the neurites, but also via contact points from nerve fibres (axon = nerve cell extension with covering) to dendrites (axon-dendritic synapses), the stimulus-receiving inhibitory function of nerve extensions as **protection of the brain** from overload. Short-term neuro-plastic reactions in this area are also possible (ÄRZTE ZEITUNG). Other protections against brain overload

are the endogenous cannabinoids with their dampening effect on the neural system (MARSICANO et al.).

Cerebral reorganizations concerning the brain serve to optimize and protect a function and suggest the assumption that similar processes are also subject to maintaining a function or a takeover of functions after failures. There are limits to these processes. An excessive demand leads to limitations in performance with negative psychological and vegetative consequences (HOLLMANN et al.), ultimately also physical consequences. Commonly used drugs such as opiates, antidepressants, glucocorticoids and others inhibit neurogenesis (BLECH). This results (with polio-related pre-damage to the subclinical cerebral) in brain-related development of the post-polio syndrome up to the clinical manifestation of this overstrain syndrome. Neural plasticity is therefore an opportunity and a risk at the same time.

Conclusion

The brief overview above clarifies the problems concerning the verification and the diagnostic confirmatory clarification of a post-polio syndrome, especially its cerebral parts. Most of the polio-related neurological damage largely eludes objective evidence. This is particularly true of the brain. In the brain itself however, extensive compensatory and protective mechanisms conceal the true magnitude of the primary polio damage that ultimately leads to the post-polio syndrome, its development and existence, as its indirect cause cannot be diagnosed. On the other hand, these findings can also contribute to a better understanding of the diverse clinical picture of this late-stage polio, without the causal processes, especially the molecular biological ones being clarified in every detail. Currently, for neurological diseases and especially for the post-polio syndrome in general, no reliable therapeutic expectations can be seen for the foreseeable future.

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HM European Polio Union

German ⇒ English translation: Thomas House-Arno (Tom House)

15th September 2021

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The Distinctive Post-Polio Syndrome (PPS)

Peter Brauer MD

The assessment of PPS as a rule is primarily based on external appearances followed by further clarification if necessary, with subsequent deeper delving into methodological subtleties. The external appearance can correspond to various existential conditions, therefore not secure in an individual definition. As a consequence, it is apparently advisable to create differentiated overall images and to characterize them as complexes, as even if they are only slightly different they may nevertheless require individual approaches with differing actionable consequences.

In the coded definition of the present case of the post-polio syndrome disease, it is essential to perceive the polio late-effects as a separate, causally clearly defined clinical picture and not to group it symptomatically in a comparative clinical picture manner. On the basis of the predominantly multiple manifestations in the central nervous system and the cause as neurological wear and tear proceeding throughout the dependent organ functions, symptomatic splitting in the direction of symptoms that appear to be superficially similar to clinical pictures is forbidden.

Even with a post-viral fatigue syndrome, causal equality is not guaranteed. Fatigue can be medication-related, the result of heavy wasting, so-called consumption disease, the functional weakening of structurally and functionally damaged structure, the result of functionally overstrained structure, but also the result of central nervous functional and regulation weaknesses or disorders. This approach is solely from a differential therapeutic point of view, especially regarding the risks involved.

In addition, the reduction based on selected symptoms leads to an increased risk of misdiagnosis, which in turn leads to incorrect treatment. The previously planned incorrect grouping into the two diagnosis groups 8B62 (PPMA) and IG83 (Sequelae of poliomyelitis) is a medical absurdum and inevitably promotes the widespread arrogant ignorance of the post-polio syndrome.

As we see it – from the point of view of the polio survivors – the planned revision of the coding was initiated bypassing those affected and their interest representatives and apparently serves purely bureaucratic technical purposes, neglecting the medical aspects.

The aim must be to obtain a code of its own for the post-polio syndrome. PPMA is a symptom based on the degeneration of absolutely, as well as relatively functionally and structurally overloaded nerve cells after their polio-related destruction, previous damage and reduction in number.

The term post-polio syndrome is also used as a synonym. According to the diagnostic criteria, this diagnosis is one-sided and incorrectly characterized with its focus on the motoric area. At the same time it would overlap as an (indirect) polio consequence with the code IG83 (consequences of poliomyelitis).

However, these are seen as residual states of poliomyelitis with the starting point of a development from the acute polio infection or from chronic polio-related deficits as a result. Thereby, the latter can only appear in the later life of the polio survivor. Polio long-term effects are cited thereby as a synonym. Examples are degenerative joint inflammation, sleep disorders, respiratory problems and various mental or, probably also meant – psychological disorders.

Again, these are symptoms, which in this context are not causally related in any way, whereby the intellect is to be excluded anyway. The unity of complexity and compactness of the post-polio syndrome, which is still given with code G 14, is thereby completely lost.

Conclusion:

The post-polio syndrome is unmistakably a long-term consequence of polio and is no longer as such correctly reproduced in the definition of the planned new ICD 11 coding.

Peter Brauer MD

HM European Polio Union

German ⇒ English translation: Thomas House-Arno (Tom House)

15th September 2021

Excerpts from: ICD-11 - 11. ICD Revision by the WHO

ICD -11 - 11th revision of the WHO ICD. (c) DIMDI. The ICD is used worldwide to encrypt diagnoses. The currently valid revision is the ICD -10.

The aim of the 11th revision

The main reasons for a revision of the ICD was the desire to be able to encode specific issues in a more differentiated manner than before, and the need to adapt the ICD to the needs of digitized health systems.

The aim was to create classifications for different areas of application as an international standard for science, communication and medical information on a coherent database. The simple integration into IT system environments were also to be ensured for the future.

Aspects for Germany

The WHO ICD-10 is used in Germany to code the causes of death for the international cause of death statistics. As a modified ICD-10-GM (German Modification), it is used to code morbidity in many application systems. Many established processes are based on the ICD-10-GM: e.g. billing of inpatient and outpatient services, morbidity-oriented risk structure compensation, quality assurance, epidemiology and statistics.

While adopting the ICD-11 for coding the cause of death is comparatively easy to implement, adopting the coding for morbidity generally requires various national adaptations. This also applies to Germany.

Study: Patient Survey on the Post-Polio Syndrome

Prof. Iris Zöllner MD & Peter Brauer MD

We would like to draw your attention here to the study of the *Baden-Württemberg State Health Office* under the lead management of Prof. Iris Zöllner MD and employees in cooperation with the *Bundesverband Poliomyelitis e.V. – Landesverband Baden-Württemberg*.

Link address to the German Post-Polio-Syndrome Survey– Baden... State Health Office (in German language):

<https://www.gesundheitsamt-bw.de › LGA › Befragung...>

(Results of a survey on the post-polio syndrome, the long-term late effects of the polio-myelitis disease – April 2020.)

The main aim of this study was to convey the epidemiological scope and characteristics of the post-polio syndrome as a late sequels of polio for basic information, especially for employees including decision-makers in the health care system.

For orientation purposes and with the kind permission of Prof. Zöllner MD, the summary of the study is shown below in *italics* and **bold type**.

4. Summary and Outlook

4.1. Summary of Results

A total of 379 persons took part in the post-polio syndrome survey. During the survey period most of the study participants were between the ages of 60 to 79 years old.

Most of the participants were living with a family at the time of the study. A third of the participants lived as single persons and one in 20 participants lived in an assisted living arrangement. At the time of the study, a sixth of the participants were still working, half of them full-time. The majority of those questioned were retired.

4.2 Results concerning the Poliomyelitis Disease

Most of the participants contracted the poliomyelitis infection between the ages of one and two. The majority stated that when they contracted poliomyelitis in childhood they had paralysis of the legs and trunk (with or without respiratory effects). Approximately one in three participants also had paralysis of the arms. Every tenth participant had difficulty swallowing or speaking due to poliomyelitis. Ventilation via an "iron lung" was required for every thirteenth participant. However, the actual proportion of these could also have been higher, since the question concerning the "iron lung" was answered by a relatively large number of people with "don't know" or "not at all".

Almost all of the participants had experienced a hospital stay due to the polio infection. Most people were hospitalized for months up to a year. The longest hospital stays lasted for several years.

4.3 Post-polio syndrome study results

The first symptoms of the post-polio syndrome appeared with most of the participants between the ages of 40 to 60 years. The first symptoms developed gradually in the majority of those

questioned. In contrast, every eighth affected experienced a sudden onset of the first post-polio symptoms.

The first symptoms for almost all of the participants included decreased load bearing, muscle weakness and muscle paralysis. For three quarters of the participants, there were also restrictions in daily activities such as running, climbing stairs, getting dressed, personal hygiene, etc. as well as states of exhaustion that could not always be explained from load stress. Around two thirds of all participants had muscle, joint or bone pain. The first symptoms were often defined as a pronounced sensitivity to cold, muscle cramps and muscle twitching. Among the first symptoms, every fourth participant experienced respirational disorders and every fifth affected person experienced swallowing and speech disorders, inter alia.

It often took several years from the appearance of the first symptoms to the final diagnosis of the "post-polio syndrome". About half of the participants stated a period of 0-9 years. One in six participants took 10-19 years until diagnosis, and almost one in ten participants even took more than 20 years to be diagnosed with the post-polio syndrome.

Two thirds of the participants had seen up to four doctors from the onset of the first post-polio symptoms to the diagnosis of the post-polio syndrome. About five percent of those affected had seen five to ten doctors before the post-polio diagnosis was made. Every thirteenth sufferer had even seen more than ten doctors before the diagnosis of post-polio syndrome was made.

The diagnoses (or similar) most frequently made according to the free text information provided by the participants were: post-polio syndrome (of which in about every third case "late" was diagnosed), "simulant" or "hypochondriac", rheumatic disease, overload or improper strain, aging symptoms, no diagnosis / "doctor clueless", nerve diseases, bone diseases, polio-(myelitis), late effects after poliomyelitis (ICD code: B91), diseases of the knee / spine, general weakness, under-strain and inflammation such as otitis or (poly-)myositis. In addition, further diagnostic groups were made such as paralysis of body parts, stiffness, cardiovascular problems, fibromyalgia, nerve entrapment, breathing disorders / sleep apnea, lung diseases or the result of falls. Cancer diagnoses, HIV / AIDS or diabetes were made less frequently. Since the first post-polio symptoms are usually not very specific and the diagnosis "post-polio syndrome" (G14) is more of a diagnosis of exclusion, in view of the results shown in Tables 6 and 8*, it can therefore be assumed that there could be quite a number of post-polio sufferers who have received similar diagnoses as in Table 8* - without knowing that they may also be affected by the post-polio syndrome. * (Remark: See the 58 page German study)*

When asked about their health situation at the time of the surveys, most of the participants stated muscle weakness in the legs and arms. Muscle weakness in the trunk was also reported by almost two-thirds of all participants, the majority of which were also respiration related. Almost one in four participants had difficulty swallowing and / or speaking. Almost a tenth of all participants required breathing apparatus.

Most of the participants had muscle pain after exertion, and almost half had such pain even whilst resting. These pains mainly occurred in the legs, shoulders, neck and trunk. Almost half of the participants also reported muscle pain in their arms.

Almost three quarters of those surveyed had joint pain after exertion, and many also experienced such pain whilst resting. Every second person had nerve pain after exertion, although most of those affected also experienced this pain whilst resting.

Four out of ten participants reported respiratory problems after exertion. One seventh of all participants reported respiratory problems even whilst resting.

When asked: “compared to last year, how would you describe your current state of health?”. A quarter of the participants answered “currently much better than a year ago”, “currently a little better than a year ago” or “about the same as a year ago”. Three quarters of the participants were a little worse off at the time of the survey or much worse off than the year before.

Difficulty walking is often one of the possible consequences of the post-polio syndrome. Three quarters of those questioned reported having difficulty walking on level ground. The walking distance to be covered without a break was less than 100 meters for almost every third participant. Nearly every fifth participant was able to walk more than 1000 meters without a break.

The majority of participants reported having difficulty climbing stairs. Two out of three participants stated sensitivity to cold as a symptom that occurs in their everyday life. The proportion of participants who stated sudden states of exhaustion experiences in everyday life was similarly high.

Six out of ten participants stated they needed help around the house. One in four participants required help with personal hygiene. One in four participants required both household help and personal hygiene help. About half of the participants received help from family members. One in eight people surveyed needed the help of a nursing service. Almost a tenth of those surveyed received help from a nursing service and family members.

114 of the 379 participants had past experience problems with anesthesia at least once and 50 participants had already experienced problems with dental treatments.

The most frequently used therapies and measures given were physiotherapy and swimming. Rehabilitation stay(s) to prevent an early need for care were stated by around two thirds of the participants. In most cases, the stays were in patients. Some of the participants had received an outpatient rehab measure.

The aids used in everyday life by many of those affected included wheelchairs, orthopedic shoes, orthotics, structural changes in the living area, hand-/ walking sticks, and car modifications.

4.4 Prospects

The results of the present study concerning the situation of those affected by post-polio, are intended to contribute to informing the public and those working in the health care system, about the post-polio syndrome, as there is currently very little known by the public about the symptoms and peculiarities of the consequences of a previous illness from poliomyelitis (Polio). The "childhood disease" poliomyelitis is now rare thanks to the possibility of vaccination and is only endemic in a few countries. Some of the knowledge about poliomyelitis has been lost. Even less well-known is that even healthcare professionals are unaware of the fact that decades after a polio infection symptoms known as a post-polio syndrome can appear. Misdiagnosis and mix-ups with other chronic diseases can have serious consequences in the treatment for those affected and, in the worst case, even harm them. It is therefore important that doctors and other healthcare stakeholders are informed about the post-polio syndrome.

From the results available to-date on the post-polio syndrome, there is a need for further research into the causes, possible influencing factors and treatment options for the post-polio syndrome.

In an article on the topic “post-polio syndrome: Eine häufig übersehene Entität” (An often overlooked entity), Rüdiger Meyer wrote in the German Deutsches Ärzteblatt (2000):

“The information on the frequency of the post-polio syndrome (PPS) varies between 20 and 80 percent of all patients after spinal poliomyelitis. According to this, there should be between 10,000 and 50,000 PPS patients in Germany. However, the diagnosis is seldom made for three reasons:

First, it is no longer certain with many patients today whether they really had poliomyelitis. ... Most patients are therefore likely to be receiving neurological, orthopedic or internal treatment without the consideration of a possible post-polio syndrome. Of course, the patients would benefit from the correct diagnosis, even if there is currently no reliable knowledge about specific treatment options."

There is still a lack of controlled studies for possible treatment approaches as well as long-term investigations, e.g. the effectiveness of physical therapies such as gentle physiotherapy adapted to individual performance (see Rüdiger Meyer, Dtsch. Ärztebl. 2000, 97 (7) A 357-358 / B 301 / C 281).

An international controlled study on the treatment of the post-polio syndrome with intravenous immunoglobulins (FORCE) is currently being carried out, whereby four German study centers in Hanover, Jena, Koblenz and Munster are also involved. The recruitment of participants has not yet been completed, so those interested in participating can register at these study centers:

- *Hannover Medical School (Medizinische Hochschule), special outpatient clinic for Neuromuscular Diseases Head: Prof. Susanne Petri MD*
- *Jena University Hospital, Department of Neurology, PD Julian Grosskreutz MD*
- *Clinic for Conservative Orthopedics & Polio Center Koblenz, Axel Ruetz MD*
- *University Hospital Münster, Neurology, PD Matthias Boentert MD*

Further information (in German) on the study can be found at:

<https://www.polio-initiative-europa.de/forschung/studien>.

In conversations with those affected with the post-polio syndrome, it became clear over and over again, that great importance is attached to informing younger generations about poliomyelitis as a disease and to point out the importance of poliomyelitis vaccinations for the health of the population, which should not be underestimated.

In this sense the major issue of this report is to inform decision-makers in health care and politics as well as the public about the post-polio syndrome and to draw attention to the need for action and research on this topic.

Comment

The unspecific symptoms of the post-polio syndrome and the widespread lack of knowledge about poliomyelitis and its long-term effects are highlighted as diagnostic difficulties in the study as such. The study confirms the findings of the anamnesis as the basis of the diagnosis, which is already known to informed insiders, because the study is nothing else. The questioning shows the predominantly required active procedure of the consulted medical practitioner when assessing the medical history.

Clinical as well as para-clinical findings play a very subordinate role here, as there are neither conclusive symptoms nor conclusive findings. There is a particular need for research into causes and specific therapy to be questioned. The pathological anatomical works of David BODIAN and the works of Richard BRUNO as well as many others are sufficient to clearly clarify the genesis of the post-polio syndrome. The only possible and necessary symptomatic therapy is derived from this. The very promisingly recommended treatment with immunoglobulins is already regarded as inadequate and as unreproducible and generalizing, especially since the sequelae polio late effects is not a primarily immunological process, as is sometimes assumed, but a neurologically degenerative process due to functional and structural disorders with overload and subsequent physiological immune reaction. While the motor area appears to be overrated, sensitivity, emotionality and vegetative forms unfortunately remain in the background. Overall, the clear and informative study is

to be rated very positively as an essential step towards a better understanding of the post-polio syndrome with its multifaceted and complexed differential diagnosis and symptoms. It is highly suitable for making a decisive contribution to the diagnosis of individual cases from the comprehensive symptomatic survey. From this point of view, health professions in the broadest sense right up to the major health authorities are the main addressees of the information.

German ⇒ English translation: Thomas House-Arno (Tom House)
15th September 2021
(The study comprises 58 pages.)



Merry Christmas and a Happy New Year 2022!

☺ EPU Board ☺

GOOD NEWS – WE SINCERELY HOPE!!

Although Poliomyelitis is now eradicated in all of the 19 member countries of the EPU, the directors (nine of us at present) take a keen and obviously personal interest in what is happening in the two countries where polio, a cruel and life-changing disease, is still endemic (Afghanistan and Pakistan). The splendid current news is that, after an ‘observation period’ of four years, Africa has at last been declared free of polio’s main viral infection – wild poliovirus type 1 (WPV1) in all of its 29 countries! This is as a result of the vaccination programme, an enormous task carried out by the World Health Organisation, the health authorities of the individual countries, Rotary International and, of course, the Bill and Melinda Gates Foundation. This Foundation so far has donated nearly \$5 billion to fund eradication and continues to do so. Obviously, a host of other charities have also added their weight to our fight – the Red Cross, Oxfam, Médecins Sans Frontières, etc.

Prime movers behind the worldwide fight to conquer polio are the Partners in the Global Polio Eradication Initiative (GPEI) launched in 1988. A huge amount of information about the GPEI is easily available on the Internet and they are great champions of the ‘Novel Oral Polio Vaccine type 2’. Unfortunately, many cases of cVDPV2 (circulating vaccine derived polio Type 2) are reported every week (eg 28 in six African countries w/e 8/11/21) with only 43 cases so far in Afghanistan and just eight cases in Pakistan, which is very, very good news. This compares with 308 and 136 cases recorded in the two countries in 2020, in other words, only 51 cases so far this year compared to 444 last year. What a way to have celebrated World Polio Day in October!

The good news continues with amazing figures from child vaccination flooding in, eg one million youngsters receiving the vaccination in just four days in Nigeria, which used to be one of the world’s hot spots. Money of course is needed to organise such huge projects and Germany, for instance, has just given €35 million as part of its annual contribution. The last virtual annual meeting of the GPEI raised many billions to fund eradication (UNICEF must also be singled out as great organisers of local medical programmes).

To conclude, I said in my opening lines that we sincerely hope for good news. Local wars and conflicts can wreak havoc with polio initiatives (e.g. out breaks in the Syrian refugee camps, the desperate situation in the Yemen and, of course, the return of the Taliban in Afghanistan. My Director colleague, Erika Gehrig from Switzerland, has already expressed her fears that the Taliban ideology will prevent women (who have mainly carried out vast vaccination programmes) from such work in the future in Afghanistan. We will not know any results until early 2022 and just hope and pray that the good work goes on and that soon polio will have died out.

[Note: In 1988 polio was present in more than 125 countries and paralysed more than 1,000 children every day. Immunisation has reached nearly three billion youngsters since then.]

David Mitchell

Director, European Polio Union
Member of the British Polio Fellowship

Global Polio Eradication Initiative organised by SIPS

1. POLIO TULIPS in support of polio eradication

Last spring we organised a wonderful "End Polio Now", tulip field on the flower show in Morges. It was also a Jubilee show. We were very much looking forward to this show. Unfortunately it was cancelled because of Covid.

We then made a lot of propaganda to sell the wonderful cards "End Polio Now Tulip" painted by Dutch artist Miek Verdegaal. Commissioned by Rotary/Switzerland/Liechtenstein. I have been informed that the original painting by the artist will be sold at WHO/Rotary Geneva. Through the purchase of this card, 12 children will be vaccinated against polio.

2. Sale of Tulip Bulbs

During the Summer months we were informed by Edy Bucher, a former board member of SIPS that we should ask our Polio Survivors to order Polio Tulip Bulbs. We informed our members immediately. What Switzerland is concerned we all incl. SIPS, private people of the French speaking part and Rotary members bought a total of 706 Boxes which amounts to CHF 46'600.-- together with the Bill and Melinda trust. That means 93200 children can be vaccinated.



3. Sale of the wonderful nut tarts made by Giacometti Lavin/GR Switzerland

As the sale of these nut tarts were such a success last year, WHO/Rotary GPEI decided to continue the sale again this winter until Easter 2022. SIPS alone ordered so far over 400 tarts and until now 1000 tarts have been delivered through the efforts of SIPS, Edy Bucher and Rotary. The orders are still coming in.

For every tart sold, 60 children can be vaccinated. We appreciate it very much that private persons, companies, friends, organisations are supporting us so fantastic.

Together, let us achieve something historic! Let us make sure that no child will ever again be paralysed by polio.

4. Doctors and Post Polio

My husband Claus and I sent about 15 tarts to various Doctors who know something about polio. We asked them to read our flyer and see whether they can inform young Doctors. Our two pensioned Polio Doctors have worked so much and still inform us by telephone, but cannot have patients visiting them.

We really are in a desperate situation. Many other members of EPU have the exact same problems. Let's all work on this.

Wishing you all a Merry Christmas and a Happy New Year!

Erika Gehrig,

Schweizerische Interessengemeinschaft für das Post-Polio Syndrom

World Polio Day 2021 reflected by EPU Member organisations

Czech Republic

The 2021 World polio day was promoted in the Czech Republic mainly by the [National Institute of Public Health](#) on its Czech [web pages](#) and several radio broadcastings. For example, Czech Radio 2 broadcasted Allan Marshall's famous work I Can Jump Puddles Again, also successfully filmed by the Czech film director Karel Kachyna in 1970 (in Czech language "[Už zase skáču přes kaluže](#)").

Michal Haindl, EPU Board member; Czech Polio Association

Belgium, AccessAndGo-ABP

Our association does not organise any activities but we highlight those organised by other associations such as Rotary or Handicap International.

<https://www.facebook.com/accessandgoabp/posts/898144410863407>

Emilie Cohrs, Responsible communication

France, Polio France (GLIP)

For Polio Day, our Ambassador Adda Abdelli has made a short video which we shared as much as possible . It says that he does not really wish a happy birthday to his polio, that most of us are getting old but that we are here still and still fighting and that we managed to live with polio.

Adda Abdelli is the main actor in a TV program entitled "vestiaires" (cloakrooms) taking place in a swimming-pool with people with different disabilities. All dialogues are full of humor.

Sylvie Tararbit, Polio-France

Varia

Polio & Us – 2021 edition now available

Polio Survivors Ireland is thrilled to have its 2021 edition of the book ‘Polio & Us’ hot off the presses. First published in 2007, the book consists of the personal stories of polio survivors in Ireland.

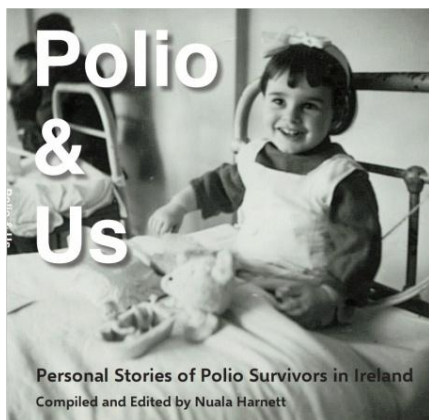
Polio & Us was originally coordinated by member, Paula Lahiff and edited by the late Nuala Harnett. Along with Nuala, a number of the contributors have sadly passed on. However, the new production remains faithful to the original edition. It is a testament to the work of Nuala Harnett and the personal and detailed stories it contains, which should not be forgotten.

By re-publishing the book, Polio Survivors Ireland strives to highlight the legacy of polio. Its release will be complemented with some media activity in the new year.

The book will be available to purchase on our website, www.polio.ie or via the office, 00 353 1 889 8920, or by writing to Polio Survivors Ireland, Unit 319, Capel Buildings, Mary’s Abbey, Dublin 7.

The book is wonderfully summed up by its cover photo of polio survivor and member, Jackie Minnock as a child - the essence of positivity and resilience.

Our thanks to everyone who supported this project once again.



Words to the Virus Which Found Me in 1942

How did you find me?
How in the name of God did you find me?
A tiny infant.... down in the heart of old
Malahide village
.... in the little house beside the coal yard.
Were you looking for me or what?
Jesus – I was only just born.
I knew nothing at all.
The name they put on you was bigger than me.
Infantile Paralysis.
That is what they called you.
You went around the place paralysing babies.
And you found me down there in that beautiful
place beside the village green
looking over the island
looking out to the sea.
You came into me and you made me cry.
What time did you come in?
What day was it because I don't know?
What brought you down that way in 1942?
Which way did you come?
Was it down New Street past Bertie Boyle's?
or did you come round from the Back Strand
under the railway arch past Lesley Riley's?
Was the tide full in?

I don't know that either.
Why did you go past Annie Daniel's house
and come into ours?
There was me and Michael, Ma and Da.
Why did you come into me?
Did I make a sound as you were going past?
Was that the way it happened?
Was the wireless on?
What could you hear?
I think it was a cowardly thing that you did.
To take the life away from my arm
and put a hidden slow wasting in my legs
was a cowardly thing indeed.
Fifty years on
I am still finding the damage of you.
Fifty years on
you find new tears in me.

Are you still alive?
Are you still doing your virus stuff?
Are you still alive
or did something wipe you out?
I would like to know your name?
Mine is Pat.
I played soccer in spite of you
and I was good.

by Pat Ingoldsby





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.

Opinion Disclaimer

The views and opinions expressed in this EPU Newsletter are those of the authors and do not necessarily reflect the official policy or position of the European Polio Union and/or its Board of Directors. Any content provided by authors are of their opinion, and are not intended to malign any religion, ethnic group, club, organization, company, individual or anyone or anything.

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