



european  
polio  
union



# POST-POLIO-SYNDROME

HOW TO DEAL WITH A SECOND PARALYSIS?

# POST-POLIO-SYNDROME

Around **20 million people** worldwide struggle with the sometimes serious consequences of earlier polio infections. Post-polio syndrome is a disease in its own right, distinct from the late effects of poliomyelitis. Affected individuals usually suffered from acute poliomyelitis with paralysis, after which they had at least partial functional improvement. After a long stable period of 30 to 50 years, a new disorder finally develops, which is characterized by new weaknesses and more. 40 % to 60 % of for-

mer polio-patients suffer of this disease in a more or less comprehensive way.

How post-polio syndrome develops is not entirely clear. However, it is suspected that the cause is a chronic overload of the motor anterior horn cells (alpha motor neuron).

It is important for affected individuals to also consider secondary effects associated with medication, surgical procedures, and anesthesia.



## THE INTERVIEW



**Prof. Frans Nollet, MD, PhD – Amsterdam UMC – is specialist in Rehabilitation Medicine and scientific-medical advisor of EPU. Since more than 25 years he is investigating on the rehabilitation of post-polio syndrome.**

**Prof. Nollet, could you tell us something about the main findings of your research of the last 10 years with post-polio patients?**

Summarizing the research of the past 10 years I think that one important insight was to have robust data for the rate of decline of muscle strength and that we now better know how to treat post-polio syndrome although there is still much research to do.

In our studies we followed patients with post-polio syndrome very precisely and found that their strength declined on average 25 % after 10 years and their enlarged motor units that were formed during recovery from acute polio, reduced in size. That is a lot if you imagine that many polio survivors already had not fully recovered their muscle

strength after the acute polio. Thus, if you had recovered to 60 % of normal muscle strength and you get PPS at the age of 40 years, your strength declines to 45 % at 50 years and so on. It is clear that this decline in muscle strength starts earlier and faster than in a sound population. That we found a decline in strength associated with a decline in motor unit size over a long period of time was really new and a valuable confirmation of what was already suspected, but was now demonstrated in a well-defined group of patients.

**What does this finding mean for post-polio patients?**

We can better inform patients about the foreseeable consequences and patients can be aware of and prepare for the future to possibly slow down this process by rehabilitation therapy and using medical and orthopedical aids.

**What are the main issues in therapy and physical aids for PPS-patients?**



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## SYMPTOMS / DIAGNOSIS OF PPS

- Prior paralytic poliomyelitis with motor neuron loss
- stable period of 15 to 40 years after the infection
- then slowly progressive and persistent new muscle weakness or decreased endurance, muscle atrophy
- Complaints of pain, fatigue, weakness, falls
- Signs of relative overuse of muscles, sometimes breathing and swallowing disorders
- Exclusion of other neuromuscular, medical and skeletal abnormalities as causes

One of our main areas of research is exercise, including the question of what the right intensity of exercise is. In the past it was recommended that you should not exercise too intensively. But it is not so easy to determine the right training-intensity. The question is also how should you do your training? We developed a training guideline that is free available and we are now working on an English translation. We are further investigating effective, partially home-based training programs and we are trying to make this more attractive.

Another important area of research is orthotics. Orthotic devices have made enormous progress and really can help to improve safe mobility and diminish muscle and joint pain from overuse. We are doing advanced gait studies in order to individually optimize the effectiveness of orthotic devices for which we work together with Delft University of Technology.

**You made also a survey among physical therapists in order to know something about their expertise in aerobic (condition) training methods for patients with muscle diseases especially with post-polio syndrome. What were the results?**

It is very important that exercise is personalized to the individual. It appeared that many therapists felt they were insufficiently skilled or experienced to the special needs of PPS-patients. Most of them found aerobic exercise important and would like to receive support to determine the right training intensity for individualized treatment. There is much interest in our training guideline, and we are considering to start classes to teach therapists.

**What do you think which role should have European Polio Union for PPS, a disease that is slowly disappearing in Europe?**

If you look at Europe there are more than a million people suffering from polio sequelae. Among them there is a considerable number of younger polio survivors with a migration background from countries where polio has stopped more recently. I think EPU is very important. It is a movement able to connect and give polio survivors a voice and point out that healthcare and therapy should be improved and become better available in many countries.

The general attitude in politics and medical care is that „polio has disappeared“ and therefore seems no longer relevant. But they forget that there are many people suffering from the life-long remaining consequences! So in my opinion EPU is a very important platform which helps to improve the quality of life, the therapy, and continuation of research for people suffering from post-polio syndrome.

# THERAPY IS MULTIDISCIPLINARY

Unfortunately, there is still no cure for people suffering from post-polio syndrome. However, the process of progressive muscle degradation can be slowed down by appropriately wise patient's behavior that avoids overloading the musculature and, at the same time, promoting the preservation of mobility by regular movement exercises and therapies. Therapies and orthopedic aids should be coordinated in such a way that patients can continue to manage their daily lives as independently as possible.

However, a prerequisite for any successful treatment is a clear diagnosis, whereby other neurological and muscular diseases must first be ruled out.



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**REGULAR EXERCISES UNDER SPECIAL GUIDANCE +++ AVOID OVERUSE OF THE NEURO-MUSCULAIRE SYSTEM +++ ADAPT EVERYDAY LIFE AND SLOW DOWN THE PROGRESSIVE LOSS OF MUSCLE STRENGTH +++ SEEK PSYCHOLOGICAL SUPPORT IN THE ADAPTATION PROCESS+++**

Basically, a balance between stress and recovery phases must be established, both in daily life and in therapy. The correct measurement must be determined individually, using medical and kinetic measuring techniques. Symptoms of fatigue must be taken seriously, and patients must learn to perform their exercises and activities below the perceived exertion limit and to plan sufficient and timely recovery breaks. The use of the BORG scale should be taken into account in determining the appropriate fatigue limit. To avoid chronic overuse in daily life, the timely use of assistive devices such as adapted lightweight orthoses and wheelchairs, including a power wheelchair if necessary, should

also be considered. Long-term drug therapy is not scientifically proven and can only be used in individual cases. In this respect, appropriate studies are still being carried out on the use of lamitrogenin or the administration of immunoglobulins under medical supervision.

A few clinics and rehabilitation facilities in Europe have special knowledge and experience in the diagnosis and treatment of post-polio syndrome. Appropriate facilities in the respective country can be obtained from our member organizations, whose websites we have listed in this brochure.



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# THE EUROPEAN POLIO UNION

EPU was established in 2007 and is an umbrella organization working for the interests of people in Europe suffering from polio-sequelae and especially the so called post-polio syndrome (PPS).

The **goal** of our organization is to bring together network experts dealing with PPS in order to jointly find parameters for safe diagnosis of the disease and medical care. To this end, it is essential to get the experts to present facts and figures and have them evaluated.

Our task is also to inform people suffering from PPS and to offer them support to cope with everyday life. In addition as a strong European association we want to give a voice to medical specialists and draw attention to the special needs faced by post-polio patients.

Under the umbrella of the European Polio Union numerous polio-patient-associations and self-help institutions across Europe have come together.

Today there are 19 countries represented by associations in Finland, Norway, Sweden, Denmark, Great Britain, Ireland, France, Belgium, the Netherlands, Germany, Austria, Switzerland, Hungary, Slovakia, Czech Republic, Poland, Italy.

## WORKING TOGETHER

At certain intervals, EPU organizes European Post-Polio-Conferences in collaboration with various universities, specialists and local associations.

The last ones took place in 2011 in Copenhagen and in 2014 in Amsterdam and attracted international attention. The congress planned for 2020 in Vitoria-Gasteiz (Spain) unfortunately had to be cancelled due to the Corona disaster. However, most of our member associations organize almost every year national information days for doctors, therapists and patients.

## WE ACHIEVE MORE



# CONTACT

We present a selection of important contacts in various countries across EUROPE.

<b>AUSTRIA</b>	Bundesverband Poliomyelitis e.V.	<a href="http://www.polio-selbsthilfe.at">www.polio-selbsthilfe.at</a>
<b>BELGIUM</b>	AccessAndGo-ABP	<a href="https://accessandgo.be/">https://accessandgo.be/</a>
	Post-Polio Belgie VZ	<a href="https://www.facebook.com/Postpolio.be/">https://www.facebook.com/Postpolio.be/</a>
<b>CZECH REPUBLIC</b>	Asociace Polio	<a href="http://www.polio.cz">www.polio.cz</a>
<b>DENMARK</b>	PolioForeningen	<a href="http://www.polio.dk">www.polio.dk</a>
<b>FINLAND</b>	Suomen Polioliitto Ry	<a href="http://www.polioliitto.com">www.polioliitto.com</a>
<b>FRANCE</b>	Polio-France-Glip	<a href="http://www.polio-france.org">www.polio-france.org</a>
<b>GERMANY</b>	Bundesverband Poliomyelitis e. V.	<a href="http://www.polio-selbsthilfe.de">www.polio-selbsthilfe.de</a>
	Polio-Initiative-Europa	<a href="http://www.polio-initiative-europa.de">www.polio-initiative-europa.de</a>
	Polio Selbsthilfe e. V.	<a href="http://www.polio-selbsthilfe.net">www.polio-selbsthilfe.net</a>
<b>HUNGARY</b>	Magyar Polio Alapítvány	<a href="http://polio.hu">http://polio.hu</a>
<b>ITALY</b>	AIDM Onlus- Associazione interregionale Disabili Motori Onlus	<a href="http://www.aidmonlus.it">www.aidmonlus.it</a>
<b>IRELAND</b>	Polio Survivors Ireland Post Polio Support Group (PPSG)	<a href="http://www.ppsg.ie">www.ppsg.ie</a>
<b>NETHERLANDS</b>	(Post)Polio Group from the VSN (Vereniging Spierziekten Nederland)	<a href="http://www.vsn.nl">www.vsn.nl</a>
	Prof. Frans Nollet – Amsterdam UMC – Medical advisor of EPU	<a href="mailto:f.nollet@amsterdamumc.nl">f.nollet@amsterdamumc.nl</a>
<b>NORWAY</b>	Landsforeningen for Polioskadde	<a href="http://www.polionorway.no">www.polionorway.no</a>
<b>POLAND</b>	Polskie Stowarzyszenie Polio+	<a href="https://postpolio.lublin.pl">https://postpolio.lublin.pl</a>
<b>SWITZERLAND</b>	Schweizerische Interessengemeinschaft für Poliomyelitis Spätfolgen (SIPS) Communauté Suisse d'intérêt pour les suites tardives de la poliomyélite (CISP)	<a href="http://www.polio.ch">www.polio.ch</a>
<b>SLOVAK REPUBLIK</b>	Asociácia polio v Slovenskej republike	<a href="http://www.polio.sk">www.polio.sk</a>
<b>SPAIN</b>	Asociación Afectados de Polio y Síndrome Post-Polio	<a href="http://www.postpolioinfor.org">www.postpolioinfor.org</a>
	Associats de Polio / Postpolio de Catalunya APPCAT	<a href="https://www.facebook.com/polioassociats/">https://www.facebook.com/polioassociats/</a>
	EPE Euskadiko Polio Elkarte (Pais Vasco)	<a href="http://www.polioeuskadi.org">www.polioeuskadi.org</a>
<b>SWEDEN</b>	Riksförbundet för Trafik-, Olycksfalls – och Polioskadade (RTP)	<a href="http://www.rtp.se">www.rtp.se</a>
<b>TURKEY</b>	PD polio derneği	<a href="http://www.polioderneği.org">www.polioderneği.org</a>
<b>UNITED KINGDOM</b>	The British Polio Fellowship	<a href="http://www.britishpolio.org.uk">www.britishpolio.org.uk</a>
	Northern Ireland Polio Fellowship	<a href="http://www.polio-ni.org">www.polio-ni.org</a>
	Polio Survivors Network	<a href="http://www.poliosurvivorsnetwork.org.uk">www.poliosurvivorsnetwork.org.uk</a>
	Scottish Post Polio Network	<a href="http://www.sppn.org.uk">www.sppn.org.uk</a>



## CONTACT

The EPU is registered in Belgium as a IVZW.  
(IVZW means: International Non-profit Association,  
pursuant to Belgium law).  
IVZW registration no.: 0817.863.022.

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THE MORE PEOPLE SUPPORT THE EPU,  
THE LOUDER OUR VOICES WILL BE.

## *Klinik Hoher Meißner*

### Post-Polio Syndrome (PPS)

**„not curable“ does not necessarily mean „not treatable“**



Our neurological department is specialized in the treatment of patients suffering from different kinds of neuromuscular diseases. More than 1,200 patients with these rare neurological diagnoses, such as post-polio syndrome, are treated in our rehab centre each year.

The medical exchange between neurologists and orthopaedics working closely together with specialized therapists are an ideal setting for a successful treatment.

Our inhouse treatment focusses e.g. on improving the physical and mental resilience of our patients, on learning to better cope with their daily routine and on relieving pain.

Especially for PPS patients, our treatment puts special emphasis on learning how to deal and cope best with available body resources and strength as well as to accept given limits.

You will find further information on post-polio syndrome and our treatment on our website:

<https://www.wicker.de/kliniken/klinik-hoher-meissner/behandlungsschwerpunkte/erkrankungen-a-z/post-polio-syndrom/>

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