EUROPEAN POLIO UNION

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May 2021

English version

European Polio Union – International Non-profit Association (pursuant to Belgium law) – Internationale Vereniging Zonder Winstoogmerk – Regist. No. IVZW 0817.863.022 – Chaussée de Gand 1434, B-1082 Bruxelles – Tel. +32 2 4216965

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Editorial

Dear Reader,

For more than a year one subject has been dominating all aspects of our daily lives – 'Covid 19'. It frightens, worries, confines and locks us down. There is no escape, it has been haunting everybody and everything. All activities of the EPU as well as those of most of its member organisations have come to a standstill or haven't gone beyond the planning stage.

But not all is doom and gloom!! We can consider ourselves lucky being able to stay in touch with each other via Skype or Zoom. Indeed, it's not the same as a physical meeting, having dinner together or debating or chatting over a glass of wine. But it does break the monotony of being confined.

And there is hope! Extensive vaccination programmes are under way all over the world and we keep fingers crossed that they will elicit the herd immunity that the polio vaccines did in the last century.

In view of the fact that some controversial news on some of the vaccines was reported in the media, many EPU members had doubts and queries as to which of the various types of vaccines would be best for polio survivors. To answer these questions the EPU has tried to find out and the information obtained has been mailed to all EPU members and is included in this Newsletter for easy reference.

A piece of news that we found interesting is a study to investigate whether the IPV polio vaccination would produce an immune response to both the polio virus and the Sars-Cov-2. Both viruses have similarities and if confirmed, it could mean that polio survivors might have better immunity against SARS-Cov-2 than the general population. We will follow these studies with great interest and will report the outcomes, if any.

As in the previous issue of our Newsletter we give you an idea about the vision and mission of some of our member organisations, this will give you an insight into what they are doing.

Hoping you'll stay in good health and looking forward to meeting you at our Zoom AGM 2021 in June.

Margret Embry
EPU Board Member

EPU President´s Address

Dear friends

More than a year has passed with Covid-19 and the many restrictions. It is almost 2 years since we met at our AGM 2019 in Lobbach, Germany. We had to cancel our AGM 2020, but we did so with the hope that we could have physical meetings in 2021. However, the Covid-19 has not yet been defeated so it is impossible to hold our AGM 2021 as a physical meeting. As mentioned before the AGM gives us a unique opportunity to meet and share our experience. We can learn from and be inspired by one another.

It is therefore with great sadness that we have to inform you that

EPU's Annual General Meeting 2021 will take place as an online meeting. The date is

Tuesday 22nd June 2021 at 15.00-17.00 hrs. ECT.

We hope you will be able to participate. An announcement with meeting details will be sent to you as soon as possible, but we ask you to reserve the date already now.

We look forward to seeing you on 22nd June. Until then take care and keep safe. There is a light at the end of the tunnel.

I send you my warmest greetings.

Gurli Nielsen – President of EPU

COVID-19 VACCINES & THE POLIO SURVIVOR

Introduction

The recent pandemic has thrown into sharp relief the crucial part that vaccines can play in subduing / mitigating and halting the spread of viruses whether that be the polio virus, yellow fever or in this case the corona virus COVID-19. However, with the availability of social media many untruths, falsehood and lies are spreading regarding who should or not be vaccinated. This paper draws on medical sources and journals around the world and sets out to help explain where polio Survivors fall, in whether they should be vaccinated or not. It purely applies to the polio Survivor but does make reference to those who may have co-morbidity.

In researching this paper and contacting medical authorities one thing has become abundantly clear – the power of the pharma companies and the fear of running foul of them or being sued.

The one clear fact, from all the regulatory bodies, European Medical Agency (EU), Medical Regulatory Health Authority (UK), Centre for Disease Control (EU/USA) Federal Food & Drug Administration (USA) and the equivalent bodies in Australasia is that whatever the risk from some vaccines might be, remaining unvaccinated and contracting COVID-19 is far more dangerous and in 1:800 cases will lead to death. Many Covid Survivors will go on to having serious long term affects that in many instances will be life changing.

The Process for Regulatory Approval

All medicines must be approved by the medical/drug licensing authority of the country or group of countries before they can be widely used in either oral or injectable solution, there are some exceptions to this in certain cases where fast tracking is needed. The Covid vaccines are no different. A pharma company will develop a new treatment and then submit it together with all supporting documentation for scrutiny by the licensing authority. Part of the documentation will be the results of trials in the tertiary stage for human volunteers. In certain cases, such as cancers the pharma company will recruit those suffering from the disease and put these volunteers through a double-blind test, meaning some will get the drugs, others not. In both cases neither the doctors involved, nor patients will know which they received until results are revealed. This same double-blind procedure has been used in all the COVID-19 vaccines currently licensed. However, there was one important difference these volunteers were recruited by self referral and were drawn from across a cross section of society. Medical histories of the volunteers were taken to ensure their safety but from what has been reported no specific groups were targeted for inclusion – although some such as pregnant women were excluded. Our enquiries have failed to reveal whether the tests included any polio Survivors. However, statistically if taking a cross section of society, one would have thought it would have done.

Post Regulatory Approval

After approval procedure and the drug / vaccine etc. goes into use a reporting system, called the yellow card system, is initiated so that doctors, medical authorities and others may report adverse effects. This how the blood clotting instances came to light and which have attracted so much

attention. It should be noted that 2 cases of blood clotting have also been reported with the Pfizer vaccine, but the majority are among those who received the AstraZeneca Oxford (now renamed Vaxzevria vaccine) and the Johnson & Johnson (branded Janssen in Europe) vaccine. What are the facts?

Blood Clots – The Facts

Blood clots, including the extremely rare cerebral sinus thrombosis (CST), occur in unvaccinated people as well as those who have had Covid and/or a Covid vaccine.

Cases that may be linked to vaccination typically occur 5 to 28 days after the first dose of Oxford/AZ . The risk of dying from one is in the order of one in a million. There have been 6 cases among the Johnson & Johnson cohort out of 6.8 million doses administered, including one death and one still critically ill. The incidence rate in the AZ vaccine is statistically similar. All those who have been affected, to date (14/4/21), are female under the age of 50. Interestingly these two vaccines are produced on the same technology and microbiology as the Polio vaccines that have been administered to tens of millions around the world with no apparent side effects reported in decades.

Symptoms of CST include a headache lasting more than four days after vaccination that is persistent, worse on coughing and straining and not relieved by simple painkillers. Others include blurred vision, stroke-like symptoms and pain in the ear/face.

Clots outside the brain (deep vein thrombosis and pulmonary embolus) can cause swelling of the leg, calf pain, shortness of breath, chest discomfort and coughing up blood.

Low platelet levels (another rare side effect associated with CST) may cause unusual bruising and a characteristic pinprick reddish/purplish rash that does not blanch with pressure (use the side of a glass).

The fact that these side effects have been reported does not show the vaccines are failing, according to medical sources, rather it demonstrates how robust the "yellow card" reporting system is in flagging up problems.

Who should and should not get the COVID-19 vaccine? – Yale Medical School

COVID-19 can cause severe medical complications and lead to death. There is no way to know how COVID-19 will affect individuals. A person who contracts COVID-19, can spread the disease to family, friends, and others, especially the elderly with the risk of much higher mortality, 1:800, than from vaccine complications.

Getting a COVID-19 vaccine helps protect the recipient and others around them from COVID-19, particularly people at increased risk of severe illness from COVID-19.

Can people with allergies get the COVID-19 vaccine? Yes, with 2 exceptions:

- People with a severe allergic reaction (anaphylaxis) to any component of the COVID-19 vaccine should NOT receive the vaccine.
- People with a severe allergic reaction (anaphylaxis) to any vaccine or injectable (intramuscular or intravenous) medication should consult with their caring physician, or the providing authority to assess risk before receiving any COVID-19 vaccine.

Everyone else with severe allergic reactions to foods, oral medications, latex, pets, insects, and environmental triggers may get vaccinated.

People with severe allergies require a 30-minute observation period after vaccination, while all others must be observed for 15 minutes. Vaccine clinics have safety protocols in place to respond to any adverse reactions, i. e. Epipens/Adrenaline.

If I am pregnant or breastfeeding? A pregnant or breastfeeding person may choose to be vaccinated against COVID-19. The American College of Obstetricians and Gynaecologists (ACOG) recommends that the COVID-19 vaccine should **not** be withheld from pregnant or breastfeeding individuals.

There are limited data about the safety of COVID-19 vaccines for people who are pregnant. Pregnant people are at increased risk for severe illness from COVID-19 and may be at risk for adverse pregnancy outcomes. If pregnant and in work places, the individual is at a high risk for COVID-19 infection, the benefits and risks of the vaccine should be discussed with the relevant healthcare provider.

Currently, there are no data on the safety of COVID-19 vaccines in breastfeeding people or on the effects of mRNA vaccines on the breastfed infant or on milk production/excretion, however mRNA vaccines are not thought to be a risk to the breastfeeding infant. Although definitive data are not yet available, maternal antibodies passed to the infant via breastmilk may provide protection as seen with antibodies to other viruses. Breastfeeding people should discuss the benefits and risks of the vaccine with their healthcare provider.

Is the vaccine as effective in people with suppressed immune systems? Specific efficacy and safety data are not yet available for people with immunosuppression due to medications or chronic illness. People with autoimmune conditions or who are immunocompromised are not excluded from getting the vaccine. Those who are vaccinated should be guided on the potential for reduced immune responses and the need to continue to follow all current guidance to protect themselves against COVID-19. If an individual is immunocompromised or has an autoimmune disease, this is a matter for discussion and decision between the individual and their doctor or other healthcare provider.

A paper published on 13th April 2021 by APNEN (a Portuguese medical body) states:

> *"It is not uncommon for patients with autoimmune disease to have doubts about vaccination. Should I get vaccinated? Is any type of vaccine compatible? What are the recommendations? To address these and other doubts we spoke with Dr. Herval Ribeiro Soares Neto, who explained the importance of vaccination in those dealing with a chronic disease or condition such as Multiple Sclerosis (MS), an autoimmune progressive disease in which the immune system attacks the central nervous system (brain & spinal cord).*
>
> *He said "There are several myths and arguments against vaccination. And when it comes to immunisation in autoimmune diseases, the misinformation is usually greater. Therefore, first of all, we need to reinforce that the gain with immunisation, in general, is very large, exceeding individual prevention."*

Can children get the COVID-19 vaccine? Not yet. No vaccine can be widely given to children until it has been tested in them. The current mRNA COVID-19 vaccines were not studied or approved in children younger than 16 years of age.

The Pfizer mRNA vaccine is authorized for people 16 years and older. The Moderna mRNA vaccine is authorized for people 18 years and older.

Should I get the COVID-19 vaccine even if I've already had COVID-19? The extent to which antibodies that develop in response to COVID-19 infection are protective is still under study. If these antibodies are protective, it's not known what antibody levels are needed to protect against reinfection. Therefore, even those who previously had COVID-19 can and should receive the COVID-19 vaccine.

I was recently diagnosed with COVID-19 can I receive the vaccine? Yes, for Dose #1 you can be vaccinated four weeks after onset of symptoms or a positive test (whichever is earlier). For Dose #2 you may be vaccinated after you have completed your isolation period.

Isolation is for 10 days or 10 days plus 24 hours with no fever and an improvement in symptoms.

OTHER OPINIONS:

As stated above the majority of those approached did not want their opinions either quoted or attributable. However, Dr Peter Brauer, an honorary EPU Member and author for many years on Post-Polio Sequalae (ICD10-CM-B91) and Post-Polio Myellitic Syndrome (ICD10-CM-G14) has informed us that ***"According to my continual research into vaccines I, according to my opinion, do <u>not</u> recommend vector vaccines such as AstraZeneca, Sputnik V and Johson & Johnson for polio survivors. The alternatives would be mRNA vaccines such as Biontech-Pfizer and Moderna. Permission for the mRNA vaccine of Curevac is pending."***

Dr Richard Bruno, another long-standing researcher and author on the subject said "*I reviewed the manufacturer's data bases and the Centre for Disease Control (USA), and then did a survey of the Post Polio Coffee House. No adverse effects with Pfizer or Moderna in polio Survivors. Just sore arm, some fever. Polio Survivors are not more likely to get blood clots, so at same risk as general population re AstraZeneca."*

Peter Thwaites who runs Polio Warriors and spends large part of his time in the Philippines said "*I gather from a conversation I had with a PPS specialist that any of the vaccines are suitable for polio Survivors and the fuss about the Johnson/AstraZeneca vaccines is completely unnecessary but the EMA/MHRA won't commit."*

<u>CONCLUSION</u>

When it was realised that vaccines were not years away but months, bodies such as the European Commission, European Medical Agency, Centres for Disease Control, Federal Drug Administration said they would run co-ordinated and co-ordinating roles. For example, in Europe central purchasing and distribution, this has fallen apart for many reasons, part political, part logistical, part nationalistic. The fact is that all the bodies have declared these vaccines safe and effective and it is only now in these extremely rare blood clotting events that restrictions have been imposed. Even then different national opinions and maybe prejudices come into play. For example, in Ireland the AsraZeneca vaccine will only be given to those over 60, in the UK over 30.

As far as polio Survivors are concerned there is little or no evidence either way as to which vaccine suits them best. In the main opinion is extremely scarce and divided. From our research, and

opinions submitted we can find no greater risk to polio Survivors from the vaccines than to the general population, including blood clotting.

UPDATE – 15th April 2021 – Denmark stops all use of Oxford AZ Vaccine – Source: The Times, London

Denmark has become the first country to stop using the Oxford-AstraZeneca vaccine in all age groups because of a putative link to a blood disease that the government believes to affect about one in 40,000 recipients.
https://www.thetimes.co.uk/article/85e10178-9d49-11eb-a908-ec96e110073e?shareToken=93cbac453be6ee1b8ed17ca732d4563b

UPDATE – 16th April 2021 – CDC USA scotch rumours on social media that vaccines cause women to become infertile and re-activate the Polio Virus, Types 1,2, & 3 – Source Washington Post, New York Times

UPDATE -17th April 2021 – Paper published by Oxford University following study on rare blood clotting events estimate chances are 4:1,00,000 for Vector vaccine (i.e. AZ / Johnson & Johnson) and 5:1,000,000 for mRNA vaccines(i.e. Pfizer & others) – Source Oxford University Research Website

Update – 17th April 2021 – Centre for Disease Control – announces mRNA vaccines approved for pregnant women following examination of records for results and yellow card system on 70,000 pregnant women vaccinated without problem – Source: Centre for Disease Control, Washington

UPDATE – 17th April 2021 – CEO of Pfizer Pharmaceutical reported as saying he anticipates 3rd jab of their vaccine will be required 6-12 months after first round as no definite data on how long vaccine created antibodies last - CNN.

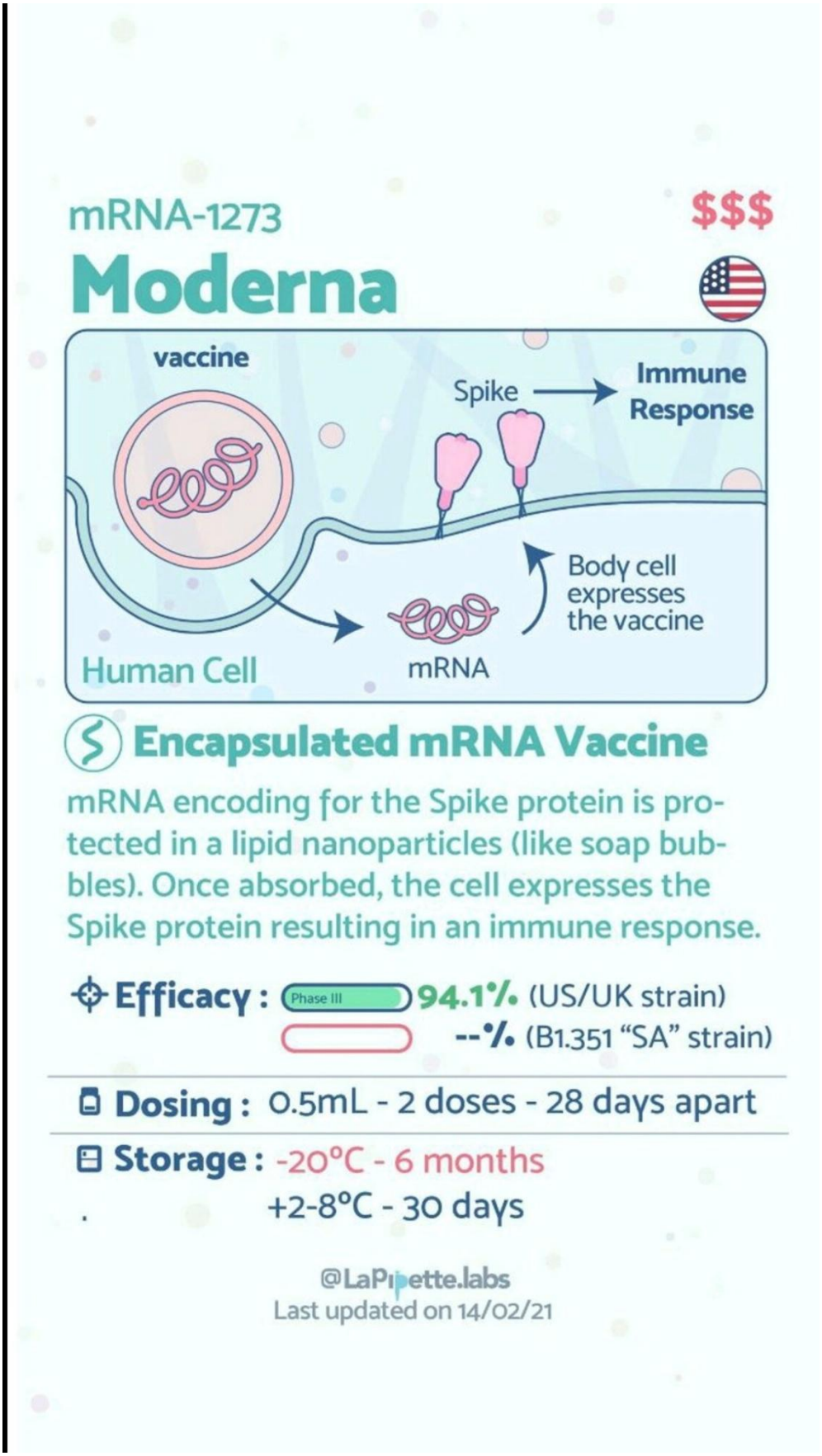
UPDATE - 17th April 2021 – BBC reports that UK Dept. of Health to start giving 3rd jab to first recipients of vaccine given in December/January 2021. Campaign expected to cover 4 most at risk cohorts and commence in October. Might be undertaken at same time as flu campaign.

John Mc Farlane
EPU Past President

Issued for and on behalf of the European Polio Union 19th April 2021

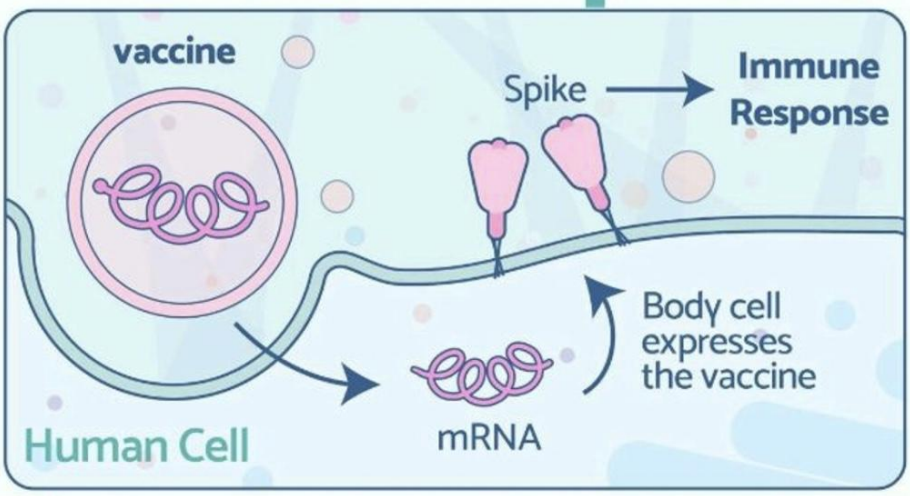
All material checked and verified but the EPU is a support group without medical authority. Errors and omissions excepted.

VACCINE DATA CARDS



BNT162b2 $$

BioNTech/Pfizer



Encapsulated mRNA Vaccine

mRNA encoding for the Spike protein is protected in a lipid nanoparticles (like soap bubbles). Once absorbed, the cell expresses the Spike protein resulting in an immune response.

Efficacy : Phase III **95%** (US/UK strain)
--% (B1.351 "SA" strain)

Dosing : 0.3mL - 2 doses - 21 days apart

Storage : -70°C - 6 months
+2-8°C - 5 days

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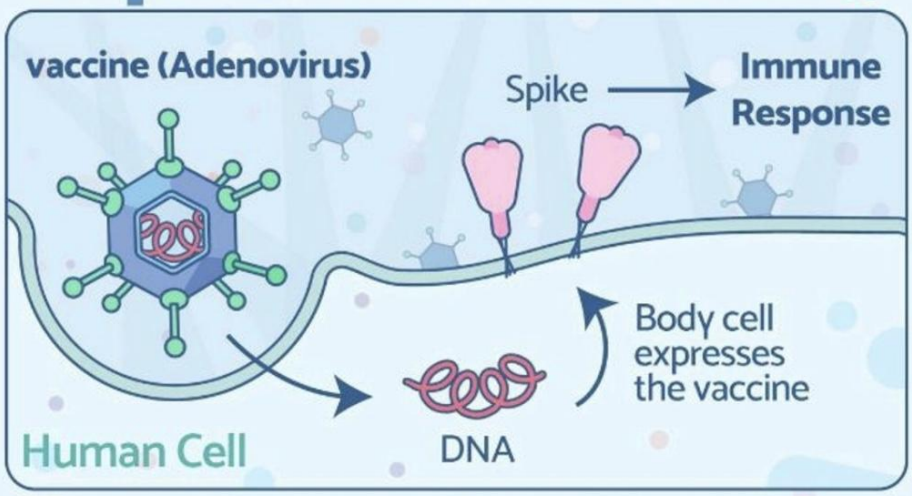
Last updated on 14/02/21

ChAdOx1 / AZD1222 (Covidshield) $

Oxford/Astrazeneca



Viral Vector Vaccine

dsDNA encoding for the Spike protein is protected in a safe virus. The infected cell expresses the Spike protein which leads to an immune response.

Efficacy : Phase III **82%** (US/UK strain)
10% (B1.351 "SA" strain)

Dosing : 2 doses - 12 days apart

Storage : +2-8°C

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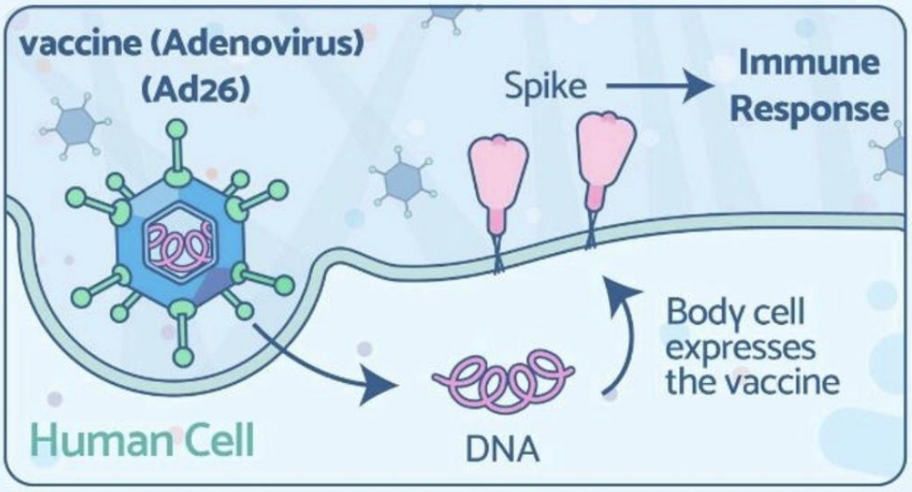
Last updated on 20/02/21

JNJ-78436735 / Ad26.COV2.S $

Johnson&Johnson



Viral Vector Vaccine

dsDNA encoding for the Spike protein is protected in a safe virus. The infected cell expresses the Spike protein which leads to an immune response.

Efficacy : Phase III **72%** (US/UK strain)
Phase III **57%** (B1.351 "SA" strain)

Dosing : 1 dose

Storage : +2-8°C for 3 months
-20°C for 2 years

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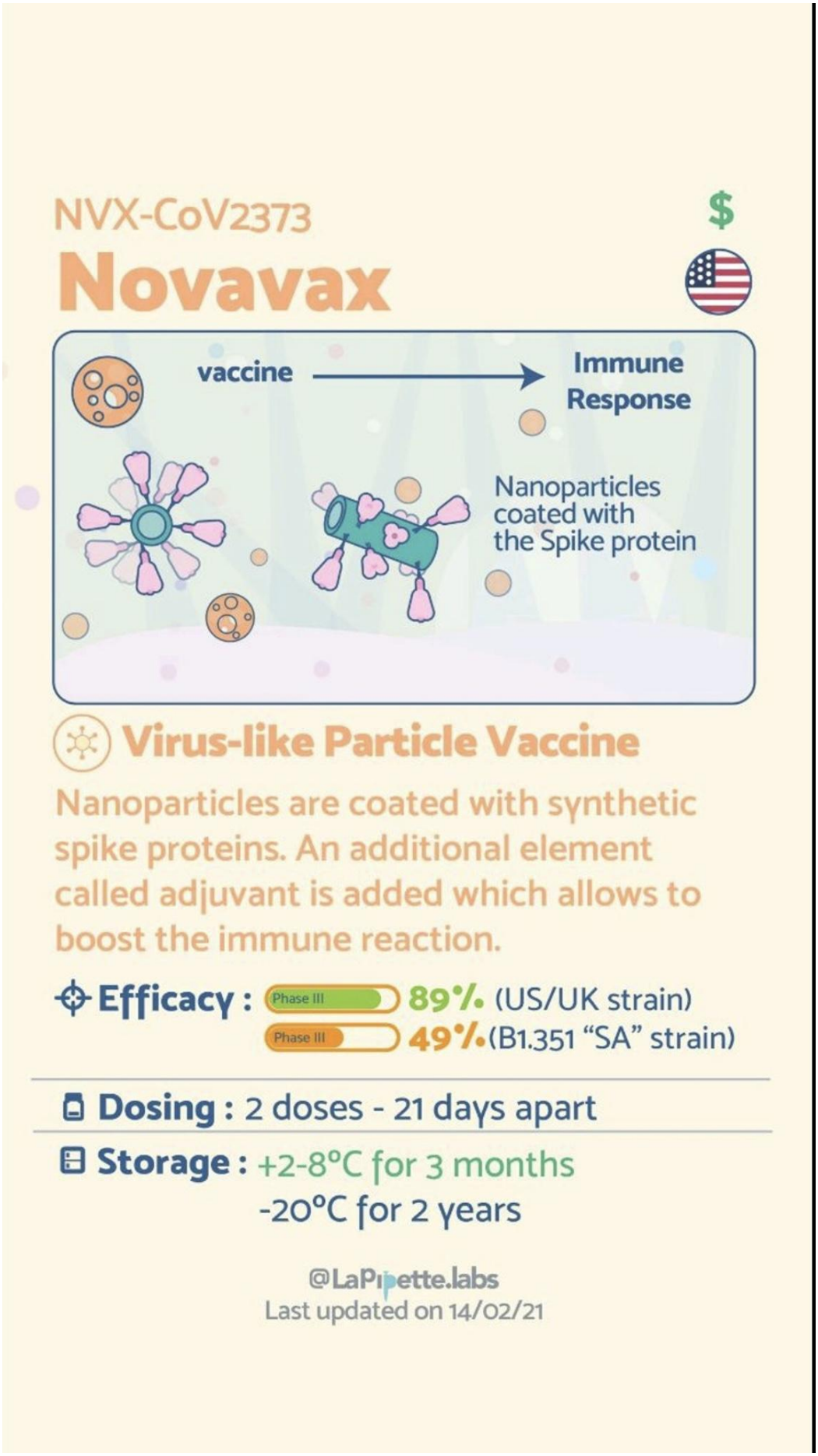
Last updated on 14/02/21


NVX-CoV2373
$
Novavax
vaccine
Immune Response
Nanoparticles coated with the Spike protein
Virus-like Particle Vaccine
Nanoparticles are coated with synthetic spike proteins. An additional element called adjuvant is added which allows to boost the immune reaction.
Efficacy :
Phase III
89% (US/UK strain)
Phase III
49% (B1.351 "SA" strain)
Dosing : 2 doses - 21 days apart
Storage : +2-8°C for 3 months
-20°C for 2 years
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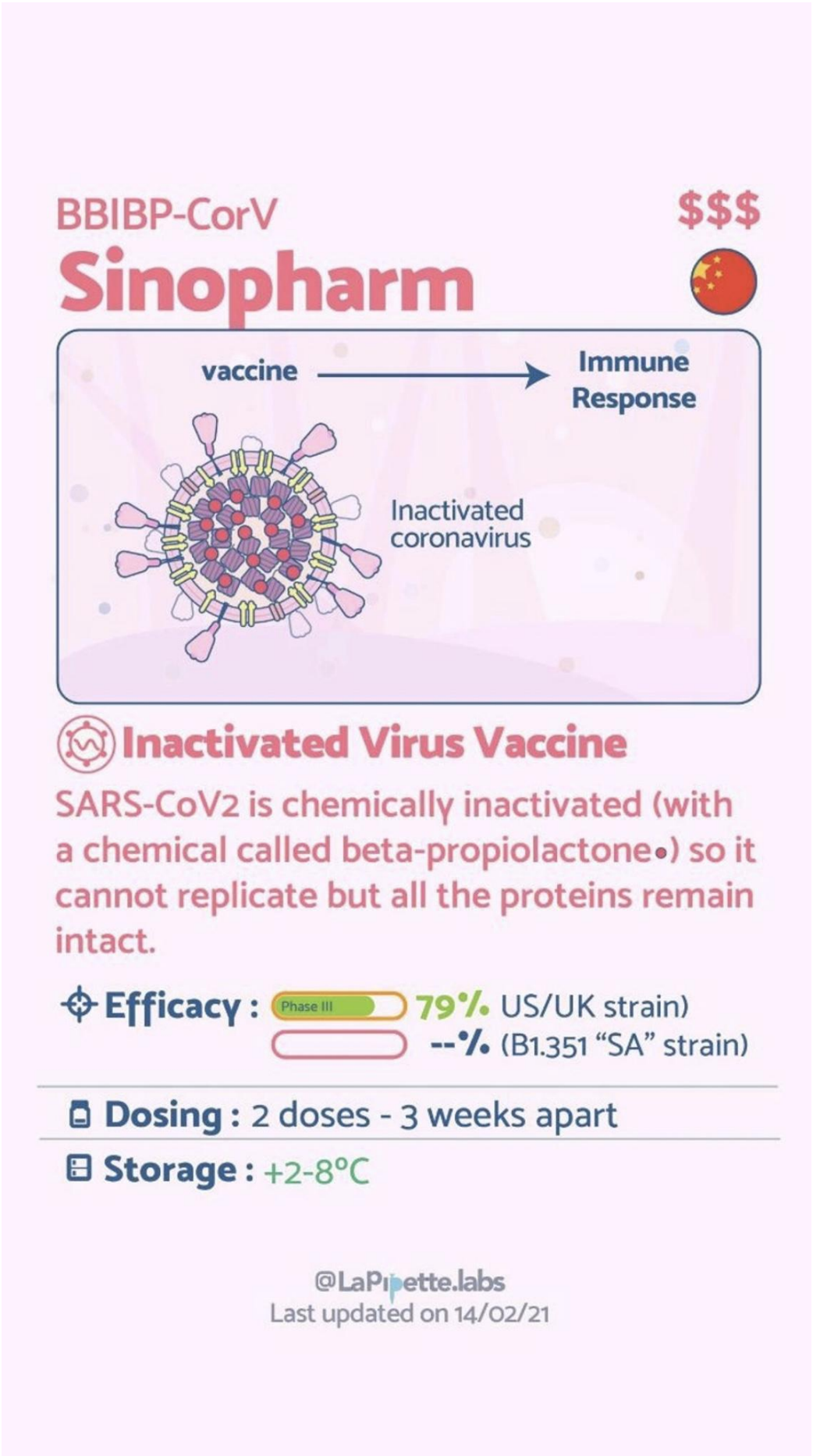
Last updated on 14/02/21


BBIBP-CorV
$$$
Sinopharm
vaccine
Immune Response
Inactivated coronavirus
Inactivated Virus Vaccine
SARS-CoV2 is chemically inactivated (with a chemical called beta-propiolactone) so it cannot replicate but all the proteins remain intact.
Efficacy :
Phase III
79% US/UK strain)
--% (B1.351 "SA" strain)
Dosing : 2 doses - 3 weeks apart
Storage : +2-8°C
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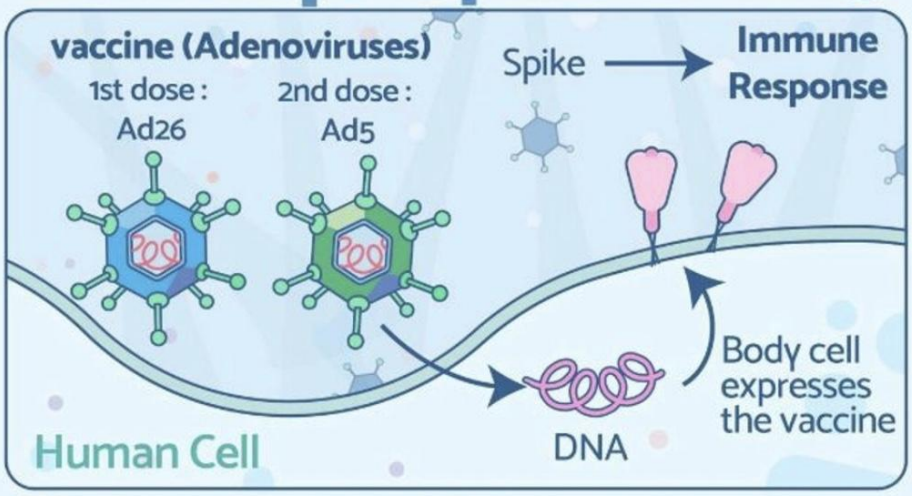
Last updated on 14/02/21

Sputnik V /Gam-Covid-Vac $

Gamaleya (Sputnik V)



Viral Vector Vaccine

dsDNA encoding for the Spike protein is protected in a safe virus. The infected cell expresses the Spike protein which leads to an immune response.

Efficacy : Phase III **91%** (US/UK strain)
--% (B1.351 "SA" strain)

Dosing : 0.5mL - 2 doses - 28 days apart

Storage : +2-8°C for 3 months
-20°C for 2 years

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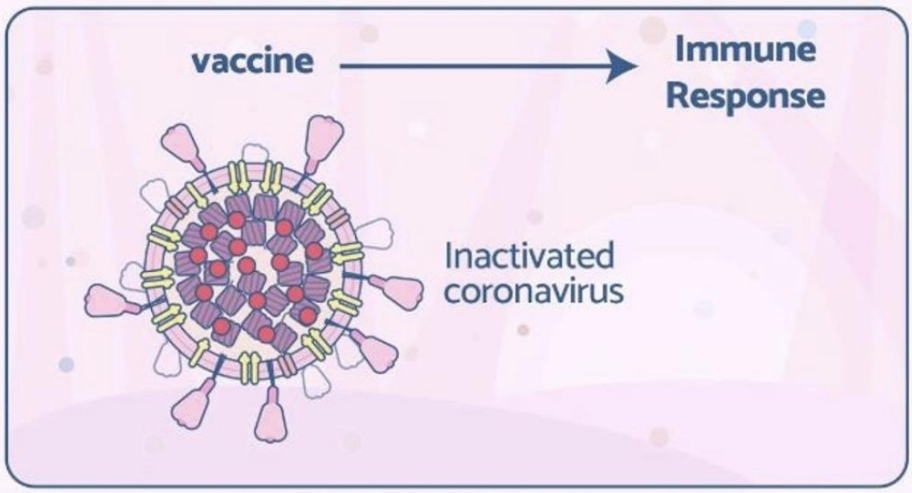
Last updated on 14/02/21

CoronaVac

SinoVac

$$$



Inactivated Virus Vaccine

SARS-CoV2 is chemically inactivated (with a chemical called beta-propiolactone) so it cannot replicate but all the proteins remain intact.

Efficacy : Phase III **50%** (US/UK strain)
--% (B1.351 "SA" strain)

Dosing : 2 doses - 3 weeks apart

Storage : +2-8°C

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Last updated on 14/02/21

How to evaluate vaccination against COVID19 in the light of a Post-Polio-Syndrome

Interview of 'Polio Nachrichten' (Polio News) with Mathias Tröger, M.D., Senior Physician, Neurology, Kantonspital Aarau, Spokesman of the Medical Scientific Advisory Board of the German Poliomyelitis Association (Bundesverband Poliomyelitis e.V.), Germany

Polio News: *Dr. Tröger, there are a lot of uncertainties and questions among people living with the late effects of polio. No one can or really wants to answer them. I know it's not easy at the moment either. Nevertheless, perhaps we can come closer to some answer. So first the question: What is your overall assessment of the threat posed by the pandemic?*

Mathias Tröger: Perhaps I could start by briefly explaining that I work here in Switzerland in an acute hospital, i.e. by German standards in a maximum-care hospital. In neurology, we were not and are not at any time in the main focus of pandemic care, but whenever COVID patients had neurological problems, we saw them and treated many neurological patients who had a COVID infection or in whom symptoms that initially appeared neurological were shown to be COVID-associated. In that sense, I've been able to follow the whole thing not only as a participant in the population but also from a physician's perspective. And I've been able to hear a lot from the physicians in the COVID departments. COVID-19 is definitely not just a mild cold. COVID-19 is much more severe for an individual than influenza (the flu) in terms of its physical impact – though even the flu is an illness that can affect young people relatively severely and cause significant mortality in the elderly or old people. But the big difference in epidemiological terms is that with influenza we have a background immunity of the population so there can't be this explosive spread as there is with COVID.

Polio News: *What does this mean at an individual level?*

Mathias Tröger: Well, everyone knows the statistics. For young people the mortality rate is relatively low at 0.1 to 0.2 percent compared to what I myself would consider a normal risk, but it is still considerable. I would not drive a car all the time if I always had to accept a 0.1 to 0.2 percent risk of death. However, it is still relatively small. People underestimate that after an apparently mild infection the long-term COVID effects can occupy a person for a very long time because of a significant reduction in performance. On the other hand, mortality beyond the age of 80 is ten percent and higher. At the same time, one has to say that 80 or even 90 percent of them survive. So it doesn't mean that anybody at 80 and beyond who has Covid is doomed to die. But they are likely having to struggle with it for a very, very long time and may have to deal with new physical limitations.

Polio News: *And what does that mean for polio survivors?*

Mathias Tröger: Mortality, but also long-term consequences of the disease have something to do with the reserves. A 50-year-old with healthy lungs and a healthy circulatory system can cope with a period of severe pulmonary dysfunction and only has to manage with an oxygen saturation of 80 percent. That is often different with an old person and then he dies. And I think this is what you have

to consider with polio or post-polio patients: The reserves are simply lower compared to the healthy age cohort. Polio-survivors are always running at peak performance and are therefore at risk of experiencing a relative loss of energy which is much more existential than with a non pre-damaged person. In this respect, of course, there is no systematic evaluation available. This is also nothing specific to polio. It will be the same for a person with a severe heart disease as for a person who has barely been able to walk due to rheumatism and has been bed-ridden for several weeks. He will have a lot more trouble getting back to walking. But with polio patients it is systematically much more severe as they are operating at the limit of their capacity. In this context I would possibly fear a non-reversible drop in their physical performance. If a person was able to walk only just a little not a lot of loss in strength is needed to get them to a point where walking is no longer possible. And even a less pronounced absolute decrease in strength results in a very significant loss of function in a post-polio situation.

Polio News: *What is the connection between COVID disease and neurological deficits?*

Mathias Tröger: We now know that COVID is associated with an increased risk of stroke. That is what one has to consider most in the acute disease. What is now slowly becoming obvious is a growing knowledge of the problem of the long-term covid effect and that's where neurology comes to play an even more important part. Patients who otherwise had very good organ functions are experiencing massive fatigability and reduction in performance – also at the cognitive level - and the brain involvement is becoming much more apparent. COVID is primarily a lung disease, that's the main site of inflammation in the first place, but then very quickly becomes a multi-organ disease where the brain is directly affected by the virus. On the other hand, it is not necessarily good for the brain to be poorly supplied with oxygen over a long period of time and to be exposed to massive inflammatory factors.

Polio News: *Now, other than reducing contacts vaccination is the only way to protect against the disease. So in terms of deciding whether to vaccinate YES or NO there is not much choice. With so many different vaccines the question arises about which is the right one.*

Mathias Tröger: First of all, I have to point out: I am a neurologist and neither a vaccination specialist nor an epidemiologist. But I find it remarkable – that besides the positive fact that we actually have vaccines - in what depth of detail the differences between the various vaccines are now discussed and weighed against each other. I have asked colleagues whether they know the respective active or manufacturing principle of other vaccines that we use on a regular basis. No one knows the efficacy, whether it is 85, 90 or 95 percent, no one knows - myself included. I don't know whether a TBE vaccine, for example, is genetically engineered. I've always been completely indifferent to that because I know that in our countries the authorities do an extremely careful job of weighing up the safety of these vaccinations. That is my first comment on that. The second comment is: I am medically spoken a (EU)-"foreigner" because I practice in Switzerland. And in Switzerland, the only vaccines currently approved are the mRNA vaccines from BioNTech and Moderna. That means what is currently the big discussion, namely the vector vaccine from AstraZeneca or Johnson & Johnson, they are not yet available here. But I would have no concern for the clientele and the age cohort we are talking about in the Polio Association in Germany as regards efficacy and safety of the vector vaccines. The principle is a very proven high-tech principle. It has nothing to do with our old vaccines where dead virus particles or live vaccines were inoculated, as in the case of the oral polio vaccination. These are vehicles produced with all the blessings of genetic engineering and modern molecular biology, of which one can say exactly where in each molecular step it docks, which protein

this vector attaches to, what it pushes against in the cell, and so on. It is not very surprising that the immune response is activated more broadly by a viral vector; this is also known from other vaccines. But we have to realize that the dangers that obviously exist at the moment are highly overestimated compared to the dangers that a COVID-19 infection represents. If I now limit myself to the patient group of the over 80-year-olds, in which the numbers are so drastically high, there is a mortality rate of ten to twenty percent, and I believe that in the long or short term, few will be able to completely protect themselves from this infection if they do not get vaccinated, unless the entire environment around them gets vaccinated. We're talking here about adverse events in clusters of a completely different cohort, which is young women, at a rate of 1 in 100,000 or even 1 in 1,000,000, and that's with a vaccine that has fantastic efficacy, that protects up to 90 percent against severe and moderate courses of this disease.

Polio News: *Do I understand you correctly: You advise everyone affected by polio to get vaccinated as soon as possible?*

Mathias Tröger: Yes, from my point of view, you should get what you can get as soon as possible. This discussion about whether vaccines are two or five percentage points more or less effective is artificial. Of course, there are general contraindications, so if one is known to be highly allergic to ingredients of the vaccine or if they had a history of a massive allergic reaction where the trigger is not known then, of course, you have to weigh it very carefully at a individual level. But that's not about a little bit of a rash or a little bit of a stuffy nose after having taken a medication or a certain food, it is about reactions that have almost led you to an intensive care unit. These are very few people.

Polio News: *Are there any specific side effects that polio survivors need to be aware of?*

Mathias Tröger: There is no answer to that question. It is not known. Generally speaking, there are at least signals that the vaccination causes fewer side effects in older people than in young people because the immune system is no longer as reactive. However, it is not the case that a previous polio illness would make a person particularly sensitive. However you have to take into account: If someone is already running on reserve he will, of course, experience the flu-like symptoms all the more intense – in contrast to a healthy person who shakes it off, goes to bed, and everything is good again. With regard to the frequency of side effects, however, polio survivors can expect nothing different than all the other people.

Polio news: *Let's take a look back to the days of polio vaccination. Are there parallels with the present?*

Mathias Tröger: It is very interesting to look at the beginnings of polio vaccination. With the live polio vaccination in particular considerably more risks were accepted to carry out this vaccination, even in the environment of the vaccinated persons than is the case now with these highly technical vaccines. At that time, there was the so-called vaccination polio - in which it was accepted that one in a thousand to ten thousand vaccinated persons would develop a polio picture. That must not be forgotten. And not only those who had consciously decided to be vaccinated, but the principle was that one or two members of the family were vaccinated and then the virus was passed on. There was no long discussion. And that with a disease, which at least in terms of the frequency of fatal effects was more harmless than COVID-19 for the 80-year-olds. Of course, Polio in childhood is an absolute disaster. But the numbers say that only about one in a hundred infections has led to paralysis at all. Vaccination today is much safer. I don't think there's any great need to weigh up why

vaccination should not be done. Our members know how well vaccination can eradicate terrible diseases. However, this will not succeed with COVID, because it's a different virus that will always bounce around. But at some point it will be weakened and only cause a cold.

Original interview in German language
Source: https://www.polio-selbsthilfe.de/de/Aktuelles/AktuelleMeldung?view=publish&item=article&id=1271
Published with the approval of Bundesverband Poliomyelitis e.V., Germany, and that of Mathias Tröger, M.D.
Interview directed by Mrs. Margret Glasow (Polio-Nachrichten)
Translation from German to English by Paul Neuhaus, EPU Board Member, May 2021

Polio Vaccine (IPV) for SARS-CoV-2 and the Prevention of Coronavirus Disease COVID-19

The US Food and Drug Administration (US FDA) has recently authorized E-MO Biology Inc (EBI) of California to begin a clinical study in 25 healthy volunteers aged 18 to 80 years without a previous history of COVID-19. Volunteers will receive polio vaccination with IPV. Blood samples before and after vaccination will be tested for cross-reactivity to polio and SARS-CoV-2 viruses. The study aims to determine whether the polio vaccine elicits an immune response to both poliovirus and SARS-CoV-2. The reason for the study is the similarity of both viruses. Inactivated vaccines against RNA viruses, including poliovirus and coronavirus, induce an immune response that recognizes non-structural antigens of the inactivated virus particle. There is extensive homology between poliovirus and SARS-CoV-2 RNA-dependent RNA polymerase (RdRp), which may be sufficient to allow adults receiving booster polio vaccination to develop an immune response cross-respond to SARS-CoV-2.

If this hypothesis were confirmed, it would mean for us polio-survivors that we probably have better immunity against SARS-CoV-2 than the general population. The reason would be due to a much higher number of anti-polio antibodies in polio than in people who were only vaccinated against polio.

Source: https://clinicaltrials.gov/ct2/show/NCT04639375

Michal Haindl
Czech Polio Association

COVID-19 and people with neuromuscular disorders: World Muscle Society position and advice

The category of neuromuscular disease (NMD) covers a wide range of different diagnoses with widely varying levels of disability even in people with the same diagnosis. It is difficult, therefore to make specific recommendations that apply generally. The following are recommendations that apply to numerous neuromuscular disorders. These recommendations are designed primarily for patients who have been diagnosed with a neuromuscular disorder, their carers, general neurologists and non-specialist medical providers. They are also intended to inform neuromuscular specialists particularly regarding frequently asked questions and basic service requirements. In-depth reference links are provided.

Note: COVID-19 is a rapidly evolving field. The advice in this document is subject to regular revision. Please ensure that you are using the most up to date version of the document. This is an updated version reflecting advice updated on the 11th April 2021. Detailed advice on vaccines and vaccination is provided separately on this website.

1. Are people with neuromuscular disease (NMD) at higher risk?

So far, there is no evidence that hereditary neuromuscular disorders confer a higher risk of infection by the SARS-CoV-2 virus. However, neuromuscular diseases and their treatments may influence the patient's ability to cope with infection or its systemic effects.

National neurological associations and neuromuscular networks (Association of British Neurologists, European Reference Network EURO-NMD, others) have produced guidance on the impact of COVID-19 on neurological disorders and their management. These documents define the risk of a severe course of COVID-19 as high or moderately high in all but the mildest forms of NMD.

Features conferring a high or very high risk of severe disease include, for example:

- Muscular weakness of the chest or diaphragm, resulting in respiratory volumes less than 60% predicted (FVC<60%), especially in patients with kyphoscoliosis
- Use of ventilation via mask or tracheotomy
- Weak cough and weak airway clearance due to oropharyngeal weakness
- Presence of tracheostoma
- Cardiac involvement (and/or on medication for heart involvement)
- Conditions with a risk of deterioration with fever, fasting or infection (eg. neuromuscular junction or metabolic disorders)
- Conditions with a risk of rhabdomyolysis with fever, fasting or infection
- Frailty, concomitant diabetes and obesity and severe hypertension

- Patients taking steroids and undergoing immunosuppressant treatment (these patients need to be carefully monitored, but should continue their treatment unless advised otherwise by their neuromuscular specialist).

2. What do people with NMD need to do to avoid infection?

COVID-19 spreads through droplet infection when an infected person coughs, sneezes or talks, or potentially via touching a surface carrying infectious droplets. People with NMD and a high risk of a severe course of COVID-19 infection, as defined above, should undertake the following precautions:

- Social distancing of at least 1.5-2 metres (6 feet) is a minimum requirement. For high risk individuals (as defined in 1.), self-isolation is advised. Official advice on how to self-isolate should be followed. Decreasing infection risk may allow gradual de-escalation.
- People are encouraged to work from home or stagger their working times if possible. People with neuromuscular disorders at elevated risk should not resume office or customer contact work without seeking medical advice from their Neuromuscular Centre.
- Avoid large gatherings and public transport. People in general are urged to limit visits to vulnerable persons.
- Frequent hand-washing (20 seconds with soap and warm water), use of 60% alcohol-based hand sanitizers, and surface disinfection are crucial.
- Caregivers should be in-house, if possible. Essential visiting care givers (for instance, providers of backup support for ventilatory assistance) should wear face masks (FFP2/N95 or FFP3) and adequate PPE according to up to date official guidance, to prevent passing on the virus.
- Physiotherapists should provide advice on maintaining physical activity remotely, via phone or videolink where suitable. However, physiotherapy is important maintenance for neuromuscular patients and the updated advice has moved away from blanket recommendation against home visits, where safety procedures can be strictly observed.
- In physiotherapy sessions that require a home visit, an adapted protective setting has to be ensured (FFP2/N95 or FFP3 mask for the physical therapist and the carer present in the room, surgical or FFP2 mask for the patient, protective clothes, gloves and glasses or helmet should be used by the physical therapist).
- It is important to be prepared for all eventualities including when assistants are absent due to illness or quarantine. The person responsible for organizing home care should have an overview of the personnel situation at all times. Plans should be made for how to best meet the needs of the individual without resorting to hospitalization.
- Government advice on protection is regularly updated, and the authors advise patients, carers and medical professionals to follow the up-to-date recommendations from official websites in their country.
- People with neuromuscular disorders are advised to wear face masks (surgical masks) when leaving the home; higher grade masks may be considered in high-risk areas.
- The WMS re-emphasises its advice to work from home where possible, and p.

3. What consequences does the risk of COVID-19 infection have for treatments used in people with NMD?

- Patients must ensure they have an adequate supply of medication and of ventilatory support equipment for a period of prolonged isolation (at least 1month supply).

- Patients and carers should make use of online and telephone-based pharmacy and equipment ordering and delivery services.
- Patients and carers need to be comfortable with emergency procedures specific to their condition and their equipment.
- DMD patients on steroid regimens should continue their medication. Steroids must never be stopped suddenly, and there may be a need to increase the steroid dose when unwell.
- Immunosuppression in inflammatory muscle disease, myasthenia gravis, and peripheral nerve disease should not be discontinued pre-emptively except under specific circumstances and in consultation with the neuromuscular specialist.
- Whether and when to start new immunosuppressive treatment may be influenced by how severe the risk of infection is perceived, versus risks of deferring treatment.
- Isolation requirements may impact on treatment regimens requiring hospital procedures (i.e. nursinersen (Spinraza), alglucosidase alfa (Myozyme), intravenous immunoglobulin (IVIg) and rituximab infusions or treatments related to clinical trials). These treatments should typically not be stopped, but moving treatment to a non-hospital setting should be considered (home-visiting or outreach nurses), for which cooperation with manufacturing companies may be negotiated. IVIg can be changed to subcutaneous immunoglobulin whenever possible. Trial centres should be consulted for advice on medications in clinical trials.
- Where treatments cannot be safely continued, or where services are disrupted, the Neuromuscular Centre can provide advice on safe duration of delays to treatment, and on effective “catch up” schemes.

4. What needs to be done to assure ventilatory services when isolating (LVR bags, home ventilators etc.)

- Backup and advice hotlines should be offered by the patients’ Neuromuscular Centres.
- Patients should have an alert card/medical bracelet providing the Neuromuscular Centre contact.
- Neuromuscular Centres should actively contact patients on ventilatory support to ensure they have relevant information and adequate equipment.

5. When should people with NMD seek admission if they develop symptoms of infection?

Inpatient admission should be avoided if possible, but should not be delayed when necessary. This can be a difficult decision. People with NMD need to be aware that:

- Emergency services may be under severe pressure.
- Individual countries may have triaging procedures in place. These may affect the potential for intensive care admission for people with NMD who require ventilation. Specifically, the terms “incurable” and “untreatable” may be confused by medical staff. Neuromuscular disorders may be incurable, but they are not untreatable, and the implications for treatment decisions are very different.
- Use of patients’ home equipment (i. e. ventilators) may be prohibited by some hospital infection-control policies, or require modifications. Ideally, there should be a back-up plan.
- On attending hospital, people with neuromuscular disorders should bring with them detailed advice on use of their medical devices (eg. home ventilator) in the hospital setting provided by manufacturers and neuromuscular networks.

6. What applies to immunosuppressive treatment in patients who have suspected or proven COVID-19 infection?

- The decision to temporarily withhold immunosuppressant medication, or change to a different agent must be made in the individual situation, with the neuromuscular specialist.
- Steroid treatment should not be withheld or stopped.
- IVIg, plasma exchanges, and complement inhibitor treatment such as Eculizumab are not expected to affect the risk of COVID-19 infection or of severe disease.
- Immunosuppressive treatment is not a contraindication to vaccination, but the timing of vaccination may be influenced by preceding immunosuppressive treatment (see WMS vaccination advice).

7. Can treatments for COVID-19 have effects on neuromuscular disease?

- Numerous specific treatments for COVID-19 are under investigation. Some of these can affect neuromuscular function significantly: for example, chloroquine and azithromycin are unsafe in myasthenia gravis, except when ventilatory support is available. Cardiotoxicity and QT-prolongation though chloroquine and hydroxychloroquine can potentially worsen cardiomyopathy, and the use of Hydroxychloroquine is actively discouraged following evidence for no benefit.
- Other treatments may have effects on specific neuromuscular diseases (in particular, metabolic, mitochondrial, myotonic and neuromuscular junction disorders), and anatomical peculiarities may influence options for treatment (e.g. prolonged prone ventilation)
- Evidence-based treatment for COVID-19 such as dexamethasone, hydrocortisone and/or remdesivir can be applied in people with neuromuscular disorders, if needed through the severe phase of COVID-19
- Experimental treatments for COVID-19 may be offered “compassionately”, i.e. outside trial conditions. They should only be taken after consultation with the patient’s neuromuscular specialist.

  So far, we are not aware of trials of live virus vaccines, where there could be a risk for immunosuppressed patients (https://www.who.int/publications/m/item/draft-landscape-of-covid-19-candidate-vaccines). For more detailed advice on COVID-19 vaccines, see the WMS vaccination advice on this website.

8. What should neuromuscular specialists do to assist Emergency Medical and Intensive Care decisions on admission to units, escalation of treatment, and ceilings of care in neuromuscular patients?

Decisions on patient admission to Intensive Care may be affected by anticipated or existing capacity problems. Triaging may have been instituted. This can have practical and ethical consequences.

- There must be close collaboration between neuromuscular and respiratory physicians.
- The neuromuscular specialist must be available to play a role in ensuring fair provision of intensive care to NMD patients. Patients should not be labelled as “terminal” and triaged for non-treatment simply on the basis of their disability and diagnosis.
- Ideally, neuromuscular specialists will have involved themselves in formulating hospital policies, decision-making algorithms and documentation forms.

- Neuromuscular specialists must develop guidelines for treatment that ensure patients remain at home as long as possible.

9. What patient support should neuromuscular centres provide?

- Neuromuscular centres and specialist services should aim to provide the following:
- Patient hotlines staffed by neuromuscular care advisors, physiotherapists and other specialist personnel, with specialist physician backup (paediatric and adult).
- Support through routine specialist clinics should be continued through remote monitoring using structured telemedical phone and video links. Multiple, nationally approved platforms are now available with guidance from specialist societies.
- Many clinical assessments such as swallowing tests can be done remotely by video link.
- Outreach ventilatory support strategies should be provided.
- Strategies to maintain hospital-based treatments with minimal disruption.
- Neuromuscular specialists should be in discussion with their hospitals' Emergency, Medical and Intensive Care departments on restrictions for use of home NIV equipment.
- Neuromuscular specialists should support their hospital to define approved devices and ensure their availability (i.e. ICU mask systems with viral particle filters to permit use of patients' NIV machines in hospital).
- Liaison and shared care with Intensive Care services.
- Provide advice on rehabilitation in the home for neuromuscular patients, including Telehealth approaches
- Facilitation of mask and PPE supply for patients and carers

10. De-escalation of shielding measures – "Déconfinement"

Over the past year, periods of high incidence rates of COVID-19 in the population have alternated with periods of relative relaxation. In the latter, the safe de-escalation of some aspects of shielding and self-isolation came under consideration, in order to allow people with neuromuscular disorders to resume social interactions and education, work, or attend scheduled medical appointments.

There is considerable variation in the way national restrictions and the relaxation of restrictions are evolving, and this impacts on people with neuromuscular conditions, their families and carers, who seek advice from their neuromuscular services.

Despite the range of national approaches to this issue, the WMS agrees on the following considerations regarding risk stratification:

- People with neuromuscular disorders who have no cardiorespiratory impairment, no immunosuppression, and no significant risk-elevating factors and comorbidities, may be considered at relatively low risk (see paragraph 1). For these, we suggest the cautious following of local and national guidance. In doubt, consultation with the neuromuscular specialist is recommended.
- People with NMD with mild respiratory involvement, but no cardiac involvement or impairment of airways clearing, may be considered at medium risk. We advise a detailed discussion with their neuromuscular specialist, or with the physician responsible for their neuromuscular care. Controlled relaxation of restrictions, strictly in a secure environment, may be considered, with appropriate caution and taking into account local and national recommendations.

- People with NMD are considered at "high" or "very high" risk, in particular if they have severe or unstable respiratory compromise (FVC < 60% predicted); impairment of airways clearing, reliance on home ventilation; clinically relevant impairment of heart function; significant immunosuppression; or severe weakness requiring multiple carers or complex ongoing support (see also paragraph 1). For these patients, measures to avoid infection including self-isolation should remain in place. Carers and family members who are no longer in self-isolation must continue to use masks and barriers when in contact with the person at risk.
- For children and adolescents with neuromuscular disorders, and their parents, the major question will be whether a return to school and child care centres is acceptable. The safety of children with neuromuscular disorders will also be a concern for the schools and childcare centres these children attend. The decision to return will depend on individual factors, regarding both the individual and institution, but details such as staffing levels and hygiene protection according to national guidelines, will be important. Some recommendations are already available (see References); internationally there is significant variation.
- Patients also need to be reassured that they can safely attend hospitals for important procedures such as sleep studies, cardiac tests, and initiation of non-invasive ventilation. Neuromuscular specialists need to monitor their patient cohort to detect what medical procedures or monitoring may have been postponed during "lockdown", and begin arrangements for these services to be safely resumed. Neuromuscular services should ensure that their hospital is making adequate provisions for the safety of people with neuromuscular disorders attending, including staff adequately equipped with personal protection, designated "green" areas in hospitals for non-COVID-19 related treatments, and safe waiting areas and consulting rooms with appropriate distancing between patients and staff.
- People with neuromuscular disorders should only follow de-escalation measures where up to date and approved by their Neuromuscular Centre.

Further information links:

Note: unapproved Internet and social media sites may contain inaccuracies and disinformation. Ensure that inline information is directly sourced from official sites

https://www.theabn.org/page/COVID-19

https://neuromuscularnetwork.ca/news/COVID-19-and-neuromuscular-patients-la-COVID-19-et-les-patients-neuromusculaires/ (updated version April 3rd 2020)

https://www.youtube.com/watch?v=3DKEeRV8alA&feature=youtu.be

http://www.eamda.eu/2020/03/19/coronavirus-COVID-19-information-for-people-with-nmd/

https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-COVID-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-COVID-19

https://ern-euro-nmd.eu/

https://www.enmc.org (European Neuromuscular Centre website)

https://www.aanem.org/Practice/COVID-19-guidance (American Association of Neuromuscular and Electrodiagnostic Medicine AANEM website)

https://www.apta.org/telehealth (American Physical Therapy Association advice on telehealth)

https://filnemus.fr (French neuromuscular reference centres network with extensive advice on medical and social issues around Covid19)

http://www.filnemus.fr/menu-filiere/evenements/actualites/article/news/les-recommandations-de-filnemus-dans-la-periode-du-deconfinement/?tx_news_pi1%5Bcontroller%5D=News&tx_news_pi1%5Baction%5D=detail&cHash=56f89313ee508b50526c7dbfb952dd7a

https://www.nvk.nl/over-nvk/vereniging/dossiers-en-standpunten/covid-19/document-covid-19?dossierid=26542080

https://www.who.int/publications/m/item/draft-landscape-of-covid-19-candidate-vaccines

https://www.mda.org/press-releases/facebook-live-qa-covid-19-vaccine-development-and-impact-clinical-trials

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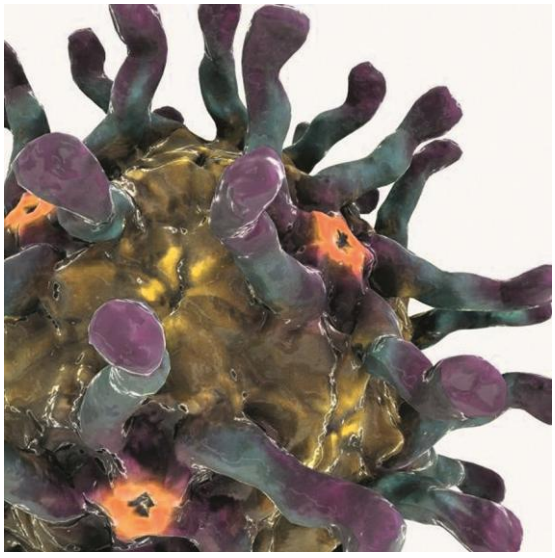
Source: https://www.worldmusclesociety.org/file/fe88150b-161d-404f-b22c-80c42b2f022d/2021-04-11-WMS-Covid-19-advice.pdf (downloaded on May 7, 2021, 7:45 a.m.)



Introducing EPU Member organisations

In our previous EPU Newsletter (No. 1/2020) we started to present short profilies of all national polio organisations and support groups throughout Europe. Again, we hope that through this it will be easier for our readers to be acquintainted with these organisations and even get to direct contact with them. Information provided may also be an inspiration for other polio support groups to broaden their own activities in case they wish so.

After the British Polio Fellowship and the Portpolio Belgium VZW now we are presenting the Basque Country Polio Association, the Czech Polio Association, the Danish Association of Polio Survivors, Bundesverband Poliomyelitis e. V., and Polio Initiative Europa e. v.

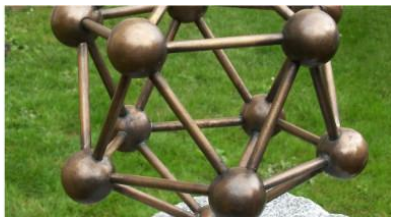
EPE-Euskadiko Polio Elkartea
EPE-Asociación de Polio del País Vasco
EPE-Basque Country Polio Association

Erregistro zenbakia / Registro número / Identification number: **AS/G/190407/2015**
EPE, irabazi-asmorik gabeko Elkartea da / EPE, es una Asociación sin ánimo de lucro / EPE, is a non-profit Association
EPE sortu zen urtea / EPE fué fundado en / EPE was founded in: **2014**

EPEaren HELBURUAK:	Los FINES de EPE:	EPE's PURPOSES:
1. **Euskadin**, Poliomielitisa, bere Ondorio Berantiarrak eta PPSa duten pertsonen **erreferentziazko Elkartea izatea**, tokiko, nazioko eta nazioarteko organismoetan, …	1. **Ser la Asociación referente** de las personas con Polio-mielitis, sus Efectos Tardíos y SPP **del País Vasco** en los organismos locales, nacionales e internacionales, …	1. **To be the referent Association** of survivors with Poliomyelitis, its Late Effects and PPS **of the Basque Country** in local, national and international organizations, ...
2. OMEk "**POST POLIO SINDROMEa (PPS)**" izenez ezagutzen duen gaixotasun berri eta arraroaren **berri ematea**, …	2. **Difundir** la nueva y rara enfermedad denominada por la OMS como "**SINDROME POST POLIO (SPP)**", …	2. **Spread** the new and rare disease referred to by the WHO as "**POST POLIO SYNDROME (PPS)**", ...
3. Indarrean dauden **politika sanitarioak eta sozio-laboralak**, PPS agertzeak dakarren **errealitate berrira egokitzea**.	3. **Adecuar las políticas sanitarias y socio-laborales** vigentes a la nueva realidad que nos presenta la aparición del SPP.	3. **Adapt Spanish current health and socio-laboural policies** to the new reality caused by the appearance of the PPS.
4. Poliomielitisaren epidemiak, Euskadin eta Espainian (1955-1976) izan dituen ondorioei buruzko **Memoria Historikoa berridaztea**, …	4. **Reescribir la Memoria Histórica** sobre los efectos de la epidemia de la Poliomielitis en el País Vasco y España (1955-1976), …	4. **Rewrite the Historical Memory** on the effects of the Poliomyelitis epidemic in the Basque Country and Spain (1955-1976), ...

EPE, bazkidea da / EPE, está asociada a / EPE, is a partner of: **EPU-European Polio Union; FEDER-Federación Española de Enfermedades Raras**

www.polioeuskadi.org



Czech Polio Association

The Czech Polio Association was founded on the 4th of August, 1990, by 1600 founding members. Today, after 30 years, our member count decreases to 44% at 700. Czechoslovakia became the first country in the world to achieve nationwide eradication of poliomyelitis in 1960, thanks to live-virus vaccination Both Czech and Slovakian polio survivors benefited greatly from treatment at Janské Lázně spa, the first sanatorium in Europe to focus on polio treatment since 1935, although the hot spring was discovered nine hundred years earlier - on June 1006. This small mountainous resort is well known for the EPU community due to one of the EPU general meetings held there. The country established a system of intensive and long-term care for polio survivors since its eradication in 1960, using a network of advisory centers.

However, the complete eradication caused a decline in attention to the problem of polio – to this day, only one advisory center remains in operation. The needs of polio survivors fell out of focus of the general public and medical professionals both. Imminent danger to cease the post-polio care and the health insurance covered spa treatment or orthopedic aids in stormy and fast profit-driven nineties for such a non-existent illness was among the chief reasons to establish our Polio Association. Other reasons were to organize conferences, cultural festivals, promote the interests of a relatively large group of disabled polio survivors, support reconditioning, acquire aids, and provide the broadest possible information helping polio survivors. Our primary information resources are our website www.polio.cz and in the printed magazine Zpravodaj (newsletter).

The Czech Polio Association is a voluntary interest organization with activities throughout the Czech Republic, associating mainly citizens with the disease poliomyelitis anterior acuta, with poliomyelitis syndrome, and is also open to their family members and supporters.

Our Association publishes a magazine “Zpravodaj”; our members from all over the country meet at rehabilitation spa stays, or at our festival “Obrnáři obrnářům (polio survivors to polio survivors)”, and we also organize conferences centered around the problem of post-polio syndrome. Despite our member base sadly growing thinner, we still have a priceless asset – our collective lifelong experience. We are trying to use that experience in many ways – lectures, popularization, and vaccination awareness; we are also hoping that the focus on post-polio syndrome treatment can help polio survivors and help understand many other neurological illnesses.

Michal Haindl
Czech Polio Association
https://www.polio.cz/

P. S.: Do you remember? See some photos from EPU AGM in Janské Lázně, Czech Republic, 2012 (https://www.polio.cz/fotogalerie/epu-v-janskych-laznich/), and in Piešťany, Slovakia, 2016 (https://www.polio.cz/fotogalerie/epu-v-piestanech/).

Specialister i børnelammelse
POLIOFORENINGEN

The Danish Association of Polio Survivors

Polio Denmark, the Danish Association of Polio Survivors was founded in the winter of 1945 as a merger of two small polio associations. From the very start Polio Denmark was strongly supported by the population and the then Queen, Ingrid, became patron of the association.

Polio Denmark grew very quickly in size and became very influential through the 1940's and 1950's when several polio outbreaks occurred in Denmark. After the great polio epidemic in 1952-53 Polio Denmark had more than 220,000 members from a total population of in the country of 5 million.

Polio Denmark concentrated its money on funding support for polio survivors, ensuring adequate rehabilitation of polio survivors, and last but not least ensuring polio vaccination for Danish children and young adults.

Since the start, Polio Denmark has continuously worked actively on the rehabilitation of polio survivors and later on other people with severe physical disabilities at its special hospital. The hospital located in Copenhagen with a branch in Aarhus, Jutland. The hospital offers polio survivors interdisciplinary treatment and maintenance training.

In addition, Polio Denmark is still an active voice for polio survivors and the association works to ensure the best possible care and treatment for polio survivors in Denmark's health care system. Polio Denmark is also working to improve accessibility and to ensure access to the necessary practical help at home.

Polio Denmark has 16 local branches and they arrange professional events, social events, and training courses for their members throughout the country.

Today Polio Denmark has about 1,800 members.

https://www.polio.dk/

Bundesverband Poliomyelitis e. V.

Founded in 1991 this organisation is a nationwide active polio support group.

The number of members has increased continuously and has reached 3000 at present. We feel we are the strongest polio support group in Germany, and in political terms we are committed to representing the estimated 50.000 to 60.000 polio survivors in Germany who are suffering from the late effects of polio.

As a support group associated to and cooperating with national and international patient organisations we are committed to exert influence on the political front. By sensibilisation of the public and regular seminars we attempt to provide information to medical professionals and patients to help fill the gap of knowledge that exists in dealing with the late effects of polio.

With more than 60 polio support groups we are strong in representing polio survivors regionally and locally while the core of the work carried out by our members are many-fold in the various regions. This work is supported by our central office. Non members and their families are also welcome.

We advocate protection by immunisation and promote exchange of experience in various aspects of patient care, mobility aids etc. Our multi-disciplinary medical and scientific committee consists of specialists in the field of orthopedics, neurology, pneumology and other important specialities. They advise the Bundesverband in dealing with the late effects of polio and the post-polio syndrome.

The German Bundesverband regularly certifies rehabilitation centres, i. e. their treatment of post-polio syndrome and the late effects of polio in specialised rehabilitation clinics in Germany where particular care is taken by using a wide range of medical and therapeutical know how. In addition, the Budesverband stays in close consultations with the only stationary polio centre of excellence in Germany which is headed by the speaker of our scientific committee Dr Axel Ruetz. At this centre and also at others the Bundesverband organises, polio open days' every year – 4x per year the Polio Nachrichten (Polio News) are sent out to members and subscribers.

For further information please refer to the link **www.polio-selbsthilfe.de**

POLIO INITIATIVE EUROPA e. V.

Deutsch-europäische Arbeitsgemeinschaft zur Förderung von Forschung, Prävention, Rehabilitation und Selbsthilfe bei Poliomyelitis und deren Spätfolgen

A Virus changed our lives: First Polio, then Post-Polio Syndrome

Did you have polio?

If as a child you are hospitalised with flu-like symptoms and then wake up feeling paralysed in an isolated ward or even in an iron lung, you do not understand that the reason for your many months of hospital stay is poliomyelitis and it is caused by one of the viruses that are named Brunhilde, Lansing and Leon.

Survived!

If you survive this horrible disease you might have to wear ortheses or orthopaedic shoes and you cannot do the same things as can your classmates and your friends. You will battle with your disability in Rehabilitation clinics and in every-day life using double the energy than others. Or you might be lucky having totally recovered and be released back into your former environment, lead a normal life, do sports and feel well.

Decades later:

Then, tens of years after your initial infection your muscles become weaker, your legs buckle, you have breathing problems, you get exhausted quickly and you are in pain. Hopefully you have a knowledgeable doctor who is able to diagnose PPS and who actually can explain to you that neither polio nor PPS is curable and your future companions will be crutches, possibly even a wheelchair. Now is the moment when you need the help for self help.

Polio Initiative Europa e. v. offers information such as flyers, brochures, quarterly magazine issues, an internet site and Newsletter as well as a personalised medical emergency card – but also regional ‚meetings' where polio survivors and their families can exchange experience, get medical, therapeutical and social-medical explanations concerning the late effects of polio. At regular intervals we organise presentations – also on every-day subjects - to which we invite competent speakers.

www.polio-initiative-europa.de

Polio Survivors Ireland

Polio Survivors Ireland is the only organisation in Ireland providing practical support (and sometimes more importantly a listening ear) to those unfortunate enough to have contracted polio when babies or young children. We work to maintain the independence and dignity of polio survivors, supporting them at work, in the home and otherwise.

Our Core Objectives are to create awareness and provide information on the needs of polio survivors and on Post Polio Syndrome and to support and advocate on their behalf.

We are member led and polio survivors are central to our work. We provide service and supports based on needs identified through consultation with members, fairly and within our financial capacity. Sensitivity, empathy and **confidentiality** are central to our communication with polio survivors.

We were set up in 1993, as the Post Polio Support Group by polio survivors experiencing the Late Effects of Polio (Post Polio Syndrome). In 2018, we changed our name to Polio Survivors Ireland. We have a membership of approximately 930 people. Additionally, we have set up a National Polio Register and are encouraging people who have never been in contact with us, to join the Register and provide strength in numbers. To date, over 360 polio survivors have signed this Register, with many also becoming members. There are thought to be 7,000 polio survivors in Ireland, all who have increasing needs as they age.

https://polio.ie/

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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