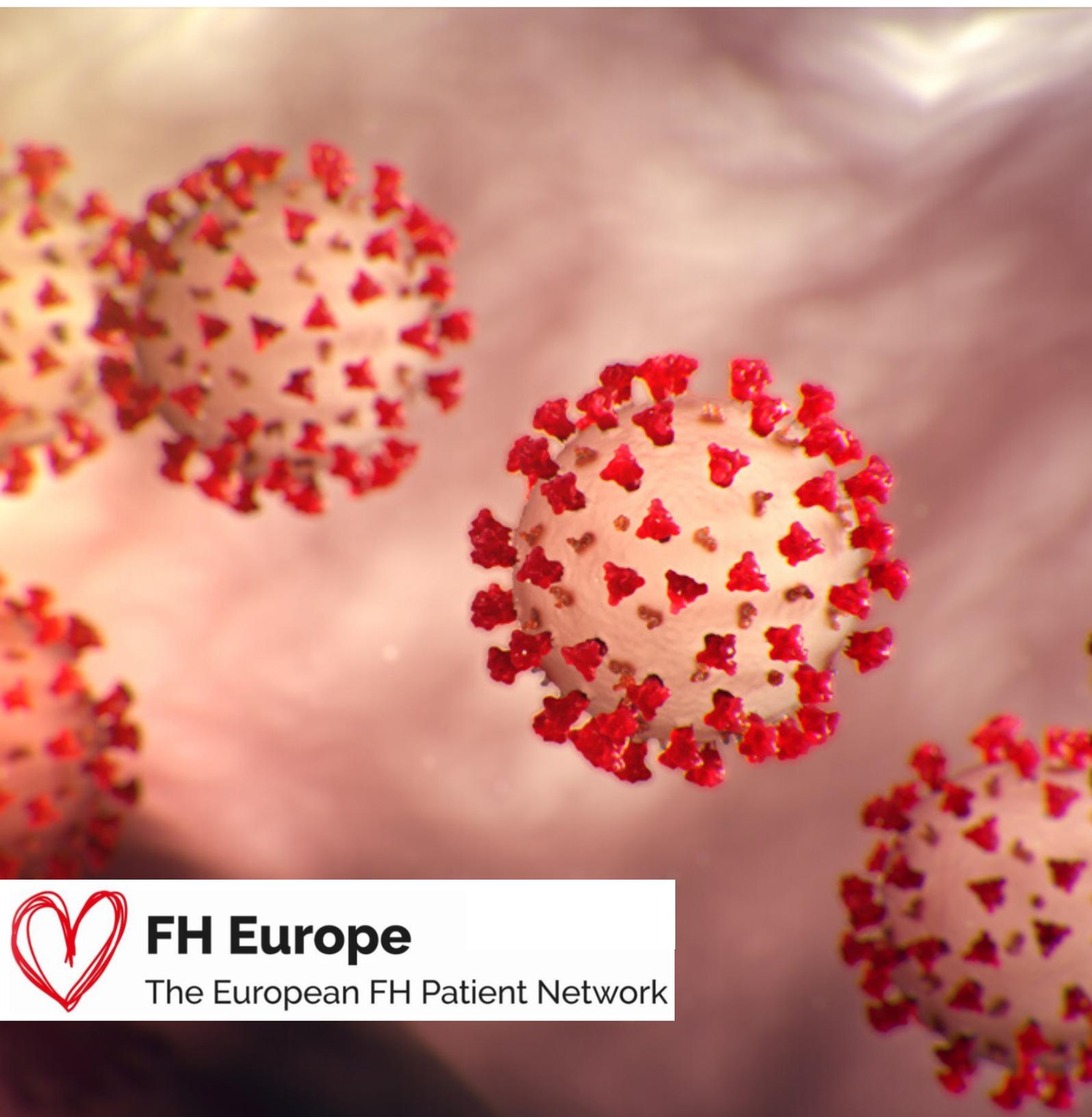


GOOD PRACTICES FROM ACROSS EUROPE FOR FH PATIENT ORGANISATIONS IN THE COVID-19 CRISIS

UPDATED REPORT BY FH EUROPE



FH Europe

The European FH Patient Network



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Introduction:

This updated list of good practices for FH Patient Organizations in the COVID 19 crises has been put together as a result of the FH Europe – the European FH Patient Network “virtual connect” event on March 24 and April 7, 2020. Those are examples and suggestions. We appreciate there might be many more other actions taken by the Network. We invite you to share via email to md@fheurope.org.

The current novel coronavirus (COVID-19) outbreak has led to a lot of uncertainty and questions, especially from individuals and families with familial hypercholesterolemia (FH) and a history of cardiovascular diseases (CVD), and other genetic lipid disorders. We have collected information from reputable sources and consulted with healthcare professionals to provide you with information on the following:

General Information

What a coronavirus is, where COVID-19 has come from, how it spreads, and the symptoms.

Remember, this is a temporary situation but if you need help, contact your local patient organization (PO) or your healthcare provider.

Impact on FH community

What the likelihood of catching the virus is and what the severity of the symptoms may be if contracted.

Recommendations

How to prevent catching the virus, your psychosocial wellbeing in self-isolation, and what to do if hospitalisation is required.



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General Information:

What is Coronavirus?

A virus that may cause illness in animals and humans. Many coronaviruses cause respiratory infections ranging from the common cold or flu to more severe diseases like Middle East Respiratory Syndrome (MERS), and Severe Acute Respiratory Syndrome (SARS).

What is COVID-19?

COVID-19 is the infectious disease caused by the most recently discovered virus coronavirus. This new virus and disease were unknown before the outbreak began in Wuhan, China in December 2019.

How does COVID-19 spread?

People can catch COVID-19 from others who have the virus. The disease can spread from person to person through small droplets from the nose and mouth.

People can catch COVID-19 if they breathe in droplets from a person with COVID-19 who coughs out or exhales droplets.

These droplets also land on objects and surfaces around the person. Other people then catch COVID-19 by touching these and then touching their eyes, nose and mouth.



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Symptoms: Fever, Dry cough, Loss of smell, Fatigue, Sore throat, Aches & pains, Runny nose.

Sometimes there may be no fever or only digestive symptoms such as diarrhoea, vomiting, and abdominal pain.

These symptoms are usually mild and begin gradually. Some people become infected but don't develop any symptoms and don't feel unwell. Most people (about 80%) recover from the disease without needing special treatment. Around 1 out of every 6 people who gets COVID-19 becomes seriously ill and develops difficulty breathing.

People with fever, cough, and difficulty breathing should seek medical attention.

What is the treatment for COVID-19?

There is no specific treatment for COVID-19. Treatment aims to relieve the symptoms until you recover.





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Impact on FH community:

People with FH are not at increased risk of catching COVID-19. However, people with FH, who have also been diagnosed with cardiovascular disease (CVD) are classed as 'high risk', meaning they are at an increased risk of COVID-19 complications.

They should therefore closely follow the social (physical) distancing guidelines set out by the local government. They should:

- Continue taking all their medications as prescribed unless their doctor indicates otherwise.
- Make sure they have their usual stock of medications available check with their local doctor's practice or pharmacy if a delivery service is available
- Maintain healthy diet and keep active as much as possible.
- In some countries in Europe some hospitals and clinics, and some specialist FH services are unable to operate as normal due to the coronavirus pandemic. There may, therefore, be delays and cancellations for routine appointments.
- Where possible, FH patients should seek information and support online from reputable websites about their health conditions, such as the national healthcare providers or patient organizations.





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Recommendations:

In general, you should follow the recommendations from your national government and health authority. These can change day by day so make sure you keep up to date with them so you have access to the latest information.

The best defence is to avoid contracting the virus in the first place. This can be done through good hygiene and avoiding unnecessary physical contact with other people.

Good hygiene:

- Wash your hands regularly and thoroughly with soap and water (for at least 20 seconds) or with an alcohol-based hand rub.
- Cough or sneeze into the inside of your elbow or a tissue. Throw the tissue away immediately after use and then wash your hands.

Avoid unnecessary physical contact:

- Stay at home - do not leave unless it is absolute essential. Work from home if possible.
- If you must leave your house, keep a distance of at least 2 metres (6.5 feet) from other people and avoid touching surfaces and objects.
- Keep your house disinfected and avoid consuming food or drinks not prepared at home. Avoid meeting family or friends who are not members of your household.
- Self isolate if you or a member of you household develop symptoms.



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Preparing for hospitalisation:

Make sure you are prepared for hospitalisation. If the recommendations on the previous pages are followed, the odds that this will be the case are very small; however, you should be prepared.

- Make sure you have a card with information about your condition and the contact details of your healthcare provider.
- Make sure you have an emergency package with medication, supplies and other items you may need when in hospital.
- Talk to your caregivers about how information is transferred in case of emergency.
- Talk to your healthcare provider if you have any questions.

Minimising psychosocial impact in isolation for adults:

- Maintain a daily structure: get up at the same hour, plan activities, have your meals at regular hours, get dressed, and pay attention to personal hygiene.
- Acknowledge your feelings. It is perfectly normal to feel worries and anxious in these uncertain times. Try to focus on things you can control not the things you can't.
- Share your feelings with people you trust. Reach out to friends and family by calling them or using social media. Reach out for help if you need it. Find professional help if you can't manage alone.
- Try to stay calm and focus on normal, daily things. Use techniques that help you deal with stress: humour, meditation, sport, yoga, a distraction, etc.
- There is a lot of information coming at you. Try to have access to correct information and update yourself once a day. Don't check the news every moment of the day. Maintain healthy low cholesterol diet and keep active as much as possible



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Updated Good Practices:

1. **Send out emails to:**

- Your affiliated patients and carers

A pulse check email to show solidarity and support, to ask any specific questions, enquire how COVID-19 is impacting them emotionally, logistically, do they have access to prescriptions, treatment or doctor visits (depending on the situation in the country)

- Connected health care professionals/GPs in your network.

Provide them with help and suggest information specific to patients with FH.

- Connected GPs.

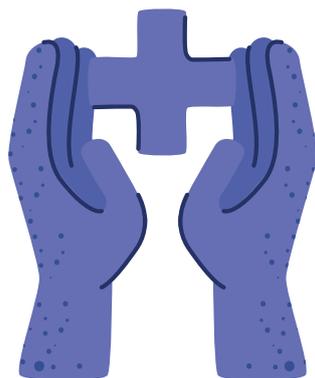
Ensure patients are treated before they get a follow up appointment in Lipid Clinic.

- Connected Lipid Nurses

See if they are still offering support to the FH patients.

- Apheresis centres. To enquire about their operational plan during the COVID-19 crisis.

(HEART UK is already doing most of it, also the Familial Hypercholesterolaemia Association of Turkey and the Greek FH Patient Organisation are leveraging email communication with patients. So is the Federation Bulgarian Patient Forum in Bulgaria).





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2. Put up on your website dedicated COVID-19 pages and its impact on FH patients, you might want to split it as follows (if relevant):

- Patient information on coronavirus
- Specific information on coronavirus and FH
- GP and prescriber information on coronavirus and cholesterol (We have already examples from La Fundación Hipercolesterolemia Familiar in Spain, the Croí Heart and Stroke Centre in Ireland and HEART UK in the UK)

3. Leverage existing & reliable resources:

Share general World Health Organization (WHO) recommendations and protective measures via your website, emails or social media channels.

<https://www.who.int/emergencies/diseases/novel-coronavirus-2019/advice-for-public>

- You can find an array of useful resources, updated regularly in reference to CVD and COVID19 on the European Society of Cardiology (ESC) website <https://www.escardio.org/Education/COVID-19-and-Cardiology>.
- Leverage existing and reliable support channels offered by your health system (example Croí Heart & Stroke Centre in Ireland connected to another organisation, whereas HEART UK added a link to an NHS self-assessment tool on their website).

4. Leverage your online community:

Share necessary updates on Facebook and/or any other Social Media channels you use (Twitter, Instagram, LinkedIn, etc) - How about sharing special cooking recipes to help FH patient parents with FP children? (FHChol in Austria and Familial Hypercholesterolaemia Association of Turkey).



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5. Reach out to your contacts at the pharmaceutical companies:

Reach out to those, who provide treatment for FH and related conditions, to ensure medicines supply is adequate in the country. Ask them also if they know about any distribution process implemented by the pharmacy or hospital, like home deliver, pick up at the hospital, etc. (HEART UK are already doing it).

6. Consider making patient support materials available in a digital format (most of the FH Europe patient organisations are already doing it, as an example of collaboration between patient organizations) FH Sverige recently leveraged the content from HEART UK, by adapting it and translating to Swedish

7. Offer a platform to ask and answer questions:

Provide help digitally or on telephone or suggest that they send you questions concerned their disease and COVID 19, which will be answered by the your local specialist (so FH Sverige in Sweden, ParSirdi.lv in Latvia and HEART UK are already planning such support. In Bulgaria there are weekly video seminars with medical experts shared via Facebook).

8. Pulse Check:

Finally, consider giving your Patient Organisation members a pulse check call to see how they are doing and if they need any help. (FOBAC in Romania and the Federation Bulgarian Patient Forum engage their volunteers to call the patient members and to check up on them, offer support and help).

For more information you can contact FH Europe md@fheurope.org .