



# Global Call to Action on FH as public health policy framework

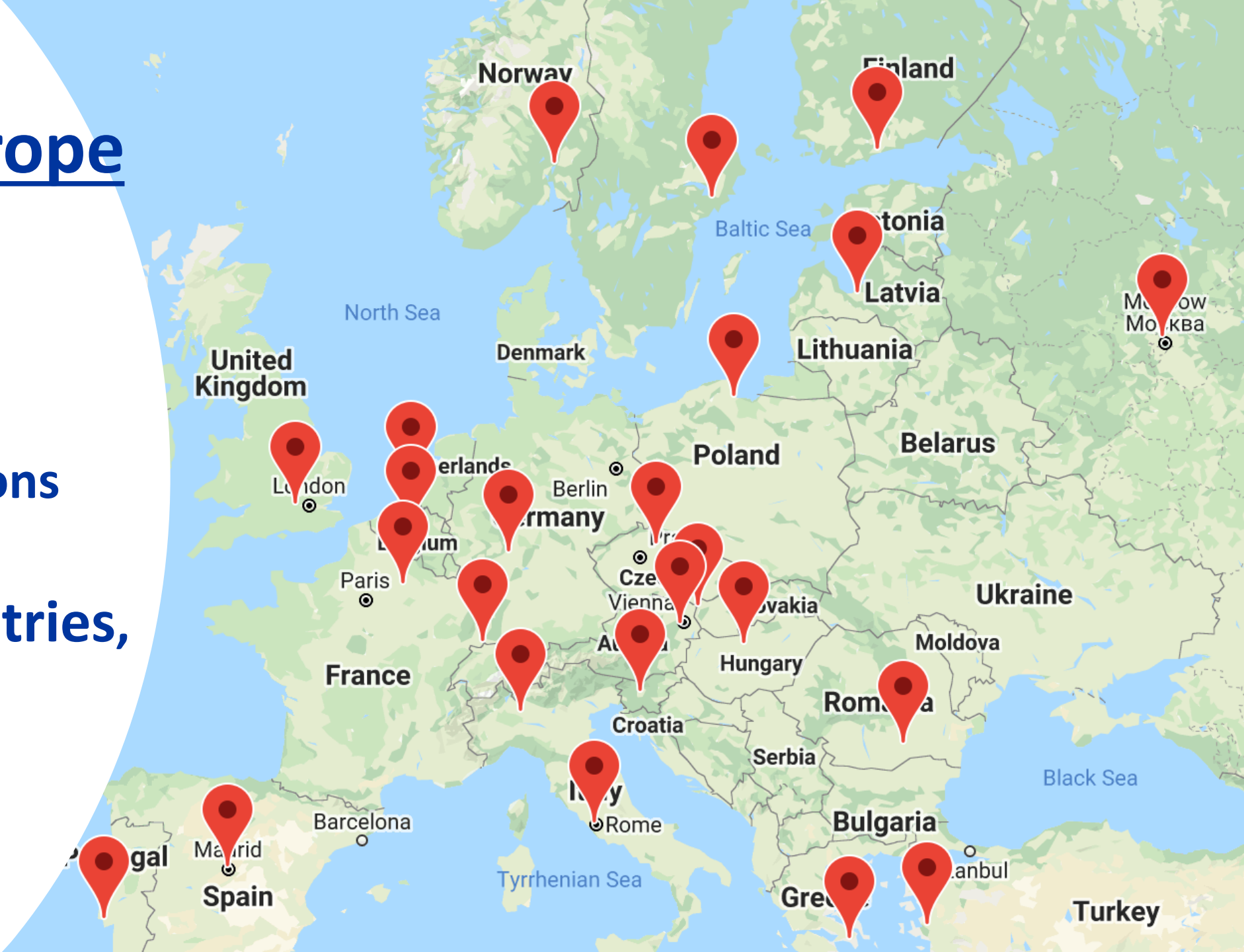
FH Europe

EURORDIS Members Meeting

13<sup>th</sup> May 2021

# About FH Europe

Network of  
25 organizations  
from 24 countries,  
and growing



# Focus on inherited lipid conditions



- Familial Hypercholesterolemia (FH) – the most common genetic condition in the world
- **Homozygous Familial Hypercholesterolemia (HoFH) – ultra rare**
- Lipoprotein(a) – very common
- **Familial chylomicronemia syndrome (FCS) – ultra rare**



# About me

- HoFH patient - diagnosed in 1994
- Founding member and former president of LDL Greece
- Active member and former trustee of FH Europe
- Nominated for the Black Pearl Awards by EURORDIS  
(Category: Young patient advocate award)



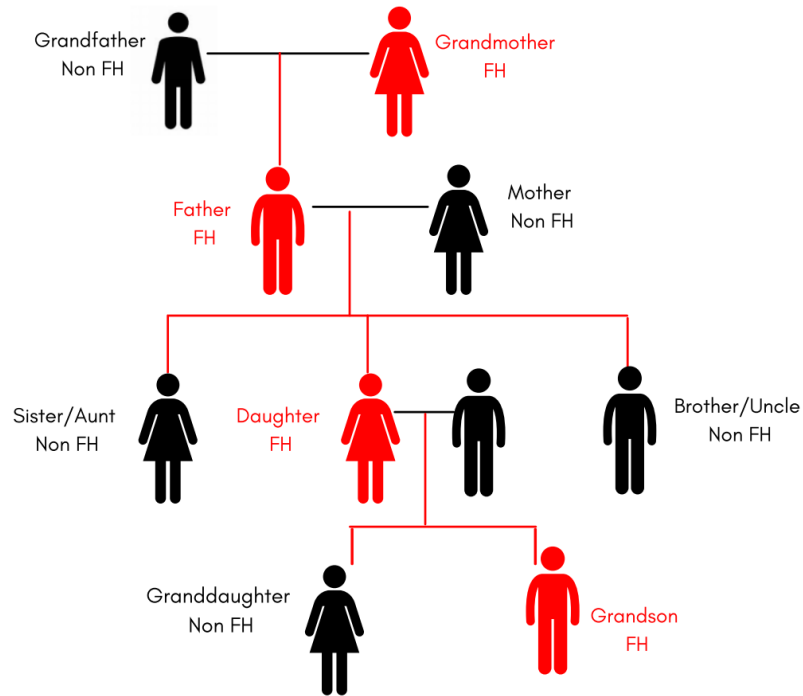
# LDL Greece

- Founded in 2013
- The board consists mostly of FH patients
- Network of HCPs dedicated to FH across Greece
- Established connection with the ministry of Health for FH policies
- Member of FH Europe and the Greek Patients Association
- <https://www.ldlgreece.gr>
- <https://www.facebook.com/oikogenis.ypercholisterolaimia>

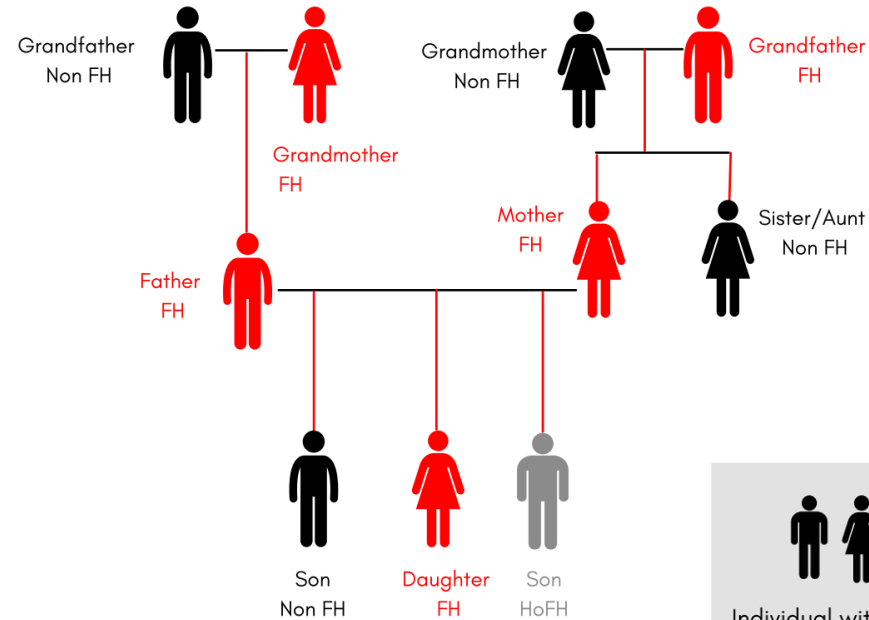


# FH, HoFH and rare disease community

**Family tree in Familial Hypercholesterolemia (FH)**



**Family tree in Homozygous Familial Hypercholesterolemia (HoFH)**



# Global Call to Action on FH

34 million people worldwide impacted | 90% undiagnosed

## Recommendations

Raise awareness

Advocate

Screen, test, and diagnose

Treat FH

Guarantee care for severe and homozygous FH

Develop family-based care plans

Research and implement

Fund FH registries

Understand value and cost



*JAMA Cardiol.* 2020;5(2):1-13. doi:10.1001/jamacardio.2019.5173



# Global Call to Action – dissemination

## International dissemination efforts

- preparation of a **shorter, summary version, translated into 21 languages**
- launch activities on **FH Awareness Day**
- creation of simple **10 interactive cards** with the 9 recommendations, for dissemination on social media
- Social media related campaign (promoted)

## Related advocacy projects

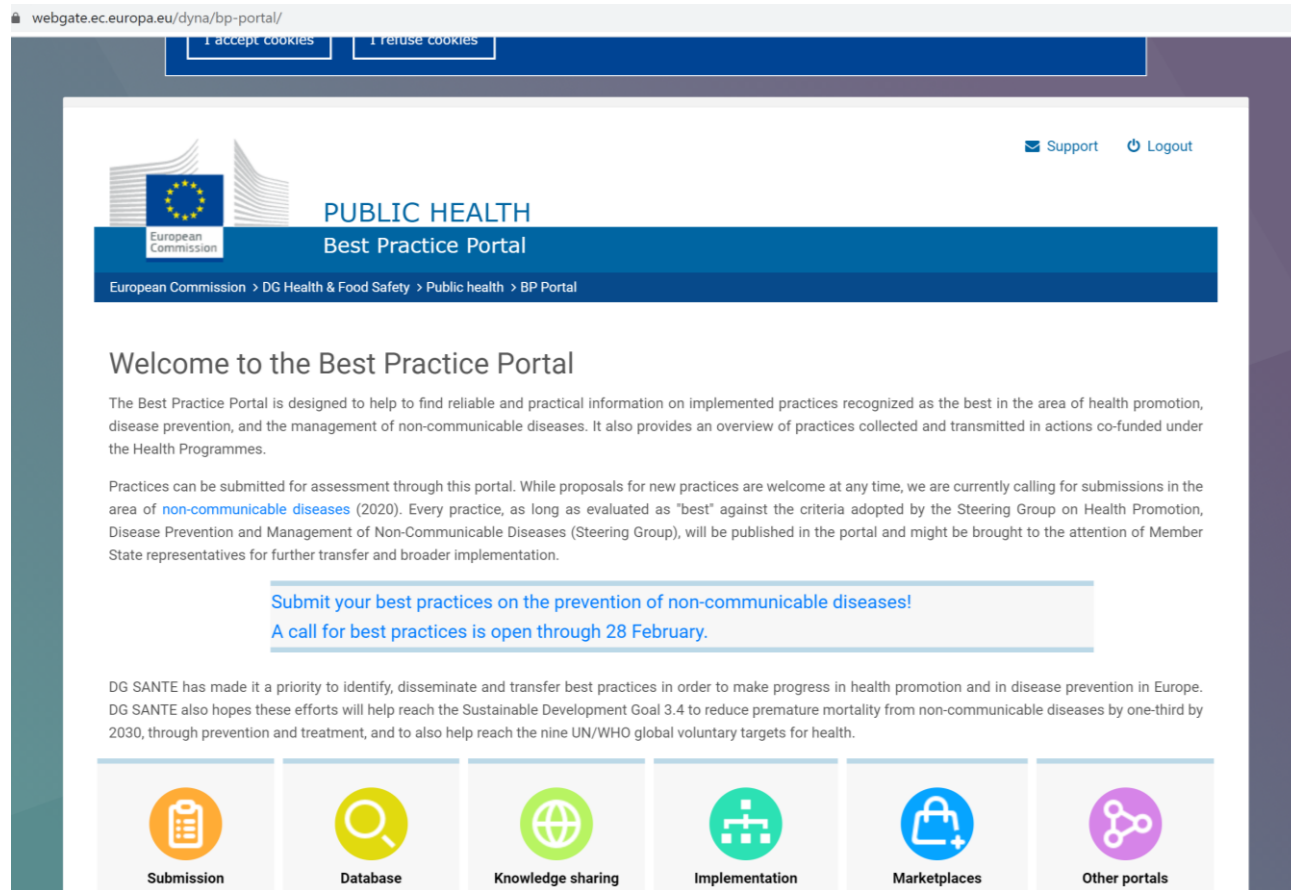




# Global Call to Action in action

Recommendation	Projects examples
<b>Awareness</b>	<ul style="list-style-type: none"> <li>• Campaigns: FH Awareness Day , Rare Disease Day, International women's Day – disease dedicated educational webinars</li> <li>• Collaboration with Medical societies to educate Young Physicians and medical students MEDizzy project with online global community</li> </ul>
<b>Advocacy</b>	<ul style="list-style-type: none"> <li>• Collaboration with Advocacy organizations ie. Eurordis, European Patients Forum, World Heart Federation, Global Heart Hup, European Societies and other patient networks</li> <li>• Advocacy Mapping Global Survey tother with World Heart Federation</li> <li>• Supporting creation of new patient organizations in counties where there are none, involving new members</li> <li>• Providing localized materials – translations</li> <li>• Creation of Scientific and Public Health Advisory Committee with 16 top international experts</li> </ul>
<b>Screening, Testing, &amp; Diagnosis</b>	<ul style="list-style-type: none"> <li>• Paediatric FH Screening Best Practice accepted to the EU Public Health Best Practice portal</li> <li>• Eurordis Newborn Screening working group</li> <li>• Creation FindMyLipidClinic portal for testing in collaboration with the EAS FHSC</li> </ul>
<b>Treatment</b>	<ul style="list-style-type: none"> <li>• Development of educational material around the guidelines as well</li> <li>• Non-promotional presentations dedicated to product understanding</li> </ul>
<b>Severe and Homozygous FH</b>	<ul style="list-style-type: none"> <li>• Many Faces One Heart Campaign,</li> <li>• Ambassadors Program to identify HoFH patients and cares, inspired to share and to raise awareness</li> <li>• Dedicated surveys with Orphanet, survey on emotional and mental health impaction of the condition</li> </ul>
<b>Registries</b>	<ul style="list-style-type: none"> <li>• Active collaboration with the Global Registry (69 counties) EAS FHSC and the newly formed specific HoFH Registry</li> <li>• Cross-promoting each other activities (education, research)</li> </ul>

# Paediatric FH screening and EU Public Health Best Practice Portal



The screenshot shows the homepage of the EU Public Health Best Practice Portal. At the top, there is a navigation bar with the European Commission logo and the text 'PUBLIC HEALTH Best Practice Portal'. Below this, a breadcrumb trail reads 'European Commission > DG Health & Food Safety > Public health > BP Portal'. The main content area features a welcome message and a call to action: 'Submit your best practices on the prevention of non-communicable diseases! A call for best practices is open through 28 February.' At the bottom, there is a row of six icons representing different portal functions: Submission, Database, Knowledge sharing, Implementation, Marketplaces, and Other portals.

- Successfully submitted the Paediatric FH Screening best practice in 2020 with 4 European countries
- Accepted in Jan 2021
- Formed an expert working group to put forward the best practice for roll-out on European level
- Collaboration with Eurordis to support the Newborn screening policy efforts



# VOTE FOR THE YOUNG PATIENT ADVOCATE AWARD

## ANTHANASIOS PALLIDIS

“*Anthanasios's commitment to Familial Hypercholesterolemia patient advocacy at a local and European level has improved care for patients and the resources available to them.*”



EURORDIS  
Black Pearl  
AWARDS

LIVE ONLINE 17:00 CET  
24TH FEBRUARY, 2021

#EURORDISAWARDS2021

