FACTSHEET and SOCIAL MEDIA POSTS

To help our Network of FH Patient Organizations and Advocates, here is a background of our initiative and **examples of ready social media posts**, to support the nomination of Thanos, an HoFH advocate, who has been nominated for the EURORDIS Young Advocate Black Pearl Award 2021 and to help raise awareness of the rare inherited high cholesterol condition.

What is Eurordis Black Pearl?

EURORDIS-Rare Diseases Europe is a distinctive, non-profit alliance of 949 rare disease patient organisations from 73 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe. FH Europe has been an active member of the organization since spring 2020.

In preparation to the Rare Disease Day, 24th February, Eurordis will host virtually the **Black Pearl Awards** event, recognizing and celebrating the exceptional work of people making a difference for the rare disease community. Since 2012, **EURORDIS-Rare Diseases Europe** has organised this event to recognise the major achievements and outstanding commitment of patient advocates, patient organisations, policymakers, scientists, companies, and media who strive to make a difference for the rare disease community. The Black Pearl is a symbol for those unique individuals, organisations and companies who demonstrate passion, engagement, and dedication in their daily advocacy work.

An HoFh patient, Thanos Pallidis is nominated for a Black Pearl Award.

Who is Thanos?

Athanasios “Thanos” Pallidis was born in 1990 in Greece. Thanos was diagnosed with **Homozygous Familial Hypercholesterolemia** (“HoFH”) at the age of four. HoFH is a rare, inherited condition, where two gene variants cause dangerously high levels of cholesterol in the blood, and dramatically increase the risk of heart disease and death in the first three decades of life. Soon after his diagnosis, Thanos was put on a combination of lipid lowering drugs followed by LDL apheresis, the only available and lifesaving treatments at the time.

Thanos is passionate about his profession, having recently received a bachelor’s degree from the Department of Nursing and is in his final year studying Nutritional Sciences and Dietetics. Outside of his studies, Thanos plays electric bass player in a heavy metal band, loves pets, walks avidly and possesses a formidable knowledge of modern history. Last but not least, he is a son and a brother.

In 2013, Thanos became a founding member and Vice-President of the Board of a Greek Familial Hypercholesterolemia (FH) patient association, progressing to become the President of the Board for a three-year term in 2015. He was also one of the early Trustees with FH Europe. Thanos’ FH global policy efforts include contributing to the “Global Call to Action on FH” and increasing awareness about FH and HoFH among the Greek medical community and public. At a local and European level, his work has led to improved care and resources available to patients. For Greek rare disease students, it led to improved access to higher education.

In 2020, Thanos was nominated by FH Europe for a prestigious Black Pearl Award by EURORDIS in the Young Patient Advocate category in recognition of his work for the Greek, European and the international patient community. And guess what? He got all the way to the final, chosen from 1720 nominees. To recognise his achievements **please #VoteThanos** here and to help raise awareness of HoFH and FH.

What is FH and HoFH?

Familial hypercholesterolemia (FH) is a common, life-threatening genetic condition that causes high cholesterol affecting around 1 in 250 people. FH leads to higher levels of cholesterol than that of the general population, often two to four times as high. iI untreated, this high cholesterol leads to atherosclerosis, premature heart attacks, strokes, and heart disease. FH is caused by a faulty gene which is inherited and passed down through families. When one individual with FH is diagnosed, it is important that all family members are screened for the condition.

Homozygous Familial Hypercholesterolemia (HoFH) is very rare, affecting 1 person in 300 000. It only happens if a child inherits two copies of exactly the gene alteration, one from each parent. Because two FH causing genes are inherited, the effects of HoFH are more severe then having one bad gene. If undiagnosed and untreated, HoFH can cause serious heart disease in childhood. It is particularly important that children with HoFH are diagnosed and treated early. Until recently, there were few treatment options for people who have HoFH. However, significant research in this area has led to exciting new developments.

How are FH and HoFH identified?

The way in which people with inherited high cholesterol are identified can vary from country to country. Most countries use an agreed upon set of medical criteria, based on LDL cholesterol levels in the patient, patterns of early heart disease or raised cholesterol in close family members, and a physical examination. Yellowish cholesterol deposits under the skin, often mistaken for dermatological issues, are the visible manifestation of the disease. Today, it is also possible to diagnose FH through genetic testing, which has become more available but can be costly. To find out more visit the **FH Europe** website and follow our hashtags #FindFH and #FindHoFH.

How can you get involved?

Make sure you share with your communities. We have prepared for you some examples of social media posts. Use the hashtags **#VoteThanos**, **#FindHoFH** and **#EurordisAwards2021**.

SOCIAL MEDIA POSTS (6):

Homozygous Familial Hypercholesterolemia (HoFH) is an inherited rare condition, which causes dangerously high cholesterol. Misdiagnosed and untreated, can cause heart disease at a very young age. As a child, Thanos was diagnosed with HoFH and has subsequently spent his adulthood becoming one of Europe's leading champions for FH patient rights. Vote for Thanos at #EURORDISAwards2021!
https://blackpearl.eurordis.org/young_patient_advocate_voting/
#VoteThanos #FindHoFH #RareDiseaseDay
(473)

Support Thanos's inspiring advocacy for people with inherited high cholesterol, while being a patient with HoFH himself. Vote for Thanos at #EURORDISAwards2021!
https://blackpearl.eurordis.org/young_patient_advocate_voting/
#VoteThanos #FindHoFH #RareDiseaseDay
(259) TWITTER

#EURORDISAwards2021 celebrates people living with rare diseases and those making a difference to their lives. Meet Thanos, HoFH patient and advocate for patient care, nominated for the 'Young Patient Advocate' award!
https://blackpearl.eurordis.org/young_patient_advocate_voting/
#VoteThanos #FindHoFH #RareDiseaseDay
(315) TWITTER

#RareDiseaseDay provides an opportunity to raise awareness for HoFH and celebrate the people who are dedicated advocates for the disease. Vote for an HoFH patient and advocate, Thanos, as 'Young Patient Advocate' at #EURORDISAwards2021!
https://blackpearl.eurordis.org/young_patient_advocate_voting/
#VoteThanos #FindHoFH
(317) TWITTER

Thanos is a qualified nurse, studying Nutritional Science and a bass guitarist. He is also a rare disease patient with HoFH, a condition causing heart disease at a young age. Read his story & vote for Thanos as 'Young Patient Advocate' at #EURORDISAwards2021!

https://blackpearl.eurordis.org/young_patient_advocate_voting/
#VoteThanos #FindHoFH #RareDiseaseDay
(311) TWITTER

Who is Thanos? Nurse, student, bass player, history buff and an HoFH patient. But he doesn't allow that to define him. Thanos is nominated as 'Young Patient Advocate' at the #EURORDISAwards2021!
https://blackpearl.eurordis.org/young_patient_advocate_voting/
#VoteThanos #FindHoFH #RareDiseaseDay
(298) TWITTER