



ERN GUARD-Heart

Europees Referentienetwerk voor Zeldzame en Lage Prevalentie Complexe Ziekten van het Hart



**Hart4
Onderzoek**

PRESS RELEASE

Haarlem, March 25th 2019

FOUNDATION HART4RESEARCH LAUNCHES APP FOR MEDICAL STUDIES AND REGISTRIES

On March 28th, foundation Hart4Onderzoek (Heart4Research) launches in collaboration with European Reference Network (ERN) Guard-Heart Cardiac PATROL: Cardiac Patient Trial and Registry Tool. The app contains relevant scientific studies and database information (registries) in the field of rare and congenital heart disease. At the launch, we also celebrate the second anniversary of Hart4Onderzoek!

Cardiac PATROL is developed for medical professionals who conduct research into rare and / or congenital cardiological disorders that provide insight into these disorders. The app allows patients to be recruited for ongoing studies. Dayenne Zwaagman, co-founder of Heart4Research and experiential expert: "(Young) adult patients with a serious heart condition would like to participate in researches, but are unable to find the right ones. Meanwhile doctors who cannot possibly be aware of all current studies and researches. The Cardiac PATROL app closes the gap between patient and professional."

Cardiac PATROL

The medical researcher registers with the help of his / her BIG registration, followed by a list of disorders. Included in the app are: ongoing studies, study schedules and inclusion and exclusion criteria. Patients who are interested in participating in a study are linked to scientific research. In addition, an overview of existing registries of rare, inherited heart diseases will be included in the future with general information and contact details from the project leader.

Hart4Onderzoek

Hart4Onderzoek/Heart4Research is a charity founded two years ago by three heart patients, including Dayenne Zwaagman. Two years later she runs the growing foundation with a new board, medical ambassadors and a number of volunteers. Heart4Research is the first platform that brings together scientific research in the field of congenital heart and vascular diseases, both nationally and within the EU. Zwaagman: "I saw opportunities with regard to collaboration and communication with the patient, but also between fellow researchers. In addition, it would make the medical world more accessible and contemporary. Zwaagman continues: With this app, patients with a rare / congenital heart condition are matched in a low-threshold way to appropriate medical scientific research."

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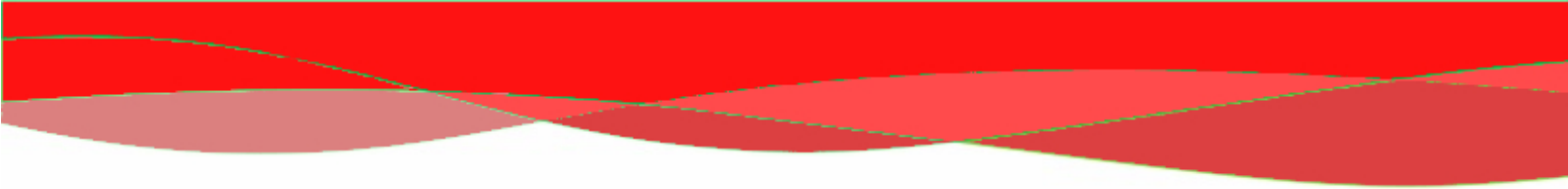
European Reference Networks (ERN's) are virtual networks involving experts from all over Europe. Professor Arthur Wilde, Cardiologist Hartcentrum Amsterdam UMC & coordinator ERN GUARD-Heart: "ERN GUARD-Heart, gateway to uncommon and rare diseases of the heart, is such an ERN. Our mission is to facilitate access to diagnosis and treatment of rare and complex heart diseases for adult and pediatric patients in the European Union (12 states). Cardiac PATROL therefore fits in perfectly with the mission that ERN Guard-Heart has in mind".

The app will be available for physicians to download on iOS and Android devices from 28 March.
The launch will take place from 4 p.m. to 6 p.m. at Hotel V, The Lobby, Fizeastraat 2 in Amsterdam.

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For more information:

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