



FH Europe

The European FH Patient Network

Introducing FH Europe 2016 directory



Working together

Providing a stronger future for individuals and families with FH

FH Europe is supported by an educational grant from Amgen Limited and Aegerion Pharmaceuticals, Inc

Familial hypercholesterolaemia (FH)

Familial hypercholesterolaemia (FH) is an inherited condition which leads to exceptionally high cholesterol levels, often double and sometimes four times those of the general population. The condition affects between 1 in 200 and 1 in 500 people. It is essential to identify these individuals and their families as early as possible as they are at high risk of an early heart attack, as early as 20s, 30s and 40s. FH is a genetic condition that is easily treated once identified, however the majority of cases remain unknown, less than 1% are identified in some European countries.

OBJECTIVE

Actively work to secure early identification and diagnosis of FH patients to prevent early cardiovascular disease.

AIMS

- Sharing information and best practice across Europe
- Work with experts to focus on themes and topics of interest to the patients and families we represent
- Support development of newer or smaller patient groups and individuals wanting to start a patient group

JOINING CRITERIA

Organisations that represent FH patients or individuals looking to set up an FH patient group

WAYS OF WORKING AND CORE ACTIVITIES

- Establish a core Steering Committee to oversee the Governance and activities of the network
- Establish sub working groups to implement the networks agreed activities
- Meet once a year to share best practice around Europe
- Attend two health care professional conferences per annum to raise awareness of their local FH patient group.
- Work together to lobby the European parliament to improve early identification and optimal treatment of FH patients.

L'hypercholestérolémie familiale (HF) est une maladie héréditaire qui se caractérise par des taux de cholestérol élevés, souvent deux et parfois quatre fois plus élevés que la population en général. La maladie touche entre une personne sur 200 et une personne sur 500. Il est primordial d'identifier ces individus et leurs familles dès que possible, car ils présentent un risque élevé de subir une crise cardiaque précoce (entre 20 et 40 ans). HF est une maladie génétique que l'on peut traiter facilement, une fois identifiée. Cependant, la majorité des cas reste inconnue (moins d'1% des cas sont identifiés dans certains pays européens).

OBJECTIF

Œuvrer activement afin de garantir dès que possible, l'identification et le diagnostic des patients HF de façon à prévenir l'apparition précoce des maladies cardiovasculaires.

BUTS

- Partager des informations et des bonnes pratiques à travers l'Europe
- Collaborer avec des experts sur des thèmes et des sujets dans l'intérêt des patients et familles que nous représentons
- Soutenir le développement de nouveaux ou petits groupes de patients ainsi que les personnes désirant fonder un groupe de patients

CRITERES D'ADHESION

Organisations ou associations qui représentent les patients HF ainsi que les personnes désirant fonder un groupe de patients HF

METHODES DE TRAVAIL ET ACTIVITES PRINCIPALES

- Etablir un Comité de Direction afin de superviser la Gouvernance et les activités du réseau
- Etablir des sous-groupes de travail afin de mettre en œuvre les activités approuvées par le réseau
- Se réunir une fois par an afin de promouvoir et partager les bonnes pratiques en Europe
- Assister une fois par an à deux conférences réunissant des professionnels de la santé afin de sensibiliser les groupes locaux de patients HF
- Mener ensemble des actions de lobbying envers le Parlement européen afin d'améliorer dès que possible, l'identification et la mise en place d'un traitement optimal envers les patients FH.

Developing organisations

FH Europe has been in contact with a number of organisations which have a strong interest in supporting patients with FH and their families. These groups are in different stages of development, either starting from a very small base, or forming part of a wider association.

BULGARIA

Federation Bulgarian Patients' Forum

Ivan Dimitrov

E. chairmanfbpf@abv.bg

W. www.fbpf.org

RUSSIA

Olga Filatova

T. +79038515479

E. olga_filatova@bk.ru

ROMANIA

FOBAC - the cardiovascular foundation in Romania

T. 021.311.00.02

E. contact@fobac.ro

W. www.fobac.ro

TURKEY

Familial Hypercholesterolemia Association - Turkey
Ailevi Hiperkolesterolemi Derneği

Meral Kayikcioglu (HCP)

E. meral.kayikcioglu@ege.edu.tr

Contents

04	FHchol Austria AUSTRIA
05	BELCHOL BELGIUM
06	Diagnoza FH CZECH REPUBLIC
07	Suomen FH-potilaiden verkosto FINLAND
08	ANHET.F Association Nationale des Hypercholestérolémies Familiales FRANCE
09	CholCo GERMANY
10	Πανελλήνιος Σύλλογος Ασθενών και Φίλων Πασχόντων από Οικογενή Υπερχοληστερολαιμία GREECE
11	FH Magyarországi HUNGARY
12	Croí Heart and Stroke charity IRELAND
13	Gruppo Italiano Pazienti FH ITALY
14	A.N.I.F. - Associazione Nazionale Ipercolesterolemia Familiare ITALY
15	ParSirdi.lv LATVIA
16	FH NORGE NORWAY
17	Stowarzyszenie pacjentów z hiperlipidemią rodzinną w Gdańsku POLAND
18	Associação Portuguesa de Hipercolesterolemia Familiar PORTUGAL
19	Rodiny S FH SLOVAKIA
20	Fundación Hipercolesterolemia Familiar SPAIN
21	FH Sverigen SWEDEN
22	Swiss FH SWITZERLAND
23	HEART UK - The Cholesterol Charity UNITED KINGDOM



AUSTRIA

FHchol Austria

VISION

Über Familiäre Hypercholesterinämie Bescheid zu wissen, kann Leben retten.

In dem wir auf die Gefahren der FH, die schon im Kindesalter Atherosklerose verursachen kann, unermüdlich aufmerksam machen, wollen wir Herzinfarkt & Co durch rechtzeitige Diagnose und optimale Therapie von FH verhindern helfen.

WAS WIR TUN

Regelmäßige Gruppentreffen sowie von Experten moderierte Patiententreffen; PR und Medienarbeit; Organisation von Workshops und Events; Vorträge bei Ärztereinbildung und Konferenzen; Zusammenarbeit mit Ärzten, dem Gesundheitswesen, politischen Institutionen und der Industrie; Lobbying bei Meinungsbildnern; internationale Zusammenarbeit, Herausgabe von Publikationen und Filmmaterial, u.v.m.

VISION

Get wise to familial hypercholesterolaemia and save lives. By raising awareness of FH, which may cause atherosclerosis as early as in childhood, we want to help prevent heart disease through early diagnosis and optimal treatment of FH.

WHAT WE DO:

Regular patient meetings as well as patient meetings moderated by experts; public relations and media work; organisation of workshops and relevant events; lectures at medical training events and conferences; cooperation with clinicians, the health sector, political institutions and industry; lobbying opinion leaders; international cooperation; publication of brochures and films, and much more.



KONTAKT/CONTACT

Gabriele Hanauer-Mader

FHchol Austria
Fürst Liechtensteinstr. 2/9
1230 Wien

T. +43 676 530 38 85

E. info@fhchol.at

W. www.fhchol.at



BELGIUM

BELCHOL

VISION

L'association de patients belge BELCHOL s'est donné pour objectif une double mission : informer les personnes touchées directement ou indirectement par l'hypercholestérolémie familiale et défendre la qualité de vie de ses membres.

A terme, BELCHOL a pour ambition d'harmoniser le dépistage et le suivi des familles ainsi que de faciliter le remboursement des tests et des traitements médicamenteux.

CE QUE NOUS FAISONS

Conscientiser le public, les professionnels de la santé et les instances gouvernementales sur la maladie à savoir:

- Conférence au Parlement belge en présence de plusieurs autorités compétentes sur la problématique de l'hypercholestérolémie familiale
- Développement de stratégie et promotion du « cascade screening » (dépistage familial) avec l'aide des médecins généralistes et des patients eux-mêmes
- Publications d'articles de presse dans différents journaux grand public et médicaux
- Présence et interactions sur les réseaux sociaux (partages d'expériences de patients, conseils relatifs à une bonne hygiène de vie, ...)

VISIE

BELCHOL, de Belgische patiëntenvereniging, heeft een dubbel doel voor ogen: de personen die direct of indirect in aanraking komen met familiale hypercholesterolemie informeren en de levenskwaliteit van haar leden verdedigen.

Op termijn heeft BELCHOL de ambitie om de screening en opvolging van families in overeenstemming te brengen en de terugbetaling van testen en behandelingen met geneesmiddelen te vergemakkelijken.

WAT WIJ DOEN

Het publiek, professionele zorgverleners en overheidsinstanties bewustmaken over de ziekte, dankzij:

- Een conferentie in het Belgisch Parlement in het bijzijn van meerdere bekwame autoriteiten omtrent de problematiek van familiale hypercholesterolemie
- De strategieontwikkeling en de promotie van "cascadescreening" (familiale screening) met de hulp van huisartsen en de patiënten zelf
- Publicaties van persartikels in verschillende kranten, zowel voor het brede publiek als voor de medische wereld.
- De aanwezigheid en interacties op sociale media (delen van ervaringen van patiënten, advies over een gezonde levensstijl,...)

VISION:

The patients association BELCHOL has two core missions: inform those directly or indirectly affected by familial hypercholesterolemia (FH) and maintain the quality of life of its members.

Over the longer term, BELCHOL aims to harmonise the screening and the follow-up of families as well as to facilitate the reimbursement of tests and drug treatments.

OUR ACTIONS

We increase the awareness of the general public, health care professionals and government bodies about the disease by:

- Holding a conference on Familial Hypercholesterolemia and related issues at the Belgian Parliament in presence of key decision makers
- Developing a strategy that promotes (family) screenings thanks to general practitioners and patients themselves
- Featuring articles in various medical journals as well as in the general press
- Being proactive on social networks (share patients experiences and tips, advice on a healthy lifestyle, etc.)



CONTACT

**Olivier Descamps
Marie Del Col**

BELCHOL
Rue des Champs Elysées 63,
1050 Bruxelles

E. info@belchol.be

W. www.belchol.be

belcholfr

belchol



CZECH REPUBLIC

Diagnoza FH

NAŠE VIZE

Chceme podat pomocnou ruku všem, kteří to potřebují - pacientům s FH, jejich rodinám a jejich lékařům. Jsme připraveni pomáhat při nedostatku informací o současné medikamentózní léčbě, životním stylu a výživě.

CO DĚLÁME

Podporujeme vznik malých regionálních skupin pacientů, v nichž je možné sdílet zkušenosti a vědomosti související s onemocněním. V neposlední řadě je naším cílem pravidelně informovat širokou veřejnost o existenci FH, dalších hereditárně podmíněných dyslipidemiích a o zdravém životním stylu v prevenci kardiovaskulárních onemocnění (tiskové konference, přednášky, letáky a brožury v lékařských ambulancích atd.)

VISION

We want to be of help to all who need it - to patients with FH, to their families and their physicians. We are ready to help with regard to the lack of information about current medical therapy, life-style changes and diet.

WHAT WE DO

We support the creation of small regional groups of patients where they can share experience and knowledge. Last but not least, our aim is to inform the public continuously of the existence of FH, other hereditary dyslipidaemias and about healthy life-style for prevention of cardiovascular disease (by means of press conferences, lectures, handouts in outpatient departments etc.).



CONTACT

Kristyna Cillikova

T. +420 608 234 466
E. cillikova@me.com
W. www.diagnozafh.cz



FINLAND

Suomen FH-potilaiden verkosto

NYKYTILA

Suomessa on 11 000 familiaalista hyperkolesterolemiaa (FH) sairastavaa. Tämä perustuu oletukseen taudin yleisyydestä 1:500. Esiintyvyys saattaa olla suurempikin, jolloin potilaita on vastaavasti enemmän.

Kelan erityiskorvattavuus perinnöllisen rasva-aineenvaihdunnan häiriön (pääasiassa FH) lääkisiin on 5 000 henkilöllä. Ei tiedetä, kuinka moni näiden lisäksi saa lääkitystä sepelvaltimotaudin perusteella tai muuten.

Suomessa ei toistaiseksi ole FH-potilaiden yhdistystä. Vuonna 2015 perustettiin Facebook-ryhmä "FH-tauti", joka kasvaa hitaasti. Toukokuussa 2016 siinä on 11 potilasta ja 7 ammattilaista.

MITÄ TEEMME

Suomen Sydänliitto on 60-vuotias, Euroopan vanhin sydänjärjestö. Tehtävämme on tukea sydänpotilaita ja edistää sydänterveyttä ja sydänsairauksien ehkäisyä.

Sydänliiton tärkeisiin tehtäviin kuuluu tietoisuuden levittäminen kolesterolistä sepelvaltimotaudin riskitekijänä.

Sydänpiirit ja -yhdistykset suorittavat kolesterolimitauksia ja ohjaavat tarvittaessa jatkotutkimuksiin.

Verkkosivuillemme (www.sydan.fi) on runsaasti tietoa FH-taudista (www.sydan.fi/terveys-ja-hyvinvointi/familiaalinen-hyperkolesterolemia-fh) ja yleisemmin kolesteroliasioista (www.sydan.fi/kolesteroli-kohdalleen). Sivuillemme on tulossa sovellus Ruotsissa kehitetyistä FH-testistä. Verkkosivuillemme, Sydänlehdessä ja muissa painotuotteissamme on säännöllisesti FH-aineistoa.

Verkkosivujen Asiantuntia vastaa -palstalla voi esittää kolesteroliin ja FH:aan liittyviä kysymyksiä. Jaamme tietoa myös Facebook-ryhmän kautta.

Sydänliitto tekee yhteistyötä ammattilisten järjestöjen kanssa FH-tietoisuuden lisäämiseksi terveydenhuollon ammattilaisten keskuudessa.

Ajankohtaisena tehtävänä on FH-potilaiden verkoston kasvattaminen Facebookissa, mikä saattaa tulevaisuudessa johtaa yhdistyksen perustamiseen, jos sellaiselle koetaan tarvetta.

CURRENT SITUATION

There are 11,000 FH patients in Finland assuming 1:500 prevalence, more if higher estimates apply.

5,000 receive Special Medication Reimbursement due to hereditary dyslipidaemias, mainly FH. An unknown number may receive statins based on diagnosed coronary heart disease or otherwise.

No FH patient organisation exists as yet. A Facebook group "FH-tauti" was founded in 2015 and is slowly expanding, comprising 11 patients and 7 interested professionals (May 2016).

WHAT WE DO

The Finnish Heart Association is a 60-year old organisation, the oldest of its kind in Europe. Our mission is to support heart disease patients and to promote heart health and prevention of heart disease in society.

Advocating awareness of high plasma cholesterol as a risk factor for coronary heart disease is a high priority for the Association.

Regional and local heart associations measure blood cholesterol concentrations and refer for further work-up and treatment as indicated.

Our web pages (www.sydan.fi) contain extensive information on FH (www.sydan.fi/terveys-ja-hyvinvointi/familiaalinen-hyperkolesterolemia-fh) and other cholesterol-related issues (www.sydan.fi/kolesteroli-kohdalleen). An adaptation of the Swedish FH test is being published on our pages. FH related materials are regularly published in our web and print media.

Our Ask the Expert section is open to questions related to cholesterol and FH. We provide information within the Facebook group.

The Heart Association collaborates with professional organisations to promote FH awareness among medical professionals.

At present, we promote the development of FH patient networking within the Facebook group, in view of a formal organisation in the future, if desired.

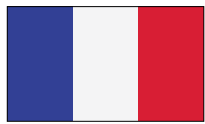
CONTACT

Dr Mikko Syvanne

T. (+ 358) 9 752 752 27
E. mikko.syvanne@sydanliitto.fi
W. www.sydanliitto.fi

sydanliitto.fi

sydanliitto



FRANCE

ANHET.F Association Nationale des Hypercholestérolémies Familiales

VISION

L'hypercholestérolémie familiale est une maladie trop peu connue en France. Aidez-nous à lui faire sa juste place pour mieux la combattre.

L'hypercholestérolémie familiale ou HF est une maladie caractérisée par une élévation du « mauvais cholestérol » dès la naissance.

Dans ce cas, l'hypercholestérolémie n'est pas le résultat d'une mauvaise hygiène de vie et d'une mauvaise alimentation, c'est une maladie familiale, la maladie génétique la plus répandue.

L'HF est une maladie invisible, plus de 90% des personnes atteintes en France ne sont actuellement pas diagnostiquées.

En l'absence de dépistage et de prise en charge précoce, le risque d'accident cardiovasculaire est augmenté dès le plus jeune âge.

ANHET est l'unique association de patients en France : rejoignez nous!

CE QUE NOUS FAISONS

Pour prendre notre avenir en main, ANHET s'engage à:

- Informer le public, le corps médical et les autorités sanitaires et médicales, à faciliter et améliorer le diagnostic et à faire connaître et reconnaître cette maladie génétique.
- Favoriser l'échange entre patients et apporter une aide technique et morale aux familles confrontées à une hypercholestérolémie familiale.
- Transmettre l'information sur l'évolution de la recherche médicale.

Nous sommes déterminés à créer un groupe important, capable de peser sur les orientations politiques en France, avec l'Europe. Nous pourrions ainsi agir efficacement et en toute indépendance pour répondre aux attentes des patients et des familles concernés par cette.



CONTACT

Association Anhet.f
16 Rue Brulee
51100 REIMS FRANCE

E. anhet.f@anhet.fr
W. www.anhet.fr



GERMANY

CholCo

VISION

Aufmerksamkeit für Familiäre Hypercholesterinämie erwecken - Wissen kann Leben retten!

Die Patientenorganisation CholCo hat es sich zum Ziel gesetzt, Familiäre Hypercholesterinämie in Deutschland bekannt zu machen. Mit einem zukünftigen Cholesterin Screening bei Kindern wäre eine frühe Diagnosestellung und Therapie gesichert, um lebensbedrohende Ereignisse wie Herzinfarkt oder Schlaganfall zu verhindern.

WAS WIR TUN

CholCo setzt auf den persönlichen Kontakt und Erfahrungsaustausch unter Betroffenen. Die Sicherstellung der frühzeitigen und optimalen medizinischen Versorgung soll gefördert werden, ebenso wie die optimale Prävention von Herz-Kreislaufkrankungen. CholCo tritt als Interessensvertretung gegenüber Kostenträgern und medizinischen Leistungserbringern auf. Wir engagieren uns in der internationalen Zusammenarbeit und Vernetzung, vor allem aber in der Bekanntmachung des Krankheitsbildes.

VISION

Raising awareness for Familial Hypercholesterolemia - knowledge can save lives!

The patient organisation's goal is to raise awareness for Familial Hypercholesterolaemia across Germany. Future cholesterol screening in children would ensure early diagnosis and therapy that could help prevent life-threatening events such as heart attack or stroke.

WHAT WE DO

CholCo fosters personal contact and exchange of experience between individuals affected by FH.

CholCo promotes the early diagnosis and optimal medical treatment of FH with the help of state funding to guarantee prevention of early heart disease. CholCo serves as an advocacy group vis-à-vis duty bearers and health insurance companies. We are co-operating and networking internationally, but above all we promote awareness of FH.



CONTACT

Michaela Wolf

CholCo e.V.
Hoherodskopfstr. 30
60435 Frankfurt

T. +49 69-95 42 59 45
E. info@cholco.de
W. www.cholco.de

[cholcoev](https://twitter.com/cholcoev)



GREECE

Πανελλήνιος Σύλλογος Ασθενών και Φίλων Πασχόντων από Οικογενή Υπερχοληστερολαιμία

ΤΟ ΌΡΑΜΑ ΜΑΣ

Ο στόχος του οργανισμού μας είναι η επαγρύπνηση σχετικά με την οικογενή υπερχοληστερολαιμία, καθώς είναι μια "αθόρυβη" γενετική διαταραχή, αλλά απειλητική για τη ζωή (αν μείνει αδιάγνωστη). Το κλειδί είναι η έγκαιρη διάγνωση και η ευαισθητοποίηση των ειδικών, των κυβερνητικών φορέων, καθώς και του γενικού πληθυσμού, πανελλαδικά. Τέλος, ο οργανισμός θέλει να διασφαλίσει πως η ιατρική περίθαλψη για τα άτομα με οικογενή υπερχοληστερολαιμία είναι δικαίωμα, όχι προνόμιο.

Οι δραστηριότητες μας

Η συνεργασία του Συλλόγου με επιστημονικούς οργανισμούς καθώς και με άλλους συλλόγους και με κυβερνητικούς αντιπροσώπους, που έχουν θέσει την οικογενή υπερχοληστερολαιμία σαν προτεραιότητα, για βελτιωμένες μεθόδους διάγνωσης και θεραπείας, καθώς και η εντόπιση ασθενών.

Η ευαισθητοποίηση του γενικού πληθυσμού, αλλά και των ασθενών που έχουν διαγνωσθεί με Οικογενή Υπερχοληστερολαιμία, για καλύτερη κατανόηση της νόσου.

Η προστασία των δικαιωμάτων των ασθενών με Οικογενή Υπερχοληστερολαιμία, και η διεκδίκηση της έμπρακτης υποστήριξης του κράτους σε αυτούς τους ασθενείς και στις οικογένειές τους.

VISION

Our Organisation's aim is to raise awareness about FH as it is a "silent" yet a life-threatening genetic disorder if left undiagnosed. The key is early diagnosis and raising awareness nationwide among healthcare professionals, policy-makers and the public. Last but not least, through advocacy, the organisation seeks to ensure that the medical care for people with FH is a right, not a privilege.

WHAT WE DO

FH Greece collaborates with medical societies, other associations, and government officials that have set FH as their priority - for improved treatments and diagnosis methods and for tracking down FH patients.

FH Greece raises general public awareness about FH, and amongst people already diagnosed with FH, to ensure a better understanding of the disorder.

FH Greece protects the rights of patients diagnosed with FH, and ensures the effective support of the government to the patients and their families



CONTACT

Athanasios Pallidis

9 Lykourgou Street,
10551 Athens

T. +30 6996906881
E. ldgreece@gmail.com
W. www.ldgreece.gr

www.goo.gl/eL3yOT



HUNGARY

FH Magyarországi

Rólunk

FH Magyarországi betegszervezete 2016 januárjában alakult meg a SZÍVSN betegszervezet irányítása alatt. SZÍVSN betegszervezet már több éve foglalkozik FH-s betegek szűrésével a Mona Lisa kampány keretében. Havonta 1-szer szervezünk méréseket illetve előadásokat ahol a magas koleszterin veszélyeiről tájékoztatjuk az érdeklődőket. A kampány célja a hazai FH páciensek megtalálása, részükre edukáció és vizsgálatok indítása.

Jönőkép

A familiáris hyperkoleszterinemia Magyarországon minden 500. felnőtt lakosból kimutatható egynél, és minden 20 magas koleszterinszintű egyén közül egyben fordul elő. Öröklődéssel a koleszterin értéke jelentősen meghaladhatja a 8 mmol/l-t is, miközben a védőfaktor HDL-koleszterin és a triglyceridszint is normális.

A kialakított FH csoport összefogásával felszínre hozhatók az egészségügyi ellátórendszer hiányosságai adódó problémák. Hazánkban 60 000 fő/év a kardiovaszkuláris betegségekből adódó mortalitás ezért a szervezet fontosnak tarja a betegség korai felfedezését és kezelését.

About Us

FH Hungary Patient Organisation was established at the beginning of 2016 under the leadership of the SZÍVSN organization. The organisation deals with screening of FH patients within the framework of the Mona Lisa campaign. We organise measurements and events on a monthly basis where we provide information about the danger of high cholesterol. The aim of this campaign is identification of FH patients by providing them with education and conducting thorough examinations.

Vision

Familial hypercholesterolaemia can be found in one in every 500 adult inhabitants in Hungary and by 1 in every 20 individuals with high cholesterol levels. Where levels of cholesterol are inherited, they can exceed 8 mmol/l while HDL cholesterol and triglycerid levels are normal.

With the creation of an FH group, we can identify the challenges of the gaps which exist in the Hungarian healthcare system. Mortality due to cardiovascular diseases can be found in 60,000 people each year and therefore the FH organisation considers early detection and early treatment to be important.



CONTACT

Aliz Varkonyi

E. fhmagyarorszag@gmail.com



IRELAND

Croí Heart and Stroke charity

About us

Croí is a not-for-profit foundation established in 1985 dedicated to fighting heart disease and stroke in the West of Ireland. We are an independent organisation, totally funded through our own fundraising activities, voluntary contributions and philanthropic support.

Vision

Our vision is to provide leadership in the prevention, control and recovery from cardiovascular disease.

We aim to increase awareness of cardiovascular risk factors such as cholesterol through our expert support, guidance and educational services.

What we do

In order to increase awareness of cardiovascular risk factors such as cholesterol (including FH), we aim to:

1. Build healthier communities through education, advocacy and empowerment.
2. Promote early diagnosis and access to treatment for those at risk of CVD.
3. Pursue the highest level of cardiovascular health care services through engagement with policy makers and health practitioners.
4. To establish partnership and cross sectional work
5. Facilitate, participate and collaborate in vital research.

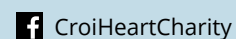


CONTACT

Neil Johnson
CEO

Croí Heart and Stroke charity
Croí House, Moyola Lane
Newcastle, Galway 91 FF68

T. 091-544310
E. info@croi.ie
W. www.croi.ie



ITALY

Gruppo Italiano Pazienti FH

OBIETTIVI E VISIONE

Promuovere l'informazione clinico-scientifica rivolta alla diagnosi precoce, ed alla terapia dell'ipercolesterolemia familiare e delle complicanze cardiovascolari ad essa associate, allo scopo di aumentare la conoscenza e la consapevolezza delle problematiche sanitarie e sociali collegate con questa patologia garantendo un adeguato supporto ai pazienti affetti da FH per fornire le terapie più adeguate.

L'associazione collabora con la società Italiana per lo Studio dell'Arteriosclerosi (SISA) per l'organizzazione di eventi e la diffusione di materiale divulgativo attraverso la news-letter pubblicata sul sito www.sisa.it.

OBJECTIVES AND VISION

GIP-FH promotes the scientific information oriented to early diagnosis and therapy of FH and its associated cardiovascular consequences, in order to increase awareness and knowledge of the socio-sanitary issues related to this pathology and guarantee support to FH patients.

GIP-FH collaborates with SISA Foundation, the Italian Society for the Study of Atherosclerosis, for the organisation of events, such as workshops, lectures and medical training, and for the diffusion of scientific informative material published in the SISA newsletter on the web site.



CONTACT

Fabio Pellegatta
Via Balzaretti 7
20133,
Milano/Milan

T. +39 02 49635252/49636373
E. Fabio.pellegatta@guest.unimi.it
W. www.sisa.it



ITALY

A.N.I.F. – Associazione Nazionale Ipercolesterolemia Familiare

CHI SIAMO

L'A.N.I.F., Associazione Nazionale Ipercolesterolemia Familiare, ONLUS, è costituita da un gruppo di genitori i cui figli sono affetti da ipercolesterolemia familiare omozigote, eterozigote, o altre iperlipidemie geneticamente determinate.

LA NOSTRA VISIONE

In Italia sono stimati cinquanta casi di omozigoti, di cui solo una trentina sono diagnosticati e curati, e 120.000 eterozigoti, dei quali, come appare nei documenti dell'Organizzazione Mondiale della Sanità, solo l'1,9% è diagnosticato con certezza. Vogliamo che questi pazienti ricevano cure adeguate.

I NOSTRI OBIETTIVI

L'associazione ha come finalità primaria la difesa degli interessi dei pazienti affetti da ipercolesterolemia familiare, e fornisce un sostegno a tutte le famiglie attraverso un'attività di informazione diffusa. Promuoviamo iniziative per favorire lo sviluppo e il consolidamento delle attività cliniche inerenti l'assistenza diagnostica e terapeutica ai pazienti, la ricerca sulla malattia e lo sviluppo delle terapie.



CONTACT

Francesco Fuggetta
Press Officer

Via dei Savorelli,
120 – 00165 Roma

T. +39 06 39378144
E. francescofuggetta@hotmail.com
W. www.associazioneanif.it

www.goo.gl/w1Xwq7



LATVIA

ParSirdi.lv

PACIENTU BIEDRĪBA PARSIRDI.LV, LATVIJA

Vīzija/Misija: Samazināt saslimšanu un mirstību no sirds un asinsvadu slimībām, tai skaitā, ģimenes hiperholesterinēmijas, popularizējot veselīgu dzīvesveidu, izglītojot iedzīvotājus par slimību riskiem un simptomiem, kā arī aizstāvēt pacientu tiesības uz kvalitatīvu veselības aprūpi un medikamentu pieejamību.

KO MĒS DARĀM

- Organizējam izglītojošas un informatīvas kampaņas par sirds veselības profilaksi un slimību simptomiem, organizējam tikšanās un izglītojošus pasākumu ģimenes hiperholesterinēmijas un citu slimību pacientu grupām
- Sadarbībā ar kardiologiem un citiem speciālistiem izstrādājam informatīvus un izglītojošus materiālus par ģimenes hiperholesterinēmijas un citu sirds un asinsvadu slimību profilaksi un ārstēšanu, kā arī veselīgu dzīvesveidu.
- Mēs pārstāvam pacientu intereses komunikācijā ar lēmumu pieņēmējiem, lai veicinātu atbilstošāko ārstēšanas, medikamentu, kā arī pakalpojumu pieejamību.
- Mēs sadarbojamies ar ekspertiem un lēmumupieņēmējiem, lai kopīgi rastu labākos risinājumus veselības aprūpes uzlabošanai.

VISION/MISSION

To reduce the impact of heart and cardiovascular diseases, including FH, by promotion of healthy living, education of society regarding the risks and symptoms of diseases, ensuring the access to health care information. Advocacy of FH patients regarding the availability of appropriate healthcare and medicines.

WHAT WE DO

- Organising heart health prevention and awareness campaigns, specific meetings and events for FH and other patient groups
- In collaboration with cardiologists and other experts we create and produce educational materials for patients related to healthy lifestyle, FH and other cardiovascular diseases and risks.
- We represent the patient interests in order to ensure that they receive the appropriate therapy and medicines, as well as services and caring.
- We collaborate with experts and policymakers in order to improve the healthcare system

ParSirdi.lv

CONTACT

Inese Mauriņa

ParSirdi.lv, Olgas street 7-3,
LV 1048, Riga, Latvia

T. +371 29197957
E. info@parsirdi.lv
W. www.parsirdi.lv
www.parsirdi.lv/en

ParSirdi

PacientuBiedribaParsirdi.lv



NORWAY

FH NORGE

VISJON

FH Norge skal ivareta FH (Familiær Hyperkolesterolemi) pasienters interesser ved å informere om FH og om behandling av FH. Videre skal foreningen virke som kontaktorgan overfor myndigheter og helsepersonell, fremme interessen for forskning og virke som kontaktledd i internasjonalt samarbeid.

HVA VI GJØR

Foreningen skal gjennom sitt arbeid bidra til økende grad av diagnostisering av FH pasienter og derigjennom forhindre alt for tidlig død, hjerteoperasjoner og uførhet blant personer med FH. FH Norge skal sette hyperkolesterolemi problematikken på dagsorden i den offentlige debatt.

FN Norge driver omfattende informasjonsarbeid mot våre medlemmer og helsepersonell, blant annet gjennom vårt FH-magasin, våre FH-dager og annen virksomhet.

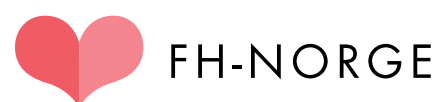
VISION

FH Norway's aim is to inform about FH and about treatment for FH. We are working as a contact point towards health authorities and healthcare personnel, raising awareness about FH and participating in international cooperation.

WHAT WE DO

Our work aims to find more FH patients and through that prevent early deaths, heart operations and disability due to heart disease.

FH Norway publishes the FH-magazine: this magazine is disseminated to patients and healthcare personnel in Norway. We also arrange FH-days and participate in other information and lobbying activities.



CONTACT

Margaretha Hamrin

FH Norge,
PB 8965, Youngstorget
0028 OSLO

T. +47 95 23 21 31

E. info@f-h.no

W. www.f-h.no

FHNorge

FH-Norge-134449449939198



POLAND

Stowarzyszenie pacjentów z hiperlipidemią rodzinną w Gdańsku

WIZJA

Misją naszej fundacji jest zwiększenie świadomości oraz zwalczanie stereotypów dotyczących Hipercholesterolemii Rodzinnej.

Stowarzyszenie pacjentów pomaga zrozumieć chorobę i pokazuje, jak z nią walczyć. Informując społeczeństwo mamy nadzieję na dotarcie do ludzi chorujących na hipercholesterolemię rodzinną by poprawić ich rokowanie i stworzyć poczucie wspólnoty wśród pacjentów.

CO ROBIMY?

Przygotowujemy akcje informacyjne w mediach pokazując społeczeństwu jak częstym problemem jest Hipercholesterolemia Rodzinna. Organizujemy spotkania, na których pacjenci mogą dzielić się swoimi problemami i doświadczeniami oraz porozmawiać z kardiologiem lub pediatrą by wiedzieć jak leczyć siebie, a przede wszystkim swoje dzieci. Promujemy zdrowy styl życia i właściwy sposób odżywiania. Bierzymy udział w konferencjach medycznych, by być na bieżąco z najnowszymi doniesieniami dotyczącymi zaburzeń lipidowych oraz nawiązujemy współpracę z organizacjami pacjentskimi z innych krajów.

VISION

The mission of our foundation is to raise the public awareness and fight stereotypes about Familial Hypercholesterolaemia.

The patients association helps understand the disease and shows how to fight it. By educating society, we hope to reach people suffering from FH to improve their outcome and create a sense of community among the patients.

WHAT WE DO

We prepare information campaigns in the media showing the public how common a problem familial hypercholesterolaemia is. We organise meetings where patients can share their problems and experiences, and talk to the cardiologist or paediatrician to learn how to treat themselves and, above all, their children. We promote a healthy lifestyle and proper nutrition. We participate in medical conferences to keep up-to-date with the latest reports on lipid disorders, and we cooperate with patient organisations from other countries.



STOWARZYSZENIE
PACJENTÓW
Z HIPERLIPIDEMIĄ
RODZINNA
W GDAŃSKU

CONTACT

Stowarzyszenie Pacjentów z Hiperlipidemią Rodzinną

ul. Dębinki 7, 80-211 Gdańsk

T. +48 530 065 430

E. kontakt@hipercholesterolemia.pl

W. www.hipercholesterolemia.pl



PORTUGAL

Associação Portuguesa de Hipercolesterolemia Familiar

OBJECTIVOS

- Divulgar, junto da população em geral, a existência de FH e de outras dislipidémias hereditárias;
- Esclarecer sobre os aspectos relativos a estas doenças e sensibilizar os médicos e os profissionais de saúde para a necessidade do diagnóstico e tratamento precoces e, assim, evitar a doença cardiovascular prematura.
- Representar os interesses dos doentes na definição das políticas de saúde e estabelecer uma ligação efectiva com as organizações parceiras de todo o mundo.

O QUE FAZEMOS

Ações de divulgação junto dos media, participação em congressos médicos, colaboração com os profissionais do sector da saúde, instituições governamentais e indústria farmacêutica; organização de rastreios e iniciativas similares; cooperação internacional entre outras actividades.

FH PORTUGAL

Objectives: • Inform the public in general of the existence of FH and other hereditary dyslipidaemias.

- To make clear all the aspects related to these diseases and to make clinicians and healthcare professionals aware of the need for early diagnosis and treatment, thus preventing premature cardiovascular disease.
- To represent the interests of the patients in the definition of health policies and to establish effective connections with partner organisations around the world.

WHAT WE DO

Activities to raise awareness in the media, attendance in clinical conferences and cooperation with the healthcare sector, government institutions and pharmaceutical industry; participation in medical conferences; organisation of screenings and related activities; international cooperation and much more.



CONTACT

NIPC: 5100334776
Rua Garrett, n. 19, 2ªA,
200-203 Lisboa

T. +351 213583120
E. info@fhportugal.pt
W. www.fhportugal.pt



FhPortugal



SLOVAKIA

Rodiny S FH

CIEL:

Rodiny s FH je občianske združenie, ktoré je prioritne zamerané na pomoc pacientom s familiárnou hypercholesterolémiou (FH) a ich rodinným príslušníkom. Hlavnou náplňou združenia je podporovať kontakty medzi pacientmi s FH, ich rodinných príslušníkov a ošetrojúcimi lekármi a pomáhať im tak lepšie porozumieť tejto diagnóze ako aj zvyšovať povedomie o nej medzi slovenskou odbornou aj všeobecnou verejnosťou.

ČO ROBÍME:

Naším cieľom je

- vytvárať priestor pre vzájomné stretávanie pacientov s FH spolu s ich rodinnými príslušníkmi, lekármi, priaznivcami
- organizovať odborné semináre, kurzy a tlačové konferencie o problematike familiárnej hypercholesterolémie pre pacientov, ich príbuzných, lekárov a všeobecnú verejnosť
- usilovať sa o úzku spoluprácu s praktickými a odbornými lekármi, medzi ktorých klientelou sa nachádzajú pacienti s familiárnou hypercholesterolémiou

VISION:

Rodiny s FH (Families with FH) is a patient association that has been founded to support patients with familial hypercholesterolaemia (FH) and their family members. The main aim of the association is to promote personal contact and exchange of experience between patients with FH, their family members and their physicians and thus to help them better understand the disease and to increase awareness of the disease both in general and throughout the professional Slovak community.

WHAT WE DO:

Our work aims to:

- create the possibility for joint meetings of FH patients, their family members, health care professionals and supporting persons
- organise seminars, lectures and press-conferences focused on FH for patients, physicians and for lay members of the public to raise awareness about FH
- support close collaboration between general practitioners and specialists dealing with patients with FH



KONTAKT/CONTACT

RODINY S FH
Borský Svätý Jur 697
90879
Slovak republic

T. +421 907 743 319
E. rodinysfh@rodinysfh.sk
W. www.rodinysfh.sk



SPAIN

Fundación Hipercolesterolemia Familiar

MISIÓN

Informar, detectar y apoyar a las familias con Hipercolesterolemia Familiar (HF) para prevenir la enfermedad cardiovascular prematura.

VISION

Ser un referente en las hipercolesterolemias genéticas

El objetivo principal de la FHF es sensibilizar a las familias con HF, a los profesionales de la salud y a las autoridades sanitarias entre otros, sobre este trastorno genético que afecta a más de 100.000 personas en España, y así, prevenir la enfermedad cardiovascular prematura. Igualmente, la FHF, proporciona información a las familias con HF y a todos sus grupos de interés, a través de la acción divulgativa: líneas de apoyo telefónico, boletín informativo, folletos y página web, con el objetivo de que

conozcan el riesgo del colesterol elevado y la necesidad de tratamiento y control, así como la importancia de una dieta sana y unos hábitos de vida saludables.

La FHF para desarrollar sus objetivos, realiza acuerdos de colaboración con sus grupos de interés, puesto que las acciones conjuntas con la implicación de los pacientes, profesionales de la salud, autoridades sanitarias, y medios de comunicación son necesarias, no solo para que la información llegue de forma más efectiva, sino también para concienciar a los políticos sobre el riesgo de la HF y la importancia de incluirla en la agenda política.



CONTACT

Mª Teresa Pariente

General Álvarez de Castro,
14 1ºE
28010 Madrid

T. +34 91 5570071/5042206
E. info@colesterolfamiliar.org
W. www.olesterolfamiliar.org

FHFamiliar
 [www.goo.gl/Jk9Qbe](https://www.facebook.com/fhfamiliar)



SWEDEN

FH Sverige

VISION

Patientföreningen FH Sverige bildades 2009 med syfte att verka för att personer med ärftligt höga kolesterolnivåer ska kunna identifieras och diagnostiseras samt behandlas redan i unga år.

Patientföreningen ska ta tillvara FH-patienters behov i Sverige oavsett bostadsort, kön eller ålder. Det är av stor vikt att sjukvården fokuseras på förebyggande verksamhet för att därmed väsentligt reducera risken för hjärt-/kärl-sjukdomar bland FH-patienterna.

VAD VI GÖR

Vi har som målsättning att innan år 2020 ska 80 % av de som har FH i Sverige, ca 40 000 personer, vara identifierade och diagnostiserade samt ha erbjudits behandling.

Föreningen deltar aktivt i det globala arbetet för att ta del av andra länders erfarenheter och åstadkomma en likartad vård över hela Europa. Detta är viktigt då svenska FH patienter har familjemedlemmar som bor i andra länder av Europa och behöver tillgång till samma FH kompetens.

VISION

FH Sweden was founded in 2009 with the aim that people with hereditary high cholesterol levels should be identified and diagnosed as well as treated at as young an age as possible.

We shall safeguard the FH needs of patients in Sweden regardless of place of residence, gender or age. It is of great importance that healthcare is focused on prevention, thereby significantly reducing the risk of heart/vascular diseases among FH-patients.

WHAT WE DO

We are working with the objective that before the year 2020, 80% of people with FH, numbering approximately 40,000, should be identified, diagnosed and been offered treatment.

The Association actively participates in global efforts in order to learn from other countries' experiences and to provide similar care in Europe. This is important as Swedish Patients have got family members living in other countries in Europe and need access to the same FH-skills.



CONTACT

Gunnar Karlsson

FH Sverige
c/o Gunnar Karlsson
Förmansvägen 28
151 47 Södertälje

E. info@fhsverige.se
W. www.fhsverige.se
 FHSverigeSida



SWITZERLAND

Swiss FH

Vision

Die Schweizerische Gesellschaft für Familiäre Formen der Hypercholesterinämie (SGFH) (gegründet im November 2014) bietet Patienten eine Plattform, auf der sie ihre tägliche Herausforderungen mit anderen Patienten teilen und Unterstützung von einander und von Gesundheitsexperten erhalten können.

Die Organisation bemüht sich, die Wahrnehmung dieser Krankheit auf den öffentlichen, medizinischen und gesundheitspolitischen Ebenen zu steigern, um die frühzeitige Erkennung der Erkrankung und mögliche Therapien zu fördern und somit kardiovaskuläre Ereignisse zu verhindern.

Was wir tun

Die Organisation bietet auf der Webseite und in persönlichen Gesprächen Informationen über die Krankheit und zukünftige Therapieformen, mit dem Ziel Patienten mit familiären Formen der Hypercholesterinämie (FFH) in ihrem täglichen Leben zu unterstützen. Wir veröffentlichen die neusten wissenschaftlichen Informationen und Abstracts medizinischer Events rund um familiäre Formen der Hypercholesterinämie.

Wir wirken gemeinsam mit Ärzten und Experten des öffentlichen Gesundheitswesens und bemühen uns ein Krankheitsbewusstsein in der Ärzteschaft zu schaffen, um den Patientenweg durch einer richtigen Diagnose und frühzeitigen passenden Therapie zu verkürzen.

Unser Ziel ist es, die medizinische Gemeinschaft in Bezug auf einer frühzeitigen Erkennung und Therapie, durch Führung lokaler Fortbildungen, Präsenz an Kongressen, Anlässe und der öffentlichen Kundgebung der Patienteninteressen, zu bilden.

CONTACT

Prof. A. Miserez

E. a.miserez@sgfh.ch

W. www.sgfh.ch

Vision

La Société Suisse pour des Formes d'Hypercholestérolémie Familiales (SSHF) (fondé en Novembre 2014) propose aux patients une plateforme sur laquelle, ils peuvent partager leurs défis quotidiens avec d'autres patients, se soutenir mutuellement et obtenir le soutien d'experts de la santé.

L'organisation s'efforce d'augmenter la prise de conscience de la maladie au niveau médical et santé publique, par le dépistage précoce de cette maladie, d'activer les potentielles thérapies et par conséquent empêcher les accidents cardiovasculaires.

Ce que nous faisons

L'organisation offre sur la page web et en entretien personnel des informations sur la maladie et les futures formes de thérapies, avec pour but de soutenir les patients avec des formes d'hypercholestérolémie familiales (FFH) dans leur vie quotidienne. Nous rendons publique les nouvelles informations scientifiques et les résumés des événements médicaux autour des formes d'hypercholestérolémie familiales.

Nous agissons ensemble avec des médecins et experts du système de santé publique et nous efforçons d'arriver à une prise de conscience de la maladie dans la profession médicale, pour réduire le parcours du patient au moyen d'un diagnostic correct et un traitement précoce approprié.

Notre objectif est de former la communauté médicale au niveau de la détection et du traitement précoces, en mettant en œuvre la formation locale, la présence à des conférences, des rencontres et des manifestations publiques dans l'intérêt du patient.

Vision

The Swiss Society for Familial Forms of Hypercholesterolemia (Swiss FH) (founded in November 2014) offers patients a common platform to share daily challenges, get support from each other and from health care professionals.

The Swiss FH organization aims to raise the awareness for these diseases at a public, medical, and health political level in order to promote the early detection of the disease and possible treatment options by preventing cardiovascular events.

What we do

The organization provides information on the website and in a form of face to face meetings to patients about the disease and future therapy options in order to help patients with familial forms of hypercholesterolemia (FFH) to be able to manage disease-specific problems in their everyday life. We publish on a regular basis the latest scientific information and abstracts of medical events around FFH.

We collaborate with physicians and public health experts and put our effort to create disease awareness in the medical community to shorten the patient journey by providing the correct diagnosis and treatment as early as possible.

Our objective is to educate the medical community with respect to early detection and treatment by holding local lectures, being present at congresses in the field, events and voice the interests of the patients in public.



Swiss FH



UNITED KINGDOM

HEART UK – The Cholesterol Charity

VISION

Our vision is to prevent premature deaths caused by high cholesterol and cardiovascular disease.

We aim for the majority of UK adults to know and understand their cholesterol levels and to be taking any necessary action. We deliver this through our expert support, guidance and education services.

ABOUT US

HEART UK –The Cholesterol Charity - is the only charity in the UK dedicated to supporting people with raised cholesterol and other blood fats and also supporting the healthcare professionals treating these conditions. We cover both the inherited form (FH) and diet and lifestyle high cholesterol and other blood fat conditions.

HEART UK has a dedicated Helpline staffed by nurses and dieticians who provide practical advice and support for people affected by cholesterol. Calls cover issues relating to diet and lifestyle, medication and support for families to help manage cholesterol, including matters relating to familial hypercholesterolaemia

HEART UK's website provides a wealth of information for both those affected by cholesterol and health care professionals. Information is updated frequently on a range of subject matters covering the latest treatment advice and guidance, diet and lifestyle and wellbeing.

HEART UK facilitates professional training, development and support in association with both Royal Colleges and Universities. Additionally, HEART UK provides educational grants towards researching a better understanding of cholesterol issues.

HEART UK hosts several professional and patient committees to help further knowledge, experience and support. Many of the professional members of the committees are world-class clinicians and advise on the development of medication and treatment for people affected by cholesterol, including familial hypercholesterolaemia.

HEART UK is an active campaigning organisation supporting patients and health care professionals in advising government and decision-making bodies. Previously, HEART UK has successfully campaigned for greater access to innovative medicines, is a major stakeholder in governmental level decision making on FH service delivery and policy legislation.

HEART UK supports a network of Ambassadors, who are people affected by cholesterol, including FH and help organise peer-to-peer group meetings, help provide a patient perspective in decision-making and campaign in the media.

HEART UK provides a product approval programme which endorses mostly food products that have cholesterol lowering properties.



CONTACT

Jules Payne

Chief Executive

HEART UK – The Cholesterol Charity
7 North Road, Maidenhead,
Berkshire, England SL6 1PE

T. +44 1628 777046

E. jp@heartuk.org.uk

W. www.heartuk.org.uk

[heartukcharity](https://twitter.com/heartukcharity)

[HEART.UK.CHARITY](https://www.facebook.com/HEART.UK.CHARITY)



FH Europe

The European FH Patient Network

E. info@fheurope.net

W. www.fheurope.net

 [fhpatienteurope](https://twitter.com/fhpatienteurope)