



Review article

Familial hypercholesterolaemia patient support groups and advocacy: A multinational perspective



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HIGHLIGHTS

- Familial hypercholesterolaemia (FH) is mostly an unidentified disease that does not discriminate.
- More awareness is required to increase the number of FH patients identified.
- Patient empowerment and the patient voice is paramount in raising awareness and getting system change to identify and optimally treat all FH cases.
- Patient organisations and healthcare professionals work together to find all FH patients worldwide, the earlier the better.
- Networking by and between FH patient organisations is important to share information and learning.

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ABSTRACT

Familial hypercholesterolaemia (FH) is an autosomal-dominant disorder associated with high low-density lipoprotein cholesterol (LDL-C). Left untreated, 50% of men with FH will develop coronary heart disease by the age of 50 and 30% of women by the age 60 [1,2]. It is estimated that the prevalence may be as high as one in 250 people, with most undiagnosed.

This article explores the development of advocacy in FH patient organisations, citing examples from Canada, the Netherlands, Spain, the US and the UK as well as the pan-European patient organisation, FH Europe. The article demonstrates that for patient advocacy, the link with medical and scientific expertise is essential to ensure that advocacy for familial hypercholesterolaemia is well-founded and credible and that patient associations are prepared to take a long-term view on achieving improvements in identification and treatment.

1. Introduction

Familial hypercholesterolaemia (FH) is an autosomal-dominant disorder associated with high low-density lipoprotein cholesterol (LDL-C). Left untreated, 50% of men with FH will develop coronary heart disease by the age of 50 and 30% of women by the age of 60 [1,2]. It is estimated that the prevalence may be as high as one in 250 people, with

most undiagnosed. Early diagnosis, family history, lipid profile and genetic testing should help doctors to identify members of the whole family as there are available treatments to avoid early premature cardiovascular disease. As the disease is inherited, once patients are diagnosed, other family members normally become involved as measures are taken to test for further family members who may have this disorder.

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This article is based on the work of five patient associations and seeks to illustrate the development of patient groups from an initial support function, focusing on education about the disease, and sharing lifestyle and treatment advice and the gradual evolution towards awareness-raising and subsequently seeking to influence the decisions that lead to early identification and improved treatment. As national influence grows, the effectiveness of coming together as a community where small and larger organisations can benefit from shared experiences becomes apparent, as does interaction with specialists in the medical and research fields. Where a history of patient action exists, a model exists for newer associations to start from a well-informed base.

Despite different health care systems which operate in differing ways, the common goal is to increase awareness of FH and work together with a wide range of health care professionals and other providers to deliver improvements to patient care.

2. How patient associations become involved in advocacy

2.1. The story of patient support groups for familial hypercholesterolaemia

The general story of most FH patient associations is the creation of small voluntary groups of patients and family members, for whom education regarding this genetic disorder is a key focus. Many patients will be anxious, fearful and often angry upon diagnosis, especially as it has implications for families and children. Initial awareness of the disease and a gradual increase in scientific knowledge can and do lead patients to desire to achieve more to ensure early identification, better and more affordable treatment with equality of access.

The shared bond between patients in national associations can take many forms - learning more about the disease and treatments helps ensure informed choices. For others, lifestyle advice on day-to-day living with their condition plays an important social and lifestyle role - advice on the importance of diet and exercise in supporting treatment, often via websites and dedicated Facebook pages, or even cookery groups.

At national level, fundraising events by volunteers can emphasise the benefits of healthy lifestyle. Both Ireland's Croí Heart & Stroke Charity and the UK organise participation in the Virgin London Marathon, whilst countries such as Switzerland set targeted distances for running teams in Swiss marathons, allowing a range of volunteers to play their part. The FH Foundation[®] organises a "Race for FH" in conjunction with their annual FH awareness campaign that includes a broad public relations campaign and a fundraising component to support the mission and work.

As groups gain in knowledge and confidence, they often seek to improve identification and improvements in availability and cost of treatment. This wider perspective requires obtaining support from decision-making authorities, be they health commissioning bodies or government officials and representatives.

The FH Foundation is a research and advocacy organisation based in the United States that serves as a global resource for healthcare providers and individuals impacted by FH. The FH Foundation started FH Awareness Day on 24 September in 2012. FH Awareness Day is now recognised on a global scale and generates publicity for FH for this highly under-recognised condition. Raising consciousness of the condition helps receptiveness in later discussions with a wider public and decision-makers. The FH Foundation is an integrated partnership of healthcare providers and individuals born with FH.

2.2. What does advocacy mean for familial hypercholesterolaemia patients?

Governments and other decision-makers (at national, EU and supra-national level) can affect the lives of FH patients – actually or potentially, positively or negatively. To improve the diagnosis and treatment of FH, members of patient associations need to express in their own words, how the decisions that are made have an impact on the lives of

FH patients.

Advocacy involves raising awareness of FH and prioritising the challenges faced within and across national boundaries. Advocacy is about interaction with decision-makers, as they adopt policies and laws relevant to patient groups. These may include government ministers, politicians or government officials in national, regional or local government.

There are various building blocks required to support successful advocacy. These include a foundation of science, accuracy and reliable evidence to engender confidence that existing and novel treatments have been fully validated.

While the internet remains a major source of information for both the public and health care professionals, it can often provide conflicting, misleading, inaccurate and often dangerous information. In order to rebut inaccurate information and 'fake news', in particular regarding cholesterol and the use of statins, patient associations are seeking to develop expertise to provide consistently high-quality information in a way that encourages public trust and supports the work of health care professionals.

The development of scientific material to support early identification of FH includes cascade screening and registries, the latter providing health care professionals and researchers with data for clinical, scientific and policy purposes. From the patient perspective, their role in improving and monitoring the outcome and quality of treatment and in reviewing best practice, becomes a tool for patient advocacy to ensure continued development and improvements are embedded in healthcare policies.

2.3. New media as a tool in patient advocacy

To maximise their reach across boundaries – both national and generational, all FH patient associations use e-media to inform and advise.

In the United Kingdom, HEART UK's website [3] has more than two million visitors a year and also provides a regular e-news both to supporters and to health care professionals.

The FH Europe website is a hub to provide general and easily understood information on the condition for patients - their families, the wider public and decision-makers - and to promote contact with members. Its private member area offers a substantial resource for reference and training material. FH Europe's e-Flash newsletter is issued on a regular basis to provide an overview of FH-related activity to interested parties in patient associations, healthcare professionals and others. Facebook and Twitter also play a part, but it is the personal contact between members that provides the motivation for network activity and can ensure that volunteers are energised.

2.4. Screening - the role of patient organisations in the development of a FH cascade screening programme

2.4.1. The example of fundación hipercolesterolemia familiar of Spain

The Spanish patient association notes that since Familial Hypercholesterolaemia (FH) is the most frequent genetic disorder, which affects 50% of the family members, besides clinical criteria, its final diagnosis should be genetic. It fulfils the WHO criteria for genetic screening: FH is a silent disease, invisible for many people. Its physical signs are not always present (xanthomas 15–20%) especially in the young, and it has serious cardiovascular consequences for young and middle-aged people.

The aim of the Spanish association's contribution to data generation is both to help improve understanding of the FH risk and to support decision-makers at the Spanish Central and Regional level, the latter being one of the purposes of the SAFEHEART nationwide Registry, which is the Spanish FH cohort follow-up study, created and conducted by the Foundation with the collaboration of 28 lipid clinics.

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