



Opinion

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Brazil's Initial Experience in Widening Awareness of Familial Hypercholesterolemia with Patients Associations

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Abstract

In this paper we describe the steps taken for broadening the public, mediatic and all heart professional awareness in Brazil of Familial Hypercholesterolemia and the cardiovascular risk it carries, carries encompassing the strategic plan, advocacy, its purpose, how the Brazilian Familial Hypercholesterolemia Patients Association was born, this mission, objectives, and the reality of familial hypercholesterolemia patients in Brazil.

Keywords: Familial hypercholesterolemia; Patients associations; Midia; Public awareness; Advocacy; Stakeholders

Abbreviations: FH: Family Hypercholesterolemia; FHPA: Familial Hypercholesterolemia Patients Association

Opinion

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Strategic Plan

Strategic objectives

1. Map people with suspected or diagnosed family hypercholesterolemia (FH).
2. Increase and engage the number of members: patients, family members and health professionals towards the Association.
3. Expand the knowledge of patients, health professionals, government agencies and society in general about the disease, its diagnosis and treatment.

4. Promote the recognition of the disease with the creation of specific ICD (International Classification of Diseases).
5. Support the development of scientific research for the treatment of FH and related diseases.
6. Influence entities, managers and politicians to guarantee patients' rights.

Advocacy

It consists of a set of actions that aim to influence the formulation, approval and implementation of public policies with the Legislative, Executive and Judiciary branches and society, through networking and media mobilization. This is a topic of interest for third sector organizations and researchers who aim to bring about changes in society from public policies in the areas of health, environment, human rights, children and adolescents, education, consumer law, work, among others.

What is an Association? What is its purpose?

How was the Brazilian Familial Hypercholesterolemia Patients Association born (FHPA)?

FHPA is a non-profit entity, founded by patients with FH conditions, which has a scientific council with the support of actions and decisions of the Association.

What is the FHPA mission?

Stakeholders' awareness about FH and promote equal access to diagnosis and treatment, making an alliance with all involved to improve disease rates.

Main objectives

- a. Promote contact between individuals, family groups and associations seeking information about FH and other genetic-based dyslipidemias in Brazil and other countries.
- b. Encourage, promote, and support alliances with national and international groups that work in the support and development of scientific research and treatments for FH patients.
- c. Support and disseminate scientific research for the treatment and cure of FH-related diseases, disseminating data and medical information on treatment and cure to patients, family members, guardians, and other stakeholders.
- d. Promote social and legal assistance to FH sufferers and their families or guardians, providing them with the guidance and defense they need.
- e. Encourage and promote extensive knowledge about FH by conducting courses, conferences, lectures and distribution of books, videos, periodicals, brochures, and all available media.
- f. Support programs to improve the medical area by conducting courses, congresses, conferences, and lectures.
- g. Encourage volunteering by training support groups for FH patients in the national territory and in other countries.

The reality of FH patients in Brazil

Challenges faced by the patient:

- I. Lack of information
- II. Ignorance of the medical class
- III. No referral for second medical opinion
- IV. Restricted access to genetic diagnoses
- V. Late diagnosis
- VI. Lack of knowledge and lack of access to adequate treatment
- VII. Lack of maintenance and follow-up of the disease
- VIII. Lack of psychological support for patients and their families
- IX. Lack of culture and difficulty in accessing healthy eating

FHPA Strategic Guidelines

Vision of the future

Mission: raise society's awareness about FH and promote equal access to diagnosis and treatment, making an alliance with all involved to improve disease rates.

Essence of the mission: raise awareness, promote access, make alliances.

Vision of the future: a country where people with FH are diagnosed early, treated appropriately, and do not die because of the disease.

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Conflicts of Interest

No conflict of interest.