

Information about the Norwegian Association for Children with Congenital Heart Disease

About us

The Norwegian Association for Children with Congenital Heart Disease works to help all children with congenital heart disease in Norway have a good life. To do this we need to identify all the children in Norway who suffer from heart disease, not just our members.

There are 500-600 children born every year in Norway with some kind of heart condition. Most of them, about 90 percent, can be treated. There are about 9000 children and adolescents with congenital or early-acquired heart disease under the age of 18, and almost twice as many over 18. This is the second most common chronic illness among children.

Giving birth to a child with heart disease changes everything in a family's life. It often leads to lengthy hospital stays and a lot of uncertainty about the future. Help and support is available from our organization by parents in the same situation, whether your child's disease is "minor" or "very serious".

Our Objectives

The Norwegian Association for Children with Congenital Heart Disease is a nationwide special interest organization that aims to protect the interests of children and adolescents under the age of 18 who have congenital or early-acquired heart disease and their families, and to help families who have lost a child who was suffering from heart disease.

One of the main objectives of the Norwegian Association for Children with Congenital Heart Disease is working to improve the social situation for children and adolescents who suffer from heart disease and their families, at all levels in society. We do this by:

- providing educational and consultative activities for the children, adolescents, their families and society as a whole
- acting as a liaison between society, hospitals, families etc.
- supporting and influencing health care professionals in continuing education and research
- following up on family rights in public forums
- acting as a forum for networking and social activities
- we offer a peer support group comprised of people who have experienced what you are going through, whether this is living with a child with heart disease or having lost a child, the members of this group understand what you are experiencing firsthand
- finding ways to finance our association's activities

The association is not affiliated with any political party or religion.

What can we do for you?

The Norwegian Association for Children with Congenital Heart Disease can open doors for you and connects you with other families in the same situation. We can provide information, advice and support throughout the course of your child's illness.

These are some of the benefits of becoming a member of our organization:

- Meeting with others in the same situation
- Receive our member magazine (Hjertebarnet) published 4 times a year
- Hjertetelefonen – A toll-free number you can call every other week for advice if you need someone to talk to
- Receive our informative pamphlets, folders etcetera, whether you are a parent, day care institution or school: Hjertepermen, Hjertevennlig oppvekst

If you have any questions about membership or what we can offer member-families or what our association is up to, feel free to contact us! You can reach us by phone at 23 05 80 00, or by e-mail ffhb@ffhb.no.

The Norwegian Association for Children with Congenital Heart Disease works so our kids will live a good and happy life.

What we can offer those who have lost children to heart disease

Our association hosts a group that tries to attend to the needs of families who have lost a child to heart disease. One activity we host is what we call a sorrow gathering. This group consists of 11 people from all over the country, with a governing board of 3 individuals. The group is composed of experts with years of training and experience, and adults who have or have lost children with congenital heart disease.

The support group's work is based on the principle of peer support, meaning people who have lost a child themselves. None of them are professionals or therapists, but everyone is able to listen and show empathy, and they are all genuinely interested in helping those who are grieving.

Being able to listen is often more important than providing consolation...

Our organization

The Norwegian Association for Children with Congenital Heart Disease is a nationwide special interest organization that aims to protect the interests of children and adolescents who have congenital or early-acquired heart disease and their families, and to help families who have lost a child to heart disease. The association was founded in 1976 by the parents of children with heart disease.

We are not affiliated with any political party or religion.

Every member of FFHB is also a member of FFHB's regional group in the district in which they live. The members of our regional groups can help by volunteering at a local level. Some districts also have smaller groups that work within a city or town.

The regional groups send delegates to the FFHB National Conference every second year. The National Conference is the primary governing body of the association. The national board is elected at the National Conference. The board is responsible for the daily operation of the organization along with FFHB's administrative staff.

Regional groups around the country

The Norwegian Association for Children with Congenital Heart Disease has regional groups around the country in all Norwegian counties.

The regional groups operate on a volunteer basis run by the parents of children with heart disease. Their main tasks are to organize local activities, cooperate with local hospitals and provide support for families in the region with children suffering from heart disease. The regional groups organize more than 200 events every year.

In the menu below and to the left of *Contact us* is a list of the webpages of all of our regional offices.

Information about diagnoses, examinations and treatments

There are many different kinds of congenital and early-acquired heart disease. Information about different diagnoses, examinations and treatment can be found here: <http://www.corience.org/>