

# **The Norwegian Association for Children with Congenital Heart Disease – our organization and our work**

## **About us**

*The Norwegian Association for Children with Congenital Heart Disease* is a nationwide patient organization. It aims to protect the interests of all children and youth in Norway under the age of eighteen who have a congenital, early-acquired or genetic heart disease, and their families, and to help families who have lost a child who was suffering from heart disease.

Every year there are between 500 and 600 children born in Norway with a heart condition. As a result there are about 9000 children or youth under the age of eighteen and almost twice as many over 18 living with a congenital or early-acquired heart disease in Norway. Most of them, about 90 percent can be treated. This is the second most common chronic illness among children.

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

Our vision is that all children born with a heart condition in Norway shall have a good quality of life.

## **Our Purpose**

One of the main objectives of the *Norwegian Association for Children with Congenital Heart Disease* is working to improve the social situation in our society for children or youth who suffer from heart disease, including their families. We do this by:

- providing information and guidance for the children, youth, their families and society as a whole
- acting as a liaison between society, hospitals, families etc.
- supporting and influencing health care professionals to continue education and research
- following up on family rights in different public forums
- acting as a forum for networking and social activities
- we offer a peer support group comprised of people who have experienced similar situations, whether this is living with a child with heart disease or having lost a child
- supporting relevant research projects, including the organization's own Research foundation

Concerning religion and Politics the organization is neutral.

## **What we offer**

*The Norwegian Association for Children with Congenital Heart Disease* can connect you with other families in the same situation and be a useful door opener in different ways. We also 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:

- Put you in contact with others in the same situation
- Receiving our member magazine (Hjertebarnet) published 4 times a year
- Hjertetelefonen – A toll-free telephone-number you can call every other week for advice or if you need someone to talk to
- Receive our informative pamphlets, folders etc., If you are a parent with a child in kindergarten or school, you can receive our "Heartbinder" which contains a wide range of useful information for parents and the staff regarding the child's day at school or in kindergarten.

## **Families who have lost their child or youth due to a heart disease**

In our organization there is a specific group supporting and following up the needs of families who have lost a child or youth to a heart disease. The group is composed of about 10 individuals who all have years of training and a wide range of personal experience. The national work is led by a governing board.

One activity offered by this group, is what we call a grief group, led by experienced people from all over the country. The work of the support/grief group 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.

Listening is usually the most important element of supporting a person in grief.

## **Our organization**

*The Norwegian Association for Children with Congenital Heart Disease* was founded in 1976, by a small group of parents of children with heart disease.

Every member of the organization is also a member of a 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 organization's national convention held every other year. The National Conference is the supreme 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 the administrative staff.

## **We have regional groups all over Norway**

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

Our regional groups are run by parents on a volunteer basis. Their main tasks are to organize local activities, cooperate with local hospitals and provide support for families in the region. The regional groups organize more than 200 events each year.

In the menu below and to the left of *Contact us*, there is a list of the webpages of our regional groups.

## **Information about diagnoses, examinations and treatments**

There are many different kinds of congenital, early-acquired or genetic heart disease. Here you will find information in English about the diagnoses, examinations and treatments:

<http://www.corience.org/>

If you have any questions about membership, what we can offer member-families or about the work of the organization, please feel free to contact us! You can reach us by phone at 23 05 80 00, or by e-mail [ffhb@ffhb.no](mailto:ffhb@ffhb.no).