

# Herzkinder Ostfriesland e.V.

Today, almost every 100. Child with a congenital heart defect and every 1,000 children born with a very serious heart defect. Care, understanding and help are essential for the affected families.

In 2007, on the initiative of the pediatric cardiologist Dr. Rainer Willing from the Ubbo Emmius Clinic in Aurich which is based in Germany / East Frisia at the North Sea, a group of affected parents came together and a parent self-help group was established.

That the need was present is evident from the steadily growing number of members. We are sure that even more children with congenital heart defects live in the East Friesland area. All families are welcome to contact us and get to know us.

Thanks to improved prenatal examinations, it is now possible to detect existing heart defects during pregnancy. For parents and their families, a world collapses when they receive such a diagnosis. The doctors can already point us out. We can help the puzzled parents with our experiences as affected persons if necessary.

## Who we are.

Since the founding of our parents' association, some children with very serious heart defects have been born in our association area. This requires either the expectant mother to be sent to a specialised centre before the child is born, or the newborn child must be brought to such a centre within a few hours, usually by helicopter. When accompanying the parents, we are immediately involved by the hospitals.

**We are all volunteers.** Nevertheless, for regional and supra-regional projects there are immense costs, which go far beyond the association fee. We need to find friends, sponsors and sponsors to support us so that we can help.

It would be very important for us to find other partners to support us in our work.

For our children of the heart it is necessary that we parents be with them always and everywhere. This is particularly true if they are often working for several weeks or months. hospital. Contact with father and mother is essential here. Children, especially newborns, are sensitive people and need direct contact with their mother and family.

This may result in financial shortages for parents which they simply cannot overcome on their own.

Here we try to support the parents financially, so that the heart child does not miss out. Because the welfare of the children of the heart is our top priority.

It is not easy to live with a HEART child, but the infinite love these children give back is the reward for our work.

Our Children of Hearts need help. In order to optimally promote the health needs and, above all, the psychosocial development of our children, we want to use our collective strength, our knowledge and our financial resources for the families of heart children. And the families always appreciate this help!

### **What are we doing for our Heartchildren?**

- Individual therapies of various kinds, e.g. hippotherapy, concentration training, physiotherapy
- Information, further education and training of parents in seminars and leisure time.
- Socialization of heart children among themselves, with siblings and healthy children.
- Weekend seminars for parents, children of heart and siblings.
- Support for adolescents with congenital heart defects (JEMAH) in the finding a job and later career.
- Improve local medical care for children with congenital heart defects
- Supporting parents in psychosocial matters, e.g. on issues such as early childhood education, support needs and integration in kindergartens and schools What are our wishes and visions for the future?
- Holiday home with therapeutic offers to breathe for affected families (e.g. after surgery)
- Regional children's heart sports group
- Support for research projects • Better networking between inpatient and outpatient social-medical support for families
- uncomplicated psychological support for local families
- improving medical care for "JEMAHS" (young adults with congenital heart defects) We want to improve our lobbying for our children throughout Germany. This can only be achieved if nationwide actions are carried out in a variety of ways in order to attract the attention of politicians and the general public.



## **Achievements**

We were able to help parents in their greatest insecurity and need with advice, action, but also with financial commitment immediately and unbureaucratically.

Since the founding of our parents' association, we have experienced in many actions and events with our children of the heart what gratitude means.

Even if we are afraid for the health of our children of the Heart, it is a great joy to see them, when they can play and have fun with each other without worries. They take away our worries and hardships through their happiness and their togetherness. For us, these children are irreplaceable. This is how it should stay and must continue!

We are happy to answer any questions or questions you may have available. Just get in touch with us!

Hoping to have aroused your interest in our association we remain

With cordial greetings

Herzkinder OstFriesland e.V.

-The board of directors-