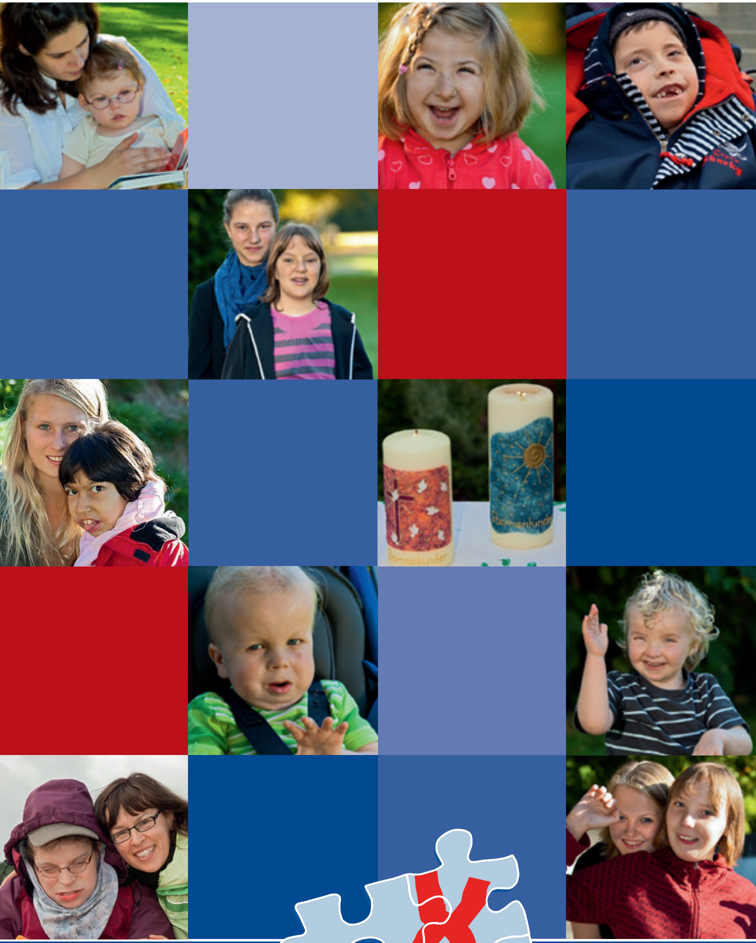
FINDING PATHS AND WALKING THEM



LEONA e.V.

Family self-help for rare chromosomal abnormalities

Englisch / English

WHY LEONA E.V.?

LEONA e.V. is a support group for parents whose children have been diagnosed with rare chromosome disorders – some shortly before or after birth, others later, when the child's development was delayed for unexplained reasons. An irreversible diagnosis like this fundamentally changes the life prospects of the affected families. Even experts have often only seen these symptoms and potential development processes in textbooks. The rarity of the diagnoses makes it almost impossible to make specific predictions. It is vital that parents in this situation do not feel that they are on their own. With the wealth of experience of affected parents and a wide network of contacts, LEONA e.V. provides help and support.

The group's namesake, Leona, was stillborn in the 43rd week of pregnancy on 2nd April 1992. She died in the womb, a day before her birth. 11 weeks before, she had been diagnosed with the rare chromosome disorder Edwards syndrome. Leona's parents set up the LEONA contact point, which later became the charity.

> *"When our child was diagnosed with mosaic trisomy 9, we felt helpless and totally alone. Most of the information we could find was full of scientific jargon that certainly did not make us feel any better. It was such a help to finally make contact with other affected parents!"*
>
> Affected mother

WHAT DO WE STAND FOR? – TOLERANCE!

The members of LEONA e.V. have very different opinions on various issues. Issues surrounding pregnancy (prenatal diagnosis, PGD, abortion) are particularly contentious, but there is also a wide range of different opinions on education (special schools, integration or inclusion).

As a charity, we do not hold a fixed position and will not be co-opted into representing particular opinions. Instead, we are a strong community that tolerates the individual opinions of our members.

OUR ROLE

FINDING PATHS AND WALKING THEM

We cannot make a decision for others, nor would we want to. The path that is right for one person is wrong for another. We want to help you to find your own way.

- We support one another.
- We put those affected in contact with one another.
- We publish reports on people's experiences.
- We gather knowledge and information.
- We give people the strength to help themselves.
- We provide practical tips.
- We offer an online discussion forum.
- We want to bolster parenting skills.
- We support siblings.
- We organise get-togethers across Germany.

NEED TO MAKE A DECISION FAST?

A prenatal diagnosis of a rare chromosome disorder confronts many expectant parents with one of the most difficult decisions of their lives. Exchanging information and experiences with other parents can help those affected to find their own path and to walk it in the most beneficial way possible.

COPING EVERY DAY

From small everyday things to dealing with authorities and difficult decisions on operations, etc., our network helps parents to make contact with and talk to other affected families.

BEREAVEMENT

Parents grieving for children who have passed away often feel very alone. Talking to others who have been through the same thing does not make the grief any less, but can help parents to cope with and accept it.

CREATING NETWORKS

Between those affected
Together, many things are easier to bear: worries and fears, pain and grief. But a love of life and the strength to love our children just as they were born can also be bolstered by sharing with others.

Our sense of community is based on exchanging experiences with one another. Be it personal contacts, regular family get-togethers or LEONA e.V.'s internal online discussion forum – there is always someone who has had the same or similar experiences and can provide emotional support and practical information. That gives courage to face everyday life and supports parents and children in finding and implementing their own life plan. We also provide additional services for fathers and grandparents.

Between siblings
When children with and without disabilities grow up together in a family, this puts a great strain on siblings.

At LEONA e.V., you can talk to other siblings, make contacts and strengthen bonds at family get-togethers, for example. Special events for siblings are held annually; useful links, addresses and tips are provided.

In public

Change can only come with acceptance. That is why public relations are so important to us. The experts that provide support, medical and social facilities and those not affected need to be sensitised to the specific situation and needs of affected families. Thanks to the wealth of experience of affected parents, LEONA e.V. has a huge collection of experience reports and information on various disorders and syndromes, treatments, aids, sources of advice and other support groups. Every member of LEONA e.V. makes a valuable contribution to our work through their very individual experiences.

LEONA e.V.

Aile içi kendi kendine
yardım nadir kromozomal
anormallikler için

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