

## Facts about rare chromosome disorders:

- Every day 10 babies are born in the UK alone with a rare chromosome disorder; this means that at least 1 in every 200 babies carries a balanced or unbalanced rare chromosome disorder
- 1 in every 1,000 live births has a rare chromosome disorder which results in disability or ill-health
- Some rare chromosome disorders such as balanced translocations can go undetected, and undiagnosed for years until a parent passes on an unbalanced form of the translocation to their child. Other balanced translocation carriers experience fertility problems, multiple miscarriages or the birth of a stillborn child.
- Some chromosome disorders are so rare that they are truly unique but, although individually rare, such rare chromosome disorders are collectively numerous.

## About **Unique**

- **Unique** was founded in 1984 by Edna Knight as the Trisomy 9 Support Group with an initial membership of just 5 families.
- In 1989 the group expanded to include families affected by any rare chromosome disorder but not the more common disorders like Down Syndrome.
- In 1993 the group was granted charity status and the new name **Unique** was adopted.
- In 1999 the group was awarded a 3 year grant from the National Lotteries Charity Board to fund a full time Development Officer
- In 2006, **Unique** became a registered company, with charitable status.
- Unique employs 4 staff, 1 full time and 3 part time and with a committee of 8 volunteers. All the staff and committee members have been through the experience of having a child with a rare chromosome disorder.

## What **Unique** aims to do

- **Unique** can help by supporting affected families whilst they try to come to terms with the fact that it might be impossible for them to be given a definite prognosis for their affected children.
- Although **Unique** can link families together on the basis of specific chromosome disorder, it often proves to be much more beneficial to link families whose children have similar clinical and or practical problems.
- Our comprehensive database has been a great help in arranging for families to assist in research into specific chromosomal disorders whilst maintaining confidentiality, in collecting information about the lifetime effects of any rare chromosome disorder within our membership and for collating information about the effects of the more frequently occurring rare chromosome disorders.

## What your fundraising and donations help **Unique** achieve

- We produce and send out a magazine for members 3 times a year. This is the face of **Unique** as members write their letters about the good times and hard times coping with their unique children. The magazine also aims to inform members on topical issues relating to new developments in genetics, health, education, behaviour and many other areas of concern and interest.
- We produce individual booklets and leaflets on some of the more frequent types of rare chromosomal disorders, which give detailed information to parents and the people who work with them.
- We continue to support those professionals working with families with children with rare chromosome disorders, informing them of our latest knowledge

*For further information telephone 01883 330766 or visit [www.rarechromo.org](http://www.rarechromo.org)*