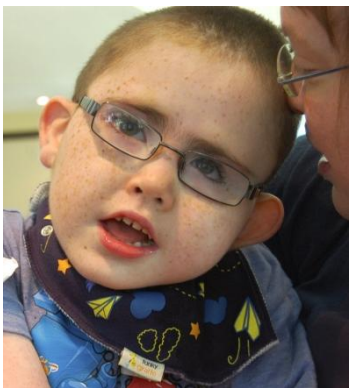
PRESS RELEASE:
Chromosome Disorder Awareness Week (7-13th June 2015), combating the isolation of families of disabled children.

'WHEN YOUR CLOSEST FRIENDS ARE VIRTUAL FRIENDS'






Social isolation is a huge problem for many parents of disabled children. Throw in a rare chromosome disorder, often a disorder that has no name, just a long, unfathomable code of letters and numbers, and the problem increases. The everyday challenges which follow, the never ending worries about the future, constant battles to make professionals and even your friends and family understand, leave parents feely confused and very alone.

To help raise awareness of these issues, Unique is running a Chromosome Disorder Awareness Week from 7-13th June. The aim is to spread the word to ensure nobody affected is left feeling isolated and alone.

Everyone needs their friends around them for support, no one should have to feel so desperately alone and yet hundreds of parents with children affected by a chromosome disorder are facing the hardest time of their lives on their own, being rejected by those they trusted most.

"When my son was first diagnosed, friends suddenly stopped contacting me. I would see pictures appear on Facebook of the things they had got up to, things that before that point I had done with them". Unique Mum

Unique, The Rare Chromosome Disorder Support Group has set up a confidential Facebook group 'Cafe' which has grown rapidly to over 3,000 members. It's a virtual place where parents can 'pop in for a cuppa', vent, ask questions, gain support and also celebrate their child's achievements.

There is nothing like feeling understood and heard by a community of people who have shared similar experiences. It has become a lifeline to parents who feel invisible to the rest of the world, giving them a support network of friends who understand, don't judge and help them make sense of what is happening to them. One mum recently told us:

"I've found that I've lost a lot of old friends because they just don't understand or want to understand my situation. I have made lots of valuable friendships since having my daughter and that's what counts."

"The Unique Facebook Cafe group became my lifeline, my access to a wealth of knowledge and my greatest source of support. I soon became friends with 3 of the mums, we quickly realised we had the same sense of humour and shared a common bond.... WE LOVE CAKE! These 3 women are my bestest, most treasured and trusted friends." Unique member

Notes to Editors

Unique is the UK charity supporting families affected by rare chromosome disorders.

For further information, please contact: Dr Beverly Searle, CEO on 01883 723356/07702 585003, alternatively you can email Caroline Pocock, Fundraising Officer at caroline@rarechromo.org

www.rarechromo.org

Available on request

Case Studies and photos: we can provide details of families in your area willing to be interviewed about their experiences and the friends they have met through the Unique Facebook Cafe. Please contact us for details.

About Unique & how we help

- We inform, support and beat the isolation of anyone born sick and disabled by any chromosome disorder, their families and the professionals working with them.

- We offer a 'listening ear' telephone and email service to parents of a newly diagnosed child as well as professionals needing information to help them counsel and plan patient care.

- We link families living with similar conditions to share their experiences, offering invaluable mutual support.

- We hold one-day social events, study days & family conferences, bringing together families and professionals to further our knowledge of specific chromosome disorders and develop the means to offer improved support.

- We work to raise public awareness about chromosome disorders and we help families face the future with hope.

Appendices

Chromosome disorders fact sheet.

Chromosome Fact Sheet

- With rare chromosome disorders some genes or parts of genes are missing, extra or rearranged, most often leading to problems with a person's development, learning ability and sometimes health.

- Rare chromosome disorders are life-long – they cannot be cured but with the right therapies and treatments for individual symptoms a child can be helped to develop to his or her full potential.

- Some rare chromosome disorders are life-threatening while most lead to a limited life expectancy.

- New technologies (such as Array CGH analysis and Next Generation DNA sequencing) mean that much tinier changes in chromosomes and genes can now be detected, often bringing to an end the gruelling journey to finding a reason for their children's disabilities and medical problems that many affected families have had to face.

- In most cells in the human body there are 23 pairs of chromosomes (46 chromosomes in total), 22 numbered from 1 to 22 and the 23rd pair comprising the sex chromosomes, XX for a female and XY for a male.

- One member of each pair of chromosomes is normally inherited from the mother and one from the father, which is why we tend to resemble a mixture of our parents.

- Each chromosome is made up of a short arm (p for petit) and a long arm (q).

- Chromosomes are made mainly of DNA (DeoxyriboNucleic Acid).

- Genes are composed of small stretches of DNA.

- Genes are the instructions that direct how our bodies form, grow and function.

- In total there are about 20,000 genes across all our chromosomes (across the genome).