

Soft UK



SUPPORTING FAMILIES,
CELEBRATING LIVES

Be part of something amazing.

SOFT UK supports families and children affected by the life limiting conditions, Edwards' and Patau's syndromes.



Soft UK Support

You may have heard of Down's Syndrome (Trisomy 21), a genetic condition occurring when a person has an extra chromosome 21.

Less well known are Edwards' (Trisomy 18) and Patau's (Trisomy 13) Syndromes. These are serious genetic conditions, which cause a range of developmental and medical difficulties.

In pregnancy the risk of miscarriage or stillbirth is very high. Babies born with these conditions normally require intensive medical intervention and sadly most children affected by Full Trisomy will not survive childhood.

How SOFT Helps...

Since 1991 SOFT UK has been providing information and support to families affected by these syndromes. We are there to help parents and the wider family through every stage of their journey. We also offer information, signposting and support to professionals working with families affected by Trisomy.



Cali, aged 4 years (Full Trisomy 18) with mum Jay



Isabel, who is now aged 6 years old (full Edwards syndrome)

Our trained volunteers, all Trisomy parents themselves, provide Befriending support to families. Our families tell us that talking to others with similar experiences helps reduce their sense of isolation. We signpost families to information and help them navigate health and social care services to secure the resources they need.



Maebh, Partial Trisomy 18, aged 5 months

We bring our families together regularly; building a supportive community, sharing and learning together, having fun and creating important memories.

And, if the worst happens, we are there to support the whole family through the darkest of times, remembering and celebrating the life of their child.

Help us continue to support families who have a child affected by these conditions and make a real difference.