

'The Compassettes...Friends are the compass that guide us. They are the inspiration to reach great heights and our comfort when we occasionally falter...'

The Compassettes



Left to right for kids on the bench: Lily May, Jackson, Stella, Grace, Hollie, Charlie and Tilly. In the photo of the Mums with two standing and two sitting, Samantha Hill is standing left, Rebecca Earp standing right, Anna Appleby sitting left and Ania Moir sitting right.

Wonderful friendships and support networks between Unique families have been formed across the world, not necessarily between families whose children have the same chromosome disorders but very often between families whose children have quite different disorders and who experience similar joys and challenges. Here 4 such friends from the UK tell us about the amazing friendships and support network they have formed.

[Samantha Hill](#)

When my daughter was diagnosed with a rare chromosome disorder, I can remember feeling lost, bewildered and unsure of what the future held for us. One thing I was certain about was that I wanted to find others in my situation and learn from their experience and know that I wasn't alone. I joined Unique in November 2012 and quickly found the group a massive source of support and reassurance. Now fast forward to January 2015 where I am sitting here writing this and thinking about 3 wonderful women who I called best friends. We are so close that we are practically family, our families do things together and we are one big unit! I dare anyone to ever challenge 'Our Unit' as they have to fear 4 determined, strong, brave, beautiful, patient and loving mummies! We call ourselves 'The Compassettes as we are based North, South, East and a tad West! Just through threads and posts on the Unique Facebook Cafe lead us to start talking on a regular basis, not just about our children, but life in general. We all come from different corners of the country but manage to speak every day, which drives our husbands crazy!

We meet up 3–4 times a year, sometimes just the mums as we all need that time to be us and not

mummies or wives and other times with the husbands and children. We have even attending family gatherings, the first being my daughter' s christening and the next gathering will be Rebecca Earp' s mum' s wedding! Our mum' s are facebook friends, our husbands are facebook friends, we are even facebook friends with each other' s friends! Our weekends consist of eating, drinking, laughing, crying and just generally being there to support each other as we guide our way through the unknown. We celebrate each of our kiddie' s achievements and treat each other' s kids as if they were our nieces and nephews. We are a constant source of support to each other through the good times and the bad times and if we ever need each other, we only have to shout. Even though we may feel life has untreated us unfairly, I don' t think about what could have been, I looked at what I have gained...3 best friends and their utterly beautiful families.

Rebecca Earp

When the geneticist told me to join Unique I wasn't interested. I didn't need a support group, I didn't need other special needs mums in my life, and I didn't want strangers sharing their experiences or giving advice. My husband joined Unique and after a few months posted on Facebook about Lily-May's unique deletion. Lo and behold someone replied with a similar deletion. From that moment on I've never looked back. The Unique Facebook Cafe 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. The love and respect I have for Anna, Ania and Sam I cannot put into words. They've become part of my extended family. They nurture my children and love them like their family and the feelings are mutual. We celebrate each other's family's achievements and are there for support when days are tough. So thank you Unique for introducing me to 3 of the most amazing women and their families I could wish to have in my life.

Ania Moir

When my daughter Stella was born, we were told on her first day that she had dysmorphic features and blood was taken for testing straight away. We were told this would take some weeks and that someone would be in touch. We were then sent home and told to 'enjoy' her... Easier said than done when the joy and excitement of your new baby has been snatched from you! Stella was undiagnosed for the first 6 months of her life and this was a very frightening and above all lonely time. We didn't feel that we fitted in anywhere with our little girl and the unavoidable lure of Google filled our heads with some really worrying possible scenarios! When Stella was finally diagnosed with 12q14.3-15q dup, our geneticist immediately talked to us about Unique. Although terrified by this unique chromosome issue and the total lack of information, the relief of finally belonging to a support network was intense. I had no idea yet of just how very special this group would become. This is where I met 3 very incredible Chromo Mummies, Rebecca, Samantha and Anna. Over the months we became very close online, decided to meet up and ever since, the bond has strengthened. I feel that I have gained a huge amount through our sharing of all things good, bad, sad and downright hilarious. They give me the ability to smile and laugh through some of the more rubbish days and the strength to fight for my daughter's rights! These 3 ladies are my amazing friends. They are the most understanding, supportive, loving, interested and non-judgemental women and I am incredibly blessed to have them in my life. A truly Unique friendship!

Anna Appleby

'The Girls' as they are referred to in my house, Samantha, Rebecca and Ania have without a doubt been the best thing about having a unique child. Even on the very hardest of days I think to myself, at least this journey has given me such a special friendship. It's has been a kind of web of chatting, texting, messaging, crying, laughing, gossiping, eating, drinking and even dancing that has created my little safety net. What I am most grateful for is that the net is growing to support my children too. I feel Tilly (7q micro deletion) has gained three incredible Aunts who will always accept her and some chromo cutie siblings. Grace my typical daughter has gained friends which the older and more aware of her position as a chromo sister she becomes are there to support her and know what she is going through. Without searching for, or speaking out the help and an understanding ear they will just be there for her. I am so eternally grateful for that and would like to thank Ania and her husband for letting me come and stay and putting the effort in to a lovely friendship between our children, thank you. I couldn't urge people enough to try and meet up with others living close by, start making your own little safety nets.

