



### **Unique family weekend: Pallister-Killian Syndrome**

With generous support from Jeans for Genes and the Grocers' Charity we are running a series of 5 groundbreaking weekend family meetings in 2010. Each weekend will focus on a particular rare chromosome disorder and will bring together families of those affected, geneticists, paediatricians, behaviour experts and therapists to help increase our knowledge of the conditions. Older families will be able to share longer-term outcomes and new families will be helped to better understand their child's condition. We trust that research studies will be stimulated and new findings reported for the first time.

We also want the weekends to be a chance for families to relax and meet others in a similar position and have carefully chosen accessible, family-friendly venues. They will take place over the course of 5 weekends in 2010 in hotels in the Midlands which will be available to our families from 2pm on the Friday to 11am on the Sunday on each weekend. Time will be set aside during the weekends to meet and chat with other families or just to relax and unwind in the hotel.

The **Pallister-Killian syndrome** family weekend will take place over the weekend of 1<sup>st</sup>-3<sup>rd</sup> October 2010 at the Barcelo Oxford Hotel, Oxford, UK.

We have negotiated competitive rates with each of the hotels and the support from Jeans for Genes and the Grocers' Charity means we will be able to subsidise many of the costs of running each of the weekends. Our aim is to keep overall costs to families as low as possible. If you would like any more information about the family weekends, please contact Prisca Middlemiss at *Unique* on email at [prisca@rarechromo.org](mailto:prisca@rarechromo.org) quoting Pallister-Killian syndrome weekend.

If someone you care for is affected by Pallister-Killian syndrome, please take advantage of this unique opportunity to meet others in the same situation and help us to improve our knowledge and help others. No other organisation is carrying out this work so please support us.

To learn more about Unique family meetings and what we aim to achieve, please visit our website to read the report from our XYY meeting held in April 2008.

Please visit <http://www.rarechromo.org/files/XYYStudyDayReport.pdf>

This meeting was held on just one day but by holding the family meetings in 2010 over the course of a whole weekend, we want them to be even bigger and better. This will give those attending an invaluable chance to meet others and unwind in a relaxed atmosphere.