



Unique Family Weekend and Conference

Friday May 16th – Sunday May 18th 2014

at

**The Hilton Blackpool
North Promenade,
Blackpool,
Lancs,
FY1 2JQ**

This family conference is your opportunity to learn more about rare chromosome disorders and associated issues in a relaxed, informal setting, a great opportunity to meet other parents and carers and expert professionals.

Come for the day on Saturday 17th or stay the whole weekend!

Please read this fact sheet carefully before completing and returning the three separate booking forms for the conference, workshops and crèche. Only those for whom we have completed booking forms will be admitted to the conference.

Outline Conference Programme

Friday 16th May 2014

The Unique team will be in the hotel reception to welcome and register you from 5pm and Promenade Restaurant in the hotel will be open from 6pm-9pm. You are responsible for booking and paying for any evening meals. Pre-booked 1:1 clinics with geneticists will run from 7pm (see details below)

Saturday 17th May 2014

8.15am	Crèche opens. Conference registration. Refreshments
09.30	Conference Welcome & Introductions
09.45 – 10.30	Keynote: Alastair Kent OBE, Director, Genetic Alliance UK. 'How the NHS plans & delivers services for families affected by 'Rare Chromosome Disorders'
10.30 - 11.00	Tea & coffee break
11.00 – 12.00	Workshops Session 1 (see list on Workshop Booking Form)
12.00 – 2.00pm	Lunch break (Children to be collected from crèche promptly) There will be exhibition stalls in the main conference corridor
1.30	Crèche reopens
2.15 – 3.15	Workshops Session 2
3.25 – 4.25	Workshops Session 3
4.25 - 4.45	Tea & Coffee break
4.45 - 5.15	Final session: Unique's 30 th anniversary
5.30	Collect children from crèche promptly
7pm – late	Family social with live music

Pre-booked 1:1 clinics with geneticists will run from 7pm. Promenade Restaurant in the hotel will be open from 6pm – 9.30pm. You are responsible for booking and paying for any evening meals.

Sunday 18th May 2014

Free time to use the hotel's leisure facilities and your chance to say farewell to all the new (and old) friends you have made during the weekend.

At the time of writing the programme is still being finalised and is subject to change. A final programme will be available nearer to the event for those who have booked.

Hotel Accommodation

We have negotiated bed & breakfast rates at The Hilton Blackpool and you must book and pay for your own accommodation direct with the hotel. To do so, call 01253-627977 and quote 'Unique Rare Chromosome Disorder Conference' and the date: 16th – 18th May 2014. Alternatively, you can book by email at reservations.blackpool@hilton.com

Rooms are available from 2pm on day of arrival. Check out is by 11am on the morning of departure.

Room Rates

Single occupancy room - **£80.00** per person per night including breakfast.

Double occupancy room - **£90.00** per room per night including breakfast.

- Children 6-15 years pay just 50% of the adult price when sharing with an adult
- Children 5 and under stay and dine for free when sharing with an adult

The hotel has 92 family rooms of various sizes with 20 interconnecting rooms available and can supply Z-beds and cots on request (first come first served!). These must be booked in advance so please discuss your requirements at the time of booking.

The hotel has 7 fully accessible bedrooms but please only ask for one of these if absolutely necessary.

Getting to The Hilton Blackpool

The hotel is situated on the famous promenade in Blackpool. It's a spacious, modern hotel with great facilities, including a health club. Contact Craig on 01883-723306 (craig@rarechromo.org) for directions.

The nearest mainline railway station to the hotel is Blackpool North, less than a mile away (at the time of writing approx. £5 in a taxi). For further information speak to hotel staff or telephone National Rail Enquiries on: 0845 7 48 49 50 (24hr).

Conference Charges & Booking

Attendance fees for the conference weekend will be **£25 per adult**. This rate includes morning & afternoon refreshments and lunch on Saturday. Children are free of charge and this includes crèche places (space is limited and allocated on a first-come first-served basis, with priority to children affected by rare chromosome disorders).

To secure your place/s you must complete and return the Conference Booking Form together with your payment. Payment can be made online or by cheque, please see booking form for details. This is separate to booking your hotel accommodation, which you must book direct with the hotel.

There are organisations that provide funding for families to attend events like this, if they feel the family will benefit and the family would not otherwise be able to afford to attend. If you would like to discuss this with us, please contact Marion at Unique in confidence on 01293 525504 Alternatively, your local council, social services dept., carers' support group or citizens' advice bureau should be able to direct you to sources of funding.

Creche

We are pleased to be able to provide a crèche facility at the event at no additional charge and have chosen Tinies to run and manage the crèche on our behalf, having worked with a branch of Tinies at a previous event.

After discussions with our crèche provider and in the interests of the safety and welfare of the children, crèche provision will be to children under 16.. Siblings of those attending are welcome in the creche. Please note that we won't be able to accommodate children in the conference workshops or plenary sessions.

Important please note:

The crèche will not have medical care facilities and we are unable to accept children with life-threatening allergies as we cannot guarantee a suitable environment for them. We are unable to provide staff on a one-to-one basis so if your child requires one-to-one care you must arrange for this yourself.

Admission to the crèche will only be by prior agreement after completing a Crèche Booking Form. Once the crèche is full we will not accept further bookings under any circumstances but will operate a waiting list to reallocate places of any cancellations on a first-come-first-served basis.

The staff in the crèche reserve the right to ask parents to remove their child if they become too disruptive or physically aggressive. You will be contacted during the conference only if absolutely necessary should your child need further assistance. Drinks will be provided but should your child require a special drinking cup/bottle please bring it with you. Please also bring nappies/pads and at least one change of clothes (making sure all items are clearly labelled with your child's name).

Workshops

A large part of the programme during Saturday May 17th is set aside for workshops on relevant topics that families tell us they would find useful. These are in smaller groups and are run by carefully selected professionals.

You will be able to attend 3 workshops during Saturday and when completing the Conference Booking Form will be asked to prioritise topics of interest in order of preference. Whilst we cannot guarantee workshops, we will attempt to allocate you to your first three preferences where possible. Places are limited and will be strictly on a first come - first served basis. If you do not get your first 3 choices, you will be offered your next alternative, please ensure you list 6 choices in order of preference.

The list of topics we are planning to include is:

- Communication – verbal and non-verbal
- Education – special provision vs mainstream integration
- Behaviour – issues around challenging behaviour and coping strategies
- The New EHC plan – a guide to the new 0-25 Education, Health and Care plan being introduced in 2014 to replace the current statementing system
- Genetics - Chromosomes in general, including the value of arrays and new microduplication and microdeletion syndromes
- Siblings – issues affecting siblings of those with a RCD

Please note: this list is provisional and may be subject to change

Attendance at the workshops is optional, if you wish to come to meet Unique families and staff, relax and use the facilities of the hotel, then it is fine to do so.

1:1 Clinics with Geneticists

A number of clinical geneticists volunteer their time to come to the conference and in addition to running workshops they hold one-to-one clinics with parents. This is your chance to ask any questions about your child's rare chromosome disorder in complete confidence.

Starting at 7.00pm on Friday and Saturday, the clinics will be 20-minute sessions in smaller, quiet conference rooms. Please note: there may be other families in the same room, talking to one of the other geneticists but at opposite ends of the room.

Please indicate on the Conference Booking Form whether you would like to see a geneticist. All genetic clinics are strictly on a first come, first served basis. If you feel you have no real need to see a Geneticist, please make sure that you tell us, so that we can offer places to families who really do need to see one.