

Rare Chromosome Disorder Support Group

Unique[™]
...but not alone



Friday 31st October –
Sunday 2nd November 2008

VENUE:

THE DAVENTRY HOTEL
SEDGEMOOR WAY DAVENTRY
NORTHAMPTONSHIRE NN11 0SG ENGLAND

Telephone: 01327 307000

Telephone for room reservations: 01455 898560

If you are booking accommodation at the Daventry Hotel, please quote 'Unique Rare Chromosomes Weekend' and only ring the reservations number Monday to Friday between 9.00am–6.00pm. Ringing outside those times, or when the lines are busy, will automatically divert you to Barcelo Hotels central reservations worldwide, who will not be able to make your reservation at our discounted rate. So you might need to dial again.

Alternatively you can book your room via email
daventry.reservations@barcelo-hotels.co.uk.

Friday 31st October 2008

For those arriving at the hotel on Friday 31st October, members of the *Unique* team will be welcoming families and handing out conference information packs from 6.30pm onwards in the foyer area.

From 7.00pm–9.00pm there will be PRE-BOOKED 1:1 genetics clinics.

Our team of Clinical Geneticists will be available to run clinics on the Friday and Saturday (1st) evenings during which you can ask specific questions about your child's chromosome disorder.

PLEASE NOTE:

There is no crèche facility available on Friday or Saturday evenings. However there is a company that most hotels use for babysitting services called *Safehands UK*. You will need to book with them direct at least 48 hours in advance; they charge around £17 per hour. Tel: 0870 844 6688.

Restaurant open 6.00pm–9.30pm. Dinner adults £21.50 children £10.75 (please book and pay for Friday evening meals direct with the hotel). Bar food also available to purchase.

Main Conference Programme

Saturday 1st November 2008

AM	9.15	Crèche opens
	9.30	Registration and refreshments
		To allow us to start promptly and remain on schedule please take your seats in the main conference room before 10.00 am to avoid disruption
		Morning plenary session
	10.00	Welcome from Edna Knight (<i>Unique</i> Founder), Beverly Searle (<i>Unique</i> CEO) and Julie Griffin (<i>Unique</i> Finance and Fundraising Officer)
	10.15–11.00	<i>Every Disabled Child Matters (EDCM) – Positive advances in services for disabled children – Christine Lenehan, Director of the Council for Disabled Children</i>
	11.00–11.15	Comfort break
	11.15–12.00	<i>Positive Perspectives on Rare Chromosome Disorders – Dr Linda Gilmore, Educational and Developmental Psychologist, Queensland, Australia</i>
PM	12.00	Crèche closes for lunch – Parents/carers collect their children from the crèche to take them for lunch in the restaurant
	12.00–2.00	FAMILY LUNCH (TWO SITTINGS), CHAT and EXHIBITION STALLS
	1.45	Crèche reopens
	2.10–4.20	Two, 1 hour seminars over the afternoon (all attendees have the chance to choose two different sessions)
	2.10–3.10	Session 1
	3.20–4.20	Session 2

(Choose two from the following):

- **Behaviour** – Professor Chris Oliver, Department of Psychology, University of Birmingham.
- **Chromosomes 1–22** – two geneticists facilitating each of two separate workshops. Doctors John Tolmie, Alex Magee, Sue Price and Helen Cox, Clinical Geneticists. You will have the chance to ask any general questions about chromosomes.
- **Translocations** – Dr Simon Holden and Professor Maj Hulten, Clinical Geneticists. You will have the chance to ask general questions about chromosome translocations.
- **Sex chromosome aneuploidies** – Victoria Leggett, researcher, Department of Experimental Psychology, Oxford University.
- **Communication** – Emma Barker, Speech and Language Therapist.
- Experienced parents to answer questions and lead an informal discussion about bringing up a child with a rare chromosome disorder.

Throughout the day, there will also be a chromosome/DNA analysis demonstration by the West Midlands Regional Genetics Laboratory team headed by Mrs Val Davison, Consultant Clinical Cytogeneticist

4.25–4.45	Comfort break with refreshments (main room will be returned to theatre style during this time)
4.45–5.15	Final session
5.30	Crèche closes
6.00–9.30	Restaurant open – come and join us for a discounted family carvery dinner (vegetarian alternative available)
7.00–9.00	Genetics clinics for those who have requested them
7.00pm	Evening family get together and disco from 7.00pm ‘til late

Sunday Morning 2nd November

Goodbye to all

Your chance to say farewell to all the new (and old) friends you have made during the weekend.

This programme/speakers may be subject to change at a late stage due to unforeseen circumstances.

Accommodation

A special daily rate including breakfast has been negotiated at The Daventry Hotel. Please quote **“Unique Rare Chromosomes Weekend”** at time of booking, otherwise the hotel will tell you they are full. It is absolutely essential to book your room(s) at least 6 weeks prior to the weekend date. After that time, rooms will be released to the general public and the hotel may not be able to accommodate you.

Rooms are available from 2.00pm on day of arrival. Check out is by 11.00am on the morning of departure.

There are various room options. Besides family rooms and interconnecting rooms, ten rooms yet to be refurbished can accommodate a cot and fold up bed. and so can take up to a 4-person family. There are 4

fully accessible bedrooms with wet floor shower; please only ask for one of these if absolutely essential. Please discuss your needs with the hotel reservations staff when you book.

Rates

Single occupancy room – £65.00 per person, per night including breakfast.

Accommodation *continued*

Double occupancy room – £37.50 per person, per night including breakfast.

Interconnecting rooms – there are a limited number of these available and will be subject to an extra charge; please check with hotel on booking.

Family room supplement – £20.00 (sleeps 4 in two double beds, 1 extra cot or fold up bed for a child under 5 can be added at £15.00 extra).

Extra fold up bed (child under 5) or cot in room – £15.00 per bed/cot (you could save

money by bringing your own travel cot). Please make sure you request a fold up bed or cot at the time of booking and it is advisable to double-check this arrangement with the hotel a week before arrival.

Please ask the hotel for breakfast cost for children 5–17 years.

Accommodation must be booked and paid for directly with The Daventry Hotel telephone 01455 898560 and is available on a strictly first come, first served basis. These prices are very competitive for this type of accommodation (4 star).

How do I get to the Conference

You'll easily find the Barceló Daventry Hotel, in Northamptonshire, just off the M1 and close to the M40. It's spacious, and modern and is well-situated for getting to Silverstone, Rockingham Speedway, and many stately homes. Surrounded by quaint, pretty villages, the NEC and opportunities in Birmingham are all within your reach.

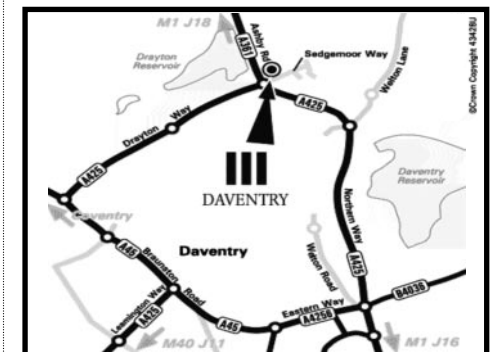
The nearest mainline railway station to the hotel is Long Buckby (10 minutes by car), it is a small station. Other nearby larger stations are Rugby or Northampton (approximately 20 minutes by car), but I would suggest for further details it is best to telephone the National Rail enquiry service on 0845 748 4950 (24 hour). The hotel is in a semi-rural location, so it is best to come by car if you can. If arriving by train, you will need to get a taxi (if you need a list of taxi companies, please ask Marion). You can download directions from one of the Internet map providers, eg aa.com.

Unique regrets it cannot help with funding to attend the conference; however there are organisations that do fund families to attend events like this, if they feel the family will benefit. Please contact your local district council, social services department, your local carers' support group or citizens advice bureau, they should be able to direct you to sources of funding.

How to get to the Daventry Hotel

(A larger version of this map will be sent to you when you return your booking form to Marion).

To the Daventry Hotel	Distance in Miles (approx)
BIRMINGHAM AIRPORT	26
BRIGHTON	133
BOURNEMOUTH	132
CAMBRIDGE	62
CARDIFF	140
COVENTRY	16
EDINBURGH	330
EXETER	192
GLASGOW	322
LONDON	89
LEEDS	121
MILTON KEYNES	24
OXFORD	38
PLYMOUTH	233
SOUTHAMPTON	83
TRURO	279
WREXHAM, CLWYD	121



Rare Chromosome Disorder Support Group



Conference Booking Form

Please complete the conference booking form, seminar booking form, genetics clinic booking form and also, if using the crèche, the completed crèche form, then detach the relevant pages and return them with your cheque made payable to *Unique*, to:
Marion Mitchell, 6 Lavant Close, Gossops Green, Crawley, West Sussex, RH11 8LN, ENGLAND by Friday 20th September 2008. Be sure to retain the remainder of this brochure for your information.

Please ring Marion on 01293 525504 or email marion@rarechromo.org if you have any questions about this form or the conference weekend in general.

Thanks to your support, nominating *Unique* for an award from the Royal Bank of Scotland (RBS) and *Daily Mail Children's* give away, we received a grant to support this year's family conference weekend. This means we are able to offer you:

- a discounted rate for adults
- FREE admission and FREE lunch on Saturday for all children!
- Subsidised family carvery evening meal (*Saturday only*)

Discounted registration fee is £20.00 per adult – 18 years and over, which includes tea, coffee, biscuits and lunch (*Saturday only*). Children 17 years and under FREE.

Please state:

- Number of adults 18 years and over @ £20.00 each.....
- Number of children 13–17 FREE.....
- Number of children 5–12 FREE.....
- Number of children 0–4 FREE.....
- Do you require a highchair? YES NO

If at all possible, it will be helpful for families to bring their own highchair, as the hotel has a limited supply (10 only) and this could cause delays at lunchtime

PLEASE STATE WHETHER OR **NOT** YOUR CHILD WILL BE HAVING A LUNCH (please tick)

- YES, my child will be having a meal
- NO, my child will not be having a meal

Lunch/conference Total £

Evening meal (*Saturday night only*)

This meal will be subsidised by *Unique* (normal cost is £21.50 per adult, child £10.75). The cost of the Saturday evening meal is £10.75 per adult 18+ and £5.35 per child 5–17, under 5's eat for free. This is payable to *Unique* in advance; please include this cost in the total.

A) How many will be staying for the subsidised carvery meal on Saturday evening?

- Number of adults @ £10.75 each.....
- Number of children 5–17 @ £5.35 each.....
- Number of children 0–4 FREE.....

B) Please state if a vegetarian or special dietary need is required?

Please describe

NO, we don't need any evening meals on Saturday

Sub-total

Donation

Total Amount Enclosed

£

NB: *Unique* subsidises your place(s) at the conference and the price you pay is a contribution towards that cost. Your registration fee includes attendance at the conference, lunch and refreshments during the main day (*Saturday*), speakers' expenses, conference room costs, crèche, genetic clinics, seminars, and entertainment (whether or not you use all or part thereof). We are sure you will agree it is excellent value for money.

Please make cheques payable to *Unique*.

C) Do you require a crèche place(s)? YES/NO

If yes, please fill in the crèche booking form and registration document

D) How many of your party will be staying overnight at the hotel itself (this is so we have an idea of numbers)?

FRIDAY Adults.....Children..... SATURDAY Adults.....Children.....

E) Full name(s) of adults attending (18 years and over) (please write in BLOCK CAPITALS):

*1.....2.....

3.....4.....

Full name(s) of children attending (0–17 years)

1.....2.....

3.....4.....

Address: (*Main Contact No. 1)

..... Post Code:.....

Telephone:..... Email:.....

Membership number, if known.....

Affected Child's Chromosome Disorder: (please tell us this even if your child is not attending)

.....

pull-out and return

Creche Booking Form

For Saturday 1st November 2008

(Crèche, Saturday only opens at 9.15am and closes between 5.15pm/5.30pm)

(Peter McKenna, experienced children's entertainer will be entertaining the children in the main crèche room with a disco, a little magic, balloon modelling, etc with one show in the morning and one in the afternoon). The crèche will be manned by experienced CRB checked, highly trained staff, who are able to look after children with special needs, sign Makaton and are first-aid trained. Please fill in as necessary, separate enclosed crèche registration forms. If you need more of these, please either photocopy before filling it in, or email or phone Marion for extra copies.

The Mobile Crèche Child Registration Form

Parent/Guardian Name

Child's Name:

DOB Male Female

Does this child have a rare chromosome disorder? Yes No

If yes, please give karyotype (if known)

Are there any details of health (allergies, illnesses, etc) including medication that crèche workers need to be aware of? Yes No

If yes, please provide including epilepsy and behavioural matters

How does your child communicate? Speech Makaton other

Other, please describe

Are there details of special dietary requirements (including feeding for babies) that crèche workers need to be aware of (ie nut, dairy, wheat intolerances)? Yes No

If yes, please provide information:

Does your child use: Toilet Nappy Potty

Does your child sleep during the day? Yes No

Does your child sleep in a: Cot Pram Pushchair

Will you be on site at all times during the conference/event Yes No

Please give a contact number:

Medical Attention – Consent

(see below)

I agree to any emergency medical treatment necessary during the running of the crèche. I agree for the staff to sign any written form of consent required by the authorities, if a delay in getting my signature is considered by the doctor to endanger my child's health and safety.

Signed Date

Print Name

Face Painting – Consent

We will have a face painter in the crèche, if your child would like their face painted (or arm for those who can't tolerate face)?

I agree for my child's face to be painted Arm painted No face/arm paint

Signed Date

Print Name

Photograph Permission

During the course of the event your child's photo may be taken. These photos may be used for media/ promotional or advertising purposes. Please indicate below if you are in agreement with this.

I agree for my child's photo to be used for the above purposes: Yes No

Signed Date

Print Name

IMPORTANT PLEASE NOTE:

We are unable to provide staff on a one-to-one basis in the crèche. If your child does need a one-to-one carer, please arrange to bring one with you. If you are able to find alternative care for your children, then it would help greatly with numbers and allow a place for children for whom there is no alternative. The staff in the crèche reserves the right to ask parents to remove their child if they become too disruptive (ie because of the vulnerability of some of the children, we could not admit any child that is physically aggressive). You will be contacted during the conference only if absolutely necessary should your child need further assistance. The crèche is suitable from birth to 12 years (discretionary). Older siblings (12+) might find it a little young for them, however, they are still very welcome providing they are able to look after themselves or help with their siblings. We are hoping to have DVD's showing (space permitting). Drinks will be provided for the children in the crèche. If your child requires a special drinking cup/bottle please bring it with you. Please also bring nappies/pads and at least one change of clothing (please make sure all items are clearly labelled with your child's name). Please also let us know about any food allergies your children have at time of registration. Please continue on a separate sheet of paper if necessary.

Saturday Afternoon Seminars Booking Form

Discussion seminars

PM 2.10–3.10 Session 1 (15 minutes in between sessions to change rooms)
3.20–4.20 Session 2

Please choose from the following subjects:

1. *Chromosomes in General (CG)*
2. *Chromosome Translocation (CT)*
3. *Sex Chromosome Aneuploidy (SCA)*
4. *Challenging Behaviour (CB)*
5. *Communication (C)*
6. *Experienced parent (EP)*

Places for the seminars are limited and will be strictly on a first come – first served basis. If you do not get your first two choices, you will be offered your next alternative, so please make sure you list 4 choices in order of preference. It is entirely optional to attend the seminars, if you wish to come and just chill out, relax and use the facilities of the hotel, then it is fine to do so.

Example

Adult Name: Joe Bloggs
1st Choice: 1 2nd Choice: 6 3rd Choice: 4 4th Choice: 5

Adult 1 Name:

1st Choice: 2nd Choice: 3rd Choice: 4th Choice:

Adult 2 Name:

1st Choice: 2nd Choice: 3rd Choice: 4th Choice:

Adult 3 Name:

1st Choice: 2nd Choice: 3rd Choice: 4th Choice:

Adult 4 Name:

1st Choice: 2nd Choice: 3rd Choice: 4th Choice:

Evening Genetics Clinics Booking Form

Friday and Saturday Evening Genetics Clinics 7.00pm–9.00pm

Starting at approximately 7.00pm the clinics will be 20-minute sessions. Please note: there will be other families in the same room, talking to one of the other geneticists but at opposite ends of the room.

Please indicate (✓) here, whether or not you would like to see a Geneticist on Friday or Saturday Evening.

YES, I would like to see a Geneticist on Friday Saturday Don't mind

NO, I do not need to see a Geneticist on either day

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.

Remember to detach the booking form, seminars booking form, genetics clinic booking form and crèche booking form(s) and return with your correct remittance (Cheques made payable to **Unique**), then send to:

Marion Mitchell, 6 Lavant Close, Gossops Green,
Crawley, West Sussex RH11 8LN, England
by **20th September, 2008**

IMPORTANT NOTE:

If you haven't received a receipt and final details from Marion following your posting of this booking form, at least 10 days before the family weekend, please contact her on 01293 525504 or email marion@rarechromo.org. There have been the rare occasions when booking forms have gone missing in the post and then people have turned up at the conference stating they have booked, but we know nothing about their booking and it can be difficult at that late stage to place people in the workshops/clinics of their choice.

pull-out and return