



**Chromosome 18 Europe  
Newsletter January 2018**



Time to get together again!

Rome Marriot Park, 2016



Novotel Manchester West, 2014

We're working on putting together the 5<sup>th</sup> Chromosome 18 Europe Family Conference in the Doubletree Hilton Glasgow on June 22-24, 2018. Will you be in the next group picture?

Funds may be tighter than ever before, but just as at our first conference in 2010, getting together will be the real benefit of all the fundraising you are doing to bring us all together to laugh learn and play. Flights and accommodation have been booked by some, and replies are coming in to my requests for speakers. Thank you to everyone for suggestions for presentations: we'll do what we can afford ;-)

**THANK YOU TO EVERYONE WHO IS WORKING HARD TO RAISE THE FUNDS WE NEED TO RUN AN INCLUSIVE, INFORMATIVE CONFERENCE.**

The conference will start on Friday morning, and crèche and Sibs4Sibs registration forms will come out at the same time as conference registration forms.

**Draft programme: to be confirmed.**

Friday am Donna Tomlin of Contact will speak on welfare rights  
Tracey Francis will talk about **Preparing Parent Carers for Transition**  
(waiting for confirmation about sessions on puberty and toileting)

**LUNCH together in the hotel**

Friday pm Executive Function: often a huge challenge for children and adults affected by C18 disorders.  
Syndrome Breakout sessions

DINNER at your own expense: lots of places to choose from on the doorstep ;-)

Saturday am Presentations by Dr Jannine Cody and Dr Dan Hale  
Chromosome 18 Europe Research Report by Prof Richard Davison

**LUNCH together in the hotel**

Saturday pm Emotional Intelligence: the ability to identify and manage your own emotions and the emotions of others. This is a challenge for many children and adults affected by Ch 18 disorders  
Workshop: how to use the internet to find support in your area Katharine Newman  
Bring your own laptop!

Additional sessions to be decided (dependant on funds)

**FREE TIME BEFORE SATURDAY EVENING DINNER AND DISCO**

Sunday am AGM  
Self Advocates Panel of adults affected by Ch 18 disorders  
Siblings Panel

LUNCH together in the hotel

Sunday pm Panel of Parents

ALL OF THE ABOVE IS DEPENDENT ON FUNDS: MORE FUNDS = MORE PRESENTATIONS

**Fun(ding) Facts:**

**The amazing crèche** will cost up to £9,000 for three days, based on the numbers, ages and stages of the children we welcomed in Manchester. Amanda has already been to the Doubletree Hilton and worked out exactly what will go where, including a sensory area and an area where electronics will be set up. Safety and security are as always top priorities, with a high staff: children ratio to ensure plenty of fun for all.

**Translation services** cost approximately £10,000, and we're glad to welcome European families who can come and get access to all of the presentations because we pay for those services.

**Conference Registration fee** actually covers less than one day delegate rate charged by the hotel. The generosity of our friends and families who work hard to raise funds covers the rest, so that as many families as possible can come together with the least amount of financial stress.

A Grandparent has offered to sponsor music therapy because she believes in the importance of it. Do you know any potential sponsors?

In 2016, Sarah Hunt, Mattia Meloni and Jonathan Rugman, with help from Phillip Moore, put together a really successful programme of activities for siblings aged 8 and up. We hope to repeat the programme, and that there is another adult sibling who would like to join the team. **If you are 18 or over and would like to take part, please get in touch.** I have a copy of the Sibshops manual to give away ;-)

I'm working on a programme for Self Advocates this year, based on requests and suggestions from parents of teen and adult SAs. If funding allows, the programme will include drama and music therapy supplied by Creative Therapies. Workshop sessions to help SAs identify and deal with executive function challenges and transitions are planned. There will still be plenty of space for the all important chill and hang out times.

Candy Place has offered to do her Laughter Therapy session again this year, and I know that several people were disappointed that they didn't know that it was open to all in Rome.

### Reserving rooms at the DOUBLETREE Hilton Glasgow

#### [Chromosome 18](#)

Right click on the link above and choose Open Hyperlink to go straight to the booking page with our discounted room rate.

Unfortunately, the discounted rate only seems to be available from June 21 – June 25.

There are many other hotels close by for accommodation without the conference facilities we need.

(if you go through easyfundraising.com to check out hotel room availability through Booking.com, Chromosome 18 Europe will get a small donation)

As funds become available, more details will be firmed up.

If you have a fantastic therapist or speaker you'd like to speak at our conference, please raise the funds to cover the costs!

More news will be coming out soon, including information about two exciting (perhaps even exhausting!) fundraisers being planned in April, and an update from Richard Davison on Chromosome 18 Europe research.

Take care,  
Bonnie McKerracher  
Secretary

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