



Information about the First European Conference

The first European conference of the Chromosome 18 Registry and Research Society will be held in Glasgow, Scotland from the evening of the 30th of July, all day Saturday the 31st of July and ending on Sunday, the 1st of August, about 4 p.m. It will be held in the Crowne Plaza Hotel, a modern hotel overlooking the Clyde in the middle of Glasgow that has good facilities including a suitable swimming pool.

The aim is to provide a meeting place for parents of children with Chromosome 18 disorders, medical professionals who are concerned with this disorder; siblings and grandparents to learn about the latest research on the disorder, the current therapies, and role of allied medical support specialist. There will be plenty of opportunities for informal discussions - the hotel has many good spaces for this. There will be a professional creche provided to look after affected and unaffected children - from 9.00 to 12.30 am and 2.00 to 5.00 p.m. on Saturday and Sunday.

Friday is arrival day - there will be an opportunity to share in a buffet meal and meet each other. During Saturday and Sunday the following topics are scheduled:

- Medical Background on Chromosome 18 disorders and Current Research

Dr. Jannine Cody and Dr. Dan Hale, the research team from the US Chromosome 18 Registry and Research Society will talk about the present state of understanding of the disorder and new developments. There will also be at least one medical speaker from Europe giving an European viewpoint.

- The role of Siblings

The unaffected brothers and sisters form an important part of the support for the affected child. There will be a presentation on this followed by discussion. At the same time there will be a workshop for siblings themselves, scheduled at the same time.

- Developmental issues

Up-dating on current therapies for encouraging development of the affected child with examples from art, music, computing ...

- Adult forum of affected persons

The panel of young and older affected persons will talk about their lives. An immensely encouraging event for parents and grandparents.

- Grandparents break-out group

This will give an opportunity for grandparents to meet as a group to discuss their concerns and coping strategies.

- Syndrome break-out groups

Families who are affected by the same disorder get together to share with each other, their stories, to ask questions and to give and receive information to help with the challenges they all face. There will be groups concerned with 18 q-, 18 p-, tetrasomy 18 and other 18 disorders (Ring 18, trisomy 18 etc.)

Rick Guidotti from Positive Exposure will be at the conference with an exhibition of his wonderful pictures of our kids.

The conference fee is £30 per unaffected adult. Affected persons and children are free. Do not let the conference fee prevent your attendance - we are prepared to waive it in the case of need - just let us know.

If you want to come but cannot afford the travelling and hotel costs, you may find that there are public bodies that are prepared to help with the costs (for example in the UK, the Family Fund may).

It would help our planning very much e-mail if you could fill in the form attached and send it back to me (secretary@chromosome18eur.org)