

CCHS FAMILY DAY CONFERENCE

2nd July 2005
Alton Towers Hotel
Staffordshire.

Fourteen families attended the first CCHS Family Day Conference. Of these, nine came from England, two from Scotland, one from Wales, one from Ireland, and one from the USA. Families had a chance to meet, form friendships, and hear from invited speakers on research and healthcare issues.



The discussions began with Dr Peter Lunt and Teresa Patrick talking about CCHS and the PHOX2B gene. They explained the genetics and the introduction of DNA diagnosis. Testing for the PHOX2B gene is now available in this country.

Next we heard from Professor Peter Fleming on the various treatments available for children with CCHS. Questions followed on the suitability and preference of the different methods of ventilation.





Teresa Patrick, Dr Peter Lunt, Prof Peter Fleming and Dr Martin Samuels enjoying lunch.

After lunch Dr Martin Samuels talked about clinical monitoring and follow up in CCHS. He also explained the setting up of the European Registry.



Finally, the speakers agreed to be put 'on the spot' and answer any questions the families wished to ask. These included a varied range of subjects such as:

- Phrenic Nerve Pacers
- Nasal Pillows
- Variability/Severity of condition
- Choice of ventilators
- Transition to adult services

Unfortunately time ran out and we had to close for the day.

Then it was off to the theme park, and for those brave enough, the white-knuckle rides. Several of the families stayed over in the Alton Towers Hotel on the Saturday night and had dinner together during the evening. This allowed the children and parents to spend more time together.

It soon became apparent the families share many of the same issues and face the same hurdles. It was great to see the younger ones running around playing together, and the teenagers disappearing to the arcade and to play football. Hopefully both adults and children left Alton Towers having made new friends.

Feedback from the day was excellent –

"We realised we are not alone"

"We realised we all have similar issues to face"

"I enjoyed meeting the other children"

"We had a great time playing footie and going to the arcade"

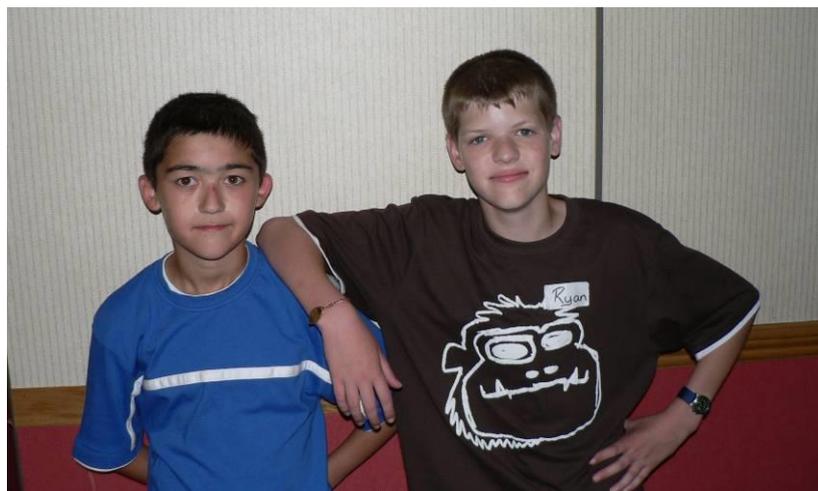
"The swimming pool was wicked!"

"All the speakers were very approachable, and it was good they were available for questions afterwards"

"All speakers were very informative and interesting"

Our gratitude goes to all the speakers for giving their time and sharing their expertise with us.

Also a big thank you to Jane Noyes and Peter Finch for their support both leading up to the event, and on the day.



St James's Place Partnership sponsored the day and we are most grateful to them for making the event possible.