

International Cystinosis Conference 2010 - FAQ

What Is The International Cystinosis Conference?

The International Cystinosis Conference is held every two years at different locations around the world. It is an opportunity for medical professionals, commercial organisations, charities, Cystinotics, their families and other individuals to meet, exchange ideas, build friendships and to move forward in our treatment and understanding of Cystinosis.

The conference usually lasts 2 or 3 days and with every one it is felt our knowledge of Cystinosis, its treatment and how to best deal with Cystinosis has been increased.

Where Are The Conferences Held?

The location of the conference is different every time. This year the conference was held in Lignano, near Venice, Italy. Previous locations include:

- 2008: Dublin, Ireland.
- 2006: Noordwijkerhout, The Netherlands.
- 2004: Tarragona, Spain.
- 2002: Vanves, near Paris, France.
- 2000: Ranica, Italy.

Who Organises The Conference?

The International Conference is overseen by the International Cystinosis Committee whose members represent the medical community and Cystinosis charities from around the world. This year (2010) the conference was held in Lignano, near Venice, Italy, with help from the Cystinosis Foundation USA, support groups in Italy and also a dedicated conference agency.

What Are The Aims Of The Conference?

Each conference has specific objectives, but the key aims, common to any conference, can perhaps be summarised as:

- Allowing the medical community (including academic researchers, doctors and commercial organisations) to meet and exchange ideas, whilst disseminating their knowledge to a wider audience, including Cystinotics and their families.
- Providing an opportunity for Cystinotics and their families to share their knowledge and experience of dealing with Cystinosis.
- Allowing Cystinotics and their families to report back to the medical community on their needs.
- Building of communities and friendships at both organisational and personal levels.

Who Can Attend?

Unlike many similar conferences, the International Cystinosis Conference has a broad audience and this year there were around 200 attendees. Attendees have included the medical community, commercial organisations, government (the Irish Minister For Health provided a keynote speech at the Dublin 2008 conference), Cystinotics, their families, charities, their supporters and anyone touched by Cystinosis.

As well as medical research presentations, the programme of events includes sessions for families to speak directly with doctors and each other to allow the sharing of knowledge across communities.

Can I Take My Whole Family?

Simple answer is yes. Childcare has been provided at the last 2 conferences for younger children and there have been trips and activities organised for older children also. In addition, the programme of events often includes specific children-only sessions with doctors to allow them to discuss their condition.

However, it is worth considering what you want to achieve from attending the conference. In 2008, I attended with my wife and child and had a great time meeting everyone, as well as reporting on the conference. In 2010, I chose to attend alone in order to focus on the reporting aspect. However, if I go in 2012 I'd be keen for my family to come along – you get so much more out of it. It depends what you want to achieve.

Who Is Writing This FAQ And Why Did You Go?

I am a volunteer and fundraiser for the Cystinosis Foundation UK. My main role is to look after the website for the Cystinosis Foundation UK, which I do on a voluntary basis. My connection with Cystinosis is that my 9-year-old niece has Cystinosis. I attended the 2008 conference in Dublin and also the 2010 conference near Venice. My aims were to learn more about Cystinosis, meet people from around the world with whom I have had contact only through email, but primarily to report on the conference for the Foundation.

What Does It Cost?

The Dublin 2008 conference was entirely self-funded through sponsorship and an attendance fee of €30 per person. Children attended for free.

The 2010 conference was held in dedicated conference facilities that included all accommodation and a phenomenal amount of food (this was Italy after all). The cost varied from approximately 100€–175€ per person for the 3 nights, depending on the room required. Children received discounts and it was possible to book only for 1 or 2 nights.

What Will I Get Out Of It?

It depends on your perspective, background and what you want to get out of it. By attending the numerous sessions you will get an up-to-date picture of what is happening in the world of Cystinosis research, increased understanding of Cystinosis, the treatments available, and advice on dealing with the day-to-day issues of Cystinosis.

For me, it was also a rare opportunity to cement friendships I had made in 2008, as well as meet many new people from the UK and further a field. It was a chance to exchange ideas with individuals and come back with a renewed enthusiasm that our efforts are making a difference.

Does The Conference Make A Difference?

OK, so there is still a long way to go before a cure is found, but I learnt about some big steps being made in the research community that gave hope. I also saw many medical practitioners and researchers talking about collaboration to further their work. I had the chance to speak to researchers and learn that the money we are raising for their work is making a difference. And now when I go out to raise money, I can do so armed with the knowledge the money is being well spent.

When Is The Next One?

The next conference is scheduled to be held in 2012. As yet, no venue or specific date has been arranged, but we will keep you posted.

Is It Worth Attending?

Hopefully from reading the rest of this FAQ, you will have come to your own conclusion and that conclusion is a resounding “yes”. I feel I benefitted from going and am already considering attending the next conference in 2012.

Matt Blackham

Website Manager, Cystinosis Foundation UK

Attendee of the International Conference, Lignano, near Venice, 2010