

International Cystinosis Conference 2008 - 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, sufferers, their families, charities and other individuals to meet, exchange ideas, build friendships and to move forward in our treatment and understanding of Cystinosis.

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

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 (2008) the conference was held in Dublin, Ireland, with the Cystinosis Foundation Ireland organising the conference itself.

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 Cystinosis sufferers and their families.
- Providing an opportunity for sufferers and their families to share their knowledge and experience of dealing with Cystinosis.
- Allowing sufferers and families to report back to the medical community on their needs.
- Building of communities and friendships at both organisational and personal levels.

The Dublin 2008 conference had the theme of “from dreams to reality”. When the first Cystinosis charities were formed, there was little knowledge or awareness of Cystinosis, and very little research taking place. The individuals involved dreamed of finding treatments, and one day a cure, for Cystinosis. This year’s conference allowed us to see how far we had come and at the time of writing a thousand papers have been written on the condition. And in Cysteamine there is now an effective treatment to control Cystinosis. However, there is still much to do, with continual research to improve the effectiveness of current medications.

Who Can Attend?

The conference has a broad audience. Unlike many similar conferences, it is not an exclusive medical conference, nor is it limited to sufferers only. It is aimed at a broad set of people, including the medical community, commercial organisations, government (the Irish Minister For Health provided a keynote speech at the Dublin 2008 conference), Cystinosis sufferers themselves, their families, charities, their supporters and anyone touched by Cystinosis.

Who Is Writing This FAQ And Why Did You go?

I am a volunteer, and occasional 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 7-year-old niece has Cystinosis. I attended this year’s conference with my wife and daughter, as part of a family holiday to Ireland, with the aim of learning more about Cystinosis, meeting people from around the world with whom I have had contact only through email, and 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 Cystinosis Foundation Ireland were (quite rightly) adamant that the conference should not use funds raised for research. The conference is organised to support, not divert from research.

What Will I Get Out Of It?

As well as entry to the conference, for your €30 the Cystinosis Foundation Ireland kindly provided a satchel containing a conference pack. This included a detailed conference programme, information on Ireland (including discounts to major attractions in Dublin) and a CD of Irish music. In addition, buffet lunches were included on each day of the conference and a barbeque was held on the final evening.

However, what you will really get out of it is an up-to-date picture of what is happening in the world of Cystinosis research, increased understanding of Cystinosis and the treatments available, and advice on dealing with the day-to-day issues of dealing with Cystinosis.

For me, it was the chance to cement friendships in person that had existed before only on email, exchange thoughts with individuals and come back with a renewed enthusiasm that our efforts are making a difference.

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 the idea of again arranging our family around the next International Conference.

When Is The Next One?

The next conference is scheduled to be held in Italy in 2010. As yet, no venue or date has been arranged, but we will keep you posted.

Matt Blackham

Website Manager, Cystinosis Foundation UK

Attendee of the International Conference, Dublin, 2008