

International Cystinosis Conference – Dublin 2008

The 5th International Cystinosis Conference will take place in Dublin, Ireland on 27th and 28th June, 2008. World experts in the field of cystinosis will attend and the latest research in this very rare disease will be presented. The event is unique as it combines a high-level scientific and medical conference as well as being a family and patient friendly conference.

Cystinosis Foundation Ireland is delighted that Ireland has been chosen by the International Committee to host this conference for the first time. Cystinosis Foundation Ireland was set up in 2003 to support those living with cystinosis as well as their families, to raise awareness about cystinosis and to support research through its fund-raising efforts. “Our group is very focussed and hardworking”, says Mick Swift, Chairman of Cystinosis Foundation Ireland, “we currently fund three international cystinosis research projects. We look forward to welcoming everyone to Ireland and fostering an atmosphere where people can listen to and meet experts in the field, as well as engage with others experiencing similar issues”.

Cystinosis is a very rare condition usually diagnosed during early childhood. An accumulation of an amino acid, cystine, causes damage to all organs and muscles of the body. The kidneys are first affected and treatment must be strictly consistent for life. The current treatment, Cystagon™, must be taken every six hours to slow down the deterioration process along with a cocktail of other medications. Most people with cystinosis require a kidney transplant by late adolescence or early adulthood.

A feature of the International Cystinosis Conference is the firm friendships that have built up over the years. “This is a unique occasion and we’re honoured to be the hosting Foundation”, says Mick Swift. “The conference takes place every two years in Europe providing attendees with opportunities to renew old acquaintances and foster new friendships. It’s also a wonderful conference for a family with a recently-diagnosed child”, continues Swift, “as there are often many questions and fears and this conference provides an ideal opportunity to provide help and support for those living with Cystinosis”.

The conference will provide a wonderful opportunity for support, friendship and learning. Researchers in the field of cystinosis will have an opportunity to network as well as engage with world pioneers in cystinosis research and practice. For those living with cystinosis and their families, the opportunity to meet world-renowned experts, to learn about existing and new research being carried out around the world presents hope for the future.

The conference will be held at the Hilton Dublin City Hotel, Charlemont Place, Dublin 2.
www.hilton.com/dublin

Please visit our website at www.cystinosis.ie for conference updates.

October 4th 2007