Cystinosis Foundation
United Kingdom

Forever Growing

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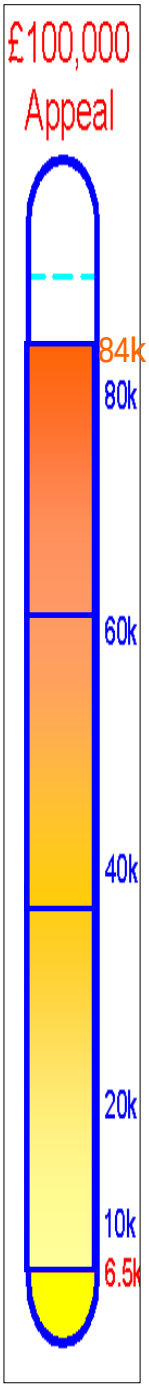
Newsletter Christmas '07

Issue 10

Editor's Note

I, your Founder, am going to apologise now if this edition of the newsletter does not conform to its usual standard. Satinder Seehra, mother of two young patients herself, has been overwhelmed by personal matters recently, without the need for the additional stresses of this duty that she does so well. We all would like to pass on our best wishes to her.
"Merry Christmas" from Satinder and all of us who run Cystinosis Foundation U.K.

Jonathan
(Founder & Advisor)



The 2007 National Cystinosis Conference U.K.

(By Jonathan Terry)

Yes, we are all preparing to look at the cold winter ahead. However, there is also the wonderful thought of our, once again inspiring, National Conference. The plan is to hold it on 16th June 2007 in York and we will send out more details when the venue has been fixed.

The Theme that we have decided on is "The Whole Family". Special guests will be Dr.William van't Hoff, President of our Foundation, and Dr.Alan Watson of Nottingham City Hospital who has made a study of the problems of siblings of sick children. Dr Roz Anderson will give us an update on the research we are supporting at Sunderland University.

Adolescence is often a difficult time, but to people with a condition like Cystinosis it can be particularly daunting. Cystinotics go through puberty as healthy people do and have the same problems as healthy people but in addition they have to cope with their drug regime, clinic appointments, etc. All adolescents can give their parents a hard time but the parents of cystinotics have more problems to cope with.

A group we plan to give time to at this conference are the siblings of cystinotics. We know that they can have a variety of concerns, including guilt that they are healthy, but usually they get little special attention. At this conference there will be a session just for siblings run by experts and people who have been through it.

So next year's conference will have special times for all members of the families of cystinotics: the patients, the siblings and the parents/carers. Our Foundation's aim is to make it possible for all to be given the 'quality time' required to comfortably open out and share how they truly feel with guidance from our experienced guests>

The 2007 National Conference will be designed to help the "Whole Family". We hope that as many as possible will come for a very special occasion where you can renew old friendships and make new ones.

We are looking forward to seeing you at the Conference and to receiving your Conference Attendance Fee of £20:00 per Room so that we can reserve your rooms.

Fundraising

Cycle ride raises over £3,000:00.

On 17th September this year Paul set out to cycle a route known as the Camino Frances, from St Jean Pied de Port in southern France to his destination of Santiago de Compostella on the west coast of Spain. One of the ancient pilgrimage trails collectively called the Camino de Santiago, the distance covered is over 800km and begins with the crossing of the Pyrenees mountain range.

Paul completed his challenge on 29th September and raised over £3,000 in the process. He undertook the trip on his own, taking 11 days to cover the distance, passing through Pamplona, Burgos and León. He had never done any distance cycle rides previously, not actually owning a bike, and only the generosity of others allowed him to borrow a touring bike for the training and ride itself.

If you would like to donate for Paul's efforts, then you can still send donations marked "Cycle Ride" on the reverse to the Foundation at the address on this Newsletter.

Paul Clifford Profile.

Paul is 29 years old and lives in Wolverhampton. He was inspired to take up the challenge of raising funds for Cystinosis research after learning about the disorder from his friend, David Benford, whose 5-year-old daughter has Cystinosis. Paul chose his proposed route after reading about this age-old trail in the book 'The Pilgrimage' by Paulo Coelho - "One of the main appeals to me of this is the freedom from the every day world". Paul has never attempted any cycling challenge of this scale before, but he has been thorough in his organisation, from the selection of equipment to enlisting the help of a world-class cycling and triathalon trainer, which can only enhance his chance of success.

Sunderland University

The Cystinosis Foundation UK is continuing to financially support the work Dr Roz Anderson is doing at Sunderland University into an alternative for Cystagon. Our conference in 2007 will be inviting her to speak and bring us up to speed on the latest research results.

Companies Donate through 'Random' Appeal Letter.

This is a great "Thank you" from the Foundation to all those companies who have responded to the 'request for generosity letters' that were sent at random in the prepaid envelopes we all receive. The letters were all thanks to one of our own Trustees allowing us to place a picture of their child on the front.

The money raised is going to the charity, enabling our work to continue within the office, without using vital Research Funding that is already held for that purpose.

Note : Information provided, either verbally or in written form, is purely on an advisory level and we recommend that you consult your doctor before making any decisions regarding the future of the patient concerned