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Editor's Note

Hello, I would just like to say thank you on behalf of everyone at the Cystinosis Foundation who has helped raise money for the £100,000 Appeal. The Foundation is very grateful to all the hard work and effort you have put in to raise this money! Please continue to support us so that the Foundation can continue to support research and benefit anyone with Cystinosis!

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£100,000 We did It! (By Jonathan Terry)

Two and a half years ago we launched our £100,000 Research Fund Appeal and at the trustees meeting in December our treasurer, Paul Doyle, announced that the total had been reached!

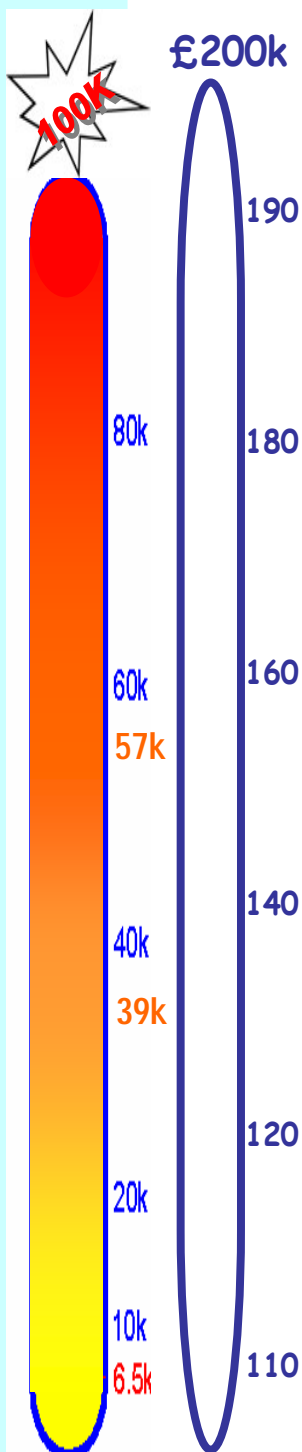
In our Christmas newsletter we showed the total at £84,000. A combination of a big contribution of £7,000 raised by Bob Rumney at his annual Golf Day, a number of smaller donations and £4,700 from the Government because of Gift Aid declarations (just note how valuable they are!) took us to the target. This is a great achievement for a small charity like ours.

A huge THANK YOU to all who raised or donated money. Special mention must go to Roy and Vicky Forsyth and their family, who raised a lot of the money, and to Bob Rumney, whose annual golf days contributed about a fifth of the total. But, however much you raised, we are very grateful.

So, where does the money go? Over the last four years we have contributed £60,000 to Sunderland University to support their ProDrug research. This consisted of an initial one year exploratory project and then a three year Ph.D. At the December meeting, the trustees committed another £22,250 for the next phase of the work.

We have also supported the ProDrug work at Robert Gordon University, Aberdeen (they are taking a different chemical approach) by purchasing a key piece of equipment for the research group there.

At this rate of spend we cannot rest on our laurels. We need to continue to raise money. We now have set the challenge to raise another £100,000. Please help! Remember that regular donations by standing order, particularly if linked to a Gift Aid declaration, can really mount up.



National Conference 2007

The Cystinosis Foundation UK will hold its National Conference on June 16th 2007, at the Manchester Conference Centre (In the Christmas Newsletter we



indicated it might be in York, but we found that it coincided with York Races, therefore we have moved to Manchester).

The MCC is just 300 metres from Manchester Piccadilly railway station and close to the centre of the city. It has a Days Inn Hotel as part of the complex and there is a large car park near by.

The theme of the conference is 'THE WHOLE FAMILY'. We shall be focussing not only on patients' needs, but also on those of parents/carers and most importantly, the healthy siblings of cystinotic children.

Of interest to all will be presentations from Dr Roz Anderson, who leads the ProDrug research at Sunderland University that we have been supporting for four years now, and she has some great progress to report. Like Dr. Anderson, Prof Don Cairns from Aberdeen University is looking at ways to make cysteamine, the active in Cystagon, more palatable, but is taking a different chemical route. His work is largely funded by the Irish Foundation, though we have purchased an important piece of equipment for his team and we hope that he too will be able to attend.

We shall have a talk on the impact of a chronically sick child on the family and in addition Suzanne Batte and Ian Hardaker from Nottingham will describe their work with siblings including a residential course that they ran for some last year. There will be break-out sessions for patients, parents/carers and for siblings where they can each talk about the particular problems they face.

We are fortunate that Orphan Drug UK have generously agreed to sponsor the conference, which reduces the costs greatly, but we need to know as soon as possible how many are likely to attend and how many require hotel accommodation. (We have blocked 15 double/twin rooms (some can take another bed for a child) and 5 singles for the nights of 15th and 16th June) The Conference will start at 10am and finish around 4:30-5:00pm. Please complete and return the reservation slip. We are asking for a deposit of £10 per adult, nothing for children though we need to know how many will be coming.

The Great North Run



(Shirley and Bev in the Great North Run Oct 6th 2006)

It was a great experience but very hard work. We are very grateful to all those who sponsored us for a very deserving charity!

Booking Form - National Conference 2007

YES we wish to book places at the National Conference on June 16th 2007 .

Name : £10 Deposit per Adult enclosed:.....

Address:

No. of Adults attending:No. of Children attending:.....

Hotel room required YES/NO (*delete as appropriate*) for June15th / June16th

Please return this slip ASAP to: Cystinosis Foundation UK, 174 Corwen Road, Tilehurst, Reading RG30 4TA