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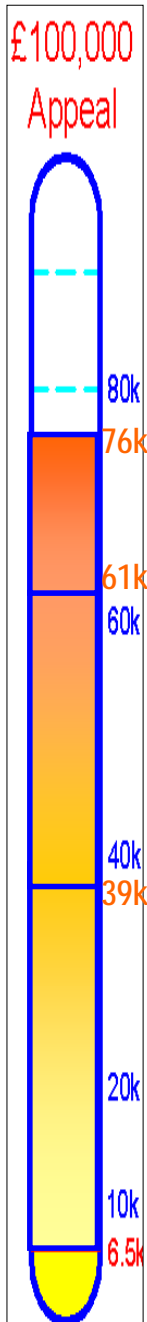
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### Editor's Note

Welcome to the 9<sup>th</sup> issue of our newsletter. Well done and a huge thanks to everyone who has helped with the fundraising! We encourage all families to raise as much money as possible for this Appeal. We have nearly reached our target of £100,000 – so get out there and do the best you can!

In this issue find out who is who on the committee – and, yes, we have pictures too! For those who can't attend the International Conference in the Netherlands, there is the CLIMB 25<sup>th</sup> Anniversary Conference in West Bromwich and the President of the Cystinosis Foundation UK (Dr William Van't Hoff) will be one of the speakers!

*Schinder*

### 4<sup>th</sup> International Cystinosis Conference in Noordwijkerhout

*(By Jonathan Terry)*

It is a great pleasure for the Cystinosis Foundation and AIRG Commissie Erfelijke Nierziekten - NVN, to invite you to the

**4<sup>th</sup> International Cystinosis Conference**  
At Noordwijkerhout, Netherlands  
From June 30<sup>th</sup> to 2<sup>nd</sup> July 2006.

The theme for this conference is 'Working together for Cystinosis'. The cystinosis conferences are based on a tradition of excellence and bring together families living with Cystinosis, international doctors and researchers. Your participation will contribute to a productive meeting which will include a challenging and exciting programme of workshops, plenary and parallel sessions. We look forward to welcoming you to the 4<sup>th</sup> International Cystinosis Conference!

#### CONFERENCE VENUE AND LOCATION

NH-Hotel Leeuwenhorst, Langelaan 3, 2211 XT  
Noordwijkerhout

Tel : +31 252 378888, Fax: +31 252 378890

Email : [nhleeuwenhorst@nh-hotels.com](mailto:nhleeuwenhorst@nh-hotels.com)

[www.nh-hotels.com](http://www.nh-hotels.com), select: "hotel - The Netherlands – Noordwijkerhout".

Close to Noordwijk beach, 30 minutes south of Amsterdam and north of The Hague.

Surrounded by Holland's famous tulip fields.

Schiphol airport 30km Train 20km Center 2km

**Hotel services:** Sauna, Fitness Centre, Jacuzzi, Heated indoor swimming pool, Tennis/Squash courts, Children's play area, Sportscafe with pooltables and tv.

(Internet users can access location details via [www.cystinosis.org.uk](http://www.cystinosis.org.uk) choose International Conference, then view 'Multi-Map')

More Information can be obtained at - [www.cystinose.nl](http://www.cystinose.nl)

*If you do not have access to the internet then contact us via the usual methods detailed at the head of this Newsletter.*

## Committee Members

### *Jonathan - Founder*



I launched the Foundation in 1999, having been motivated to set up a support group for Cystinotics in the UK after attending a meeting of the US Foundation and talking to its founder. I also consulted the leader of CLIMB, herself a mother of a cystinotic, who agreed that it was time for a separate organisation for cystinotics. Since its formation I have been the central organiser and dealt with hundreds of enquiries from patients and families.

### *Gareth Jackson - Trustee Chairman*

I am the proud father of two children, Robert 14 and Laura 11, with Robert having been diagnosed with Cystinosis when 6 months old. We visit Guys & St. Thomas' hospital quarterly to receive excellent support, but I know that this is not always the case. So when Jonathan set up the Foundation in 1999, I was glad to accept the position of Trustee Chairman. I obviously have practical knowledge from 14 years living with the issues that Cystinosis brings and also have a knowledge of management & IT to the Foundation, from my work for Honda.



### *John Terry - Secretary*



As I am Jonathan's father I have been involved with Cystinosis for over 40 years, although we did not know it for the first 7 of those. Since I retired I have become a Trustee of the Foundation and am the Secretary. I spent most of my working life with the Gillette Company working in research and development and although the work was not medical or drug related it did give me experience which has proved useful in what I do for the Foundation.

### *Paul Doyle - Treasurer/Trustee*



I have known Jonathan Terry for many years and was very pleased to assist him with the setting up of the trust and obtaining charity status for the Foundation. I have been one of the trustees and the treasurer since its inception.

I have worked in the finance sector for all of my working life and am currently with one of the major banks. I am a member of the Society of Trust and Estate Practitioners. I am married with three children.

### *Roy Forsthye - Trustee*

I became involved with the cystinosis foundation as my daughter is a sufferer. My wife and I discovered the foundation on the internet; we have been mainly involved with Fundraising for the research appeal. Last year I became a trustee.



## Fundraising

### 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.

### Rolls Royce

Thankyou to Rolls Royce in Derby for their generous donation of £125!

### Cystinosis Raffle (Jonathan)

We would like to thank and congratulate the Benford family (David and Claire) in Derbyshire for organising a raffle on behalf of the Cystinosis Foundation UK. Their daughter Darcy drew the winning tickets. Darcy turned 5 this March and was herself diagnosed with Cystinosis at 10 months old.

I am pleased to announce that our cystinosis grand draw has raised approximately £1750. What is amazing is that we only printed £1000 of tickets and the rest has been raised by kind donations from friends and family of people selling tickets. Darcy's Nanna, Mrs Ethne Wright, had 250 tickets which raised £250 as well as donations of £500 ON TOP from friends and family in Holywood, County Down, Northern Ireland. We are so grateful and thank everyone that gave for their kindness. We would also like to thank Ethne for working so exceptionally hard to achieve this result.

They are now organising a further fundraising event - a self defence class in their local village hall in Walton on Trent, Derbyshire. If anyone is interested in attending this event, please contact David on 0870 2200494.

Furthermore, friends of the family are organising a cycle across Spain later this year and are currently looking for sponsors, particularly a sponsor to provide or lend a new touring cycle. If anyone is able to help in this matter, please contact David on 0870 2200494.

### Telelogic UK Ltd

The Edinburgh office of the software company, Telelogic, made a £100 donation to the Cystinosis Foundation UK. The company provides a vending machine in the office and the profits are donated to a charity chosen by the employees. And the latest nomination was for the Cystinosis Foundation UK.

We would like to thank Telelogic and their staff for this kind donation.

### Money from Mobil



In November the Cystinosis Foundation UK received a £1,000 'safety award' from the ExxonMobil's SAGE terminal at St Fergus near Aberdeen. The safety award encourages ExxonMobil employees to apply safe working practices in their place of work, and in reward for safety record achievements donations are made to the local community. The safety committee chose the most recent award to go to the Cystinosis Foundation UK.

### Cystinosis Research Group

Earlier this year the Cystinosis Foundation UK presented a cheque for £2,542 to the Cystinosis Research Group at Robert Gordon University, Aberdeen. Dr Don Cairns explains how this money is being used:

*"In July 2005, the Cystinosis Research Group at The Robert Gordon University (RGU) in Aberdeen received £2,542 from Cystinosis Foundation UK for the purchase of a vacuum oven. The group at RGU is designing novel treatments for cystinosis which are intended to be odourless, tasteless and orally active replacements for cysteamine. It is also our intention to prolong the duration of action of the medicine to allow once daily dosing. The work is going well and a number of novel compounds have already been synthesised. These compounds will now be evaluated for their activity in depleting cells of cystine. We are very grateful to CFUK for the gift of the oven which allows samples of drug to be dried under low pressure prior to spectroscopic analysis."*

We thank Dr Cairns and all of those working with the Cystinosis Research Group for their work within the field of Cystinosis and wish them good luck in their future research.

## WELCOME TO HOLLAND (Emily Pearl Kingsley - from 'Autistic Action')



I am often asked to describe the experience of raising a child with a disability- to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas of Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later the plane lands. The flight attendant comes and says, "Welcome to Holland."

"Holland?!" you say. "What do you mean Holland? I signed up for Italy. I'm supposed to be in Italy. All my life I've dreamed of going to Italy." "But there's been a change in the flight plan. They've landed in Holland and there you must stay."

The important thing is they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place. So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people who you would have never met.

It's just a different place. It's slower paced than Italy, less flashy than Italy. But after you've been there a while and you catch your breath, you begin to look around and notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they've had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned." And the pain of that will never, ever go away, because the loss of that dream is a very significant loss. But if you spend your life mourning the fact that you didn't go to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

### Diary Dates

#### **4th International Conference**

Noordwijkerhout in the Netherlands

*June 30 - July 2, 2006*

#### **CLIMB 25<sup>th</sup> Anniversary Conference**

Park Inn Hotel, West Bromwich

*Saturday 30<sup>th</sup> September 2006*

(details available from [www.climb.org.uk](http://www.climb.org.uk) or from the Cystinosis Foundation UK)

### Final Note

Please write in with Ideas or articles or information you wish to share with others. If you should change your address, telephone or email let the foundation know so we may keep our records up to date.

You can contact me either by post or email

**Mrs Satinder Seehra**

**21 Blagreaves Avenue**

**Littleover**

**Derby DE23 2NT**

Email : [skseehra@ntlworld.com](mailto:skseehra@ntlworld.com)

Do you need help with fundraising? Do you have any ideas to help the Foundation to raise money? If you do then contact : **Gavin Reddington at:**

**2 Sitwell Villas, Morton, Alfreton, Derbyshire, DE55 6GX**

**Telephone : 01246 860133**

**Email : [GavReddo@aol.com](mailto:GavReddo@aol.com)**

*Yesterday is history  
Tomorrow is a mystery  
And today is a gift – that's why we call it the PRESENT  
A great pleasure in life is doing what people say you  
cannot do.-  
Brian Dyson CEO of Coca Cola.*

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**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**