

# Cystinosis Foundation UK News

Forever Growing



174 Corwen Road, Tilehurst, Reading, RG30 4T

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Email : [advice@cystinosis.org.uk](mailto:advice@cystinosis.org.uk)

Website : [www.cystinosis.org.uk](http://www.cystinosis.org.uk)

Registered Charity No : 1074885

HELPLINE / FAX : 0118 948 4754

## Editor's Note

Hello and welcome to our first Newsletter of 2008. The days are getting warmer and spring is in the air! The International Conference is but a mere two months away, so if you haven't already you need to register your details on-line and book your hotel. Watch out on the back page for our new on-line shopping store and trendy tabards!

Satinder

## Cystinosis Foundation UK Golf Day

The 8th CFUK Golf Day was held at Gosfield Lakes Golf Club, Essex in September 2007 and although only sixteen teams took part this year, due to their generosity £5,300 was raised. Thanks very much to the participants and to the good folks of Gosfield Lakes for their continued support.

Anyone wishing to enter a team of four or provide something for the auction for this years event in Friday 19th September 2008 should contact Bob Rumney on 07739 474 282 or [bob@rrumney0.wanadoo.co.uk](mailto:bob@rrumney0.wanadoo.co.uk).

## 5th International Conference - Ireland

The 5th International Cystinosis Conference is taking place in Dublin, Ireland on the 27th and 28th June 2008. Details of how to register and book your hotel room at Hilton Dublin City Hotel, Charlemont Place, Dublin 2 are shown below.



### Registering & Booking the Hotel

- ◆ To register visit the Cystinosis Foundation Ireland website [www.cystinosis.ie](http://www.cystinosis.ie) and follow the link for registering. Enter your details and submit. In a few days time you will receive confirmation from Cystinosis Ireland.
- ◆ A registration fee of 30 Euros is required to attend the conference. This is payable at the start of the conference on day one.
- ◆ To book your stay at the Hilton once again you should visit the Cystinosis Foundation Ireland Website [www.cystinosis.ie](http://www.cystinosis.ie) and enter the relevant details. If you haven't heard from the hotel within 24 hours then call the Hotel Hilton for confirmation on this number 00-353-(0)-1402-9988

*We look forward to seeing you there!*

*The Trustees of the Cystinosis Foundation UK have set aside limited funds to assist needy families living in the UK to attend the International Conference in Ireland but need to receive requests for assistance by the end of April. To make a request contact Jonathan Terry (0118 948 4754).*

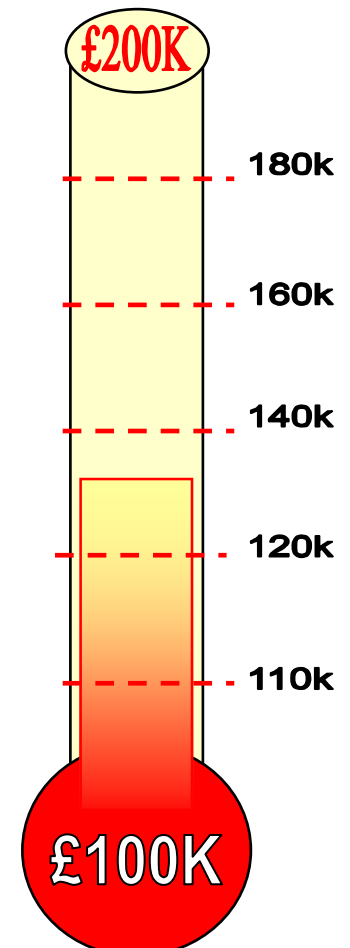
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If I had my life to live over, I would start barefoot earlier in the spring and stay that way later in the fall.



Nadine Stair





This newsletter is distributed to over 350 professionals, sufferers and parents/carers in the UK.

This newsletter is a way for you to share information and voice your opinions so please write in with ideas, articles, information and suggestions.

You can contact me either by post or email

**Mrs Satinder Seehra**  
21 Blagreaves Avenue  
Littleover  
Derby DE23 2NT  
skseehra@ntlworld.com

If you need any help with fundraising or have any ideas yourself then please contact our fundraising manager.

**Gavin Reddington**  
2 Sitwell Villas  
Morton, Alfreton  
Derbyshire  
DE55 6GX  
Gavin@greddington8.  
orangehome.co.uk

## Inspirations...

*"Spring has its hundred flowers, Autumn has its many moons. If useless thoughts do not cloud your mind.*

*Each day is the best day of your life"*

*In a Zen Garden  
by Judith Glover*



## Make Free Charitable Donations From Internet Shopping

**GAME**

**ASDA**

IN ASSOCIATION WITH  
**amazon.co.uk**

mothercare

next

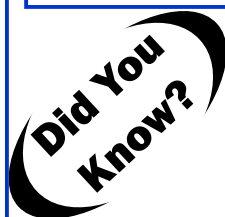
The Cystinosis Foundation UK has recently signed up with <http://www.buy.at>, which allows on-line retailers to make donations to the Cystinosis Foundation whenever someone makes a purchase via their website. Please support us, it costs you nothing and raises money for a good cause!

All you have to do is first visit [www.buy.at/cystinosis](http://www.buy.at/cystinosis) before you go shopping and click on the link for the retailer you wish to use.

The Foundation will then receive a donation once you have completed a purchase. There is no additional cost to you - the retailer makes the donation at their cost. The donation received differs from retailer to retailer, but can vary from a one-off payment of up to £50, to a percentage of every purchase you make.

The number of retailers is massive such as Amazon, Asda, Carphone Warehouse, CD-Wow, John Lewis, Marks & Spencer, Mothercare, Next, Play.com, Tesco and many many more!!!

We hope you'll consider first visiting [www.buy.at/cystinosis](http://www.buy.at/cystinosis) every time you go shopping online and click on the link. Alternatively, if you are generally browsing the web and find something you intend to purchase, please try to remember and check [www.buy.at/cystinosis](http://www.buy.at/cystinosis) to see if they are on the list and click the appropriate link before proceeding with your purchase.



### Did You Know ...

*That a product called Crystal Breath can be used to help eliminate the smell of Cystagon.*

- ◆ Natural gel capsules
- ◆ Contains natural extracts with a splash of spearmint
- ◆ All natural ingredients
- ◆ Comes in packs of 90 capsules

These are available from DEN TEK and you can get them on prescription.



### Did You Know ...

*The CFUK can lend out the tabards shown on the right.*

- ◆ For people wishing to borrow for fundraising and awareness
- ◆ These will be lent out on a immediate returns policy when finished
- ◆ They come in sizes 9-12 years & Adult size
- ◆ Contact the Cystinosis Foundation UK



## Diary Dates

### International Cystinosis Conference

27th & 28th of June 2008

Hilton Dublin City Hotel, Charlemont Place, Dublin 2, Ireland.

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