

Cystinosis Foundation UK News

Forever Growing



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Editor's Note

Hello readers,

Its been quite an exciting time for us all as the International Cystinosis Conference took place in Dublin on the 27th and 28th June 2008 . But for those of you who couldn't make it - don't worry as we have a special piece included in this newsletter. The Foundation is looking for a new committee member so if you are interested take a look at page 4 to see what's involved !

Thank you to everyone who has sent articles for the newsletter and if your article doesn't appear in this issue then look out for it in future issues!

Satinder

Jonathan & Ranjit @ RadioFox

Appearing on the radio isn't easy as it might "sound". When there was an opportunity to represent the Foundation on radio I just had to say YES! Satinder (my wife) has a niece who does radio presentation work in Leicester for Radio Fox and in May this year she was asked to run a month of programmes highlighting the work of charitable and volunteering organisations. When she asked if we



would go along for a live interview on behalf of the Cystinosis Foundation, the scene was set for Jonathan and myself to attend. The week before the interview a list of questions appeared in our emails—so that's how the answers always seem so good! This gave us an opportunity to make sure our minds were clear on what to say because in the short time on air the answers have to be concise and to the point otherwise the impact can easily be lost; although in practice the actual interview didn't go according to a specific plan.

In the two hours at the studio the actual interview time was about 45minutes fitted in between music requests, news updates and weather reports. We covered the causes of Cystinosis, my own experience of having two children with the condition, symptoms , medication, regimes, the work of the Foundation, fundraising activities and how people can help the Foundation.

We were made to feel very welcome and also to understand how a radio station works. It was a great way to let people know about some of the daily hardships that we as parents, children and sufferers go through.

If anyone gets a chance to go on the radio then I would strongly urge them to take it and contact Jonathan for some brilliant advice.

Ranjit Seehra

Inside this issue:

First Ministers Support! 2

Pampered Chef Evening 2

Gosfield Coffee Morning 3

Well Done Lundin Runners 3

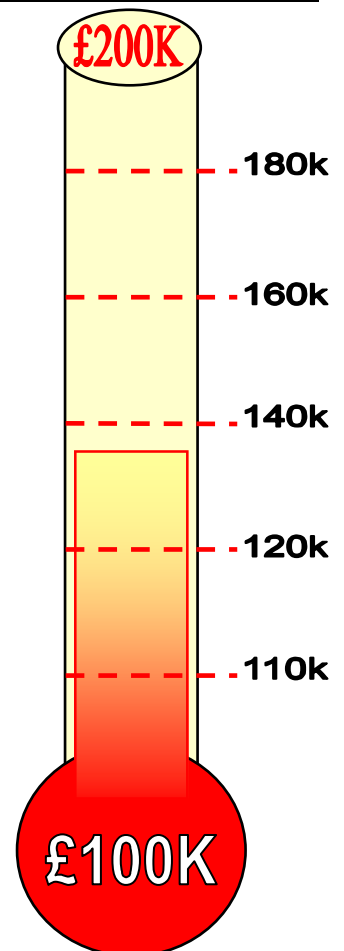
A Bit Of Hope 3

CFUK Committee 4

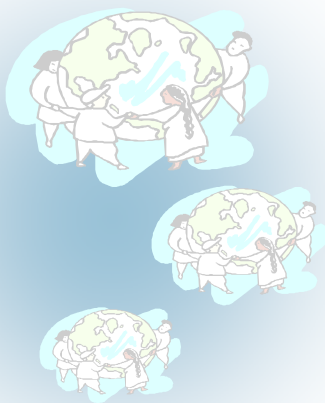
Did You Know? 4

Donation of prizes 4

Inspirations 4



First Minister's Support for Fundraiser



On Sunday 9th August, the Fishermen's Mission held their annual Peterhead Harbours Open Day. This event involves various stands and stalls from local organisations and charities, including a stall for the Cystinosis Foundation UK, organised by long term supporter Elizabeth Forsyth of Mintlaw, Peterhead in the North East of Scotland. A variety of items were on sale to raise funds for the Foundation, ranging from quizzes, hand made baby knitwear, home made jam and Cystinosis Foundation branded tea towels. And one of the purchasers of a tea towel was none other, than Alex Salmond, First Minister for Scotland.



Elizabeth Forsyth's Stall



Elizabeth & Jimmy Forsyth, Alex Salmond (First Minister for Scotland) & Janet Sladdin

Alex Salmond, who at one time was the MP for Peterhead's constituency of Banff and Buchan, was keen to hear of the work of the Foundation and the fundraising efforts of the grandparents of local seven-year-old Lena Forsyth, who suffers from Cystinosis. And continuing the local theme, Mr Salmond learnt of the Cystinosis research being undertaken by Professor Cairns at the Robert Gordon University in Aberdeen. As well as raising funds for the Foundation, the Peterhead Harbours Open Day served as a wonderful opportunity to increase awareness of Cystinosis, which is particularly hard given the rarity of the condition. The Foundation would also like to highlight the efforts of Lena's grandmothers - Elizabeth Forsyth, whose stall **raised £258.60**, and Janet

Sladdin, who produced the jam and also designed and organised the tea towels. To date, 417 tea towels have been sold **raising £1,324!** A big thank you is due to both grandmothers for their continued efforts.



"The Benford Family help raise £1300 for the Cystinosis Foundation"

Pampered Chef Evening

On the 6th June 2008 the Benford Family held a Pampered Chef Evening to help raise money for the Cystinosis Foundation. Their daughter Darcy suffers from Cystinosis. The family wanted to raise money to aid research and to ultimately find a cure for Cystinosis



Darcy Benford

to try the food and purchase the cookery equipment. All the host's commission was donated to the Cystinosis Foundation UK.

The event was so well organised that even a crèche was available where the children took part in games and activities. A raffle was also held and Cystinosis Foundation tea towels were also sold.

To help raise funds, the Benfords held "Pampered Chef" evening. Admission was £2.00 per adult which included light refreshments. There was a cookery demonstration by Cathy Thacker, the local Pampered

The amount raised was approximately £1300. Well done!

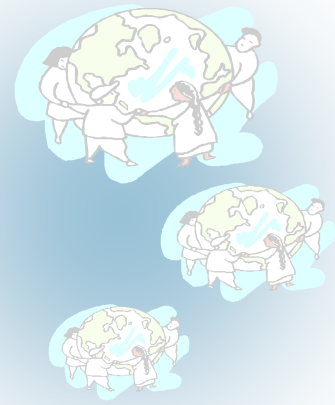


Gosfield School Coffee Morning

Thank you Mrs Sandra Canhill who has managed to raise **£221.18** for the Cystinosis Foundation.

Sandra works at Gosfield School in Halstead, Essex where she held a coffee morning to raise money for the foundation.

She is responsible for administering medicines and looking after Bob Rumney's son Joe who suffers from Cystinosis.



Well Done Lundin Runners

On May 25th 2008 6 runners, from oil firm Lundin, ran in the Baker Hughes 10K in Aberdeen. And we are pleased to announce that the successful runners managed to raise £1118 - money that will be going directly to our research appeal. And the Foundation would like to say a sincere thank you to all the runners for choosing to support us, and for their efforts in training and participating in the run!



A Bit Of Hope

My daughter was diagnosed at about two years of age. Prior to that she had not managed to thrive. She was always drinking, vomiting in the morning and never wanted to eat. She only weighed about 18lbs at the age of one.

They never really did a lot for her apart from giving us Sando K and Sando Phosphate tablets. Later on she was given One Alpha. They told us she would die at the age of ten. How wrong the doctor was!!!

The doctor hadn't taken into account Jodi's fighting spirit and a miracle man named Dr Alan Watson. In June 1985 I had twin boys, Andrew and Richard. When the boys were six months old Jodi, Andrew, Richard and I traveled fifty miles to Nottingham twice a week for over night dialysis for Jodi. It was very exhausting but we had loads of support from the Renal Team.

The following July Jodi had a transplant followed by a fairly severe stroke. With lots of help Jodi soon began to walk, and write with her left hand again. She went back to junior school the same September. Secondary school soon beckoned.

By the age of 15 she even acquired a boy friend. Short lived I'm afraid but she soon met Simon. She went to college and learnt hairdressing and beauty. Unfortunately she developed epilepsy.

When she was 21 she married Simon. They brought a house together and settled down. In March the following year brought loads of worries as Jodi discovered she was pregnant. Two months early, due to complications our little Chloe was born weighting 2lbs 4ozs! Chloe has grown up and is now nine years old.

Jodi had another transplant five years ago. She's had some nasty illnesses along the way but she's a fighter. She's just been diagnosed with diabetes her biggest worry is not being able to eat Mars bars! She's thirty-two in November and the doctors said she'd never make it. I think Dr Watson and Jodi make a good team. The nurses at the Renal Unit at the City Hospital (Notts) who look after her, they do a grand job. If your son or daughter has Cystinosis and they're having problems, remember Jodi and keep fighting!

"The doctor hadn't taken into account Jodi's fighting spirit and a miracle man named Dr Alan Watson"

Chris (Jodi's mum)



We would like to know what you think of the newsletter and we would be grateful if you could share any ideas with us on how to improve it.

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

You can contact me either by post or email

Mrs Satinder Seehra
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Derby DE23 2NT
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 Gavin would be very grateful if any one could help him with items suitable for Prizes or Selling. This will help him with his fundraising activities.

Gavin Reddington
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Inspirations...

*This is my wish for you
Comfort on difficult days,
Smiles when sadness intrudes,
Rainbows to follow the clouds,
Laughter to kiss your lips,
Sunsets to warm your heart,
Hugs when spirits sag,
Beauty for your eyes to see,
Friendships to brighten your being,
Faith so that you can believe,
Confidence when you doubt,
Courage to know yourself,
Patience to accept the truth,
Love to complete your life.*
Lynn Buttercup

Want to be on the CFUK Committee?

Our charity is now nearly 10 years old and during this time has run with a small committee of trustees who meet around 6 times a year, together with Jonathan Terry our founder. We would now like to expand the committee by adding a new member to broaden the range of views considered, have another person to contribute different ideas and of course to add another set of hands to share the work we do.

So what is involved ?

At the moment we meet in the evenings (3 trustees live within 20 miles of each other) and the fourth trustee "attends" via phone conference. In the future, we have thought about trying to set up a PC based web conference. From each meeting there are a number of action points or activities which are allocated out by consensus, which means there is a varying amount of time required outside the meetings for each person.

What type of person are we looking for ?

Firstly & foremost we are looking for someone who is passionate about the aims of the charity - Patient Support, Education and Research Support. Three out of the current trustees are fathers of a Cystinotic and brief details of all the trustees & the founder are on the website.

Secondly, we obviously need to find someone who can establish a good working relationship with the other trustees and is ready to share their

own views, but is also flexible when listening to other's views and ready to help build a consensus on actions or decisions.

Lastly but very importantly, as trustees we have an individual & collective legal responsibility for directing the affairs of the charity. Anyone who is interested should therefore fully understand this commitment of "trust" - a good explanation of what a trustee needs to know is on the Charity Commission's website (<http://www.charitycommission.gov.uk/publications/cc3.asp#e4>).

How will we do this ?

Before we add a new committee member, we will meet up so that both the committee and the candidate can establish whether both sides can effectively work together. We can also explain in more detail how the charity functions, including the governance & controls that safeguard it's operations (like dual signatures on cheques). Hopefully, there will be more than one person interested and so we will then need to make a choice of which applicant we think will be the best addition to the committee.

What to do if you're interested or have questions ?

Please contact
Gareth Jackson (Chair of Trustees)
by
Email : gareth.jackson@honda-eu.com
Or
Phone : 0777 474 6951



IKEA is now offering a donation to the Cystinosis Foundation UK. When you make a purchase via our webshop. IKEA offers a wide range of well-designed, functional home furnishing products at low prices. 2% of what you spend at IKEA will be given to Cystinosis Foundation UK. And remember it is the retailer, not you who makes the donation. See our webshop at <http://www.buy.at/cystinosis>

Remember: You must click on the link from our webpage, or go to the link above, in order for the retailer to make a donation following your purchase. If you don't click the link, we don't get the donation...



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.