



Editor's Note

Hello & welcome to our new look Cystinosis Foundation newsletter! This newsletter is a way for you to voice your views. So please send me any articles whether it be about diagnosis (your story), poems, any fundraising which you have done or simply what you would like to see in the next issue of the newsletter. My details are on the back page so please get emailing or snail mailing. I look forward to hearing from you soon!

Satinder

Cystinosis National Conference - 'closed'?

It is following the unfortunate need to cancel the Foundation's National Conference this year that I am writing to you all. Since the committee and myself made the decision to cancel, having received few requests for Conference Registration, we have all been attempting to identify what makes a *Good Conference*? Why do we see the same problems arising as many other organisations have in the past, that cancellation has been necessary, having had a low level of our members' registration requests being returned?

When you receive notice that a conference is to be held, what is it that you think of? It seems difficult for the Foundation to identify what reason a Member would have to come. Are we too keen to cover specific issues, or should we perhaps generalise the whole event, enabling more time for you to make conversation with other families?

Having had people very close to me, put in so much effort to organise the conferences we have had since we began in 2000, then finding that their hard work lead to nothing, I personally feel that to establish what our future is to be must be identified.

Is the way forward to stop *National Conferences* (whether *By-Annual* or *Annual*), only to assist in the organisation of *International Conferences*, as we are now and attending them instead? If we take this route, then the pleasures we do capture at a *National Conference*, such as the meeting of Professionals and other families living here, is lost.

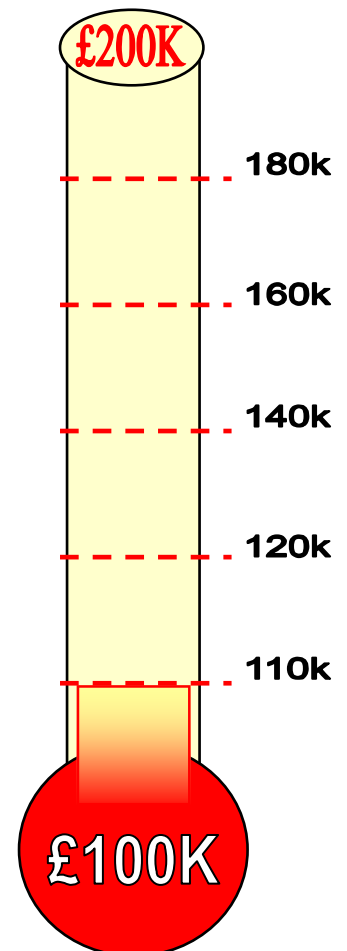
Reliance on the Newsletters produced and the Internet for information can be reverted to, if this is all that you want. But of course, we then lose that one-to-one more personal feeling achieved when we can talk to one another face to face.

So, do please read again if necessary to decide where you feel the Foundation should be going. We need to know and will take serious note on feedback from this item. I personally look forward to hearing from you. My address, telephone and email are at the top of this newsletter.

Jonathan Terry
 (Founder & Advisor)

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Wine Sweep in Chamonix

How many bottles of wine will be drunk during the 2006/7 winter ski season in our catered chalet?

A good questions you may ask, and believe it or not as the owners and operates of Chalet

VertetBlanc, going into our second season we had no idea.

The answer is 697.....

Let me introduce ourselves, I am Jackie and my partner is called David, we moved to Chamonix three years ago to set up and run our ski chalet, and this year we decided we had a great opportunity to raise some money for Cystinosis. We persuaded each of our guests to part with 10 euros, to enter into our wine sweep and guess how much wine would be drunk during this last ski season.

The wining entry was Louise Steer who guessed 698 bottles. She won a week's holiday for two during the 2007/8 winter ski season. Thanks to all of our guests who took part we managed to raise 1500 euros.

Myself and David were touched by Cystinosis when we met Darren and Emma Clare whose beautiful daughter Millie had been diagnosed with the illness. Darren, Emma and Millie quickly became very close

friends and now some 6 years on are they are the most amazing family that we have pleasure in calling our best friends.

Millie has the most amazing courage and spirit and this year at 8 years old she came out to Chamonix skiing herself for the first time, with her Mum, Dad and little brother William. Life in a chalet is a fantastic experience as you meet lots of different people staying at the Chalet. The same week that Millie was with us was another little girl the same age called Amelia. On the last night of their holiday Millie and Amelia put on a surprise piano concert to the other 18 guests in the chalet..... to say there wasn't a dry eye

in the house is an understatement.

It is really at a time when you see two children of the same age next to each other that you realize the full impact that Cystinosis has on a child.

This was only our first attempt at fund raising for Cystinosis and we are fully committed to continuing to raise funds for research into

this illness and any drug breakthroughs that can be made. We already have a plan up our sleeve for fund raising next winter.

We are also happy to offer a 15% discount to all guests that come to stay at our chalet during the winter and preferential rates will also apply during the summer period. We hope to be able to welcome some of you out here in Chamonix in the future. Our website is www.vertetblanc.com or we can be contacted at info@vertetblanc.com



North Sea Oil Platform



The Cystinosis Foundation UK would like to thank the crew of the North Sea oil platform Stena Spey for their kind donation of £900. The Foundation was one of 13 charities chosen to receive a donation after being nominated by one of the platform employees, Alison Macrae.

Alison decided to nominate the charity after hearing about local girl, Lena Forsyth, who suffers from Cystinosis. Alison presented Lena with a cheque (pictured) in April 2007.

Fashion Show

On Wednesday 18th April a fashion show was held at the New Inn in Ellon, Aberdeenshire in aid of the Cystinosis Foundation UK. The night, which featured local models wearing clothing by Skinners and a display of shoes by S&G Paterson, both of Ellon, was a complete sell out, with all 250 tickets being sold! The event was organised by Janet Sladdin, the grandmother of 6-year-old Lena Forsyth who suffers from Cystinosis. Mum, Vicky Forsyth, who also assisted with the event, stated *"Research costs money, but if it works then it will be worth every penny"*.



Over £3,350 was raised on the night with all proceeds going to the Cystinosis Foundation UK to assist in our current campaign to raise further funding for on-going research projects. Lena currently takes her medicines 3 times a day although it is hoped this may be reduced in future. Lena attends the local primary in Mintlaw and is a keen dancer having recently been involved with a dance show that also raised money towards Cystinosis research - Janet Sladdin, along with other family, friends and local organisations, worked hard to make the night such an enjoyable success for many people and raise such a significant amount for the Foundation. We'd like to take this opportunity to thank Janet and all those involved for their efforts.

London Marathon Success

After months of preparation, on April 22nd, Lisa Bennett completed the London Marathon in a time of 3 hours 38 minutes! In the process, Lisa has also managed to raise over £550 for the Cystinosis Foundation UK, with donations still coming in! Additionally, the amount she has raised will be further increased through Gift Aid.

Lisa has run several marathons in the past, including New York, Boston, Chicago and last year's London Marathon. Lisa states she found this year's marathon harder than most due to the hotter weather and found she was suffering from a lack of salt; *"to be honest I may have pulled out if I hadn't been running for the charity, so it got me to the finish"*. Lisa was inspired to run the marathon through her friendship with Millie, a young sufferer of Cystinosis.



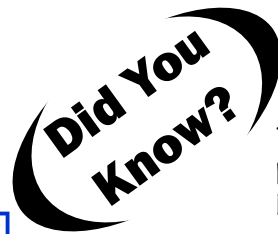
Congratulations from all those involved with the Cystinosis Foundation UK to Lisa in completing yet another marathon and raising a significant amount of money in the process for the Foundation. We appreciate not only your efforts on the day and raising money, but also in all the training and preparation leading up to the marathon. Well Done!

Apache Donation

The Cystinosis Foundation would like to thank the charity committee on the Apache Forties Alpha oil platform, in the North Sea near Aberdeen, for their kind donation of £250 to the Cystinosis Foundation UK.

The committee nominated the Foundation after hearing about 6-year-old Lena Forsyth of Mintlaw in Aberdeenshire who suffers from Cystinosis. This money will help us in our continuing effort to fund research projects within the UK.





That if you have access to the internet you can look at www.gov.uk/bluebadgemap website to find a blue badge parking bay in any town/area/postcode right across the UK. Remember you do have to have a blue badge to use the parking bay.



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

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

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Inspirations...

*May the sun bring you
new energy by day,
May the moon softly re-
store you by night,
May the rain wash away
your worries,
May the breeze blow new
strength into your being,
May you walk gently
through the world and
know its beauty all the
days of your life.
Apache Blessing*

That if a UK tax payer makes a donation to a charity, they can specify their donation as 'Gift Aid'. This allows the charity to claim back the income tax on the donation, at no cost to the donator, but making the donation worth up to nearly 30% more to the charity! Please gift aid all your donations.

Diary Dates

QAC Sight Village

An event for people who are blind or partially-sighted, for professionals supporting and advising VIPs and for all businesses and other organizations wishing better to meet the needs of their vision impaired customers.

17th July 2007 (10am—5pm)

18th July 2007 (10am—5pm)

19th July 2007 (10am—4.30pm)

The Clarendon Suites, 2 Stirling Road, Edgbaston, Birmingham.

For further information contact the marketing team on 0121 428 5041 or visit the website at www.qacsightvillage.org.uk Admission is free

Climb Conference

20th October 2007

Copthorne Hotel, Merry Hill, Dudley

For further information call 0800 652 3181 or visit the website at www.climb.org.uk

Children Learn

(Chicken Soup for the Soul—J Canfield & M Victor Hanson)

- If children live with criticism, they learn to condemn.
 - If children live with hostility, they learn to fight.
 - If children live with fear, they learn to be apprehensive.
 - If children live with pity, they learn to feel sorry for themselves.
 - If children live with ridicule, they learn to be shy.
 - If children live with jealousy, they learn what envy is.
 - If children live with shame, they learn to feel guilty.
 - If children live with tolerance, they learn to be patient.
 - If children live with encouragement, they learn to be confident.
 - If children live with praise, they learn to appreciate.
 - If children live with approval, they learn to like themselves.
 - If children live with acceptance, they learn to find love in the world.
 - If children live with recognition, they learn to have a goal.
 - If children live with sharing, they learn to be generous.
 - If children live with honesty and fairness, they learn what truth and justice are.
 - If children live with security, they learn to have faith in themselves and in those around them.
 - If children live with friendliness, they learn that the world is a nice place in which to live.
 - If children live with serenity, they learn to have peace of mind.
- With what are your children living ?

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.