



Design Our New Logo

The Cystinosis Foundation UK has launched a competition for a new logo and are inviting you to design it. We have no pre-conceptions of what this new logo should look like, so only your imagination is the limit! However, when coming up with your ideas, here are a few things to bear in mind:

- The logo must be easy to reproduce in large and small sizes.
- Your design must be original (i.e. not infringe any other person's copyright).
- Ideally it should reflect the Cystinosis Foundation UK and its aims.
- Please be aware of the competition rules below.
- Full rules and regulations can be found on the web site.
- You must submit your logo before the deadline of midnight 4th April 2010

There will be a small prize for the winner (TBA), and the knowledge that you are helping promote the Foundation. You can email or send your entries to the address below. Please remember to include your own name and address with your entry.

- Email: LogoCompetition@cystinosis.org.uk
- Cystinosis Foundation UK 174 Corwen Road Tilehurst Reading RG30 4TA

International Conference

September 23rd - 26th 2010

The Sixth International Cystinosis Conference is going to be held in Lignano Sabbiadoro Italy at the Village GeTur which is located between Trieste and Venice. This important event, which families, patients, physicians and researchers from around the world look forward to attending.

Details of the conference can be found on the web site.

Editors Note

This will be a 2009/2010 to remember, not only the start of a new decade but a winter to surpass all, the worst for at least 30 years countrywide. My husband and I have taken on the role of editing the newsletter for the time being from Satinder Sehra. We would like to thank her very much for publishing the newsletter for the last few years. We wish her and her family well. If any one has any snippets or articles they would like included in the next issue please get in touch at erdhouse@talktalk.net or write to Janet and Tony Sladdin at Erd House, Stuartfield, Aberdeenshire AB42 5DU. We have included a link word quiz hope you enjoy doing it. Winners will be announced in next edition.

Fundraising events

Support Jo Grant's run

Jo Grant will be running in the [Kingston Breakfast Run](#) on 11th April 2010 to raise money for the Cystinosis Foundation UK. Jo states, "I only recently became aware of this charity as my friend's god-daughter has Cystinosis", and it was this that has inspired her to don her running shoes and support the Foundation. You can support Jo by making a donation at www.justgiving.com/Jo-Grant2010. And everyone at the Foundation thanks Jo for her support and wish her all the best in her training and the run.

April 4th 2010—65 Mile Walk

On April 4th 2010, a group of walkers, led by Colin Buist will undertake a 65 mile walk along Speyside in North East Scotland. The group have been inspired to undertake the walk in aid of Mr Buist's cousin's daughter, 9 year-old Cystinotic, Lena Forsyth, also from the North East. Anyone who wants to donate money can call Mr Buist, from MacDuff, Aberdeenshire on 01261 833476, or you can donate on-line at their www.justgiving.com/walkthespeysideway



Young Motorcycle Racer Promotes

Team Twister is delighted to announce that throughout 2010, Tim Hastings will be promoting the **Cystinosis Foundation UK**. One of Tim's long term supporters and sponsors is Tony Sladdin, whose eldest granddaughter Lena has the condition. In thanks and recognition of Tony's continuing support, Tim aims to promote awareness of the disease and publicise the tremendous work of the Foundation by carrying the name of the Cystinosis Foundation UK on his bike throughout his 2010 campaign in the Metzler National Superstock 600 series. Tim is one of Kawasaki's Team Green Junior Superstock riders.

Research Fund Appeal Total (March 2010)



Dubai Runners Update

Stephen Crowder and Scott Kerins have a friend who's daughter, Jessica Spencer has cystinosis.

The two have just completed the Dubai Half Marathon on January 22nd 2010 and so far have raised £2761.00. Their web page is www.justgiving.com/scott-stephen

Well done to both

This recipe was provided by Michael Corrigan, a nineteen year old cystinotic who is training to become a chef. He carried out a display of cookery at the Kidney Kids Scotland Event in 2009.

Lamb/Beef Burgers.

200gms of minced lamb or beef

Haloumi Cheese or Feta

1 Red Onion

pinch of salt and pepper

mixed herb



Mix all the ingredients in a bowl and coat in a little flour to stop sticking to pan. Cook on each side for 3–4 minutes and serve in a buttered bun with a mixed salad.

Research update

Visit to Sunderland and an update on the Pro-Drug Research by John Terry secretary

At the end of January our Chairman, Roy Forsyth, and I visited Sunderland University to review the progress of the Prodrug research that is being sponsored by the Foundation. To recap, Prodrugs are chemical compounds that contain a known efficacious drug combined in a way that allows it to get to the places it is needed in the body without causing any problems on the way. In this way side effects such as the taste and odour from Cystagon could be overcome, but also much of the Cystagon that is swallowed by our patients is wasted, secreted from the body before it has chance to get to work. A successful Prodrug would lead to much lower doses being required. While with Roz Anderson we discussed a new technique called Proteomics. This allows the detailed effects of drugs on individual proteins in cells to be studied. It could be applied to see precisely what cysteamine does as well as checking in detail what prodrugs do. We are expecting a proposal from her in a few months and that will be for an expensive programme. Although this sounds like very basic research it could deliver new knowledge of real value. Lisa's work has over 2 years to run and, assuming that she is successful, there could be as many as 15 more years before an improved treatment is available. This seems a very long time to wait for an improved treatment but there is news of a promising first step along the way. If you visit the website of Raptor Pharmaceuticals Corporation you can see their progress with Cysteamine (the active in Cystagon) which has been coated with an enteric coating. The enteric coating protects the drug as it goes through the stomach where a lot is normally lost. The work so far indicates that the dosage can be reduced by about a third and the dosing frequency to just twice a day by this. They are in discussions with the authorities about Phase 3 Clinical Trials this year. Enteric coatings are not a magic bullet but could make the lives of our patients more tolerable. A successful Prodrug or a successful gene therapy could provide that magic but at this time we don't know if either is going to work. We have put most of our resources into Prodrugs because they seemed more practical when we started. However, there is work going on targeting gene therapy in Ireland and we are keeping our eyes on that too.

Letter from the Chairperson

Roy Forsyth

The last year has been a good year for the foundation in the fundraising front, there have been a lot of "new people" wanting to help us with fundraising events. To see people come forward and offer this help is extremely encouraging, it really does make a huge difference.

For us as trustees it's encouraging too, as being in contact with such a small cystinotic community is difficult as we are spread thinly over the country. Attracting the support of people lets us know we are getting things right, we are able to show you what we want the charity to do and how with your help we can make a difference. The research work we are supporting is extremely important in the cystinotic world and it will be long term so our requests for help won't stop. Fundraising isn't easy and you may feel that if you aren't able to do the big event then perhaps it's not worth it or important, that isn't the case. Personally we have put a lot of effort into events that we think are going to be good fundraisers and had little return and likewise the things you don't think will work often do. Whether an event raises a lot of money or not isn't really important, it's the fact that you want to do something and go and make the effort for us and you may even enjoy it. **Every pound we are donated will be put to good use.**

We aren't a big organisation and don't have teams of people to help you, we do have our own experiences that we can share or offer suggestions if you want. The range of events used to raise funds for us over the last few years has been fantastic there are real simple ones that anyone can do. You'll find a quiz in this edition of the newsletter, something that for our family has been a core fundraising tool that just keeps going in the background. Alternatively use the "buy at" facility if you are shopping online, it doesn't cost you anything more but the charity receive a donation. We can provide a "fundraising pack" with ideas and sponsor forms in there and leaflets for distribution. Contact us through the website or our postal address. The foundation has changed a lot in the recent years and has a lot to be proud of in its achievements but we are only going to succeed with your help, Please try to be involved in whatever way you can. If you want to make suggestions or comments then please do we welcome any feedback."

Contacts **Email** : advice@cystinosis.org.uk **Website** : www.cystinosis.org.uk
Helpline/Fax : 0118 941 4232 **Charity address** : 174 Corwen Road Tilehurst Reading RG30 4TA

Welcome to the New Web Site

After 5 years of the same website, we were feeling old and felt it was time for a face lift - welcome to the new Cystinosis Foundation UK website! We hope you feel it is fresher, easier to navigate and simply more useful. We appreciate all comments, so please [contact us](#) with any feedback.

You may notice the older news and events are not on the site - we will be working over the coming weeks to make these available, as well as updating you with all the current news.

Wishing you all the best for 2010.

The Cystinosis Foundation Team

Special thanks to Matt and Philippa Blackham who manage the site on a voluntary basis.

Shop for Less and Support the Cystinosis Foundation

- See our webshop at <http://www.buy.at/cystinosis>
- Shop from the comfort of your home
- Escape the hassle of parking and queues
- Find great prices and gift ideas all in one place
- Save with online discounts
- Many retailers offer free delivery

The retailers involved pay commission on everything you buy—but only if you do it through our webshop



Mailing List Update

We regularly update our mailing list and wish to ensure the details we have for you are correct. You may no longer wish receive this newsletter. You can download the newsletter from the website. If you wish to change your details, or be removed from the mailing list please complete the form below and return it to Cystinosis Foundation UK 174 Corwen Road Tilehurst Reading RG30 4TA

Current details

Name.....

Address.....

.....Postcode.....

New Details

Name.....

Address.....

.....Postcode.....

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.