

July 2011

I hope you don't mind me contacting you, but I've recently been given the 'all clear' after being diagnosed with a 'molar pregnancy'. All those reading this letter will have either gone through a similar experience, or know somebody close to them who has. Without going into too much detail let me tell you my story, as I know you'll all be able to relate in some shape or form.

In May 2010 I was the happiest girl ever as I found out I was pregnant with, what I thought would be, our first child. In July 2010 I was no longer the happiest girl, as I found out I'd miscarried. I had a D&C and subsequently discovered I had suffered from a 'molar pregnancy'. In September 2010 I was admitted to Charing Cross Hospital (CXH) to start a course of chemotherapy. Like many of you, this was the first time I'd ever heard of this condition and was in total shock at what had happened. I couldn't understand how I'd gone from one of the most beautiful moments in life to possibly one of the darkest - and in such a short space of time. Unfortunately it took 8 long months consisting of several courses of methotrexate, followed by Actinomycin D, followed by Ema-Co to bring my HCG levels to zero. It was undoubtedly the worst period of my life. The fact that I'd lost a baby; the fact that I still long to have a baby and yet have to wait what feels like an eternity to even begin to try to become pregnant again; the stress of each blood test and the dreaded wait for each result; the chemotherapy and all the nasty side effects that came with it; the anxiety; the fatigue; the questions . . . the list goes on.

All that being said, thankfully I was given the 'all clear' in mid April and only now am beginning to get my life back – although it's still far from easy. I don't know about you but I feel passionate about raising the awareness of 'Gestational Trophoblastic Diseases'. I'd like to be able to give something back to the amazingly supportive team at CXH, and help those that sadly will also go through the same painful experience as we all have.

You may already know this, but The Cancer Treatment and Research Trust (CTRT) is a registered charity that was founded in 1985 and is now headed up by Prof. Michael Seckl and Dr Philip Savage at CXH. Its main role is to raise funding for research; improve ways of detecting and monitoring cancers; finding and testing new treatments as well as providing support for patients and their relatives and improving their entire 'in' and 'out' patient experience.

One thing in particular CXH would like to develop is a test that would enable patients to know from the onset if they would require further treatment. As soon as a patient is diagnosed with a 'molar pregnancy', they would know via a 'unique genetic fingerprint' if their cells would become malignant or if they hopefully would remain benign. I'm not sure what your particular experience was, but in hindsight had this technology been in place, I personally would have known and started my chemotherapy two months earlier – and ultimately got my life back two months earlier. The teams at CXH have already started working on this project and are eager for this testing to be in place, however unfortunately do not yet have the sufficient funding. Something like this would cost in the region of £2million, once you've accounted for the technology and staffing. Although this is a huge amount of money, as I'm sure you can appreciate, it would make an enormous difference to all future 'moles' in the UK and in so many ways make the entire process a less stressful one.

Having been inspired to help CXH raise these funds I've just set up my own 'JustGiving' page (which was very easy to do!). I'm still recovering from all the chemo so need to build up strength before I plan something big to help raise funds. For the time being, I wanted to contact you and see if you too would be willing to do something to help achieve this goal. If all of us are able to raise money (no matter how big or small) the target is definitely achievable. The team at CXH, are so busy helping people like you and me they have little time to focus on fund raising, which is why I'm offering my support in terms of trying to co-ordinate this . . . and why I am now contacting you!

Approx 1350 patients (past and present) are reading this letter. Some patients may have suffered from a molar pregnancy as long as 30-35 years ago and some will have done so within the last year. Whether treated at Charing Cross Hospital in London, Weston Park in Sheffield or Ninewells in Dundee, in total 900 of us needed treatment and thankfully 450 didn't. If we are all to somehow raise an average of £500 each year, we could reach our target within 3 years.... which would be an unbelievable achievement!

Overleaf I've listed various initiatives that may help you raise money and support CTRT. In terms of getting the actual money to the charity, attached is a generic CTRT sponsorship form and cheques can be made payable to CTRT Appeal and sent direct to Carol Sammut (CTRT) in the Oncology Dept at Charing Cross. In addition to this CXH already has a 'JustGiving' page in place that you can simply donate to. If however you want to set up your own page, to make it even easier for you, you are more than welcome to copy and adapt mine. See below for both links.

<http://www.justgiving.com/ctrcharingcross>
<http://www.justgiving.com/charlotte-solomon>

If you want to contact me personally my email address is charlottectrt@hotmail.co.uk and I'd be more than happy to help you in any way I can. I am also part of the 'molar pregnancy forum' (molarpregnancy.co.uk) – user name charlottectrt and have posted this letter onto their site. CXH will monitor money being donated to the charity appeal and I will subsequently keep you in the loop of how much we've raised. If enough of you email me personally, I'll also start up an email group to keep everyone abreast.

Finally I'm so sorry to write such a long letter but there is so much to say, and it's so important to try and get your support. I really hope to hear from you and that together we can reach the £2million goal!!!

Thank you so much for your time
Charlotte

PS

As my first fundraising initiative, I'm putting together a 2012 calendar. 28 'amazing' friends of mine have all agreed to go completely out of their comfort zone and bare all for the calendar! As well as increasing awareness of 'Molar Pregnancies, money is being generated through sponsorship and calendar sales. Top photographer, 'Chris Dunlop' www.chrisdunlop.co.uk has agreed to shoot the campaign and Bellapierre Mineral Cosmetics are sponsoring the shoot and working with Dani Guinsberg and The Session School (www.thesessionschool.co.uk) to provide hair and makeup.

The 'Get Naked' JUSTGIVING site went live on Saturday 30th July and within the first 5 days raised over £15,000! The link has now gone viral on both Facebook & Twitter! Should you wish to support please visit www.justgiving.com/calendar2012