

The Thalidomide Trust

DIRECTOR'S UPDATE AUGUST 2015

People News

We're really proud to report that three of our beneficiaries have recently been awarded honours in recognition of their amazing campaigning and charity work. Rosie Simmonds has been awarded an OBE for her work on equal rights for disabled people; Lorraine Mercer was awarded an MBE for her community and charity work, particularly her role as a hospital visitor; and Mikey Argy received an MBE for her fantastic campaigning work on behalf of all beneficiaries.

Unfortunately Freddie Astbury has had to resign as a member of the NAC due to personal circumstances and Fiona Carr has had to stand down as a Volunteer Visitor for personal reasons. Thanks to both of them for the valuable contributions that they've made.

Two new Trustees have joined the Board since my last update. Mark Benstead has been appointed as a financial Trustee and Professor Tim Briggs has been appointed as medical Trustee. Both will bring a wealth of knowledge and experience to the Trustee Board.

Sadly two beneficiaries – Derek Rich and David Williams - have died in 2015. We have not accepted any new beneficiaries during this period.

We are all delighted that Mark Gizewski was released from prison in New York in March and would like to acknowledge all Guy Tweedy's hard work in campaigning for this to happen. Mark is committed to making a fresh start and would love to connect with other beneficiaries. If you would like to get in touch with him by letter, email or skype just let us know and we will share Mark's contact details with you.

Communications Update

The Communications Working Group is now up and running and has begun work on developing a Communications Framework for the Trust in line with our Long Range Plan.

One of its first tasks was to agree a new 'brand' for the Trust – as we had so much feedback about the fact that communication from the Trust looked formal and old fashioned and the information we provided wasn't user-friendly or inviting. This Update provides a 'sneak preview' of the new branding which will be rolled out during September. I hope you like it!

The new branding was developed by one of our beneficiaries, Ed Graham, who works as a graphic designer and we are really grateful to her for giving her time for free to develop our fresh new look.

Media News

You may well be aware that there was a reference to Thalidomide in the very last episode of the last series of 'Call the Midwife'. This storyline is going to be developed in the new series in early 2016 and the programme makers have been talking to members of the NAC and the Campaigns Team about this.

You may also have heard in the news that a number of individuals are taking legal action against Diageo and Grunenthal alleging 'product liability and negligence for injuries arising from the consumption of Thalidomide'. The Trust has received data access requests from the lawyers representing most of the 28 people involved so we are aware that none of them are currently beneficiaries of the Trust and a number have previously applied unsuccessfully to become beneficiaries. The legal proceedings have been stayed (put on hold) until 31 December 2015.

We are now regularly including Thalidomide stories in the media in the News section of the Trust's website so do check it out.

Research

You should all have received a copy of the latest Firefly survey recently. This is a really important piece of research as the results will be used in the Trust's forthcoming negotiations with Diageo and will help us make the case for continued funding of the Health Grant. We will also use the information to help us ensure that we are providing the right sort of support to you. A **BIG** thank you if you have already completed and returned the survey (over 40% of you did in the first week which is brilliant!) and a reminder if you haven't yet done so- it's really quick and easy to fill it in, especially online.

As you may be aware there have been some teething problems at UCL in relation to the blood pressure study so there has been a delay in arranging appointments for those beneficiaries who have been referred. We are pushing hard to move this important piece of work forward and have been promised that the first appointments will take place before the end of September.

Beneficiary Events

Plans for this year's NAC Annual Conference – which is taking place on 24 October in Durham – are progressing well and it is shaping up to be an excellent event. The agenda for the daytime event includes a session on 'Managing pain before it manages you' from Dr Mark Chorlton (an Australian Thalidomider who is an expert on the subject), initial findings from the Firefly survey, an update on campaigning activities and practical sessions on managing your finances (including advice on protecting your finances both now after you die). The evening event has a James Bond theme and will include a casino as well as a disco. Please note that to secure your place we need to receive your booking form **by 25 September 2015**.

The dates for the 'Fit for the Future' event in Loughborough have been confirmed as 15/16 April 2016. A small group of beneficiaries, led by Simone Illger, have begun planning the event which is designed to encourage and support beneficiaries to adopt a healthier lifestyle in order to protect and improve their health. It is going to be a practical and enjoyable – and hopefully inspirational! – event. Further information will follow soon.

And if you are hearing impaired please hold the date for the next hearing impaired conference on 6 February 2016 at the Park Inn at Heathrow.

And finally...

We've been making quite a few changes here as we update our systems and try to ensure we are working as efficiently as possible whilst maintaining a personal touch and reaching out to all our beneficiaries. We always appreciate feedback so do let us know what you think.