

The Thalidomide Trust

DIRECTOR'S UPDATE September 2018

People News

Since my last Update, Emily has given birth to twins – Jack and Josephine – so has had her hands very full.

Lucy returned to work part-time at the start of June, following her maternity leave, but found it difficult to adapt to her new part-time role and quickly decided that she wanted a new challenge that was easier to balance with her childcare responsibilities. She left the Trust in mid-August and started training to become an ante-natal teacher at the beginning of September. And, just after she left the Trust, she shared the exciting news with us that she and her partner, Robert, are engaged. We have now begun the process of recruiting her replacement and hope to have a new member of the team in place soon.

Following Jenny's departure in late June, we are delighted that Jane Darlington joined the staff team in early July as our new Finance Director. She has quickly got to grips with her role, has fitted very well into the staff team and has had a very busy first two months.

I am also really pleased that Maggie Boyd was elected, through the ballot held in May, to take up the final place on the NAC and am looking forward to working with her in her new role.

The trustees recently made the decision to accept two new beneficiaries and I will be meeting them in the next few weeks. And I am sorry to have to report that one of our beneficiaries, Heather Clark, sadly passed away at the beginning of June. This means that the total number of beneficiaries now stands at 466.

Beneficiary Events

Our very first 'Future Money Matters' event took place in Birmingham in May and 29 beneficiaries attended. There are videos of a number of the sessions available [here](#). All the attendees who completed a feedback form told us that they found the event helpful – and most of them have taken some sort of positive action (such as making a Will, putting a Lasting Power of Attorney in place or seeking advice on future investments or retirement planning) as a result of the day. Based on this feedback, the Finance Team have already started planning the next event – which is scheduled to take place on 1 March 2019 in, or close to, London.

Our local event in Belfast on 4 July also received a lot of positive feedback from the beneficiaries who attended – who particularly enjoyed hearing about the recent changes and future plans for the Trust and having an opportunity to spend time in a relaxed and informal setting with other beneficiaries living in Ireland.

There are still places available for our local event in Bristol. This is being held on 9 October at the Aztec Hotel & Spa which has easy access from the motorways and free parking. Guest speakers include a Pain Specialist from the Bristol Pain Clinic as well as Finance professionals. If you are interested in attending, please let us know by filling in the [booking form on our website](#), emailing us at hello@thalidomidetrust.org or ringing the office, so that we can ensure we have enough biscuits!

In 2019, in addition to the 'Future Money Matters' event in London on 1 March, we will be holding local events in Brighton in June and the North West in October and organising another Beneficiary Open Day in St Neots in September. The dates are listed at the bottom of this Update – a couple are still to be confirmed but we will let you know as soon as they are.

Website

We are continuing to develop and add content to our website – including an increasing number of real stories from beneficiaries who have been willing to share their experiences. You can find these in the [Your Stories section](#) of the website. We are also receiving more recommendations from beneficiaries across the UK telling us about services and support that they have found particularly helpful. We add these to the Service Provider map on the homepage of our website, so you can search for recommendations near you.

The website is where we add all the latest health and wellbeing information -as well as the latest news from the Trust and from beneficiaries - so it's a good idea check it regularly. In the coming months we will be adding information about different medical specialists and new resources from the Finance Team. We are very excited that our first beneficiary forum and discussion boards will be going live before Christmas, so watch out for more news about using that to talk to other beneficiaries and share advice or just connect. So if you haven't visited the website for a while, do check it out – and if you have ideas or suggestions about how we can continue to improve the website, please let us know. We really appreciate your feedback.

Research Update

Our new cardio vascular risk research project is now underway. Two beneficiaries have already taken part in the study – and three more are scheduled to do so in the coming weeks. If you think you may be having an operation in the near future and are interested in finding out more, look at [our website](#) or call the office and Cheryl can talk you through what's involved.

Many of you have already completed the 'Mood Survey' which was sent out recently as the first stage of our emotional wellbeing research project with the University of York. The closing date has been extended to 8 October so, if you haven't already done so, please don't miss out on your chance to help us gain a better understanding of the emotional health of the beneficiary community and support this important study. We have had an overwhelming response from people who want to find out more about the next stage too – so don't forget to send your Permission to Contact form back so that you can find out more about what is involved.

The NAC-led research project looking at the cost of care that beneficiaries may face in the future is in the final stages of planning. A specialist company will be appointed towards the end of this year to undertake in depth interviews with a small representative group of beneficiaries and these will take place throughout 2019.

Holistic Needs Assessments (HNAs)

The feedback from beneficiaries who have had an HNA continues to be overwhelmingly positive. Of those beneficiaries who returned their feedback forms to us:

- 91% said they received helpful information during the visit
- 95% said they found it useful to be able to talk to someone about their current situation and health
- 98% said they felt they could be open and honest with the person who visited them
- 87% said that they would be more likely to contact the Trust for help in the future
- And 94% said that they would recommend an HNA to another beneficiary.

What is really encouraging is that so many beneficiaries told us that they have made changes following their HNA. These covered a range of different areas including eating less and more healthily, being more proactive into getting health problems investigated, changing their GP, employing a PA, modifying their shower room, reassessing the benefits they are entitled to, paying off their debts – and spending their Health Grant on things to help them lift their mood.

We are continuing to roll out the HNA (Holistic Needs Assessment) programme and have now conducted over 250 HNAs so are on target to have done an HNA with every beneficiary in the UK by the end of 2019.

And finally....

If you haven't yet drawn down your 2018 Health Grant, we would encourage you to do so in order to meet your health and wellbeing needs. And if you are unsure how you can spend these funds or have any other questions about the Health Grant, please get in touch with Jeff by calling the office or emailing jeff.prevost@thalidomidetrust.org and he will be able to help.

Our new TalkTogether service which offers peer emotional support to beneficiaries has now gone live and the feedback from beneficiaries who are using – and providing - the service has been really good. If you are interested in finding out more about this service, please contact Michelle by emailing michelle.robinson@thalidomidetrust.org or call the office and ask to speak to her.

With best wishes
Jefford

2019 Beneficiary Events

| | |
|--------------------------|-----------------------|
| Future Money Matters | 1 March 2019 |
| Local Event – Brighton | 12 or 13 June 2019 |
| Beneficiary Open Day | 30 September 2019 |
| Local Event – North West | 28 or 29 October 2019 |