

The Thalidomide Trust

DIRECTORS' UPDATE July 2019

People News

Very sadly, we have to report that Steve McKay passed away earlier this month. He died peacefully in his sleep at Worthing Hospital where he was being treated for pneumonia as a complication of kidney cancer, which had spread to his lungs and bones. Steve knew a lot of other beneficiaries from his time at Chailey school and because he often attended beneficiary events and was very active on Facebook. He will be sadly missed and our thoughts are with his family. As we have not accepted any new beneficiaries in the last three months, the total number of beneficiaries now stands at 463.

There have been no staff changes since our last Update, but Emily Bates will be returning from maternity leave later this month on reduced hours.

The NAC had to delay their planned Awayday in June but they are rescheduling this for later in the year. One of the key items they will be discussing is the findings of the recent Beneficiary Feedback Survey and how best to respond to these, so there will unfortunately be a short delay in you receiving feedback on this important survey.

Trust Events

Our local event in Brighton took place on 12 June and – as a result of feedback from beneficiaries living in the area – the focus of the day was very firmly on health and wellbeing issues. The feedback we received from beneficiaries who attended the event was really positive about everything apart from the parking (and the weather!). [Click here](#) to see photos of the event on the website.

Our next Beneficiary Open Day at the Trust's offices in St Neots will be on Monday 30 September – and we'd love to see you there. It's a great opportunity to meet the staff team and NAC representatives in an informal and relaxed setting.

We are also planning another local event in the North West in October. The final date and venue are still to be confirmed – but if you have any recommendations of venues that are disability-friendly and have plenty of accessible parking then please let Charlotte know by emailing hello@thalidomidetrust.org.

Holistic Needs Assessments (HNAs)

We have undertaken a large number of HNAs and Health Grant Review visits over the last two months and there are now less than 30 of you living in the UK who have not yet had one.

This means that we now have a large amount of useful information that we have been able to share with both Diageo and the four UK Health & Social Care Departments to demonstrate how your needs are changing and the vital – and growing - importance of the Annual Grants and Health Grant you receive.

Towards the end of the year we will be starting on 'round two' of our HNA visits so we may be in touch with you to arrange a second HNA.

New and Updated Trust Policies

More than a year after the introduction of GDPR, we have reviewed and updated the Trust's Data

Protection policy and made some changes, including explaining how we deal with any data breaches that occur. We will be re-issuing our Privacy Statement for beneficiaries in the next few weeks to reflect our updated Data Protection policy and clarify a small number of points.

In response to suggestions from some beneficiaries and NAC members, we will also be producing an Anti-Bullying and Harassment policy over the next few months.

Website

We've had a busy few months producing new content for our website and you may have even received our recent 'Website – what's new?' update. We will continue to send these out to you regularly to keep you in the loop with new content. If you didn't receive it, please get in touch with someone in the office and we can ensure that you are on the distribution list. Alternatively check your spam folder.

The first week of June was National Volunteers' Week which gave us a great opportunity to thank our wonderful volunteers for all their hard work and share some stories of the amazing things they do to support their fellow beneficiaries. The blogs are all still available in the "Your Stories" section - which you can now find in the "Thalidomide Community" pages of the website. You can also [click here](#) if you want to find out more about volunteers.

The forum has been up and running for a few weeks now and we have had several beneficiaries logging in to ask questions, share their stories and even upload old photographs to track down lost friends! If you haven't had a chance to take a look yet, [click here](#) to visit the "Thalidomide Community" and get involved. Don't forget to click "subscribe" on the forums you are interested in so you are notified when people reply.

This week we have an awareness week about food and nutrition including blogs from our medical adviser Dr Susan Brennan. Just head to the homepage and look for the awareness week banner. Coming up in the next few weeks we'll be sharing information on the menopause, so keep checking back to the homepage for that.

As ever, if you would like to use the website but are not sure how, contact us and we'll help you get online.

Improving the Way We Communicate With You

Over the last six months we have been exploring new ways of communicating with beneficiaries. We have introduced a couple of new options – 'Easy Read' documents for people who can find it difficult to understand written information (particularly on complicated topics) and 'Sign Live' (as the name suggests, a live online sign language service) – both of which are now being used by a small, but growing, number of you.

If you would like to try out either of these two options, just let us know. And if you have other suggestions as to how we could better communicate with you personally, please get in touch with Danielle (danielle.goodwin@thalidomidetrust.org) and let her know and we will do our best to meet your needs.

And Finally...

If you haven't yet drawn down your 2019 Health Grant, we would encourage you to do so in order to meet your health and wellbeing needs. 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 him (jeff.prevost@thalidomidetrust.org) and he will be very happy to help.



Deborah Katy Suzanne