

The Thalidomide Trust

DIRECTORS' UPDATE December 2024

People News

After 11 years as a Trustee, with the last two years as Chair, Mark Spofforth has decided that the time is right for him to step down from his role at the Trust at the end of 2024. Mark will leave a lasting legacy, not least the implementation of the new approach to Beneficiary Engagement, and he leaves the Trust in a strong position to continue under the new Chair, David Body. On behalf of all the Trustees and staff, we thank Mark for his invaluable contribution and wish him the best for the future.

We are pleased to have appointed two new Trustees - Matthew Thorogood and Jill Manthorpe will join the Trust in January as Finance & Governance and Health & Wellbeing Trustees respectively.

Our new Finance Administrator, Cathy Freshwater started with the us on 9 December. She will be working with Jeff to provide financial support to beneficiaries and supporting the Finance Team.

We have had two weddings this year, which has been very exciting, and now we have two name changes for you to be aware of. Hannah Overton who supports our beneficiaries who lack capacity is now Hannah Harper and Katy Sagoe, joint Chief Executive, also got married and plans to use her married name from January – she will be Katy Singh. Congratulations to them both!

We are sorry to have to report the very sad news that one beneficiary – Joy O'Connor – has passed away since the last Directors' Update in September. We have however accepted one new beneficiary to the Trust in the last three months, so the total number of beneficiaries remains at 426.

Finance Update

Our auditors, Saffery, recently completed our annual audit for the financial year ending on 30 September 2024. We are pleased to report that they gave us a clean bill of health. The Annual Report and Accounts will be considered by the Board of Trustees at their meeting in late January and the signed accounts should be available to download from the website in February.

The Future Money Matters event took place in November and was a very successful event with 42 beneficiaries participating across the two days. Thank you to all of you who attended. As well as some interesting sessions from speakers on a wide range of financial topics (including making a will and inheritance tax planning), there were some really good questions asked by beneficiaries. If you weren't able to attend but would be interested in seeing the recordings of the sessions, these will be up on the website soon.

One of the sessions presented during the Future Money Matters event was about the 'Special Needs' funding available from the Grünenthal Foundation. They provide funds towards one-off capital items, such as kitchen, bathroom, and vehicle adaptations. They have also recently introduced a new programme for accompanied travel which provides funding to enable individuals with severe mobility problems or sensory impairment to travel with a companion.

The amount they pay varies according to what the item is, but kitchen adaptations are funded up to €11,000 and bathrooms up to €16,000. Accompanied travel is paid at an hourly rate. There is a ceiling of €27,000 paid to each individual in a two-year period. but you can make multiple claims up to this value – and of course you can re-apply after the two years has elapsed.

In the last two years the Grünenthal Foundation has also paid for some beneficiaries to have essential medical treatment that is not available on the NHS in a reasonable timeframe. This is not publicised on their website because this funding is currently only available to thalidomide-affected people in the UK.

The application process is quite simple. If you want to make an application and would like a letter of support from the Trust, then we can provide this and if you struggle to complete forms, we can put you in touch with a beneficiary volunteer who can help you with your application.

The Trust office will be closed over Christmas from 25 December to 1 January inclusive. If you have weekly, monthly, or quarterly payments already scheduled for release during this period then we will make sure these are paid to you before Christmas. Please note, this will mean some of you will receive your payments earlier than usual – so please budget for this.

If you need any other payments to be made to you between Thursday 19 December and Sunday 1 January, you must contact us **by 5pm on Wednesday 18 December** to let us know so that we can set these up for you. Any requests received after this time will not be paid until after 2 January. Please send your payment requests to the new finance email address which is: finance@thalidomidetrust.org

Beneficiary Engagement

Trustees continue to be delighted that so many of you are engaging with our range of new Beneficiary Engagement activities.

We have appointed two new Beneficiary Representatives to work alongside Trustees on our Health & Wellbeing Committee. David Fullerton and Annie Bates attended their first meeting in November and made a really positive contribution to the discussions.

In September we held our third Trustee webinar to discuss the Beneficiary Feedback Survey, and the Beneficiary Insights Panel held their third Panel Meeting in November which focussed on the topic of 'Social Connectivity'. There were a fascinating range of discussions exploring the barriers, as well as the many positive experiences and benefits of staying connected in our communities as we age.

We are currently finalising plans for our fourth Beneficiary Feedback Survey which will be sent to beneficiaries in January. It is a really important way for us to understand how well the Trust is working for you, so please take the time to complete it and let us know what you think.

We have now fixed a date for the Beneficiary Open Day in St Neots next year. This popular event will take place on Thursday 27 March 2025 and further details and booking information will be available in the new year.

Health & Wellbeing Update

We know that care is an important issue for many of you and something that some of you are having to think about for the first time. We have recently produced some important new resources on 'How Care at Home is Funded' and these are available [on our website](#). The team are also looking at what resources could be beneficial for planning future care, which will include an event next year.

We have a number of Health and Wellbeing webinars coming up. On Tuesday 17 December at 2.30pm there is a 'Looking after your Mental Health in Winter' Webinar, on Wednesday 15 January at 2.30pm, we are holding a 'Making the most of your GP appointment' Webinar and on Thursday 30 January there will be a 'Back Care' Webinar delivered by Annelize Ferreira, a physiotherapist who has worked with a number of beneficiaries.

You can see details of all our [beneficiary events](#) on the website. And why not join the popular online Christmas Quiz, run by Darren Mansell, on Wed 18 Dec at 7.30pm

The Vehicle Adaptions Working Group continue to work well. Some of the group met with Motability in November to discuss how Motability can support beneficiaries requiring modifications to their vehicles. Our plan is to provide updated resources on the website, and we will let you know when these are available.

We would like you to start sending in photos of you and your pets to be shown on the website as part of National Pet Month April 2025. From our HNA visits we know that many of you are pet owners, and it would be great to celebrate the benefits of pet ownership. Email your photos to hello@thalidomidetrust.org and put Pets in the subject header.

Research

This is our final call to contribute to our Pain Management research project by completing a questionnaire before the end of December. Just get in touch and we can send one out to you, and in return you will receive a £30 shopping voucher.

The Trust asked the University of Nottingham to carry out this research because beneficiaries were telling us that pain is a key issue affecting their lives and they would like to understand more about how to manage and treat it. The more questionnaires received, the more accurate the advice, so please if you have one sitting at home, get it completed and sent back to us before Christmas. Thank you.

Earlier this year the Department of Health and Social Care (DHSC) decided to commission an evaluation of the Health Grant, and a joint team from RAND Europe and the University of York were chosen to undertake this work. The project is being led Dr Jenny Bousfield and Dr Liz Newbronner (who some of you will know from her previous research work for the Trust).

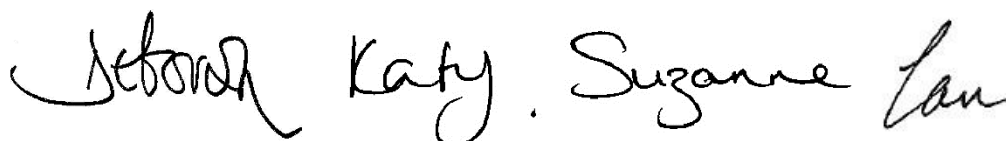
Jenny and Liz are very much aware of the importance of the Health Grant to you as beneficiaries and understand that you may have questions about how they plan to evaluate it, so they have produced a [Q&A about the evaluation](#). They are committed to ensuring that the voice of thalidomide survivors will be central to their work and one of the ways they are doing this is through an Experts by Experience Panel of six thalidomide survivors, who will help shape how the research is carried out. If you are interested in joining this panel, [click here](#) for more information. They also asked us to reassure you that evaluations like this are a routine aspect of a government department's role and shouldn't be a cause for concern about the future of the Health Grant.

And Finally...

Our Annual Workplan for 2024/25 was agreed by the Trustees at their Board meeting in September and copies are available on request by emailing hello@thalidomidetrust.org or calling **01480 474074**.

We also wanted to give you prior notice that the Trust staff will be finishing at 3.30pm on Thursday 12 December for our Christmas meal – and the Office will be closed for the Christmas break from 4pm on Tuesday 24 December through to 9am on Thursday 2 January 2025.

Merry Christmas and a happy new year from everyone at the Trust!



Deborah Katy. Suzanne Lan