

The Thalidomide Trust

DIRECTORS' UPDATE

September 2024

People News

Since our last Update in June, there have been no changes to our Board of Trustees.

However, Charlotte McCawley has now returned from her maternity leave and has quickly settled back into her role (it feels like she's never been away!). We're delighted that Bex Chamberlain, who provided such excellent cover during Charlotte's maternity leave, has agreed to help out when we need cover for staff holidays or additional support in the coming months.

We are also really pleased to announce that we have appointed a new Director of Health & Wellbeing. Ian Silver will be joining us on 1 October 2024 and brings with him a wealth of experience working at a senior level in both health and housing.

This means that we will be able to move forward with the new Joint-Chief Executive arrangement we previously told you about. So, from the beginning of October, Deborah and Katy will be sharing the role of Chief Executive – with Deborah working on Mondays, Tuesdays and Wednesdays and Katy working on Wednesdays, Thursdays and Fridays. We will have a joint email account so messages you send to either of us can be seen by us both to avoid any delays in getting back to you.

We are sorry to have to report the very sad news that three beneficiaries – David Townsley, Stephen Crilly and Leigh Gath - have passed away since the last Directors' Update in June. As we have not accepted any new beneficiaries to the Trust in the last three months, the total number of beneficiaries now stands at 426.

Finance Update

Due to increasing demand from you for guidance and support on financial matters, we are currently recruiting a new part-time member of staff to join the Finance Team. They will work alongside Jeff and will be another point of contact to assist you. In light of this, we are launching a new shared email inbox called 'finance@thalidomidetrust.org' which we advise you to use to contact the Finance Team instead of emailing Jeff, Keith or Wendy directly. Using this email address will ensure that someone is always there to respond to you as quickly as possible. If you email a staff member directly, they will still get back to you, but it just might take a little bit longer. You can start using this new email address straightaway.

We are busy planning our next virtual Future Money Matters event which is scheduled to take place on **Wednesday 27 and Thursday 28 November**. It is going to cover a range of topics including Lasting Power of Attorney, Planning for Inheritance Tax, National Savings and Investments (NS&I), the Grünenthal Foundation and Making a Will (including where to leave important information for your loved ones). You can find further information about the event and a booking form [on our website](#) and, if you asked us to keep you updated on Trust events, you will receive more information in the next few weeks.

And, on the subject of making a Will, we just wanted to let you know that October is Free Wills month. We know that a number of you are thinking of making, or updating your Will and this is the perfect opportunity. You can find out more about Free Wills Month and planning for your future [here](#).

Health & Wellbeing Update

We still need many more of you to contribute to our Pain Management research project by completing a questionnaire. We know many of you really suffer with pain every day and we want to understand more about the type of pain you experience and the ways it impacts on your everyday lives.

If you haven't yet completed a questionnaire, please can we encourage you to do so – just get in touch and we can post one out to you together with a postage paid envelope to send it back to the research team – it really is that easy, and very important.

Our Vehicles and Vehicle Adaptions Working Group has been continuing to work really well together. One of the recent tasks they completed was to define the role of a 'Beneficiary Adviser on Vehicle and Vehicle Adaptions' and we're really pleased to announce that we have now appointed seven beneficiaries to this important new volunteer role, they are: Darren Mansell, David Bickers, David Gillhespy, David Read, Kevin Donnellon, Rowland Bareham and Stuart McLeod. We know how important your cars can be to maintaining your independence – so if you have any questions or would like some advice on vehicles or vehicle adaptations, please contact Annabelle and she will put you in touch with the most appropriate Beneficiary Adviser.

We have started writing to beneficiaries in different regions of the UK on a phased basis, to tell them about the availability of Cardiac CT scans close to where they live. These are special non-invasive scans of the heart that help identify your risk of heart attack or stroke, and you can [read more on our website](#).

We can only email beneficiaries who have told us they want to receive Health & Wellbeing communications, so if you have not had an email and you want to find out more, please make sure that you have opted into receiving Health & Wellbeing information. If you're not sure about whether you have, just contact the office and they can confirm and update your communication preferences.

We are constantly surprised by how many beneficiaries are not aware of all the information and resources that are available on our website. We are regularly improving and updating the information and introducing new sections on topics that you frequently ask us about. One new section is 'Life in your 60s' which has a wealth of information on topics including how benefits change when you reach state retirement age, how NHS services change when you are over 65 and how to age well – as well as practical information on planning for your future, such as making Wills and putting Power of Attorney in place. [Do check it out](#).

Because our website is constantly evolving, we send out short 'Website – What's New?' emails every three months to let you know about the latest content. If you don't already receive this and would like to, just email hello@thalidomidetrust.org and we will add you to the circulation list.

Beneficiary Engagement

The Trustees are really pleased that so many of you are engaging with our new Beneficiary Engagement activities.

The Beneficiary Insights Panel held their second Panel Meeting, which focussed on the topic of 'End of Life', at the end of June and the discussion provided some very valuable insights into this important area – that it is clear many of you are thinking about.

We also held our second Beneficiary Focus Group in mid-July. This group was specifically for beneficiaries who have a sight impairment that significantly impacts on their day-to-day life. The discussion focussed on the additional challenges these beneficiaries face and provided Trustees and staff with a lot of food for thought. Two key themes emerged. One was how having a physical disability alongside a vision impairment was a greater impairment than 'the sum of the parts'.

The second was how other beneficiaries who experience sight problems later in life could benefit from the knowledge and experiences of the small group of beneficiaries who have lived with sight impairment for many years and developed creative solutions to the challenges they face.

You can see anonymised summary notes of both the Beneficiary Insights Panel and Beneficiary Focus Group discussions [on our website](#).

Our next Trustee Webinar is going to be held on **Thursday 19 September between 5.30pm and 6.45pm**. This time the topic is going to be our Beneficiary Feedback Survey which is an important way for the Trustees to find out the views of a large number of beneficiaries. If you would like to join the Webinar to find out more about the survey and give your views on any new areas you think we should be asking about in your next survey, you can [register here](#) or you can call Annabelle.

Beneficiary Events

Our next Local Event is due to take place on **Tuesday 8 October** at the Holiday Inn in Winchester. In response to feedback from beneficiaries who live in that area, the day will include sessions on 'Ageing Well with Thalidomide Damage', 'HNAs – what they are telling us about you as you age' and 'Beneficiary Engagement - what we are doing to increase engagement and ways you can get involved'. If you would like to attend you can [register here](#).

And we also wanted to give you early notice that the next Beneficiary Open Day is going to be held on **Thursday 27 March 2025** here in St Neots. Please put the date in your diary (if you already have a 2025 diary!).

And Finally...

The Thalidomide Society are now in a position to continue with the second instalment of their 'Thalidomide Stories' Oral History project. This phase, which will run for two years, is funded by the Society and all the interviews, conducted by trained thalidomiders, will be housed by the British Library.

If you are interested in taking part, or just want to find out more about the project, you can contact Julie Dixon at info@thalidomidesociety.org.

Once all the interviews with thalidomiders have been completed, they are planning to interview your siblings and your children, so do ask them if they would be interested in taking part and sharing their stories too.

Deborah Katy Suzanne