

The Thalidomide Trust

DIRECTORS' UPDATE December 2023

People News

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

We are, however, delighted to have recruited a new member of staff to join the Health & Wellbeing Team to make sure we continue to be able to respond quickly and effectively to the increasing number of requests for information, advice and support from beneficiaries. Louise Millsip joined the team at the end of November and will be working very closely with Danielle to provide support to our three Medical Advisers and to co-ordinate and manage the growing demand for our Private Referrals and Private Treatment Schemes.

I am sorry to have to report the sad news that in the last three months, we have lost two beneficiaries, Craig Brownlie and Steven Fletcher. Both of them passed away at home – Craig in his sleep and Steven, surrounded by his family. As we have not accepted any new beneficiaries to the Trust in the last three months, the total number of beneficiaries now stands at 433.

But I'm pleased to be able to share happier news of the safe arrival of Charlotte (and Adam)'s baby, Oliver John on 29 October - weighing in at 6lb 7oz. They are all doing well and recently popped into the office so that we could say hello to Ollie.



Health & Wellbeing Update

Following a competitive bidding process, we have recently appointed the Nottingham University Pain Centre to undertake an important piece of research into Understanding and Managing Pain for Thalidomide Survivors. This is a major, 12-month research project and we hope that it will commence before the end of 2023.

Since the last Directors' Update, we have held two health and wellbeing webinars – one on health screening and the other on Diabetes. If you were unable to attend and are interested in finding out more, you can see copies of the presentations in the [health and wellbeing resources section of our website](#).

Due to increasing concerns about adapted vehicles, we have brought forward our planned work in this area. We are in the process of setting up a 'Vehicles and Adaptions Working Group' and have written to all beneficiaries who we understand drive adapted vehicles to see if they are interested in contributing to this. The role of the Group will be to identify the main problems and issues, agree the priority areas to focus on, and consider what expertise we need, inside and outside the Trust, so that we can develop the right information and support for beneficiaries. The Working Group will also explore a new role of volunteer 'Beneficiary Experts' on cars and adaptations, and consider what external organisations (e.g. adaptation companies and Motability) it may be valuable to develop partnerships with. If you drive an adapted vehicle and weren't contacted about this but would like to be involved, please email hello@thalidomidetrust.org

A number of beneficiaries contributed to a research project on 'Age-Related Changes in Upper Limb Thalidomide Damage' led by Wee Lam from the University of Edinburgh. The findings were recently published in the Journal of Hand Surgery, and we have a lay summary available on our [professional resources research section of the website](#).

Winter can be a challenging time for us all in terms of both our physical and mental health, so we have created new resources to help you prepare for winter and the Christmas period, please have a look. It contains a lot of practical information and also signposts to lots of other useful resources. You can [access it on our website](#). As always, our Medical Advisers encourage you all to have your flu vaccination and the Covid top up too if you are offered it.

If you are struggling with your mental health or emotional wellbeing at this time, or at anytime, please remember you can now access six free sessions of talking therapy with a member of our new Specialist Mental Health Network. Just speak to one of our Health & Wellbeing Team and they can arrange this for you.

We are continually updating and enhancing the health and wellbeing content on our website so please do remember to regularly check it, to see what else is new. We know from your feedback, that you find other beneficiaries' experiences particularly helpful and interesting, so we are keen to continue to build the number of beneficiary stories on our website. If you have a personal story that you are willing to share – particularly about 'travelling', 'around the home' or 'SMART technology' – we'd love to hear from you.

Beneficiary Engagement

Our first Trustee Webinar went ahead on Monday 25 September and was attended by five Trustees and 28 beneficiaries. Although the theme of the webinar was Beneficiary Engagement, the discussion covered a wide range of different topics - and provided Trustees with a lot of food for thought.

We asked beneficiaries who attended the Webinar to answer three quick questions afterwards and we were really pleased that 25 attendees completed the questions and all of them said that they were likely to attend a future Trustee Webinar.

We have now completed the selection and election processes for our new Beneficiary Insights Panel. There are 24 members of the Panel and they have all been appointed for two years. We won't list them all here, but you will recently have received an email or letter telling you who they are and the information will also be on our website. All Panel Members will attend a virtual induction session early in the new year and we are hoping that the first meeting of the Panel will be held in February.

We are also planning to hold our first Beneficiary Focus Groups in January on the current 'hot topic' of adapted vehicles and the specific challenges faced by beneficiaries as a result of the move to electric vehicles. If you have any suggestions for future Focus Group topics - that would enable Trustees to understand issues that are important to beneficiaries in more depth - then please let us know by emailing engagement@thalidomidetrust.org

Following the Trustees' decision to decommission the NAC, five of its members decided to set up a separate body so that they could continue to support the beneficiaries who had elected them.

In order to contact Thalidomide Voice and become a supporter, visit www.thalidomidevoice.org or email info@thalidomidevoice.org.

The Directors of Thalidomide Voice stress that they fully endorse the Trustees' plans for beneficiary engagement.

Other Actions from our Independent Governance Review

Although the key changes introduced as a result of the Independent Governance Review related to strengthening and broadening the way that Trustees engage with beneficiaries, there were a small number of additional recommendations for strengthening our governance processes.

It was recommended that we create a written 'Code of Conduct' which sets out what is expected of staff, Trustees and beneficiaries who formally engage with the Trust. This has now been produced and shared with all Trustees, staff and representatives on Trust Committees. It will apply to all beneficiaries who are members of the Beneficiary Insights Panel and they will receive a copy as part of their Induction Pack. You can find the [Code of Conduct on the Trust website](#), or you can request a copy by calling us on 01480 474074 or emailing hello@thalidomidetrust.org

Compass, who carried out the Independent Governance Review, also recommended that the Trustees should introduce a new annual agenda item on 'Staff Engagement, Development and Satisfaction' particularly as, because our office is in St Neots but most Board and Committee Meetings are in London, the Trustees have limited face-to-face contact with most of the staff team. We had the first of these discussions in September and it focussed on the staff responses to the recent 'Best Employer' survey which covered a range of topics including staff engagement and training & development and provided a good indication of staff satisfaction. This will now become a routine annual agenda item.

Finance Update

Our auditors, Saffrey, recently completed our annual audit for the financial year ending on 30 September 2023. 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.

In response to concerns from beneficiaries about the increase in phishing and online scams, we have recently produced a new finance factsheet all about reducing the risk of financial abuse. This practical [resource is available on our website](#) or you can request a copy by calling us on 01480 474074 or emailing hello@thalidomidetrust.org.

This year's virtual 'Future Money Matters' event took place on 29 November and 47 beneficiaries participated on the day. One of the most popular sessions was on National Savings & Investments (NS&I) who offer a range of different secure options for investing any funds you have that are not required to meet your immediate needs. This is just a reminder that funds that we hold for you at the Trust do not earn any interest so please do consider withdrawing them and investing them to meet your future needs.

If you have any regular payments scheduled for release during the Christmas period when the office is closed, we will make sure these are paid to you before Christmas. However, if you need any additional payments to be made to you between Tuesday 19 December and Monday 1 January, you must contact us **by 5pm on Monday 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.

Beneficiary Events

Our Local Event in North Queensferry (near Edinburgh) in October went very well. It was attended by 16 beneficiaries and 13 family members/carers and the feedback provided by attendees was very positive. One of our Trustees, Andrew Owens, attended the day and found meeting beneficiaries in this informal setting both useful and enjoyable.

We will be confirming details of our planned Local Events in 2024 and 2025 in January so you all have plenty of notice – and can put the dates in your diaries.

But I can confirm now that the Beneficiary Open Day in St Neots next year will take place on Thursday 21 March 2024. Further details and booking information will be available in the new year.

And Finally...

Our Annual Workplan for 2023/24 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 14 December for our Christmas meal – and the Office will be closed for the Christmas break from 4pm on Friday 22 December through to 9am on Tuesday 2 January 2024.

Best wishes for a Merry Christmas and a Happy New Year from everyone at the Trust!

Deborah Katy Suzanne