

The Thalidomide Trust

DIRECTORS' UPDATE

June 2023

People News

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

We have however recruited a new Medical Adviser to replace Dee Morrison who left the Trust at the end of May. Tim Fenn starts work at the Trust on 13 June. He has been a GP for 18 years and has a special interest in both disability and mental health – and we are really looking forward to him joining the staff team.

I am sorry to have to report the sad news that in the last three months, one beneficiary, Martin Anderson, has suddenly and unexpectedly passed away. As we have not accepted any new beneficiaries to the Trust, the total number of beneficiaries now stands at 436.

Health & Wellbeing Update

Our 'Round Three' of HNAs are going well – and staff have been travelling the length and breadth of the UK to visit you. In addition to scheduling HNAs with beneficiaries who had their last HNA in 2020, we are also contacting beneficiaries who had their last HNA by Zoom in 2021.

We have now received completed health and wellbeing questionnaires from almost two thirds of our beneficiaries who live outside the UK. If you are an overseas beneficiary and haven't returned yours yet, please do – we really want to have a complete picture of the needs of all our beneficiaries.

The new Private Treatment Scheme for UK beneficiaries has now officially launched and, because of the current pressures on the NHS, we have seen a lot of interest from beneficiaries. Two beneficiaries have already had funding from the Trust for essential private surgery and there are a number of other referrals in the pipeline.

We have seen a big increase in the number of successful applications to the Grünenthal Foundation – and have trained beneficiary volunteers to be able to support you with your applications.

Some of you have reported difficulties with getting your Blue Badges renewed and we know that more of you are thinking about applying for one for the first time. In response to this, 10 beneficiary volunteers have now completed training to be able to support you with your applications.

Last month we held a very interesting webinar on staying balanced, helping pain, improving strength and reducing falls. This was delivered by Fraser Simpson, a physiotherapist who has worked with several beneficiaries. If you missed it, [click here](#) to watch it back.

Katy completed her marathon charity walk around the North Norfolk Coast in May and would like to thank everyone who so generously sponsored her. She was surprised and delighted to meet one of our beneficiaries, Robin Hindle-Fisher, en route. Unfortunately, Charlotte was unable to complete the London Marathon in April due to health concerns but £1,486 was still raised for Disability Rights UK (DRUK), a charity that supports people with disabilities. She'd like to thank everyone who donated. She has deferred her place to 2025 as she is now expecting her first baby later this year.



In the last two years, a number of beneficiaries have purchased new prosthetic limbs from Dorset Orthopaedics and have been happy with the results. We are planning a webinar to demonstrate how Dorset Orthopaedics work with people to improve your prosthetic experience and the best new technology. If you are a prosthetic user, look out for an email with more information in due course.

Finance Update

As you are all aware, there have been significant delays in finalising our new Health Grant funding agreement with the Department of Health & Social Care (DHSC) which means that we were later than usual writing to you this year and the level of Health Grants paid did not include an increase for inflation. However, despite these challenges, the grant payments went ahead as usual on 1 June and more than 70% of you requested, and received, funding.

We are still awaiting a decision from the DHSC in England over the inflation measure to be used. All three devolved administrations have now confirmed they will align to whatever they agree. Once we know the inflation measure, we will write to you to let you know what has been agreed. Those of you who have already requested your Health Grant in full, we will pay you the balance without you needing to contact us again – you will only need to contact us if you **do not** want us to pay this to you yet.

If you have requested a partial payment of your Health Grant, we will keep the extra funds here at the trust until you ask for them.

For those of you who receive your Health Grant in weekly or monthly instalments, we will keep the additional funds here at the Trust until you request them. This is different to what we said in our letter on 9 May – we had originally planned to automatically update your regular payments accordingly. However, we received feedback from a number of you who said that you didn't want us to do this – some people wanted to take the extra payment in one go and others wanted us to keep the funds at the Trust until later in the year. So, on reflection we feel that it is better to allow you the choice over how you would like to receive these extra funds. You can contact us in the usual way, either by email at hello@thalidomidetrust.org or by phone on **01480 474074** when you have made the decision. Alternatively, you don't need to do anything now and we will hold them here for you for future unexpected needs.

It is possible that we will receive some news from the DHSC in between recording this update and you receiving it – if that happens, we apologise in advance. We will let you know what is happening as soon we can.

Our investments continue to perform well, and we are currently beginning the process of 'de-risking' our investment portfolio – in other words, moving to safer investments with lower returns – as agreed in our Covenant with Diageo.

Beneficiary Engagement

Thank you to all of you who completed the recent Beneficiary Engagement Consultation – the Trustees were really pleased that more than two thirds of you took the time to do so.

They will be looking at the results at their forthcoming Trustee Awayday and these will inform their decision about the new ways they will engage more directly with the community. We will be in touch to let you know when we have a clear way forward.

Beneficiary Events

Our Beneficiary Open Day was a great success – and it was lovely having so many visitors to our new offices. 25 beneficiaries attended and many of them brought family, friends or carers with them, so it was a busy, buzzy day. Feedback from attendees was generally very positive – and some beneficiaries made helpful suggestions about how we could improve the format of the day which we will be taking on board for next year's event.

Our next Local Event is going to take place on Tuesday 4 July in Wrexham and will include sessions on pain management and planning for the future, as well as providing an update on recent changes and future plans at the Trust. Details of the event have been sent to all beneficiaries who live within one hour of the venue, but if you live further afield and are interested in attending, you can find out more by emailing hello@thalidomidetrust.org, by calling **01480 474074** or you can [click here](#) to book your place on our website. You need to book your place by midday on Friday 23 June.

And Finally...

Copies of our summary Five Year Strategic Plan are now available. If you would like to see it, you can find it in the [resources section](#) on our website. Alternatively, you can email us at hello@thalidomidetrust.org or call us on **01480 474074** and we will send you a copy.

A handwritten signature in black ink that reads "Deborah Katy Suzanne". The signature is written in a cursive, flowing style.