

The Thalidomide Trust

DIRECTORS' UPDATE March 2024

People News

Since our last Update in December, there have been no changes to the Board of Trustees or to the staff team.

We are sorry to have to report the sad news that one of our beneficiaries, Jackie Goodsell, passed away recently in hospital, following a short illness, with her mum, her sister and her niece by her side.

As we have not accepted any new beneficiaries to the Trust in the last three months, the total number of beneficiaries now stands at 432.

Finance Update

You will all now have received your Annual Grant letters and many of you have already advised us of how you would like your payments to be made. If you haven't yet done so, please log into the website to [complete the online form](#) or return your Annual Grant Request Form by post or email as soon as possible, so that we can ensure we have everything in place well ahead of the 6 April payment date. If you don't want to receive your Annual Grant yet, then you don't need to do anything. We will only release payment upon request, so if you would rather leave your Annual Grant funds at the Trust for now, please don't feel that you need to contact us to tell us that.

And just another reminder that there is no interest earned on funds held at the Trust so, if you do not have an immediate need for your Annual Grant funding, we recommend that you think about moving it into a savings account where you will earn interest. If you would like to talk about how you can move your money into a savings account - and ensure that your money remains safe - please get in touch with Jeff.

Savings and investments held with NS&I (National Savings and Investments) are 100% secure, no matter how much you save or invest with them, because they are backed by the government. If you are interested in finding out more, you can watch the presentation on NS&I Savings from last year's Future Money Matters event [here](#).

This year, because there is a change to the way the annual inflationary increase on your Health Grant is calculated, we will not be able to notify you of the amount you will receive until mid-May, but we will be in touch as soon as the information is available to advise you how much you will be allocated and the next steps.

Health & Wellbeing Update

The new Pain Management Research project has now commenced and, as a first stage, the team from the Nottingham University Pain Centre are currently analysing all the data we have gathered on pain from HNAs. The researchers are committed to involving beneficiaries at every stage of the project and have set up a Beneficiary Advisory Group (BAG), to advise and guide the research process. Thanks to all of you who expressed an interest in getting involved.

The next stage is to send out questionnaires and arrange interviews with those of you who would like to share your experience of living with pain and the impact it has on your life. More information about this will be sent out in the next few weeks.

Our new 'Vehicles and Adaptions Working Group' has now been established and includes 10 beneficiaries with different experiences of adapted vehicles. The group met for the first time in February and they identified the key issues and priorities and agreed a clear way forward to help us develop the right information and support for beneficiaries in this important area.

We are continuing with our programme of Health & Wellbeing Webinars. The next one will be held in May and will focus on helping you to find the best ways to assess and monitor your level of cardiovascular risk. This is because heart and circulation problems increase once people reach their 60s and we know many of you have difficulties having your blood pressure taken in the traditional way. We will share further details once these are confirmed but, in the meantime, if you are interested in attending, please let Annabelle know on annabelle.blackham@thalidomidetrust.org

We have produced a new resource pack for anyone starting to work with you as a carer or PA. It is called the Frontline Social Care Worker Pack and is available on the website to download [here](#).

We are also putting together some information under the heading 'Now We Are 60'. This will include a guide to benefits and how they change after you reach state pension age (as you may need to plan for that now), alongside information on how NHS health services change after the age of 60 and what you are entitled to. This will be launched soon and will be on the website.

Beneficiary Events

Our annual Beneficiary Open Day is taking place on Thursday 21 March here in St Neots and we are delighted that over 30 beneficiaries have booked to attend. Because the focus on the event is on informal interactions between beneficiaries, Trustees and staff, it is an in-person only event so, unfortunately, it is not possible for you to attend virtually.

We recently wrote to you with details of our two Local Events in 2024 – one in the West Midlands in June and the other in the South-East of England in October.

Whilst we can confirm that the June event is going to be held at the NEC Crowne Plaza on Thursday 27 June, the hotel in Kent we were planning to hold our event at has just cancelled our booking – so it's, unfortunately, back to the drawing board. We'll update you as soon as we have a new venue and a date confirmed.

If you would like to book a place at the Birmingham event you can use our online booking form [here](#) or you can email us on hello@thalidomidetrust.org

Beneficiary Engagement Update

Things are moving forward with our plans for wider Beneficiary Engagement.

Since our last Update in December, we have held our first **Beneficiary Focus Group** on the impact of the transition to Electric Vehicles which provided us with a greater understanding of the challenges and concerns for beneficiaries.

Our next Focus Group will be specifically for beneficiaries who have a sight impairment as Trustees are interested in understanding the additional challenges that they face on a day-to-day basis and the ways in which the Trust can offer support with these.

All members of our new **Beneficiary Insights Panel** had an induction session in January and we held our very first Panel Meeting earlier this month on the important topic of 'Care'. 20 of the 24 Panel members attended the meeting – and they spent some time together as a large group and some time in smaller groups which allowed discussion of individual experiences of care, their feelings about Care and their concerns for the future. Four Trustees attended the meeting – two as Co-Chairs and two as 'observers' – and they found it incredibly valuable to hear about the breadth of experiences within the group and the common themes that emerged. Summary notes from the meeting will be shared with all Trustees and will feed into the discussion at the Trustees' Awayday in June.

We have also now recruited two new beneficiaries to act as **Beneficiary Representatives on Finance Committee**, alongside Craig Millward. Following their recent induction with Suzanne, Chris Murray and Colin McCreesh will be attending the Finance Committee meeting on 12 March. They bring a lot of financial knowledge and experience to the role, and we are delighted to have an overseas Representative (Colin lives in Canada!)

Following the success of our last **Trustee Webinar**, we are planning to hold another one on Monday 29 April between 5.30 and 6.45pm on the topic of 'How the Trust Finances Work' as financial oversight is such an important element of the Trustees' role – and it is the topic we receive most questions from beneficiaries about. You need to register to attend and you can do this by using our online booking form [here](#).

And Finally....

As part of our Strategic Plan, we agreed to undertake a new project over the next three years to capture the 'Legacy' of Thalidomide in terms of the lessons learned that could benefit others in the future.

One of the early areas we are looking at is the important role that parents played in campaigning for justice and support for you. If your parents are still alive and were involved in campaigning in any way, Ruth Blue (who is leading on this work for the Trust) would love to hear from them. Either Ruth can interview them, or she can send them some questions to answer – whichever is easiest for them. If you think your parents would be interested in helping us with this project, please let us know by emailing hello@thalidomidetrust.org or calling us on 01480 474074.

Seborah Katy Suzanne