

The Thalidomide Trust

DIRECTORS' UPDATE June 2024

People News

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

Charlotte McCawley will be returning to work in mid-July, following her period of maternity leave and we are looking forward to having her back. However, it does mean that we have to say goodbye to Bex Chamberlain, who has done a fantastic job providing cover, in August. She's been a great member of the team and we will really miss her!

We are also really pleased to share the happy news that Keith in Finance is the proud new father of baby Juno, who arrived in the world on 9 May.

Following the Trustees' decision to introduce a new Joint-Chief Executive position (to be filled by Deborah and Katy), we have commenced the process of recruiting a new Director of Health & Wellbeing. It is hoped that we will move to the new management arrangements on 1 October 2024, but this will be dependent on us recruiting someone who is able to start then.

We are sorry to have to report the very sad news that three beneficiaries - Phil Cashman, Stephen Dawson and Steve Manning - have passed away since the last Directors' Update in March.

As we have not accepted any new beneficiaries to the Trust in the last three months, the total number of beneficiaries now stands at 429.

Finance Update

Since the last Directors' Update, we have processed both your Annual Grant and Health Grant payments. To date 85% of you have drawn down some or all of your Annual Grant funding – we have paid out a total of £15.9 million so far. And for the Health Grant, 86% of you have drawn down funds totalling £10.1 million.

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 making your money work harder for you - and ensure that your money remains safe at the same time - please get in touch with Jeff.

Health & Wellbeing Update

Our Pain Management Research project is moving forward, supported by the Beneficiary Advisory Group (BAG). You will all have received an invitation to take part with the option to complete a questionnaire or take part in an interview (or both!) If you haven't yet completed the questionnaire, please can we encourage you to do so – the researchers at Nottingham University want to hear about as many of your experiences as possible in order to gain a full picture of the type of pain you experience and the ways it impacts on your day-to-day lives.

They also want to hear from a selection of carers (including family carers) and health professionals who work with you – people like physiotherapists, GPs personal trainers etc – so please feel free to send their details in too. We know that 94% of you suffer with pain and two thirds of you are in pain every day, so this is an important opportunity to help us find solutions. If you have lost your invitation, you can find the details [on our website](#).

We are continuing with our programme of interesting and informative Health & Wellbeing Webinars on topics you tell us are important to you. Since our last Update, we have held two Webinars. In May, the [‘Know Your Numbers’ Webinar](#) focussed on helping you to find the best ways to assess and monitor your level of cardiovascular risk. And earlier this month, Dr Anthony Papatomas, from Loughborough University, ran a webinar on why it is important to keep active as you age. All our webinars are recorded so, if you missed them, you can watch the session via our website.

We also recently held one of our regular Men’s Health Webinar – hosted by Tim, our Medical Adviser - which, as always, included lot of lively discussion! The beneficiaries who took part in the group were keen for us to remind you all of the wide range of resources and support that are available to health professionals to enable them to support you better. These include our [Resource Pack for GP Practices](#), the advice on [taking blood pressure in the leg](#) and the option to borrow a vein viewer and/or Air Glove from the Trust to make [taking blood](#) a bit easier.

In fact, this is a good opportunity to remind you that we have lots of really important and useful information on the website. It covers all the important areas of health and wellbeing, living independently and planning for the future, as well as lots of interesting videos and webinars. To see the whole range of information available it is best to be logged in, so just give us a call if you have forgotten your log in details.

We are encouraging you all to think about how healthy your heart is and understand your risk of having a heart attack or stroke with lots of new information [available on the website](#).

Beneficiary Events

Our annual [Beneficiary Open Day](#) took place on 21 March here in St Neots. The staff and trustees who attended really enjoyed having the opportunity to meet beneficiaries in an informal setting - and the feedback from the beneficiaries who attended was really positive.

Our next Local Event is due to take place on Thursday 27 June at the NEC Crowne Plaza and, in response to feedback from beneficiaries who live in that area, will include sessions on ‘HNAs – What they are telling us about you as you age’, Understanding your risk of heart attack or stroke and how to reduce that risk’ and ‘Recent Changes at the Trust and Our Future Plans’. In addition, there will be plenty of time for chatting informally with staff, Trustees and other beneficiaries.

We are pleased to also be able to confirm details of another Local Event later this year. This is going to be held at the Holiday Inn in Winchester on Tuesday 8 October. We will circulate further information shortly but, if you are interested in attending, please put the date in your diary or complete the [online booking form](#).

Beneficiary Engagement

We are really pleased that so many of you are getting involved with our range of Beneficiary Engagement activities.

Since our last Update, we have held our second **Trustee Webinar** on the topic of 'How the Trust's Finances Work'. This was attended by 28 beneficiaries.

We have also established our first **Task & Finish Group** to develop proposals on how we can best support overseas beneficiaries and gather information on their needs in a structured way, in the absence of HNAs. Five overseas beneficiaries are members of this group and they have already held their first meeting and provided some very valuable insights.

We now have dates scheduled for our second **Beneficiary Insights Panel** - which will explore the topic of 'End of Life' – and also our second **Beneficiary Focus Group** which is specifically for vision-impaired beneficiaries and will focus on the additional challenges they face because of their sight impairment and the ways that the Trust may be able to provide support with these.

We are in the process of recruiting two **Beneficiary Representatives for our Health & Wellbeing Committee**.

And Finally....

We are looking for volunteers to take on the role of Beneficiary Experts in relation to Vehicles and Vehicle Adaptations. This new role is one of the outputs of our new Working Group on Vehicles and Vehicle Adaptations. The closing date for applications is 15 July 2024 and if you would like to find out more, you can get in touch with Michelle at michelle.robinson@thalidomidetrust.org or by ringing **01480 474074**.

Handwritten signatures of Deborah, Katy, and Suzanne.