

The Thalidomide Trust

DIRECTORS' UPDATE June 2020

People News

There have been no changes within the staff team or our Board of Trustees since our last Update in March.

We are all keeping safe and well and have adjusted to our new remote ways of working.

Sadly, we have to report that one of our beneficiaries passed away in early April and, as we have not accepted any new beneficiaries to the Trust, the total number of beneficiaries now stands at 459.

Finance Update

We are really pleased to report that the Health Grant payment process went smoothly – despite the extra challenges this year – and we would like to thank you for returning your paperwork so promptly (and in most cases electronically) as that really helped.

We also wanted to share the news that, following a competitive tendering process, we have appointed a new company to undertake the Trust's annual Audit to replace PwC who have been our auditor for many years. Our new Auditors are called Saffery Champness and they are based in Peterborough.

We also wanted to make you aware of a new lender who has provided mortgage funding to a number of beneficiaries who have been turned down by other lenders. Reliance Bank is a not-for-profit lender that donates 75% of any profits to Salvation Army International. Their focus is on helping people get on the housing ladder for the first time but they are also willing to lend to our beneficiaries if it enables them to move or make improvements to their main home. If you would like to find out more, please speak to Jeff Prevost in our Finance Team.

Health Grant Renewal

Because the government is rightly focussed on its response to the coronavirus, the Campaigns Team have made the decision to put public campaigning around the renewal of the Health Grant on hold. However, there is a lot of work going on behind the scenes. A Health Grant Renewal Working Group – made up of trustees, staff and members of the NAC and Campaigns Team - has been set up to agree a clear plan to maximise the chance of us getting in renewed in 2023 on the best possible terms. And the Trust is pulling together as much evidence as possible on the current and future needs of beneficiaries – drawing on both data from recent HNAs and the research undertaken to quantify future care costs.

This means that we will be in a strong position when we begin discussions with politicians and civil servants.

Health and Wellbeing

Our focus over the last few months has been on supporting you all during these strange and unusual times and we are pleased that so many of you have found our Wellbeing Calls and regular Coronavirus Updates so helpful.

Our HNAs and other Beneficiary Visits are still on hold because of the restrictions on travel and need to socially isolate but we will be resuming these as soon as it is safe to do so.

We have been regularly updating the content on our website so do check it out as there is a lot of new information that you might find useful. Use of our online Community Forum has also increased a lot over the last few months as you have been sharing tips and advice with each other so please do visit that area of the website.

We have started work on two new resources. The first is a 'Resource Pack for GP Surgeries' which has been developed in response to feedback that your GPs and other practice staff do not have a good understanding of thalidomide and the way your thalidomide damage affects you. The second is an emergency card that you can carry either as a credit-sized card or as an app on your phone (or both!) so that, in the case of an emergency, the healthcare staff treating you have access to information about you, your thalidomide damage and your health issues.

To make them as useful as possible, both these resources will be tailored to reflect your specific thalidomide damage and health issues.

Trust Events

We have made the decision to cancel all the scheduled Trust events for the remainder of 2020 because of Coronavirus. Even though we hope that restrictions on travel and meeting up will be eased later in the year, it may be some time before large groups are able to meet and we know, from talking to you, that many of you feel nervous about both travelling and meeting people in large numbers.

We have, however, introduced 'virtual coffee mornings', hosted by beneficiary volunteers, which have enabled you to meet up – even if only via a computer screen. These have proved very popular and we now have some arranged in the afternoons and evenings too! Feedback from people who have taken part has been incredibly positive so, if you'd like to join one, please get in touch with Annabelle Blackham and she can provide further information.

And Finally...

We have recently had a few questions about beneficiary funeral expenses. So, just to clarify, the Trust does not automatically cover the cost of a beneficiary's funeral. When a beneficiary sadly passes away, we offer emotional and practical support to their families at that difficult time and, where there are financial pressures, we will offer to provide assistance with funeral expenses, very much on a case by case basis.

Handwritten signatures of Deborah, Katy, and Suzanne.