

The Thalidomide Trust

DIRECTORS' UPDATE June 2022

People News

Since our last Update in December, Professor Tim Briggs has stepped down as a trustee after six years with the Trust. Unfortunately, he did not feel able to make the necessary commitment alongside his important responsibilities in the NHS, but we are delighted that he has agreed to continue to offer us ad hoc advice when we need it.

In addition, two of our long-serving members of the Board – Robert Nelson and Kevin Wesbroom – will soon be reaching the end of their final term as trustees, so we have begun the recruitment process for their successors. Details of these trustee vacancies are on our website so please do share the details with anyone who has the skills and experience that we are looking for.

Hannah Overton recently joined the staff team to offer support to the small group of beneficiaries who lack capacity. She has settled very quickly into her new role and has already visited a number of the beneficiaries who she will be supporting.

Since our last Update, both Phil Williams and Sue Gooding have resigned as members of the NAC. We would like to record our thanks to them for their contributions during their time in the role.

Unfortunately, we have to share the sad news that two of our beneficiaries – Gillian Thomas and Neil Kaveney – have passed away since our last Update in March. As we have not accepted any new beneficiaries to the Trust, the total number of beneficiaries is now 441.

Finance Update

Since our last Update, we have paid both the Annual Grants and Health Grants to all beneficiaries who requested them. The payment processes went very smoothly and I'd like to thank those of you who provided all your paperwork well ahead of the payment date – it made a big difference.

We are delighted that both the Scottish and Welsh governments have now made a formal commitment to pay annual Health Grants to beneficiaries for the whole of their lives.

The situation in Northern Ireland is more complicated because of the recent election but we are in close contact with the civil servants there and they have reassured us that a similar commitment is likely to be made in the next few months.

We have now commenced the Diageo Chairs' Reviews and so far our discussions have been very positive and constructive. At our first meeting, we shared a summary of the results of the NAC's consultation exercise with Diageo and they were very encouraged by the level of engagement. There will be a series of meetings between now and November with the NAC, trustees and staff working together to make the strongest possible case for increased support, drawing on all the evidence that we have gathered through HNAs and our various research projects.

As you are aware, this year's virtual 'Future Money Matters' event is going to take place on Tuesday 5 and Wednesday 6 July. There are a range of interesting sessions planned – including inheritance tax planning, inflation and Trust grants, safeguarding gifted assets and reducing the risk of financial abuse. There's still time to [register for the event](#) and you can attend as many, or as few, sessions as you would like to.

Health & Wellbeing Update

Our programme of HNAs is continuing apace. We are enjoying getting out and about visiting beneficiaries and we have already completed more than 90 HNAs since the start of the year.

We are conscious that, because of our HNA programme, we know far more about beneficiaries living in the UK than we do about our overseas beneficiaries. To help address this imbalance, we will shortly be sending out a questionnaire to all our beneficiaries living outside the UK to help us understand more about their current situation, their health issues and the challenges that they are facing so that we can ensure we are providing the right sort of support.

You may not be aware, but once you reach the age of 65, your benefit entitlements change and some of the financial support currently provided through PIP (Personal Independence Payments) will no longer be available to new applicants. So if you do not currently receive PIP, please get in touch with the Health & Wellbeing team to discuss the changes and whether it would be advisable for you to apply for benefits before you are 65. We will be providing more information about these changes in the coming months, so watch out for that on the website.

We continue to regularly update the health & wellbeing content on our website – so do look out for our ‘Website-What’s New?’ emails that let you know what has changed. We are also planning a webinar on how to make best use of the Trust website and what you can find on it, which is on 4 July so do join us to find out more about the resources that are available to help you.

Since our last Update, we have had two health & wellbeing webinars – one on ‘Looking after your Mental Health in Uncertain Times’ and the other on ‘Men’s Health Issues’. Both of these can be viewed by visiting the health & wellbeing section of our website.

Our next health webinar – ‘Let’s get to the bottom of it!’ - is taking place on 23 June to coincide with World Continence Week. It promises to be a relaxed and informal event so if you have any questions about bowel issues or just want to find out what’s normal and what’s not, why not sign up?

And then from 15 August we will have an Online Awareness week all about protecting yourself from online scams and staying safe online.

All our upcoming health & wellbeing webinars and MeetUp events are listed in our [online events calendar](#) - as you can see there is a wealth of information on the website, so make sure you join us on 4 July and find out how to make the most of it.

Beneficiary Feedback Survey

A big thank you to all of you who completed the recent Beneficiary Feedback Survey. We had an encouraging 65% response rate and the NAC, trustees and staff are all currently reviewing the survey results and the feedback provided by individuals. We will share the findings with you shortly and let you know what action we will be taking in response to them.

And Finally....

Our current five-year strategic plan ends this year, so we have already begun work on our new strategic plan which covers the period from 1 October 2022 until 30 September 2027. The trustees, staff and NAC have been working closely together on the new plan and once finalised, copies will be available to those of you who are interested.

Deborah Katy Suzanne