

The Thalidomide Trust

DIRECTORS' UPDATE March 2022

People News

There have been no changes to the Board of Trustees since our last Update in December. However, we are delighted to have welcomed Sarah Holyoak to the staff team in February. Sarah has joined our Admin Team and replaces Danielle who recently took up a new role in the Health & Wellbeing Team. She has settled in quickly and I know she has already spoken to a lot of you on the phone.

I am sad to have to report that, after five years at the Trust, Sarah Green – who looks after our beneficiaries who lack capacity – has made the decision to move onto pastures new. Sarah is a qualified lawyer and is returning to private practice, so we hope to continue to benefit from her knowledge and expertise in the role of deputy. We have advertised for her replacement and will be interviewing in early April.

Unfortunately, a number of staff have tested positive for Covid-19 in the last few weeks - and some have been quite unwell – so apologies if you haven't been able to speak to a specific member of the team or we have been a little less responsive than usual.

As you will be aware, there are no NAC elections this year as we only had three candidates for the four vacancies. However, I am really pleased to be working with Rowland and Nick for a further four-year term and I am delighted to welcome David Alexander onto the NAC as a new member. You can [click here](#) to read more about what Rowland, Nick and David have pledged to do over the coming year on your behalf, on the website.

Unfortunately, we have to share the sad news that we have lost four beneficiaries since our last Update in December. Marie Hampshire, Andrew Mills, Gwen Williams and Leslie Millar have all sadly passed away.

As we have not accepted any new beneficiaries to the Trust, the total number of beneficiaries is now 443.

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, please complete the [online form](#) or return your Annual Grant Request Form by post as soon as possible so that we can ensure we have everything in place well ahead of the 6 April payment date.

We are aware that, as you are getting older, some of you are finding it more difficult to find affordable life-insurance cover. We have been looking into some options and are in the process of doing a small-scale pilot using two different providers with the help of a small group of beneficiaries. We will share the results of the pilot with you when it has been completed.

Plans are moving ahead for this year's 'Future Money Matters' event and, following the success of the virtual event we held last year, we are looking to hold it by Zoom in the week commencing 4 July 2022. Further information will be circulated when the dates and agenda are finalised.

One beneficiary recently told us that some of you do not feel able to express your views about the Trust because you are worried that your money would be withheld by us if we were not happy about what you

said. This is not something we have heard before, but I just wanted to reassure you that although there are certain limited circumstances when we would not pay a beneficiary's Trust grants in full (for example, if we were worried about financial exploitation), we would never withhold funding because of something that a beneficiary said to, or about, the Trust.

We are always really keen to hear your views. In fact, even where a beneficiary's behaviour is classified as vexatious under our Vexatious Behaviour Policy, they will continue to receive their Trust grants as before, although we may restrict our communication with them and limit the non-financial support we offer them in order to protect the wellbeing of staff.

And a final reminder that this is the last year we will be able to offer group car insurance to beneficiaries. Our current insurers, RSA, have declined to offer us cover from next year and no other insurer is willing to offer us a policy. If you are one of the 21 beneficiaries who are still insured through the Trust, you will need to arrange your own personal cover from June 2022. If you need any help with this, please let us know as soon as possible.

Health & Wellbeing Update

Now that almost all Covid-19 travel restrictions have lifted, we are back to full-steam ahead with our HNA programme and are enjoying getting out and about to visit you. All staff carrying out HNAs have been fully vaccinated and we are continuing to take lateral flow tests before we visit. We are hoping that by the end of this year all of you living in the UK will have been offered a second HNA if you haven't already had one.

We have recently produced a short report called 'Earlier, Greater & Longer: Understanding & Meeting the Needs of Thalidomide Survivors – Now & in the Future'. This report provides a summary of the findings of an important piece of work we undertook to understand the current needs of beneficiaries – drawing on the data from the first round of HNAs - and identify your future needs and the costs of effectively meeting these. You can [read this report](#) on our website together with a Q&A that has been produced by the NAC to explain more about the report and the project.

Copies of the report have been sent to our funders as it clearly demonstrates the importance of current funding and the need for this to continue, and increase, as you all get older. If you would like to find out more or have specific questions about the report, there will be two webinars held – one at 7pm on Thursday 7 April and the other at 2pm on Friday 8 April. If you want to join a meeting, please contact admin@ttnac.org or sign up on MeetUp.

There are a number of awareness weeks planned which will include interactive webinars. Once the dates are confirmed, they will be listed in our [online events calendar](#). The first of these is our Mental Health Awareness week in May – which will include a webinar about things you can do to protect your mental health in uncertain times – and future events include Men's Health Week and World Continence Week.

We recently held a webinar on Trauma and PTSD, given by Bonita Ackerman du Preez, a trauma specialist which was well-attended and received a lot of positive feedback. [Click here](#) if you would like to watch it.

Although the government has now lifted almost all Covid-19 restrictions, the incidence of Covid-19 remains high, so it is important that you continue to keep yourself as safe as possible by social distancing, ensuring good ventilation when indoors, regularly washing your hands, avoiding picking up things with your mouth (if possible) and taking up the offer of both Covid and Flu vaccines/boosters. This is particularly important if you have an underlying condition which makes you vulnerable to Covid-19, such as diabetes, asthma or other respiratory problems. In addition, please go to any health screenings

you are invited to and keep up with any routine or urgent appointments at hospital or GP if you've been asked to attend.

We have now formally launched our new programme to encourage you to get, and stay, physically active. Seven beneficiaries have been trained by the team at Loughborough University to take on the role of Activity Champions – and they are raring to go! Making a few simple changes to increase the amount you move on a day-to-day basis can make you feel better in a number of ways. Moving more can help reduce pain levels, keep you flexible and independent, help with weight loss and your mood, and doesn't require an exhausting exercise programme. If you want to find out more about how to get involved, get in touch with Annabelle.

Diageo Chairs' Review Process

As you know, we will shortly be beginning our discussions with Diageo as part of our programme of periodic Chairs' Reviews. These are very important discussions, so we are very lucky to have a wide range of skills and expertise within our Board of Trustees that we can draw on.

Thanks to all of you who responded to the NAC consultation about these discussions. Your feedback was really valuable and helped shape the 'Asks' that have been developed by the small group of trustees, NAC members and staff who are leading on this process.

There will be a series of meetings with Diageo staff between April and November this year. One of the key messages you gave us was that you think it is important that Diageo understand how your needs are changing as you get older. Please be reassured that we will share all the evidence we have gathered through our HNAs, your contacts with the Health & Wellbeing team and the various research projects that we have undertaken with them.

And Finally...

... just a reminder that our trustees give their time to the Trust free of charge. We are lucky that they contribute expertise from their successful careers - in medicine, law, research, health and social care policy and financial management/investments – but we need to be mindful that they are busy people.

If you have any questions about how the Trust operates or suggestions about how we could do things differently, these should be directed to the staff team in the first instance, rather than to trustees. The staff will then liaise with trustees, if necessary.



Deborah Katy Suzanne