

The Thalidomide Trust

DIRECTORS' UPDATE December 2020

People News

There have been no changes to the staff team in the last three months apart from the fact that Harriet Maisey has not returned to work at the Trust following her 12 month period of Maternity Leave. And Annabelle Blackham has now been appointed on a permanent contract to the new role of Volunteer Co-ordinator to reflect our increased emphasis on developing beneficiary volunteering within the Trust.

There have also been no changes within our Board of Trustees since September, however, Sir Robert Nelson has made the decision to stand down as Chair at the end of this year, after almost nine years in the role. Mark Spofforth will take over this important position with effect from 1 January 2021.

Very sadly, we have to report that three beneficiaries have passed away in the last three months – Dominic Galvin, Chris Taylor and Julie Duffy. Our thoughts are with their families at this very sad time.

As we have not accepted any new beneficiaries to the Trust since our last Update, the total number of beneficiaries now stands at 452.

NAC Elections and News

It's almost that time again when we hold elections for the NAC and this year, in response to your feedback, we are making some changes. First of all, the process will not start until after Christmas, secondly we will be introducing online voting as an alternative to the traditional paper ballot and finally we will be encouraging candidates to record their manifesto in a video format to make it more accessible.

There will be three vacancies to fill this year as Simone, Graham and Guy all reach the end of their current term of office. We would like to encourage you to consider standing for a place. We feel it's really important for new voices to be heard, new views and ideas to be included in discussions and for the NAC to be as representative as possible of the beneficiary community.

If you are interested in standing, you will need to let us know by 5pm on Monday 8 February 2021 - and if you would like to talk to a current NAC member about what's involved ahead of this date, you can get in touch with Carolyn (carolyn@ttnac.org) or Phil (phil@ttnac.org) who will be happy to provide more information and answer any questions that you have.

At the recent NAC meeting, members voted for a new Chair to replace Geoff who recently stood down from this role and also a new Vice Chair to take up the role in May. I am pleased to report that Rowland Bareham was elected as Chair and Craig Millward as Vice Chair. Because Rowland held the position of Finance Team leader on the NAC, there was also an internal election for this role and Phil Williams was appointed.

Finance Update

This year we appointed a new audit firm to replace PricewaterhouseCoopers who have been the Trust's auditors for a number of years. Saffery Champness – who were appointed in the Summer – completed our annual Audit in November and I'm delighted to report that they gave us a clean bill of health and did not identify any areas that need attention.

Our new Exceptional Needs Fund was launched on 1 October and in the first three months we have received four applications for funding. In three of these cases, alternative solutions emerged from discussion of their Stage One application. The fourth application is currently at Stage Two of the application process. Unfortunately, there seems to have been some misinformation posted on social media about this new Fund, but please don't let this put you off. If you are experiencing unexpected and exceptional health and wellbeing needs and would like to find out more about the Exceptional Needs Fund and whether you would be eligible to apply, please read our Q&A document or watch the [short video on our website](#).

If you have any scheduled regular financial payments during the Christmas period when the office is closed, we will make sure these are paid to you before Christmas. However, if you need any additional payments to be made to you between Tuesday 22 December and Monday 4 January, you must contact us by midday on Monday 21 December to let us know so that we can set these up for you. Any requests received after this time will not be paid until January.

Future Funding

I know that some of you have expressed concerns about future funding in these uncertain times, so I just wanted to reassure you that:

- Your Annual Grant from Diageo is guaranteed for life and their funding commitments are set out in a robust legal agreement and are not affected by fluctuations in financial markets.
- The Health Grant Renewal process is well underway. We have set up a working group made up of trustees, staff and members of the Campaigns Team and NAC who are working together to achieve a renewal on the best possible terms once the current funding agreement ends in 2023. At the moment, we are focussing on pulling together as much evidence as possible on your current and future health and wellbeing needs (and the associated costs) and also continuing to build political support. We know that both Ministers and senior civil servants are very supportive of the continuation of the Health Grant and we have been asked to submit a detailed 'Case for Support' to the Department of Health & Social Care early in the new year.
- The Campaigns Team are continuing to explore ways of securing funding from the German Government now that we are no longer part of the EU and once travel restrictions are lifted, they will be reinstate their programme of visits to meet European politicians. They are also undertaking research to establish whether there is any new evidence to suggest that there are other potential sources of funding linked to the early origins of thalidomide.

Health and Wellbeing Update

Our focus over the last three months has continued to be on supporting you all during the challenging times we are all facing. We have now commenced our second round of wellbeing calls and have continued to provide Coronavirus Updates when changes are introduced or new information becomes available.

As we have had to put all our physical events on hold from March until the foreseeable future, we have been holding a series of virtual events online – and have been really enjoyed seeing some new faces at these. There are a number of health and wellbeing events scheduled over the next month or so, including a death café, a trauma workshop and a webinar on diet and healthy eating. If you are interested in registering for an event or just finding out more about one, please get in touch with Annabelle. And if you have any ideas of topics that you'd like us to cover in the future, please let us know – we're always open to new ideas!

Our volunteers have been playing an increasingly important role in both supporting beneficiaries and bringing them together in recent months. They have organised and hosted a range of online

groups through MeetUp and these online events will continue during the Christmas period – you even choose to meet up on Christmas Day to say Cheers! There is a fun filled Christmas Quiz on Sunday 20 December at 6pm, and Twixmas Bingo (that’s that weird ‘what day of the week is it?’ time between Christmas and New Year) on the 30 December. Get in touch to find out how you can get involved.

You will now have all received a copy of our new Resource Pack for GP Practices and many of you have also asked us to send a copy to your GP practice so that they have a better understanding of your thalidomide damage and associated health issues. If you haven’t yet, and would like us to do so, please let us know.

We have also started sending out information about our new E-Card (which has been designed to provide paramedics and other health professionals with key health information about you in an emergency situation) and instructions on how to create your own personal card – to print out or view on your phone. We are sending this information out on a phased basis, so don’t worry if you haven’t received your email or letter yet, it will be coming soon.

We always appreciate your feedback on new initiatives so please do let us know if you use either of these new resources, and tell us if you find them helpful and if you have suggestions as to how they could be improved.

Talking of feedback – we are really keen to know more about your use of the Trust website and we have launched a short website survey with just a few questions to help us ensure the website meets your needs. We would like as many of you as possible to complete the survey, even if you rarely use the website. It will only take a few minutes – just go to <https://www.thalidomidetrust.org/website-survey-2020-21/>

And Finally...

... just to let you know that the Trust Office will be closed from 4pm on Thursday 24 December through to 9am on Monday 4 January 2021.

Best wishes for a Merry Christmas from everyone at the Trust – and here’s hoping that 2021 will be a happier (and more normal) year for us all!



Deborah Katy Suzanne