

The Thalidomide Trust

DIRECTORS' UPDATE September 2021

People News

Marlene Winfield stepped down from the Board at the end of August after the maximum 12 year period as a trustee. During that time, she was Chair of Health & Wellbeing Committee, Deputy Chair of Trustees, a member of Claims Committee and also contributed to a lot of important projects. We are really grateful for the amount of time and level of commitment she has given to the Trust.

Whilst we are really sad to say goodbye to Marlene, we are delighted to welcome Ruthe Isden as a new trustee. Ruthe brings a wealth of experience in health and social care policy and is currently Head of Health and Care Influencing at Age UK.

There have been no changes to the staff team since our last Update but we are in the process of recruiting new staff to the Health & Wellbeing team, including a third part-time Medical Adviser to respond to the growing demand for information, advice and support on health-related issues.

Unfortunately, I have to share the sad news that Nick Tryon passed away in June, surrounded by his family, after being diagnosed with cancer and Phil Spanswick died suddenly and unexpectedly in his sleep earlier this month. He was not unwell before he passed away, but his cause of death was subsequently identified as Covid-19.

As we have not accepted any new beneficiaries to the Trust since our last Update, the total number of beneficiaries now stands at 447.

Finance Update

Our first virtual 'Future Money Matters' event took place in June and was really successful. Eight different financial topics were covered, including 'Making A Will', 'Lasting Power of Attorney', 'Savings & Investments', 'Mortgages', 'Life Insurance', and 'Switching Utility and Insurance Providers'. Suzanne gave a presentation on how the Trust's Finances work, and then two of our Finance trustees, Kevin Wesbroom and Mark Benstead, gave an overview of the Trust's investment strategy.

29 individual beneficiaries attended at least one session. At the end of each webinar beneficiaries were encouraged to complete a short feedback survey and all sessions were rated really highly - with an average score of 9.28 (out of 10). All the sessions were recorded and you can watch them by [clicking here](#) to visit the website. You will need to log into the website to view these recorded sessions – if you have any difficulty logging in or if you need to obtain your login details, please call us and one of the admin team will be able to assist you.

Following the Chancellor's announcement of lifetime Health Grant funding for beneficiaries living in England, we have now submitted a detailed tailored 'Case for Support' to the Health (and Social Care) Departments in Scotland, Wales and Northern Ireland asking for the same commitment. We will keep beneficiaries in those countries updated on our progress in securing the same level of support for them.

Health and Wellbeing Update

It has been lovely to see so many of you over the last couple of months as the staff team have

restarted face-to-face HNAs. We know that this continues to be a challenging time for many of you, so please don't hesitate to contact the team if you are struggling with any aspect of your health and wellbeing.

There are a number of Health & Wellbeing Awareness Weeks coming up.

We have a Sleep Awareness Week from 20 to 24 September as we are aware from talking to you at HNAs that poor sleep is an issue for many of you, particularly where it is connected to pain. There will be lots of advice and information available on the website about sleeplessness and persistent pain. We will also be talking about conditions such as Sleep Apnoea and on 23 September you can join a webinar session with beneficiary Kevin Donnellon where he will talk about using a CPAP machine at night to keep his airways open.

In December we will be holding a Bereavement Awareness week to offer support and information for people struggling with bereavement issues at a difficult time of the year. This will take place between 13 and 20 December.

We are lucky enough to have Helen Wall, a very experienced Continence Nurse & Adviser, providing free advice to beneficiaries at the moment. We know incontinence is a distressing and life limiting issue for many of you and Helen can give individual advice about what can be done for you if you are experiencing issues such as leaks, frequency and urgency – just contact the Health & Wellbeing Team if you would like to have a chat with her. She will also be doing a webinar on incontinence issues in October – the date will be on the website soon or you can email us if you want us to remind you.

You may have taken part in the recent NAC consultation events on the Government's Green paper on proposals to change disability benefits. The Health & Wellbeing team are working on a response to the consultation to be submitted alongside the NAC's response. There is still time for individuals to send their comments too – the closing date is Tuesday 12 October – and you can find more information about how to do this by [clicking here](#).

Communications

The NAC are continuing to try different ways to improve communication with you all as a community. These include a new Facebook group to catch up on news from the NAC, ask questions and contribute ideas. Visit their page www.facebook.com/groups/ttnac/ to join. But if you aren't on Facebook, you won't miss out. The NAC will still be producing regular newsletters – the next one is due next month – and there are now regular zoom sessions after each NAC meeting and at other times on important topics, such as the current government consultation on changes to benefits.

If you want to get in touch with the NAC at any time, you can email feedback@ttnac.org or find the contact details of individual NAC members on the NAC page of the website [here](#).

Thank you to all of you who have returned your updated 'Communications Preferences Form' that we sent you back in June. And if you haven't returned yours yet, please do so as soon as possible so that we know exactly what information you do and do not want to receive from us. [Click here](#) to fill in your form online.

And another reminder, that if you live in the UK and need to use our Freepost address then please use the new, shorter address - **Freepost THALIDOMIDE TRUST** written all on one line with the name of the Trust in capitals as shown. We have received a number of letters using the old address in the last few months and this has incurred additional charges.

Policy Update

The trustees recently agreed a new Staff Whistleblowing Policy which sets out the process that

staff should follow if they have any concerns about the charity or the conduct of any staff, trustees or other people working on behalf of the charity. This reflects the published guidance from the Charity Commission. If you would like to see a copy of the policy, you can call us to request one or email hello@thalidomidetrust.org

And Finally...

We are just about to begin the final year of our five-year strategic plan – which covers the period from October 2017 to September 2022. The trustees recently reviewed the progress made against the agreed plan and were pleased to see that, despite lots of unplanned activities and challenges – including responding to the Covid-19 Pandemic – most of the planned activities have been delivered or are in progress.

We will be starting the process of developing our next five-year plan (2022 – 2027) early next year and, as last time, it will be developed by the trustees, staff and NAC working together. If you have ideas of things that you think the Trust should be doing during that time period, you will have the opportunity to tell the NAC about them so that they can feed into the new planning process. They will be in touch shortly to explain how this will work.

Deborah Katy Suzanne