

The Thalidomide Trust

DIRECTORS' UPDATE December 2022

People News

Since our last Update in September, Sue King, our Finance Assistant, has sadly decided to leave the Trust to devote more time to supporting her family through some challenging events. The recruitment process to replace her is underway.

We also have successfully appointed a new legal trustee to replace Sir Robert Nelson who will soon have completed his maximum period of 12 years as a trustee. Dame Caroline Swift who has worked as a High Court Judge and is currently Chair of the Medical Practitioners Tribunal Service will take up her new role in January and we are looking forward to having her as a member of our Board.



I am delighted to share the exciting news that Mandy Masters, has become a great-nanny. Her great-granddaughter, Mila (pictured here with Mandy) was born in October. We think that Mandy is the first beneficiary to become a great-grandparent but do let us know if you have a great-grandchild too.

I am pleased to report that no beneficiaries have passed away in the last three months. As we have not accepted any new beneficiaries to the Trust, the total number of beneficiaries remains at 438 – 400 living in the UK and 38 living abroad.

NAC Election & News

The NAC election process will start in the new year and, once again, we will offer you the option of either voting online or using a traditional postal ballot paper.

There are five positions to fill this year as there are currently two vacancies and Craig, Carolyn and Helen all reach the end of their current term of office. Craig has now completed three consecutive terms on the NAC so is not eligible to stand this year. We would like to encourage you to consider standing for a place on the NAC. 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 6 February 2023 - 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 Graham (graham@ttnac.org) Nick (nick@ttnac.org) or Guy (guy@ttnac.org) who will be happy to provide more information and answer any questions that you have.

At their recent NAC meeting, members voted for Geoff Spink to take on the role of NAC Chair with effect from May 2023 and Mikey Argy to be the Vice Chair. Helen was elected to take on the role of Co-Chair of Health & Wellbeing Committee, subject to the results of the forthcoming election.

I would like to thank Rowland and Craig for all their hard work whilst they have had the positions of Chair and Vice Chair of the NAC. It has been an incredibly busy and important time for the Trust with the development of the new five-year strategic plan and the recent discussions with Diageo and they have both made an enormous contribution.

Health & Wellbeing Update

We have now almost completed our second 'Round' of HNAs – with over 170 HNAs having already been carried out in 2022.

Our 'Alcohol and Health' Webinar took place on 17 November and prompted a lot of interesting questions and discussion. If you were unable to attend but would like to find out more, a recording of the session will be available on the website later this month. All our upcoming health & wellbeing webinars are listed in our [online events calendar](#) alongside our varied, ongoing programme of MeetUp events. It's constantly being updated so do take a few minutes to check what coming up.

We have recently introduced a new area on the website especially for those who have vision impairment. This new content - which includes beneficiary stories, information on age-related vision impairment and sources of support for people with vision impairment – was generated by the MeetUp group for beneficiaries with a sight impairment, who have been meeting online to share experiences and discuss technologies that can help them make the most of their remaining sight.

In addition to our wide range of online meetings, groups and webinars, in 2023 we are going to introduce some local In-Person Coffee Meetups, hosted by a beneficiary. We will let you know if there's going to be an event near you – so watch out for news in the new year.

Following our email to you all ahead of the Government's Autumn statement, the good news is that there will be no means-testing of PIP and DLA, in spite of fears that this might be introduced. And it has been confirmed that benefits will go up by 10.1% next April, in line with the September 2022 Consumer Price Index.

It was also announced that the government is pushing back the migration of people who currently receive income-related Employment Support Allowance (ESA) across to Universal Credit (UC) to 2028. This means that if you are currently receiving income related ESA, and your circumstances do not change, you will stay on it until 2028. We know this change had been a concern to many of you and the fact that it is being delayed is more good news.

As always, please talk to us if you need any support or advice about benefits, we are really keen to ensure that you all receive all the money to which you are entitled.

There is still time for you to provide anonymised feedback to the Care Quality Commission (CQC) on your experience, as a disabled person, of NHS services and care. There is more information on our website here <https://www.thalidomidetrust.org/tell-us-about-your-care/> or you can visit the [website](#) set up by the CQC to give your feedback.

Finance Update

Our auditors, Saffrey Champness, recently completed our annual audit for the financial year ending on 30 September 2022. We are pleased to report that they gave us a clean bill of health. The Annual Report and Accounts will be considered by the Board of Trustees at their meeting in late January and the signed accounts should be available to download from the website in February.

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 20 December and Monday 2 January, you must contact us **by 5pm on Monday 19 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 after 3 January.

Diageo Chairs' Review

We have now concluded our series of meetings with Diageo. This was very much a team effort with trustees, NAC members and staff working together to make the most powerful 'case for support' possible.

For the first time were able to share a wealth of evidence from HNAs on your health and wellbeing needs and how these are increasing as you get older, together with a number of beneficiary stories and a film, featuring five beneficiaries, illustrating 'A Day in the Life of Thalidomiders'. Our trustees working in the fields of health and social care were also able to paint a picture of the current challenges in the NHS and social care provision and how these are impacting beneficiaries.

Mark Spofforth and Rowland Bareham are writing separately to you all to share the outcome of the Review process and what it means for you.

Independent Governance Review

We recently commissioned an external company – the Compass Partnership - to undertake a review of our governance arrangements to ensure that the Board of Trustees has a good understanding of the needs of beneficiaries – now and in the future – and we have the right people and processes in place to lead the organisation through the challenging years ahead.

This initiative was something that the NAC were very keen to take place. They have been very involved in the process and Compass will also be looking at how well the NAC is working - and how effective it is in representing the beneficiary community and advising the Board on a range of issues.

Compass will share their initial findings with the Board at their meeting in January and will present more detailed recommendations in February.

And Finally...

... you may be interested to know that the Christmas-special episode of Call the Midwife re-visits their thalidomide storyline.

We also wanted to give you prior notice that the Trust staff will be finishing at 3pm on Thursday 15 December for our Christmas meal – and the Office will be closed for the Christmas break from 4pm on Friday 23 December through to 9am on Tuesday 3 January 2023.

Best wishes for a Merry Christmas and a Happy New Year from everyone at the Trust!

Handwritten signatures of three individuals: Deborah, Katy, and Suzanne. The signatures are written in a cursive, flowing style.