

The Thalidomide Trust

DIRECTORS' UPDATE September 2019

People News

There have been no staff changes since our last Update, but Harriet Maisey will be going on maternity leave at the end of this month and we are currently advertising for maternity cover for her role.

Very sadly, we have to report that two beneficiaries - Anne Cronin and John Hardwick - have passed away in the last three months. As we have not accepted any new beneficiaries during this time, the total number of beneficiaries now stands at 461.

Trust Events

This year's Beneficiary Open Day at the Trust's offices in St Neots is taking place very soon (on Monday 30 September) and we are now in the process of planning our last beneficiary event of 2019 – a local event in the North West of England in late October/early November.

The final date is still to be confirmed as we are finding it quite tricky to find a venue that ticks all our boxes – so if you have any recommendations of venues that are disability-friendly and have plenty of accessible parking then please let Charlotte know by emailing hello@thalidomidetrust.org.

Holistic Needs Assessments (HNAs) and Health Grant Review Visits

We have almost completed our first round of HNAs and Health Grant Review visits so there are now only a handful of beneficiaries living in the UK who have not yet had one.

We will very soon, start scheduling 'round two' of our HNA visits so, if you had an HNA in late 2016 or early 2017 we may be in touch with you to arrange a second HNA.

Health & Wellbeing Information and Support

A record number of you have been in contact with the Health & Wellbeing team this year for information and support about your health and wellbeing – so you've been keeping the team busy!

As a number of you hit your 60s, we are planning for 2020 to be the Year of Health & Wellbeing. The Trust staff and NAC members are pulling together a range of initiatives to help you maximise your health and fitness and prepare for the decade ahead, focussing on the health challenges that have been identified through HNAs.

Website

We continue to regularly update the information on our website and are delighted that so many of you have opted to receive regular alerts letting you know about the new content we've added. If you haven't and would like to receive our 'Website – what's new?' updates, just let Charlotte know.

As ever, if you would like to use the website but are not sure how, contact us and we'll help you get online.

Health Grant Renewal

Although our current Health Grant agreements with the four UK Health & Social care Departments cover the period to March 2023, the Trust, the Campaigns Team and the All Party Parliamentary Group (APPG) on Thalidomide have already started to take steps to ensure an early commitment to its renewal.

You should have received a letter from Mikey recently asking you to send a letter to your MP asking them to sign a letter to Matt Hancock asking him to commit to renewing the Health Grant for a ten year rolling period (which would mean that you would always be confident of funding being secure for the next ten years).

There has been a really positive response to this mailing and we already have over 110 MPs – across all the main political parties - who have agreed to add their signatures. If you haven't yet sent your letter off, please consider doing so – despite all the political uncertainty at the moment, we want to secure as much support as possible for this important initiative.

Oral Histories Project

The Thalidomide Society is still looking for beneficiaries who are willing to share their personal story as part of the Oral Histories project that they are undertaking in partnership with the British Library. The final audio recordings and transcripts will be transferred to the British Library Sound Archive where they will become part of one of the largest collections of recorded sound in the world.

If you are interested in taking part – or just finding out more – please contact Ruth Blue on ruthblue@thalidomidesociety.org and she will be happy to give you more information and have an informal chat about the project.

And Finally...

As part of their drive to encourage new people to stand for election, the NAC will be piloting two observation places at a future NAC meeting to give interested beneficiaries (who have not previously been members of the NAC but would consider standing for election in the near future) an opportunity to gain first-hand experience of the NAC's work.

You will shortly receive further information about this new initiative and an invitation to apply for an observation place but if you would like to find out more now, please contact Carolyn, Graham or Simone ([just click below their photos on the NAC page of the Trust website](#)).

Handwritten signatures of Deborah, Katy, and Suzanne.