

# The Thalidomide Trust

## DIRECTORS' UPDATE

December 2019

### People News

Harriet Maisey has now started her maternity leave – and we are delighted to report that baby Adam arrived safely on 21 October and mother and baby are both doing well. We have recruited Annabelle Blackham to provide maternity cover and she has already settled quickly into her role.

We have also recruited two new medical trustees to our Board to reflect the Trust's growing emphasis on the health and wellbeing of beneficiaries. Professor Adrian Newland and Professor Andrew Owens will both be taking up their new roles in January and we are really looking forward to having them on board.

Very sadly, we have to report that one of our beneficiaries, Paul Croney, passed away in early November. As we have not accepted any new beneficiaries in the last three months, the total number of beneficiaries now stands at 460.

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### NAC Elections

It's almost that time of year again when we hold elections for the NAC. This year there will be three vacancies to fill as Geoff, Mikey and Phil all reach the end of their current term of office. Geoff and Phil are both eligible to re-stand, but as Mikey has now served the current maximum of three terms, she will not be able to stand for election again this year.

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.

If you are interested in standing, you will need to let us know by 5pm on Monday 6 January 2020 - 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](mailto:carolyn@ttnac.org)) or Craig ([craig@ttnac.org](mailto:craig@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 NAC Deputy Chair to replace Mikey and Simone Illger was elected to this position. I would like to record my thanks to Mikey for all her hard work and commitment over the years she has spent as a member of the NAC. During that time she has taken on many key roles including NAC Chair, NAC Deputy Chair and Deputy Chair of Heath & Wellbeing Committee.

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### Finance Update

You will all have received a letter from Jeff recently explaining how important it is that we have the correct account-holder name for your nominated bank account. This is in order to ensure that payments are processed smoothly when the new banking regulations are introduced in the New Year.

Thank you to those of you who have already returned your completed forms – and a gentle nudge to those of you who haven't yet done so. It is important that the details we hold for you are completely accurate as incorrect information will delay or stop future payments and create additional work for the Finance Team.

If you have any 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 Friday 20 December and Thursday 2 January, you must contact us by midday on Friday 20 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.

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## Research Update

Research Committee have recently agreed three additions to our research programme:

- Two beneficiaries are working with researchers at Exeter University as Patient Advisers on a project to develop a computer model that converts a leg blood pressure measurement to an equivalent one taken in the arm.
- Beneficiaries with upper limb damage in Scotland will be invited to attend a special clinic in Edinburgh that will run regularly over the next few months. This will follow up an earlier study that some of you may remember attending in the 1990s. The clinic will involve an assessment of your pain and functionality to build a picture of the long term impact of your damage.
- A study with Loughborough University will start in January to understand the barriers and facilitators for beneficiaries in undertaking physical activity. This project will take place throughout 2020. We will be sending out more information and an invitation to get involved in the New Year so please consider taking part - whether you are regularly active, are thinking about starting or never intend to exercise at all!

Talking of which...

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## 2020 - The Year of Wellbeing

We know many of you want to lose weight and increase your fitness and flexibility but can find it very challenging to do so.

So, in recognition of this, 2020 is going to be the Trust's Year of Wellbeing. Over the next 12 months we will be introducing lots of initiatives to support you in achieving your personal goals. The first of these is our '100lb weight loss challenge' which will kick off in January. So watch this space...

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## Update of Health Grant Renewal Campaign

An enormous thank you to all beneficiaries who sent the letter about the forthcoming Health Grant renewal to their MP. Despite all the political noise and competing priorities over the last few months, 239 of the 650 MPs in Westminster have already signed the letter to the Secretary of State for Health asking for a commitment for the Health Grant to be renewed on a ten year rolling basis.

The Campaigns Team are taking an enforced rest during the election period but will be renewing their efforts in the New Year. If a new MP is elected in your constituency, they will be in touch in January asking for you to write to them to ask them to sign the letter.

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## Important Information to Support PIP Applications

Because so many of you raised concerns about the lack of thalidomide knowledge and understanding amongst PIP assessors, we spoke to the DWP about this and, as a result, they agreed that we could provide information about thalidomide to all PIP assessors.

We recently worked with them to produce a 'Condition Insight Report' which every PIP assessor should have received. We will also be referring to this report and sending a copy of it with the letters of support we produce for PIP applications.

You will receive a copy of this document – and you will also be able to download one from our website – and, if you have a PIP assessment, we encourage you to check that the assessor has read it ahead of your assessment and have a copy to hand to show them.

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## Local Event - North West England

A reminder that the next Local Event is on Tuesday 14 January 2020 in Liverpool. It's a great opportunity for you to meet staff, NAC members and other beneficiaries in a relaxed environment. If you haven't already booked and wish to attend, please use our online booking form: [www.thalidomidetrust.org/news/events/local-events/north-west-england-local-event/](http://www.thalidomidetrust.org/news/events/local-events/north-west-england-local-event/) or alternatively contact the office for a booking form.

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## And Finally...

... just to let you know that the Trust Office will be closed from 4pm on Tuesday 24 December through to 9am on Thursday 2 January 2020.

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



Suzanne Katy Deborah