

# The Thalidomide Trust

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**DIRECTORS' UPDATE** March 2020

## People News

There have been no changes in the staff team since our last Update in December, but I am delighted to report that we have recently recruited a new trustee with significant research experience to join our Board. Professor Rosemary Varley will replace Caroline Glendinning who 'retired' in December 2019 after 12 years as a trustee.

As you know, the results of this year's NAC election were recently announced and I would like to congratulate Geoff Adams-Spink and Phil Williams on their re-election and welcome Gary Skyner as a member of the NAC.

Very sadly, we have to report that one of our beneficiaries, Janet Benham, passed away in February following a late diagnosis of cancer. We also accepted one new beneficiary in late December so the total number of beneficiaries remains at 460.

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## Finance Update

We are now making final arrangements for the payment of Annual Grants on 6 April. Over 70% of you have already returned your Annual Grant forms to let us know how and when you want these funds to be paid to you. If you haven't yet done so, please let us have your form as soon as possible.

We know how important it is to you that grant payments are not delayed so we have been taking steps to ensure that the process will go smoothly even if some staff are ill or the whole staff team has to self-isolate and work at home due to concerns about the Coronavirus.

We have received some questions from beneficiaries about whether the recent poor performance of financial markets – and particularly the drop in Diageo's share price – will impact on the amount of funding available to beneficiaries. I would just like to reassure you that, even though share prices can fluctuate, the amount you receive in your Annual Grant each year has been agreed with Diageo and will not change, irrespective of stock exchange performance.

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## Volunteering at the Trust

Since our last Update, we have introduced two new peer-support volunteering roles. The first focusses on helping other beneficiaries who want to improve their health and fitness and make lifestyle changes but need some support with this. The second focusses on providing technical help and support to other beneficiaries – which could be in a wide range of areas (including aids, equipment and home adaptations, IT and internet, Smart Technology, and electric vehicles).

If you think you have the necessary knowledge and skills to take on one of these new roles and have the time to offer support please get in touch with Annabelle and she can tell you more about what's involved. And if you would find support in any of these areas helpful, please also talk to Annabelle.

Annabelle has been increasing the level of support we provide to our volunteers – who provide such valuable support to their fellow beneficiaries - and also introducing new ways of them sharing information and providing support to each other.

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## Trust Events for 2020

The local event in Liverpool in January went really well. So thank you to everyone who came along and helped make the day such a success.

Our first 'Capacity to Connect' event for Case Managers and Professional Deputies working with our beneficiaries who lack capacity took place last month. It was really well attended and the feedback from attendees was overwhelmingly positive.

We have now finalised our programme of Trust events for the remainder of 2020.

- Our next local event is going to be held in Newcastle on 10 June
- Our 'Wellbeing 2020' event is going to be held on 25 September in Loughborough
- And our next Future Money matters event is going to take place in Manchester on 20 October

Thank you to Kevin, Dawn, Carolyn, Bob and Roz for undertaking venue visits to ensure that we are confident that the venues selected are fully accessible for beneficiaries.

As you may be aware, the Thalidomide Society and NAC have made the difficult decision to cancel their joint conference planned for 25 April at Radisson Blu in Stansted. This is because the health of beneficiaries is paramount and there is an elevated risk of the coronavirus due to the venue being an airport hotel. The event will be rescheduled and we will let you know the details as soon as confirmed.

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## 2020 - The Year of Wellbeing

Our '100lb weight loss challenge' is well underway and we are already a third of the way towards our target of losing a combined 100lb. You can still join the challenge – just sign up on the website and as well as tracking your weight loss, you can access support and advice from the forum.

Our project with Loughborough University exploring how to remove barriers to physical activity for beneficiaries has kicked off, with a number of focus groups having taken place and more due to be scheduled. We would love to hear from you about what you think of physical activity – good or bad – especially if you live in Scotland or Northern Ireland. Just contact Annabelle if you are interested in being involved

As Deborah mentioned earlier, our Wellbeing 2020 event is planned for 25 September. This will be an interactive health and wellbeing expo – with the opportunity to have on-the-spot medical checks, alongside cookery demonstrations, fashion and image therapists, gadgets and equipment and lots more. We would like as many people as possible to come along and find out a bit more about successfully moving into a healthy later life.

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## And Finally...

The coronavirus is impacting on all our lives – and the guidance on how to deal with it is changing almost daily. At the Trust our priorities have been:

- to make sure that we have robust plans in place so that we can continue to provide support (and payments) to you all, even if key staff become ill or have to close our office, and
- to ensure that our most vulnerable beneficiaries have support and contingency plans in place in their care arrangements.

We have already sent out a couple of updates to beneficiaries (and will send more if there are significant changes) but our advice is to regularly check the guidance from the Department of Health & Social Care - [www.gov.uk/coronavirus](http://www.gov.uk/coronavirus) and get in touch with the Health & Wellbeing team if you have specific questions or concerns.

Handwritten signatures of Deborah, Katy, and Suzanne.