

# The Thalidomide Trust

**DIRECTORS' UPDATE** September 2020

## People News

There have been no changes within the staff team or our Board of Trustees since our last update in June and we are all still keeping safe and well.

Very sadly, we have to report that four of our beneficiaries have passed away in the last three months – Angela Cairnduff, Karl Davies, Douglas Glover and Ian Arthur. Their causes of death were all very different – and Angela, Douglas and Ian had all been dealing with health problems for quite some time – but it was still a real shock and incredibly sad to lose four people in such a short space of time. Our thoughts are very much with their families.

We understand the impact that these deaths can have on you as individuals and as a community, so please do contact us if you have been affected by this news and would like to talk to one of the team or find out more about the support that is available. We do have some information on the website about Death and Dying that you may find useful and in addition we are planning to hold an online 'Death Café' which provides a supportive open space for people to discuss their feelings, fears and experiences about death and loss. We will be circulating information about this shortly, but if you are interested in taking part, do let us know.

Because Karl was a member of the NAC, his death left a vacancy. However, I am pleased to report that Helen Shore – who received a small number of votes less than Gary Skyner in this year's election - has agreed to join the NAC and will complete the remainder of Karl's existing term.

As we have not accepted any new beneficiaries to the Trust, the total number of beneficiaries now stands at 455.

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## Finance Update

We have just completed the annual Independent Review of our Health Grant processes and reporting for the period from 1 June 2019 to 31 May 2020 (which is a requirement of our agreement with the department of Health & Social Care) and I'm pleased to report that there were no concerns identified. So thanks to all of you who have provided details of your Health Grant expenditure over the last 12 months at HNAs (Holistic Needs Assessments) and Health Grant Review Visits.

As the number of HNAs carried out over the last six months has been minimal we may need to request further information from you in writing next year to enable us to fulfil our reporting requirements. We'll give you plenty of notice if that is the case but please make sure that you are keeping a record of your Health Grant expenditure.

We are planning to launch our new Exceptional Needs Fund later this month and will be accepting applications from 1 October 2020. It is designed to make additional funding available to beneficiaries who face unexpected and exceptional cost related to their health and wellbeing which cannot be met from their own resources or existing Trust Grants. We will be writing to you all in the next few weeks with further information.

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## Trust Policies

You will all have recently received a copy of the Trust's new Anti-Bullying and Harassment policy. We have an ongoing process of reviewing our policies to ensure that they remain up-to-date and reflect any changes in the law. In the last few months we have reviewed and updated a number of policies including our Data Protection Policy and our Policy for Beneficiaries who Lack Capacity.

If you are interested, copies of our current policies can be found in the 'Resources' section of the Trust's website or you can request a copy to be sent to you.

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## Health & Wellbeing Update

Our focus over recent months has continued to be on supporting you all during the challenging times we are all facing.

We have recently undertaken a detailed risk assessment in relation to staff visiting beneficiaries in their homes and have now re-introduced HNAs on a limited scale. These are taking place only where both the beneficiary and staff member are comfortable and with additional precautions in place to keep us all safe and well. We will review the situation shortly and make a decision as to whether to undertake these in larger numbers over the Autumn.

For Men's Health Week, we carried out our first interactive virtual event for male beneficiaries and it was good to see some people who don't usually come to trust events getting involved. This included the opportunity to ask Dr Susan Brennan - one of the Trust's Medical Advisers – questions and stimulated a lot of useful discussion on the day and some new web content including a factsheet on erectile dysfunction.

Whilst restrictions on travel and gathering in groups remain in place we are looking at holding more of these virtual events. So if you have any ideas of topics you think we could usefully cover, please let us know as we can consider them for our 2021 events programme.

Our new Resource Pack for GP practices is now finalised and we will be sending these out to both you and your GP practice (where you've given us permission to do so) in the next few weeks. Over two-thirds of you have asked us to send a copy to your GP practice but, if you haven't done yet, it's not too late. Just drop us an email or call us to give your consent.

We are also continuing to extend our peer-support volunteering activities. Last month we launched our Lift Up service to support beneficiaries experiencing low mood using structured peer support and a personalised work-book. And looking forward, we are launching an exclusive Meet-Up group for beneficiaries – called Positively Connected. This will provide a place to join other beneficiaries on virtual events such as book clubs, art groups, chats, discussions and much more. We will be sending round more information soon - so watch this space...

Our project where beneficiaries are working with Loughborough University to develop an approach to support each other to become more physically active is entering its final stage, which is to trial the new approach. We already have a group of beneficiaries to take part in the trial but would like to include a few of you who have not been involved so far. So if you are someone who has been thinking about being more active, knows you ought to do something about it, but just haven't been able to motivate yourself so far, then this is for you. Get in touch with Annabelle to find out more – you will get a 5 week programme of support to start to make the changes you want to make – they can be small changes like moving more every day or something bigger like finding and starting a new activity. It's more important than ever to do what you can to stay healthy so why not give it a try?

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## And Finally...

Just to let you know that our latest Annual Report and Accounts (which cover the period from 1 October 2018 to 30 September 2019) are available on the Trust's website. If you'd prefer a paper copy of the report let us know and we can post you a copy.



Deborah Katy Suzanne