

# The Thalidomide Trust

DIRECTORS' UPDATE

June 2021

## People News

There have been no changes to the staff team or to the Board of Trustees in the last three months. However, we are sad to report that, after almost six years in the Health & Wellbeing team, Emily Bates will be leaving us on 20 July to pursue other interests. Emily has provided invaluable advice and support to many beneficiaries during her time at the Trust and she will be greatly missed by her colleagues.

As you will hopefully be aware, Graham Kelly and Guy Tweedy were both recently re-elected to the NAC. They are joined by Mikey Argy – who has returned to the NAC after a 12 month break - and Sue Gooding who was elected for the first time.

Unfortunately, I have to share the sad news that one of our beneficiaries, Paul Walkinshaw, passed away in April. As we have not accepted any new beneficiaries to the Trust since our last Update, the total number of beneficiaries now stands at 449.

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## Finance Update

The Health Grants were all paid on 1 June to those who requested funds. If you want to receive your Health Grant but haven't yet returned your Declaration and Payment Request Form, please send these through to [hello@thalidomidetrust.org](mailto:hello@thalidomidetrust.org) as soon as possible.

Now that the elections have taken place in Scotland and Wales we are moving forward with the process to secure the renewal of the Health Grant on the same basis as in England. We are currently working on a 'Case for Support' - similar to the document we produced for the Department of Health & Social Care and the Treasury but tailored to reflect the position in these countries.

Unfortunately no firm commitment can be made in Northern Ireland until after the elections next year but we will be continuing discussions with the NI Health & Social Care Board so that we have everything in place ready for then.

We are about to hold our first virtual '[Future Money Matters](#)' event and I am really pleased that so many of you have signed up to take part. Sessions on a range of topics – including making a Will, life insurance, beneficiary mortgage options, how the Trust's finances work, and the Trust's Investment strategy - will take place over three days, the 22, 23 and 25 June. We will be filming all the sessions so that all beneficiaries have access to the information provided.

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## Health & Wellbeing Update

We are delighted that from 17 May, we have been able to re-introduce face-to-face HNAs with additional precautions in place, including all staff taking a Covid-19 test two days before they visit a beneficiary. Because we are playing 'catch up' there may be a gap of slightly more than three years between HNAs but we hope that all of you living in the UK will have been offered a second HNA by the end of 2022.

Even though the world is slowly opening up, we are continuing with our programme of volunteer-led online MeetUp events and webinars as the feedback on them has been overwhelmingly positive. If you are interested in registering for an event or just finding out more about the different sessions coming up and how to take part, please get in touch with Annabelle

on **01480 474074** or email [annabelle.blackham@thalidomidetrust.org](mailto:annabelle.blackham@thalidomidetrust.org)

Now that the NHS is scheduling routine appointments, PIP assessments are re-starting and we are doing more HNAs, our Medical Advisers are busier than ever dealing with your enquiries and requests for information and support. So please be patient and bear with us if it takes a little longer for them to get back to you, particularly if your health issue isn't urgent.

Finally, we know that a number of beneficiaries have had trouble getting appointments with their GP or have had appointments with specialists cancelled because of Covid-19. If you are having these problems, please do speak to the Health & Wellbeing Team – your health is really important and we may be able to help.

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## Communications

Both the Trust staff and the NAC are really keen to continue to improve the way we communicate with you.

The supplier of our database – which holds all our information about you and how you like to receive communication from us – is in the process of upgrading its software and this means that we need to make some changes too.

Over the Summer we will be sending out an updated Communications Preference form to you all. Please look out for it and return it so we know exactly what information you do, and don't want to receive from us.

If you need to use our Freepost address (applicable to UK based beneficiaries only) then please note that this has changed. Please do not use the previous address, as this incurs additional charges for us. The new, shorter freepost address is **Freepost THALIDOMIDE TRUST** (It is important that this is written all on one line and that the name of the Trust is in capitals as shown).

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## Website

We are continually updating the information on our website on a range of topics so please do check in to see what's new. And if you are having trouble logging in or have lost your password just call the office and speak to Charlotte or Danielle.

One of our recent developments is the introduction of a new [online events calendar](#) which provides details of all our events. Just click on a date to find out more and, in most cases, you can register the event online.

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## And Finally...

We have sadly had a number of cases recently where beneficiaries have shared their banking details and PIN numbers with friends and family members they trusted, but who have gone on to steal money from them. Unfortunately, in these cases, the police are unable to bring charges because the bank details were willingly shared and so some beneficiaries have lost considerable sums of money. So please think very carefully before you share your financial information. We strongly recommend that you do not share your banking details with anyone else and, if you are having trouble managing your finances without assistance, please contact Jeff on **01480 474074** or [jeff.prevost@thalidomidetrust.org](mailto:jeff.prevost@thalidomidetrust.org) who can offer advice and support.

Handwritten signatures of Deborah, Katy, and Suzanne.