

The Thalidomide Trust

DIRECTORS' UPDATE March 2021

People News

There have been no changes to the staff team or to the Board of Trustees in the last three months. However, Gary Skyner resigned from the NAC in early February.

Unfortunately, I have to share the sad news that two beneficiaries have passed away since our last Directors' Update. Richard Williamson passed away in late December and Freddie Astbury, in early January. Neither of the deaths were linked to Covid-19.

As we have not accepted any new beneficiaries to the Trust since our last Update, the total number of beneficiaries now stands at 450.

Joint Event with the Thalidomide Society

You should all have recently received information about the forthcoming joint event with the Thalidomide Society over the weekend of 15/16 May.

When we cancelled our original joint event in April last year, we were confident that we would all be able to meet face to face 12 months on... but sadly that's not the case. However, the event planning team have been working with a company called Rockitfish who have loads of experience of organising interactive virtual events, to create a programme of talks and fun activities, with as much opportunity to socialise as possible.

Please put the dates in your diary for now – and further information will follow shortly.

Finance Update

I am sure that you have all heard the good news that, in his budget earlier this month, the Chancellor, Rishi Sunak made a very public commitment to continue providing a Health Grant to beneficiaries living in England for the whole of their lives.

We are now in discussion with the other three UK governments to secure a similar commitment for beneficiaries living in Scotland, Wales and Northern Ireland as early as possible. We have had no indication that this will not be agreed but the devolved administrations have their own processes to follow and there are also elections planned in Wales and Northern Ireland before the current Health Grant agreement ends which may delay the process. We will, of course, keep those of you in Scotland, Wales and Northern Ireland updated when we have more news.

We haven't yet started discussions with the Department of Health & Social Care about the details of the new agreement but we know that they will still require us to collect and report data on how the Health Grant is being spent and the difference it is making – so please continue to record this for discussion at your next HNA.

We are now making final arrangements for the payment of Annual Grants on 6 April. Over 65% 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 – and almost half of those received so far were requested via the [new online form](#). If you haven't yet done so, please let us have your form as soon as possible.

Health & Wellbeing Update

The topic of Covid-19 and its implications is something that we take very seriously and which is discussed at every level within the Trust, by trustees, the NAC and staff – and over the last three months we have continued to focus our efforts on providing support to you all during these challenging times.

We've been making lots of wellbeing calls to check how you are doing in this latest lockdown which we know some of you have found particularly difficult – and a record number of you have been contacting us for information, advice and support on a range of issues, including Covid-19 vaccinations. We have sent out two more Coronavirus Updates since the start of the year and hope that there will be less of a need for these as life returns to some sort of 'normal' over the coming months.

We are continuing to add new content to our website all the time – and have recently added information on prosthetics and a whole new section on pain as we know it affects so many of you on a daily basis. We have just finished putting together our website plan for the year ahead and will be running a number of awareness weeks on topics you've told us you want to find out more about. The first of these is Benefits Awareness week which will be running from 12 to 17 April. This will focus on encouraging those of you who have not yet done so to apply for the benefits you are entitled to – especially PIP. This is particularly important as the benefits regime changes once you reach age 65 and you could lose out on help to meet the costs of mobility. You can join a webinar to hear about all things PIP on Wednesday 14 April and ask any questions you may have – contact Annabelle at the Trust if you would like to join in.

Since our last update, most of you will have received information about the new [Emergency-Card](#) which has been designed to provide paramedics and other health professionals with key health information about you in an emergency situation. I know from talking to some of you that you missed our letter or email telling you about this and explaining how to create your own personal card, as it got lost in the avalanche of communication around Christmas and the New Year. If that is the case, please let us know and we can re-send the information and instructions to you. We have produced two short videos showing you how to set up your personal card and will be also be happy to provide you with any support you need with this. You can find the video by following the link to the Emergency card in blue above.

It's been nice to see so many of you taking part in our continuing programme of online MeetUp events and webinars. 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 annabelle.blackham@thalidomidetrust.org

We have also been undertaking a limited number of HNAs by Zoom in recent weeks, but we are all looking forward to being able to get out and about again and see you face-to-face.

Finally, our volunteers continue to be an important part of the support we are able to offer you and we really appreciate all the hours they put in. We are looking to recruit some additional volunteers to provide beneficiaries with information and support in relation to benefits, including PIP applications, so if you think this might be something that you could help with, please contact Annabelle for an initial chat.

Keeping in Touch with You

We are increasingly using emails to keep in touch with you and share important information from the Trust but we know that email providers frequently change their spam filters to stop you getting too much junk mail and sometimes this means that our emails get blocked or sent to your 'junk' or 'clutter' folders.

So this is just another reminder that, to make sure you never miss important information from us, you should add the two email addresses we use to your safe senders or add us to your contacts list. These are hello@thalidomidetrust.org and [The Thalidomide Trust@mail.vresp.com](mailto:The_Thalidomide_Trust@mail.vresp.com). If you're not sure how to do this, just call the office and someone will talk you through it.

New Policies

The trustees are currently putting the finishing touches to a new policy that sets out the emotional, practical and financial support that the Trust offers after a beneficiary sadly passes away. We will be sending a copy of this policy to all of you in the next few weeks.

The trustees have also recently produced another new policy which sets out how the Trust will deal with the small number of beneficiaries who act in an unreasonable and vexatious way, taking up a significant amount of Trust resources, diverting staff time away from those that really need it and causing unnecessary stress. We will not circulate this policy as we know it will only apply to a tiny proportion of beneficiaries but, if you are interested, you can see it on the [Trust website](#) or request a hard copy to be sent to you from the office.

And Finally...

I have previously explained that the Annual Grant payments that you receive are not linked to the performance of financial markets, but you may be reassured to know that, after taking a big dip last year, the value of the Trust's investments have now returned to pre-Covid levels.

I have also produced a new factsheet that explains how the Trust's finances work. If you log in to the website, go to My Account and then Resources, you will find it listed under the [Factsheets for Beneficiaries](#). Alternatively, please feel free to call the office and we will send one to you.

 Deborah . Katy . Suzanne