

The Thalidomide Trust

DIRECTORS' UPDATE December 2021

People News

There have been no changes to the Board of Trustees since our last Update, but there have been some changes to the staff team.

First of all, we are sad to report that, after over five years in the Health & Wellbeing team, Mitch Lambert will be leaving us at the end of December to concentrate on her successful bridal business. Mitch has provided invaluable support to many of you during her time at the Trust and we know she will be greatly missed by both her colleagues and many beneficiaries.

We have, however, appointed three new staff to the Health & Wellbeing Team to help meet the growing demand from beneficiaries for information, advice and support. Helen Smith and Claire Blythe both started with us in early November – Helen as our third part-time Medical Adviser and Claire as our Health & Wellbeing Co-ordinator for Independence and Care. Danielle Goodwin – who many of you will know as she has been part of the Admin Team for the last three years – has now moved to the Health & Wellbeing Team to provide admin support to our three busy Medical Advisers and also to look after our private referrals which have increased significantly due to the pressures on the NHS. We have now begun the process of recruiting a replacement for Danielle in the Admin Team.

If you want to keep up to date with all the changes, there are photos of all the staff and a little bit of information on what we all do on the Trust website.

Unfortunately, we have to share the sad news that we have lost two beneficiaries since our last Update. George Cherry passed away in his sleep at home with his wife, Rhonda, by his side in October and Fiona Elliott – who had a number of health issues – passed away in hospital, in November.

We also accepted two new beneficiaries to the Trust in November, so the total number of beneficiaries remains at 447.

NAC Elections & News

It's almost that time again when we hold elections for the NAC and, like last year, the election process will start in January, and we will offer you the option of either voting online or using a traditional postal ballot paper.

There will be three vacancies to fill this year as Rowland, Nick and Maggie all reach the end of their current term of office. 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 of the beneficiary community.

If you are interested in standing, you will need to let us know by 5pm on Monday 8 February 2022 – 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 Craig (craig@ttnac.org) or Carolyn (carolyn@ttnac.org) who will be happy to provide more information and answer any questions that you have.

At their recent NAC meeting, members voted for Carolyn to continue as Co-Chair of Health & Wellbeing Committee for another year and for Guy to continue in the role of NAC budget-holder for a further two years.

Finance Update

We submitted a detailed 'Case for Support' to the Departments of Health (and Social Care) in Scotland, Northern Ireland and Wales in September and we are awaiting their response to these. We remain optimistic that the governments in all three devolved administrations will commit to lifetime Health Grant funding, with regular four-yearly reviews of the level of funds required. This would bring them in line with the position for beneficiaries in England, announced in March this year.

As we have previously advised you, this is the last year we will be able to offer group car insurance to beneficiaries. Our current insurers, RSA, have declined to offer us cover from next year and no other insurer is willing to offer us a policy. This means that the 21 beneficiaries who are still insured through the Trust will need to arrange their own personal cover, though we will offer support to anyone who needs it.

Our auditors, Saffrey Champness, recently completed our annual audit for the financial year ending on 30 September 2021. We are pleased to report that they gave us a clean bill of health. The Annual Report and Accounts will be considered by the Board of Trustees at their meeting in late January and the signed accounts should be available in February.

If you have any scheduled 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 Tuesday 21 December and Monday 3 January, you must contact us by 5pm on Monday 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 after 4 January.

Beneficiary Feedback Survey

Our third Beneficiary Feedback Survey is scheduled to take place early next year and you should all receive an email from Marketing Means – the company who have done our previous two surveys - in the week commencing 17 January with an invitation to take part. Please look out for this email and if you don't receive it check your spam or clutter folders as we don't want you to miss the opportunity to tell us what you think about the Trust – our staff, trustees and the NAC – your feedback is really important to us.

And rest assured, the data we provide to Marketing Means to enable them to carry out the survey on our behalf will be treated in the strictest confidence and managed in line with GDPR.

Health & Wellbeing Update

We have continued our programme of HNA visits over the last three months and, despite the impact of Covid-19, we are on target to have completed HNAs with a third of all beneficiaries living in the UK by the end of the year.

Thank you to all of you who contributed to the recent NAC consultation on the Government's Green paper on proposals to change disability benefits. In total, 37 of you fed into the process – either by providing individual responses or by taking part in the MeetUp session – and your inputs were reflected in the detailed 16-page response submitted by the NAC. The Trust staff also submitted a response based on their experience of supporting beneficiaries through the benefits application and appeals processes. If you would like to see a copy of these submissions they are [available on the website](#).

Between 13 and 20 December we will be holding a Bereavement Awareness week to offer support and information for people struggling with bereavement issues at a difficult time of the year. If you want to find out more, please get in touch with one of the Health & Wellbeing Team.

We continue to hold our programme of online MeetUp events on a range of different topics. A new MeetUp group has recently been set up specifically for beneficiaries who have a serious

vision impairment or are registered blind. As well as a sociable element, it will provide an opportunity for beneficiaries to share challenges they face in everyday life and what solutions they have found or would like to! The next meeting of this group is on Tuesday 25 January. Please get in touch with Annabelle to find out more information and get involved.

We are really pleased that a number of you have applied to take on the new volunteer role of 'Activity Champion'. Training for Activity Champions begins in mid-January and there are still a few spaces still available. So if you are interested in starting the new year by helping other beneficiaries get and stay active, please get in touch with Annabelle to find out more.

And Finally...

... just to let you know that the Trust staff will be finishing at 3pm on Thursday 16 December for our Christmas meal – and the Office will be closed for the Christmas break from 4pm on Friday 24 December through to 9am on Tuesday 4 January 2022.

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



Suzanne Deborah Katy.