

# The Thalidomide Trust

DIRECTOR'S UPDATE December 2017

## People News

In my last Update I told you that we were in the process of recruiting a new member of staff to work alongside Michelle in supporting the Health & Wellbeing team and providing wellbeing advice to beneficiaries. I am delighted to report that we recruited Cheryl Pinkney into this role and she started with the Trust last month. She has thrown herself very much 'in at the deep end' and some of you may already have spoken to her.

The reason for Cheryl's appointment was that we are receiving more and more enquiries from you about health & wellbeing issues and HNAs are also generating lots of follow up work – particularly for the Health & Wellbeing team. In the last year, 362 (almost 80%) of you have had contact with the team! A big part of this has been an increase in demand for advice and support on medical/health issues so the trustees recently made the decision to appoint a second Medical Adviser to work alongside Dee. We will be advertising the role before Christmas and hope to have someone in post in the first half of 2018.

Unfortunately Lesley Hutchinson, our new Finance Co-ordinator, resigned in October for personal reasons. Jenny took this opportunity to review the structure of the Finance Team because Jeff has grown and developed his role and our new finance system has simplified a lot of finance processes. As a result, we are now in the process of recruiting a part-time Finance Assistant who will concentrate on payment requests and day-to-day finance tasks and provide support for Jeff and Jenny.

We have accepted no new beneficiaries since my last Update but I am sorry to report that one of our beneficiaries, Heather Bird, sadly passed away earlier this month.

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## NAC Elections

It's almost that time of year again when we hold elections for the NAC. This year there will be three vacancies to fill – as Rowland, Nick and Kim all reach the end of their current term of office – and we would like to encourage you to consider standing for a place. We feel it's important for new voices to be heard and for the NAC to be as representative as possible.

If you are interested in standing, you will need to let us know by Monday 8 January - 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 Phil ([phil@philipdavidwilliams.co.uk](mailto:phil@philipdavidwilliams.co.uk)) or Carolyn ([cdesforges2004@aol.com](mailto:cdesforges2004@aol.com)) who will be happy to provide more information and answer any questions that you have.

At the recent NAC meeting, members voted for a number of internal posts. Rowland Bareham was elected as NAC Chair (for a third year), Mikey Argy was elected as Deputy NAC Chair (for a two year term) and Nick Dobrik was elected as Shadow Finance Team Leader (for a third year). All these appointments will commence in April 2018 - subject to Rowland and Nick being re-elected to the NAC. Guy Tweedy will remain as Deputy NAC Chair until April and I would like to thank him for his contribution over the two years he has held this position.

## Beneficiary Events

In October we had our second 'Fit for the Future' event in Liverpool - organised by the same great team as last year's successful event. It was attended by 18 beneficiaries - 6 who had also attended last year - and the feedback from participants was really positive. There will soon be a short film of the event available on the website so you can get a flavour of the experience.

Many thanks to all of you who responded to Jeff's survey about our planned Finance event on 10 May next year in Birmingham. We received lots of helpful feedback on the topics that you would like to see covered and 60 of you expressed an interest in attending - so it's now full speed ahead with planning the event. We will send out further information once the agenda is finalised and the booking process is open.

In 2018 we are planning a number of other beneficiary events including another beneficiary Open Day in St Neots and local events in Bristol and Northern Ireland. So watch this space....

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## Thalidomide Society

We have been working more closely with the Thalidomide Society recently and are currently talking to them about running a joint Society/Trust event in Spring 2019 which will bring together all the best elements of NACAC and the Society's AGM - and hopefully attract a larger group of beneficiaries than either of these two events do on their own. The Society has recently made the decision to offer free life-time membership to all beneficiaries and their partners, friends and family. [Click here](#) for a flyer which tells you more about the Society and how to become a member.

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## Website Update

We are continuing to add content to our website. We have recently introduced a breadcrumb trail and will very soon be introducing a new 'mega menu' which will help you find your way around the site and see where you are at any point. We always welcome your feedback so please let us know what you think.

We have recently gone live with a new interactive feature on our website. 'Beneficiary Articles' can now be found in the My Account section and gives you the ability to share your thoughts and recommendations in comments below. The first article focuses on Falls and Balance Awareness so please have a read and share your thoughts on the subject with other beneficiaries. Just go to the My Account page and scroll down to the bottom.

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## Data Protection

We take the confidentiality and security of your personal information very seriously and will never share your information outside the Trust staff team without your explicit permission. We have produced a factsheet on Confidentiality which you can [see here](#).

We have also recently updated the Trust's Data Protection policy after discussion with the NAC. The current arrangement that the Trust has in place is that when a beneficiary dies his or her file is transferred to the Wellcome Trust for permanent preservation as archives, with a view to their use in historical or other research under restricted conditions after a 'closed' period of at least 50 years from receipt.

The NAC requested that every beneficiary has the opportunity to 'opt out' of this arrangement and instead have their personal file destroyed or sent to a nominated third party. We have therefore created an [Opt Out form](#) which allows you to make this choice. Please note that if we do not receive a completed form we will assume that you are happy to have your file sent to the Wellcome Trust in the event of your death.

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## Finance Update

We have recently finished implementing our new finance system. So we are now in the process of designing new individual beneficiary reports which will allow you to see information about your Trust money in a more user-friendly format – similar to the statements that you can see when you use online banking websites.

In response to questions and concerns raised by some of you about the security of your financial information, we have ensured that all your financial data is fully encrypted and will now hold all financial information outside the website on our separate finance system. However you will still be able to log into the finance system via a button on the website. We will shortly be setting up new user names and passwords for you so that you can access this information and we will be in touch soon with further details/instructions.

Also, another reminder that next year your Health Grant will be paid on 1 June, rather than at the same time as your Annual Grant in April. If you are worried about how this change will impact on your finances, you can contact Jeff in Finance ([jeff.prevost@thalidomidetrust.org](mailto:jeff.prevost@thalidomidetrust.org)) to talk through your concerns.

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## Planning for the future

We have recently finalised our five year Strategic Plan. This was developed jointly by the trustees, NAC and staff team working in partnership and aims to translate our five agreed strategic goals into a clear plan which sets out how we will work together to focus our energy and resources into making our Vision for the Trust a reality. If you would like to see a copy of the plan you can download it from our [website here](#) or request a hard copy by calling us or emailing [hello@thalidomidetrust.org](mailto:hello@thalidomidetrust.org).

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## And finally....

... just to let you know that the Trust Office will be closed from 4pm on Friday 22 December through to 9am on Tuesday 2 January 2017. If you have any regular financial payments during the closure period, these will be made as normal. However, if you need any additional payments to be made to you between 19 December and 2 January you will need to contact us by Monday 18 December to let us know so that we can set these up for you.

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



With best wishes  
Leborah

