

# The Thalidomide Trust

## DIRECTOR'S UPDATE

December 2018

### People News

Since my last Update, Danielle Goodwin has started work with the Trust as our part-time Administrative Officer, working alongside Charlotte. She has been in post for over a month now and many of you will already have spoken to her.

The NAC have also recently appointed someone to specifically provide support to them as much of their work is done outside normal office hours. We are delighted to have Gillian Sherwood on board and look forward to working closely with her.

As many of you will be aware, Louise Medus-Mansell sadly passed away in early November. She will be greatly missed. We have not accepted any new beneficiaries in the last three months so the total number of beneficiaries is now 465.

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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 Carolyn, Craig and Karl 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 5pm on Monday 7 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)) 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. Geoff Adams-Spink was elected as NAC Chair, Rowland Bareham was elected as Shadow Finance Team Leader and Carolyn was elected as Co-Chair of Health & Wellbeing Committee. All these appointments will commence in April 2019 - subject to Carolyn being re-elected to the NAC.

I would like to record my thanks to the current post-holders - Rowland Bareham, NAC Chair; Nick Dobrik, Shadow Finance Team Leader and Simone Illger, Co-Chair of Health & Wellbeing Committee – for their hard work, enthusiasm and commitment over their time in these roles.

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### Future Money Matters

On Friday 1 March 2019, the Trust will be holding its Future Money Matters event at the Blu Radisson Hotel at London Stansted Airport.

Future Money Matters' is a finance themed event for beneficiaries that will provide you with up to date information about a range of important future financial planning topics, as well as the opportunity to meet with the various finance professionals that will be attending on the day. The financial topics that we hope to cover at the event include Mortgages & Personal Loans, Inheritance Tax Planning, Universal Credit and Making a Will/Lasting Power of Attorney

The event is also a great way to meet up with fellow beneficiaries, and there will be time set aside within the day's agenda to enable you to meet up and socialise with each other.

Information about the event is available now on the Trust website – just visit the Money Matters section and click on Future Money Matters.

We will be contacting you again in early January to formally invite you to book onto the event, but if you would like to book your place now you can do so by completing the online booking form which is available to download from the Future Money Matters section of the website.

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## Website

We continue to develop the Trust website and there has been a lot happening behind the scenes in the last few months in preparation for new features and content going live.

We've built a 'Professionals Directory' which is now available within the Health and Wellbeing section. This is a list of surgeons, doctors and other medical professionals who have been working with the Trust and you can read reviews from their patients and colleagues as well as find out whether they have treated any beneficiaries before. This is to help you and your GP make an informed decision about your care.

The Finance team have been working hard on new information for the 'Money Matters' section and this will be coming soon. In the meantime, if you haven't seen them yet, there are some really helpful videos on the Future Money Matters page which are worth a watch!

Speaking of videos, we have recently uploaded footage from the local event that we held in Bristol in October. The first session was an update from Deborah, Katy, Craig and Phil about the recent changes and future plans of the Trust. And the second session was about health and pain management, presented by Dr Susan Brennan and Matt Kinal who is a Physiotherapist and pain specialist. The videos were shot with the BSL interpreter in the frame and we have also included subtitles on them to make them more accessible to you all.

And finally we are in the process of creating a bespoke Beneficiary Community which will include a Forum alongside the existing 'Your Stories' section. You will be able to discuss a range of topics with each other and give advice as well as ask for it so keep an eye out for that in the New Year.

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## Research Update

We are about to start an exciting project to investigate the likely care and support needed by beneficiaries in the future and to estimate the cost of this care.

There is an accepted and well-established way of calculating these costs that is routinely used to calculate the amount of damages to be awarded in a personal injury claim. We are working with one of the leading national companies - Bush and Co - that assesses individuals and costs their future care and support needs for such claims. Bush and Co are adapting their conventional approach especially for people damaged by thalidomide.

We will be carefully selecting 15 people who are broadly representative of the beneficiary community to take part in the study. Each person will have a detailed assessment of their future care needs carried out by trained and experienced assessors from Bush and Co. These needs will then be costed and will be used as an indicator of the likely costs for all people with similar thalidomide damage.

This project will provide strong evidence that will help us explain to Diageo and the government how important their funding is and how much money beneficiaries will need in the future to meet their needs.

The Trust will be identifying people to take part and contacting them directly, so you don't have to do anything. The study will take about 18 months to complete – in time for the next funding rounds.

..... and, as always a reminder – please let the Health & Wellbeing Team know if you think you might be having an operation in the next year or two and are interested in participating our Cardio Vascular Risk research study.

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## **Holistic Needs Assessments (HNAs)**

We have now exceeded our annual target of 150 HNAs in 2019 – which means that more than two-thirds of beneficiaries have now had an HNA. If you haven't yet had one, we will be in touch to arrange one at some point during 2019.

To comply with the terms of our agreements with the four UK Departments of Health & Social Care, we need to meet face-to-face with every beneficiary living in the UK at least every three years to find out what they are spending their Health Grant on. We hope that this discussion will be part of a broader HNA but, if for some reason you do not want to have any HNA, a member of the team will still have to come and visit you to discuss your Health Grant expenditure.

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## **Benefits**

Just a reminder that if you are unable to work and are thinking of applying for Employment Support Allowance (ESA) you should do so as soon as possible. This is because, once Universal Credit is rolled out, many beneficiaries will receive less money under the new arrangements. If you would like to find out more, please get in touch with one of the Health & Wellbeing Team.

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## **Bank account information**

Price Waterhouse Cooper have recently completed their annual Audit of the Trust's finances and one of the recommendations they have made is that, ahead of changes to banking regulations, we verify the nominated bank account details for all beneficiaries to ensure that we have the correct account name as well as sort code and account number as incorrect information will delay or stop future payments. The Finance Team will be in touch with you over the next few months to explain what we require to ensure that there is no disruption to your payments from the Trust.

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## Thalidomide Society AGM & Conference

The Thalidomide Society AGM and Conference 2019 is to be held on Saturday 6 April 2019. at Hilton at St George's Park near Burton upon Trent. There is a packed and interesting programme ending with a conference dinner and entertainment. For the first time the NAC will be hosting the afternoon programme with a focus on Health & Wellbeing – with the opportunity to hear from Dr Susan Brennan, Medical Adviser to the Trust.

If you would like to attend this event, please contact Dr Ruth Blue, Secretary to the Board of Trustees of the Thalidomide Society on 020 8464 9048 or [ruthblue@thalidomidesociety.org](mailto:ruthblue@thalidomidesociety.org)

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## New 'Connect' volunteer role

There is an exciting new opportunity to be involved in volunteering in the Trust. We are looking for beneficiaries throughout the UK to become 'Connect Volunteers' for their local area.

The role of a Connect volunteer is to help other beneficiaries in that area to find out about local services and activities and offer support to access them if necessary. This might range from helping someone book an appointment with a benefits advisor, to helping them find a reliable plumber or a Pilates class.

If you are knowledgeable about your area , would like to help other beneficiaries and can use the internet easily – this role might be for you. Contact Michelle - [michelle.robinson@thalidomidetrust.org](mailto:michelle.robinson@thalidomidetrust.org) – at the Trust to find out more.

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## New Oral History project

The Thalidomide Society has received National Lottery support for **Thalidomide Stories – an Oral History of Thalidomide Survivors**. The project will capture the voices of at least 46 beneficiaries over the course of the next two years and is supported by the British Library and the Science Museum. A team of volunteer interviewers from the Society membership will be trained to conduct some of the interviews and there will be a number of exciting dissemination events across the UK. The final audio recordings and transcripts will be transferred to the British Sound Library archive - <https://sounds.bl.uk/Oral-history> where they will become part of one of the largest collections of recorded sound in the world. The Thalidomide Society are now seeking to recruit more interviewees from across the Thalidomide Trust's nationwide beneficiary community and would love to hear from you. Please contact Dr Ruth Blue, Secretary to the Board of Trustees of the Thalidomide Society at [ruthblue@thalidomidesociety.org](mailto:ruthblue@thalidomidesociety.org) and she will be happy to give you more information and have an informal chat about the project.

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### And finally....

... just to let you know that the Trust Office will be closed from 4pm on Monday 24 December through to 9am on Wednesday 2 January 2017. If you have any regular financial payments during the closure period, these will be made as normal but may arrive a little early. 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 midday on Wednesday 19 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!

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