

# The Thalidomide Trust

**DIRECTOR'S UPDATE** April 2019

## People News

Since my last Update, two new members of staff have joined the Trust. Harriet Maisey joined the Health & Wellbeing team in February and will be working alongside Michelle and Cheryl to provide front-line information and advice to beneficiaries and support other members of the team. And, in March, Suzanne Lluch (pronounced Luke) started as our new Finance Director – replacing Jane Darlington, who decided that the job at the Trust was not the right one for her.

As you will be aware, following the recent NAC elections, Carolyn Desforges, Craig Millward and Karl Davies were all elected for another term. I would like to congratulate all three of them and thank the other candidates – Bob Hepple, Jacqueline Fleming and Anne Bancroft - who stood for election. I would also like to thank Rowland Bareham who recently stood down after three years as NAC Chair for all his hard work and commitment. We recently had our first NAC meeting under the Chairmanship of Geoff Adams-Spink and I look forward to working with him to ensure that we are doing all we can to meet your needs.

I am pleased to report that Sir Robert Nelson (Chair of Trustees) and Kevin Wesbroom (Chair of Finance Committee) have both recently been appointed to serve a final four-year term as trustees. Caroline Glendinning, Chair of Research Committee, will be standing down as a trustee in June after 12 years in the role. During her time as a trustee she has been instrumental in shaping the Trust's research programme and overseeing a number of important research projects including the 2015 Health & Wellbeing survey.

As many of you will know, Peter Williams passed away very suddenly and unexpectedly in March, and our thoughts are very much with his wife Marian and his twin brother Andrew.

We have not accepted any new beneficiaries in the last four months so the total number of beneficiaries is now 464.

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## Beneficiary Feedback Survey

A big thank you to everyone who completed and returned the recent beneficiary feedback survey. It is really important for us to hear what you think about the Trust staff, trustees and NAC and the ways in which we work to support you.

302 completed surveys were returned to the independent research company – a 67% response rate – and just over half of these were completed online.

The results of the survey will be reviewed by the trustees at their next meeting in May and will also be discussed by the NAC at their Awayday in June. We will also share them with you and let you know how we plan to respond to the survey findings.

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## Finance Matters

We will very shortly be writing to you individually about your 2019 Health Grants which will be allocated on 1 June 2019. This year, for the first time, we are asking you to confirm your primary address (the place where you live for at least 6 months of the year) when you sign your Health Grant declaration. This is one of the small number of changes that have been introduced as a result of the independent audit that was carried out last summer.

The trustees review the fees payable on Emergency, Major and Short-Term Advances from the Trust every year and they recently agreed that these should stay at the same level as last year - £40 per £1,000 advanced for Major and Emergency Advances and £60 per £1,000 advanced for Short-Term Advances.

As previously mentioned, over the next 12 months, we will also be asking you to verify the account name(s) of the nominated bank account(s) used to receive funds from the Trust, ahead of changes to banking regulations. This is to ensure that there is no disruption to your payments from the Trust when the new regulations come into force.

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## Trust Events

Our second 'Future Money Matters' event was held at London Stansted on 1 March and those that attended provided very positive feedback on the day. Ahead of the day, we asked for your views on the subjects that you would like to be included and, as a result, there were sessions on a number of new topics including Inheritance Tax, Mortgages & Personal Loans and Universal Credit.

The sessions on Universal Credit and Inheritance Tax were filmed and, if you were unable to attend the event but are interested in finding out more, you can watch them in the 'Money Matters' section of the Trust website.

Our next local event is due to take place in Brighton on 12 June at the BAi360 on the seafront. We sent a survey out to beneficiaries who live in the locality to ask them what sort of sessions they would like to see included and will be finalising the agenda in the next week. However, early responses indicate that there will be a strong focus on health and wellbeing issues.

If you live in the South East you will receive information about the event as soon as plans for the day are finalised. There will be information and a booking form on the Trust website and you can also contact us by calling 01480 474074 or emailing [hello@thalidomidetrust.org](mailto:hello@thalidomidetrust.org) if you are interested in attending.

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## Holistic Needs Assessments (HNAs)

We are now in year three of our HNA programme so, if you live in the UK and haven't already had an HNA you will be offered one at some point this year.

The HNAs have provided a wealth of useful information that we have been able to share with both Diageo and the four UK Departments of Health & Social Care. In particular, the data on current health issues and the way that they impact on your day-to-day lives has been invaluable in demonstrating the growing importance of the funding you receive from the Trust and the vital need for the Health Grant to continue post-2022.

We hope that you will be happy to have an HNA but if, for any reason you do not want one, a member of the team will still have to come and visit you in your home to discuss your Health Grant expenditure as this is a requirement of our Health Grant agreement.

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## Website

We continue to develop the Trust website and add new content so please do regularly check what's new. Recent new content includes a brand new section on Diabetes (introduced to coincide with Diabetes Awareness Week) and factsheets on sweating and making a complaint about your GP or hospital. A vlog from the menopause expert, Dr Hannah Short, and accompanying factsheets will also shortly be added to the website.

And I am delighted to let you know that the beneficiary forum has now gone live providing you with a dedicated space on the website to share information and ideas, ask questions or just chat to each other. Anyone can read the forum posts, but you will need to login (using your website login, not your finance one) to be able to add your own post. If you are new to using forums, contact us and we will put you in touch with someone who can help you get started. Family members, carers and professionals can also apply to us to join the forum – providing them with a way to engage with each other and the beneficiary community too. Everyone who uses the forum must agree to stick to the forum rules that set out what is acceptable behaviour online. You can find the forum in the 'Thalidomide Community' area of the website, where you can also now find 'Your Stories'.

Following feedback from the NAC, we are also looking into introducing an additional function which allows beneficiaries to make 'private posts' on the forum if they want to raise sensitive issues that they don't want to be seen outside the community.

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## Social Care Disregard

I wrote to you earlier in the year to share the good news that the governments in England, Wales and Northern Ireland have all agreed that funding you receive from the Trust should not be taken into account when assessing whether or not you are required to make a contribution to the cost of your care and have introduced new legislation/guidance to reflect this. We hope that similar changes will be introduced in Scotland soon.

So this is just a reminder that, if you live in England, Wales or Northern Ireland and are currently contributing toward the cost of your care package because of your level of savings, you should contact your Local Authority as soon as possible to request a financial re-assessment which will take into account the new 'rules'. And if you have never requested a social care assessment because you thought that you wouldn't be entitled to any funded care because of your savings, you may want to consider doing so now. You can discuss what's involved with one of the Health & Wellbeing team.

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## Benefits Update

A number of you have raised concerns about both the frequency of PIP assessments and the fact that many assessors do not seem to have even a basic understanding of Thalidomide and its impact on you, so we have raised these issues with the DWP. I recently met with the PIP policy team to discuss these concerns and they have agreed to include information about Thalidomide in the resource/training information for PIP assessors (who are employed by two private companies – Capita and Independent Assessment Services).

They also acknowledged that your health and functionality is not going to improve as you age so you should not be required to have frequent reassessments (unless you request one due to a deterioration in your condition). They advised us that it is important to stress the fact that your damage is non-reversible and will only deteriorate with age when you apply for PIP, so we will include this information in all letters of support that we provide and would encourage you to make this point yourself to the assessor.

They also advised us that it is possible to appeal (or request a mandatory reconsideration) of the length of a PIP award, so if you are assessed and are awarded PIP for less than 6 years, please contact the Trust as soon as possible and we will help you to request a review of this.

If you would like to find out more about the benefits that you are entitled to or have any other questions, please get in touch with one of the Health & Wellbeing Team.

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### Government consultation on air travel

There is currently a government consultation into the future of UK Aviation which is open for submissions until 20 June. This is an important opportunity to improve air travel for disabled people, so both the Trust and the Thalidomide Society will be making submissions.

We would also like to encourage individual beneficiaries to make their own submissions so please get in touch with Simone Illger – via the Trust website – if you are interested in doing this and she can explain more and also share a template letter you can use as a starting point.

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### And Finally.....

A big thank you to all the Welsh beneficiaries who came to the recent event in Cardiff Bay attended by Vaughan Gething, the Minister of Health & Social Services - and special thanks to Gill Tyrer who gave a short presentation about the growing health needs of beneficiaries and the importance of the Health Grant (which the Minister asked for a copy of!)



With best wishes  
Leborah