

The Thalidomide Trust

DIRECTOR'S UPDATE May 2018

At the request of the NAC, for the first time, we are also producing this Director's Update in a video format. So if you'd rather hear me (and see me!) than read this report, check our website... it is due to go live in the next few days.

People News

There have been a number of staff changes since my last Update and there are more to come!

In January, Keith Everest started in the role of part-time Finance Assistant. He settled into the role very quickly and successfully dealt with the large volume of Annual Grant payments at the beginning of April – so it has been very much 'in at the deep end' for him!

We also recently appointed Dr Susan Brennan as our second part-time Medical Adviser to work alongside Dee in responding to the growing number of requests for health-related information, advice and support. She joined us just after Easter and has already spoken to a number of you. As well as advising and supporting individual beneficiaries, Susan will also be producing new health-related information resources and developing our network of external medical specialists.

As many of you will be aware Emily is pregnant – she is expecting twins! – so we have recently undergone the recruitment process for maternity cover for her role. We attracted some really good candidates and we are delighted that Sally Sheehy will be starting with us in the middle of June. And, on the subject of maternity leave....

Lucy Cummings will be returning from her maternity leave at the beginning of June and has chosen to return on a part-time basis – working 16.5 hours per week. Charlotte McCawley did an excellent job of providing maternity cover so we are delighted to be able to keep her on when Lucy returns. Charlotte will be sharing responsibility for office administration with Lucy and will also have responsibility for developing and updating the website and supporting the growing number of beneficiary events.

Finally, I have to share the sad news that Jenny Tunbridge has decided to move on to pastures new after five years working at the Trust and will be leaving at the end of June. This was her first Finance Director position and she is keen to build on the experience she has gained at the Trust so that she can take the next step in her career. Her new job as Finance Director of a hospice in Cambridge will give her experience of fundraising which will be something new for her. She will be greatly missed and we wish her well in her new role.

I am really pleased that you elected both Rowland Bareham and Nick Dobrik for another term as your representatives on the NAC. Following the recent internal NAC elections, Rowland will continue in his role as NAC Chair and I would like to congratulate Mikey Argy on her appointment as Deputy Chair.

As you will be aware, although Glenn Harrison was elected as the third NAC member, he made the decision to stand down before formally taking up his position. We are therefore in the process of conducting a ballot to appoint the final NAC member. The closing date for ballot papers to be submitted is Wednesday 9 May at 5pm so if you haven't already voted, please consider doing so –we are keen that you have your say.

We haven't accepted any new beneficiaries since my last Update but I am sorry to report that two of our beneficiaries, Mark Gizewski & John Whitmore, sadly passed away during April. This means that the total number of beneficiaries now stands at 465.

Beneficiary Events

We held our second Beneficiary Open Day in St Neots on Tuesday 13 March and the day went really well. It was attended by 15 beneficiaries, 11 family members/friends and one dog! All the feedback received so far from beneficiaries who attended has been positive and everyone seemed to really like the relaxed and informal format of the day.

We have two further events planned in the next few months.

Our very first 'Future Money Matters' event is going to take place on Thursday 10 May in Birmingham and the varied agenda covers savings, retirement planning, VAT, making a Will and putting Lasting Power of Attorney in place. 27 of you have already booked to attend and all three members of the Finance Team will be there, along with Phil Williams from the NAC.

We also have another local event taking place in Belfast on 4 July. Based on feedback from beneficiaries living in Northern Ireland, the day will include sessions on living well (health, diet and fitness), financial planning and on recent changes and future plans for the Trust. Booking forms will be sent to all beneficiaries living in Ireland very soon. If you don't live in Ireland but would like to attend, please email hello@thalidomidetrust.org or give us a call and we will send you a form to complete.

We are also planning a similar event in Bristol in October and more information will be on the website soon and posted out closer to the time.

Research Update

We are delighted to announce the launch of a major new research partnership with the Royal National Orthopaedic Hospital (RNOH). The research study is designed to understand how accurate blood pressure measured in the leg is and will also look at what constitutes a normal blood pressure for someone with thalidomide damage

We know that many of you have difficulty having your blood pressure taken, especially those of you with short or no arms. This is a concern as the risk of developing cardiovascular disease increases as you age. Accurately measuring your blood pressure is a key part of understanding your risk of developing this disease and possibly having a heart attack or a stroke.

Some of you have your blood pressure measured in your leg, but we don't currently know how accurate this is. This means that we can't be sure that this way of taking blood pressure is reliable in understanding your risk of cardio-vascular problems.

The study will be running for a couple of years and it is really important that as many of you as possible take part. It will compare your blood pressure in your artery (the most accurate measure) and your blood pressure in your leg when they are taken at the same time. **For this reason you have to be having surgery to take part** as the blood pressure in your artery is only measured when you are under anaesthetic.

Please contact the Trust and let us know if you think you may be having an operation in the near future and are interested in finding out more, or look at [our website](#).

There are three other research projects that we will be taking forward over the next 12 months:

- A study to look at the use of prosthetics, including the current prosthetic services available and the issues and challenges faced by beneficiaries who use them.
- A joint project with the University of York which will focus on emotional wellbeing and will adapt an established programme of emotional support for people with depression to specifically address the issues faced by Thalidomiders and introduce a new model of peer support.
- A major project, led by the NAC, to identify and quantify the current and future care costs of beneficiaries.

Data Protection

As you may well be aware new legal rules are due to come into force next month. The General Data Protection Regulations (or GDPR as they are known) are designed to increase the security of personal information that anybody holds about you.

In order to comply with the new legislation, we are having to make some changes to the way we work – including introducing password protected documents whenever we send you information about your health or your finances. Jenny is working with Rowland and Phil from the NAC to update our data protection policy and processes.

We will also be writing to you very soon to explain what information we hold about you and why we hold it - and to ask you to let us know what sort of information you would like to receive from the Trust going forward.

Finance Update

Annual Grant payments were allocated as usual, on 6 April and most of you have now drawn down your funds in full or asked us to send you regular monthly payments.

As you have previously been advised, this year your Health Grant will be allocated on 1 June and, in the next week, we will be sending you a Grant Request form and a Health Grant Declaration form (which needs to be signed and returned before we can process your payment). This change in the allocation date has been implemented at the request of the Department of Health.

The trustees recently reviewed the fees payable on Emergency and Major Advances from the Trust and agreed that these should stay at the same level as last year - £40 per £1,000 advanced. In response to an increasing number of requests from beneficiaries, we have recently introduced a new policy which allows us to provide Short-term Advances when money is only needed for a limited short period, for example if you are moving home and need to arrange adaptations to your new home before moving. The fees for these advances are higher - £60 per £1,000 advanced. If you want to find out more about this option, contact Jeff by email (jeff.prevost@thalidomidetrust.org) or call him on 01480 474074.

Holistic Needs Assessments (HNAs)

We are continuing to roll out the HNA programme and have now conducted almost 200 HNAs. The feedback from beneficiaries who have had an HNA continues to be very positive –and 97% of you have said that you would recommend one to another beneficiary.

As a result of HNAs, we have increased the level and type of support we are providing to individual beneficiaries and we are also beginning to get a clear picture of the communities' needs, challenges and worries about the future. This information is enormously helpful to us in planning services and support for you and also being able to communicate to both Diageo and the four Health Departments the value of the funding they provide and the importance of this continuing.

We hope to have undertaken an HNA for every beneficiary in the UK by the end of 2020 so, if you live in the UK and haven't already had one, expect one of the team to get in touch with you over the next 18 months.

Once we have completed the programme of HNAs in the UK, we will be introducing a similar process for beneficiaries who live overseas.

Changes to the legal structure of the Trust

On the advice of our lawyers, we recently restructured the Trust so that it now operates as a Trustee Company. Under the new arrangements, we remain a registered charity with the same role and remit and this change makes very little difference in practice. However it means that legal liability for any contracts we enter into sits with the Trust as a legal entity, rather than with the individual trustees (as it previously did). The changes came into effect on 31 January this year.

Although all the individuals who served as trustees before that date are now officially 'Directors' of the new Thalidomide Trust Company, their role remains unchanged and we will continue to refer to them as trustees to reflect this.

We hope that this change will help us to continue to be able to attract excellent trustees to oversee and direct the work of the Trust.

If you have any questions about this change, please do not hesitate to get in touch with me and I will be happy to answer them.

Foot Steering News

For those of you who prefer the traditional foot plate steering adaptation, Motability has recognised that this is a unique and high-cost adaptation. There is only one garage in the UK, Jim Doran Hand Controls, offering this particular type of foot steering adaptation and Motability is now able to offer a discounted rate for this particular type of foot steering to beneficiaries of the Trust who are on the Motability scheme.

Therefore, from 1 October 2017, any members fitting traditional foot steering to their Motability vehicle at inception (start of the agreement), Motability will offer £1,500 off of the price. In effect, you will pay £1,500 less than the quote and Motability Operations will pay Jim Doran this amount

And finally...

I am pleased to report that we have succeeded in getting the benefits disregard extended to cover Council Tax Reduction (sometimes referred to as Council Tax Support) in England, Scotland and Wales and Rate Relief in Northern Ireland. What this means is that if your household income (excluding your Trust income) is low, you may be entitled to a reduction in your Council Tax or Rates because your Trust Grants will be now disregarded when assessing your income and savings. If you would like to find out more about this, please get in touch with one of the Health & Wellbeing team.

With best wishes
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