

The Thalidomide Trust

DIRECTORS' UPDATE

September 2023

People News

Since our last Update in June, there have been no changes to the Board of Trustees.

We have recently recruited a new member of staff to cover Charlotte's role whilst she is on Maternity Leave. Bex Chamberlain started with us a couple of weeks ago and is currently learning the ropes so that there will be a smooth handover when Charlotte starts her Maternity Leave in mid-October. Some of you will already have spoken to Bex on the phone.

Because the recruitment market is increasingly competitive, the Trustees recently commissioned an external salary and benefits review to check that ours are in line with other similar organisations. We are pleased to report that the results show the pay and benefits we offer staff are in line with the local market - and also with the national market for specialist roles.

In August, we participated in an employee feedback survey as part of the 'Best Employer' initiative, which not only provided us with feedback on the views and satisfaction of our staff, but also benchmarked our results with over 600 other organisations in the East of England. Every member of the staff team completed the survey, and we were delighted that our results were better than the majority of other organisations participating. We scored particularly highly in terms of clarity of vision, staff-motivation, teamwork, staff engagement and our customer/beneficiary-focus.

I am sorry to have to report the sad news that in the last three months, one beneficiary, Noel Thompson, sadly passed away in hospital. As we have not accepted any new beneficiaries to the Trust, the total number of beneficiaries now stands at 435.

Health & Wellbeing Update

As expected, we are seeing a lot of interest in the Private Treatment Scheme, and we are delighted to be able to provide this much needed support. To help us work with you to plan your treatment carefully and to make sure you have a smooth experience, we ask that your surgery is booked with at least eight weeks' notice. This gives us the time to establish all costs in advance and allow enough time for all funding options to be fully considered.

We are close to finalising our cardio-vascular risk assessment pilot project. This looks at how a non-invasive CT scan of the heart can be used to assess cardio-vascular risk for beneficiaries who have trouble getting reliable blood-pressure measurements. Non-invasive means that it doesn't need any needles or injections, just lying under a scanner for a short time. The initial feedback from beneficiaries who have taken part has been really positive and, once the project is completed, we will share the findings and recommendations with you all.

We met with Motability last month to discuss the challenges for beneficiaries who drive adapted vehicles as petrol and diesel vehicles start to be phased out in favour of electric vehicles. They are actively campaigning to raise awareness of the potential impacts on disabled drivers and we were able to alert them to a number of issues that weren't already on their agenda, including foot-steering. We had a really helpful discussion about ways we can work together to influence policy in this area.

We have had a lot of interest from researchers in our planned Pain Management research project. The closing date for tenders is 3 October and we will be shortlisting and carrying out interviews during October and hope to start the project before the end of the year.

In response to an increasing number of questions about cancer, we have produced two new factsheets – one general one (which covers key signs and symptoms of cancer, cancer screening and how to reduce the risk of cancer) and the other specifically on checking breasts. Both are available in the [resources section](#) of our website.

We are holding a webinar on health screening on 28 September and then later in October and November there will be webinars on Diabetes, with Dr Susan Brennan and on PIP with the Health and Wellbeing Co-ordinators who support you with your applications and assessments. As you know, we are keen to encourage you to consider claiming PIP before you hit retirement age, when your entitlements change.

And finally, to link with ‘Stoptober’ we will be including some [new information on the website](#), together with signposting to other helpful resources to support those of you who would like to stop smoking. We know that you smokers out there know what a difference it would make to your health if you managed to stop, so please have a look at the website and get in touch with us if you would like more advice and help to quit. We are looking to set up a beneficiary support group for those of you who would like to support each other to give up, so let us know if you would like to find out more.

Beneficiary Engagement

Following the letter we wrote to you in July, plans are moving ahead to introduce the new ways for Trustees to hear directly from more, and different, beneficiaries.

By the time you receive this update, you should already have received an invitation to register for our first Trustee Webinar which is being held on Monday 25 September between 5.30 and 6.30pm. Each Webinar will have a specific topic and the first one will be all about Beneficiary Engagement as we know from the responses to our recent consultation that a lot of you are interested in this and have questions about the new approach. Webinars are really easy to join using a mobile phone, tablet or computer. Just let us know in advance if you need help to get online.

We have also made progress in planning our new Beneficiary Insights Panel and will be writing to you in the next few weeks to explain more about the Panel and how it will work and to invite you to put yourself forward as a potential Panel Member. Trustees are keen to hear the views and lived experience of a wide range of beneficiaries so we really hope you will consider applying.

We have also begun to think about potential topics for Beneficiary Focus Groups and it looks likely that the first one we hold will focus on the current ‘hot topic’ of adapted vehicles and the challenges faced by beneficiaries as a result of the move to electric vehicles.

If you have any suggestions for future Focus Group topics - that would enable Trustees to understand issues that are important to beneficiaries in more depth - then please let us know by emailing engagement@thalidomidetrust.org

Beneficiary Events

Our local event in Wrexham in July went well and beneficiaries who attended and filled in the evaluation form were really positive about the day. As a result of feedback from beneficiaries in the

North-West, we included a session on 'Planning for the Future' for the first time - and this generated a lot of interest and discussion.

Our next local event is going to take place on Tuesday 10 October at the Queensferry Crossing (Doubletree by Hilton) Hotel. We asked beneficiaries in Scotland what topics they would like to see covered at the event and, in response to their answers, we are going to include sessions on Pain Management and Planning for the Future, as well as providing an update on recent changes and future plans at the Trust. Beneficiaries will also have the opportunity to have a short one-to-one meeting with a member of staff or Trustee.

You are all welcome to come to the event – no matter where you live! If you are interested in attending, you can find out more by emailing hello@thalidomidetrust.org or by calling **01480 474074** or you can [book your place on our website](#). You need to book your place by midday on **Friday 29 September**.

Finance Update

Shortly after our last Update, the DHSC confirmed the good news that Health Grant payments will increase each year in line with the Consumer Price index (CPI) which is the inflation measure that best reflects the sort of expenditure that you use your Health Grants for.

Those of you who drew down your Health Grant in full, will have received the additional payment automatically back in July. But if you haven't yet drawn down these funds and would like to do so, then just get in touch with the Finance Team and they can arrange this.

And Finally...

The beneficiary volunteers had their annual training day in Loughborough in August. They covered a wide range of topics including the support we provide for care assessments, incontinence referrals, and supporting beneficiaries with planning for their future. If you are interested in finding out more about volunteering opportunities within the Trust, contact Annabelle on **01480 474074** or by emailing annabelle.blackham@thalidomidetrust.org

Handwritten signatures of Deborah, Katy, and Suzanne.