

The Thalidomide Trust

DIRECTOR'S UPDATE

DECEMBER 2016

People News

I am really pleased to report that we have successfully recruited to the new position of Finance Co-ordinator (Beneficiary Support). Jeff Prevost will be joining the Trust on Monday 9 January with the important task of providing guidance and support to beneficiaries on day to day financial issues and longer term financial planning – as well as ensuring that we are able to meet the additional reporting requirements arising from the recent Department of Health (DH) Audit. Although he doesn't officially start work until January, Jeff came along to the recent NAC Conference and really enjoyed having the opportunity to meet some of you in an informal setting.

Another exciting bit of news is that Lucy Cummings is expecting her first baby in early May next year – possibly the first Thalidomide Trust staff baby? We are delighted for her but will obviously miss her whilst she's on maternity leave. We will be advertising for someone to provide maternity cover early in the new year.

We will also be advertising another new post in January – specifically to provide support to the small number of beneficiaries who lack capacity and to ensure that their needs are being fully met. This position was agreed with the DH as part of our post-audit discussions and is linked to the fact that many of these beneficiaries are not currently spending their Health Grants in full.

I am sorry to have to report the death of one of our beneficiaries. Neil Carter sadly passed away in early December.

I know it is not a very cheery subject but a little while ago I mentioned that a number of beneficiaries had asked me whether it was possible to find a better way of informing all of you when a beneficiary has died so that you can attend their funeral and/or offer your condolences to their family (as currently by the time you find out it is generally too late). Now that our new database is in place we are able to record this information, so I attach a simple form for you to complete if this is something that you are interested in. It also gives you the opportunity to tell us whether you would like others to be told about your own death.

NAC Election

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 Guy, Louise and Simone all reach the end of their current term of office – and we would like to encourage you to consider standing for a place as we feel it's important for new voices to be heard. If you are interested in standing, you will need to let us know by Monday 9 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) or Carolyn (cdesforges2004@aol.com) who will be happy to provide more information and answer any questions that you have.

Communication matters

A number of you have reported not receiving important emails from the Trust recently. This seems to be the result of us moving to a more up-to-date IT system which uses a bulk-mailing facility and many email providers tightening up their spam filters. The net effect is that Trust emails are either ending up in people's 'junk' or 'clutter' folders or are being completely blocked by your email provider. To prevent this happening, please can you ensure that you identify The_Thalidomide_Trust@mail.vresp.com as a safe sender and /or add it to your contacts list.

Some of you have also complained that you are not receiving regular emails updates from the Campaigns Team. This is because the Team only send these emails to beneficiaries who have 'opted in' to their mailing group. If you want to make sure that you are receiving all the information you want, please ensure that you have completed and returned a Communications Survey. You can request a copy of this from Lucy (lucy.cummings@thalidomidetrust.org).

Our new website (which some of you had a sneak-preview of at the NAC conference) is due to go live by the end of December. Initially it will just have the same content as the existing website- but in a more user-friendly format – but over the next 12 months we will be developing new web content and introducing new features and functionality.

Health & Wellbeing issues

The Health & Wellbeing team continue to provide information, advice and support to beneficiaries on a range of issues and the number of beneficiaries contacting the team continues to rise – with 1 in 2 of you contacting them in the 12 month period from 1 October 2015 to 30 September 2016. The two most common issues continue to be pain management and benefit advice.

We received a lot of positive feedback about our recent PIP awareness week so the team are planning another awareness week which will take place from 9 to 13 January. The aim will be to raise awareness of pain management, particularly living with chronic pain, and to highlight the information and resources available from the Health and Wellbeing team. We know this is an important issue for many of you, so please do check out the website in January.

Research

I would like to thank those of you who participated in our recent research into your experiences of healthcare and use of social care. The results are currently being analysed and these two research reports will be finalised early in 2017. Further topics to be researched in the next six months will be Falls/Loss of Balance, Emotional & Mental Wellbeing and Incontinence – all issues that were highlighted in last year's Health & Wellbeing survey.

The report of our recent research into loss of earnings was published last month and can be accessed via our website.

Campaign Update

The Campaigns Team continue to make excellent good progress in their campaign against the German Government. In my last update I reported that their three priorities were: to secure a meeting with Sir Alan Duncan (who now has Ministerial responsibility for Europe); to arrange for a Resolution in Strasbourg to further consolidate EU support; and to get a date for a back bench Debate in Westminster. I am delighted to report that they have succeeded in the first two and are making good progress on the third!

The meeting with Sir Alan Duncan – which took place in mid-November – was very positive and he offered to support the campaign in a number of different ways. In Strasbourg, there will be a short presentation on the Campaign on Wednesday (13 December) followed by a vote on Thursday (14 December) which will call on the German government to take responsibility for its illegal interference in 1970 and pay an annual sum to all survivors across Europe.

And finally we are hoping to have a (dubbed or sub-titled) English version of the documentary about the campaign which was shown on German TV available by the end of January 2017.

News about Diageo and the Department of Health (DH)

You should all have received an email or letter last week advising you of the outcome of the recent negotiations with Diageo. As I explained then, the arrangements for the one-off capital/health payment (of 1.5 times your Annual Grant in 2016) will be agreed by the Board of Trustees at their meeting in late January and I will write to you with an update then.

It is hoped that I will also be able to update you in January on the changes that are going to be implemented as a result of the current discussions with the DH, following the audit they commissioned earlier this year. A number of you have raised concerns that you will be required to keep copies of receipts for every item of expenditure (a return to the 'Bad Old Days') so I would like to reassure that this will not be the case. Going forward we will be asking you to tell us what you have spent your Health Grant on so that we can report back to the DH but this will only need to be in general terms and no evidence of expenditure will be required.

And finally....

I wanted to remind you that the Trust Office will be closed from 5pm on Friday 23 December through to 9am on Tuesday 3 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 20 December and 3 January you will need to contact us by Monday 19 December to let us know.

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

