

The Thalidomide Trust

DIRECTOR'S UPDATE April 2017

People News

It feels like there's been quite a few staff changes since the beginning of the year.

Lucy Cummings has now started her maternity leave (her little girl is due in May) and although we will miss Lucy, we are really pleased to have recruited Charlotte McCawley to provide maternity cover. Charlotte joined us at a particularly busy time and many of you will already have spoken to her as she has been dealing with a large volume of enquiries over the last few busy weeks – and has also been doing lots of skype calls to verify that beneficiaries are alive and well! We attracted a number of excellent candidates for the maternity cover position and one who really impressed us – Tara Rhodes - agreed to provide additional part-time admin support on a flexible basis. As well as providing general admin support as required, Tara will be specifically helping with arranging HNAs (which are very time-consuming) and providing support with the planning of events.

Jeff Prevost has now settled really well into the new position of Finance Co-ordinator (Beneficiary Support) and there are further changes ahead for the Finance Team - as Keith Hammond has sadly decided to leave us after three and a half years with the Trust, in order to achieve a better work/life balance. Although we are really sorry to see Keith leave, we are delighted to have recruited Lesley Hutchinson to take on this role. Lesley has a wealth of experience in financial management and reporting and will be starting in early May which will allow a short handover period with Keith before his last day on 4 May. I am sure you will join us in wishing Keith all the best for a relaxing future.

We have also recruited a new member of the Health & Wellbeing Team specifically to support those beneficiaries who lack capacity and are registered with the Court of Protection. Sarah Green started last month as Health & Wellbeing Coordinator (Complex Cases) and has already visited a number of beneficiaries and met their carers and deputies. We are delighted to welcome her to the team.

I am sorry to have to report that two beneficiaries have died since my last update in December. Stewart Pote and David Brewster both sadly passed away during February. Trust representatives attended both funerals.

You have already been advised of the outcome of the NAC Elections but I would like to take this opportunity to welcome Graham Kelly as a new member of the NAC and to congratulate Simone Illger and Guy Tweedy on being re-elected. I would also like to record my thanks to Louise Medus-Mansell who made an excellent contribution in the six years she represented you as a member of the NAC.

Health & Wellbeing issues

Thank you to all of you who have participated in the research that Firefly has undertaken in the last few months. A briefing paper on 'Access to Healthcare' is now on the [Trust website](#) and further briefings on 'Balance and Falls' and 'Incontinence' are currently being prepared. As well as being shared with the four UK Health Departments, the research findings will help shape the services and support provided by the Trust's Health & Wellbeing team.

The new Holistic Needs Assessments (HNA) process is now being rolled out across the UK – and to date almost 70 HNAs have been carried out by staff and trained beneficiary volunteers. The feedback from those of you who have had an HNA has been overwhelmingly positive – and 100% of those who returned a feedback survey have told us that they would recommend one to another beneficiary which is great to hear!

Changes arising from the Department of Health (DH) Audit

I would like to thank you all for your patience and co-operation whilst we have implemented the changes required to satisfy the DH – specifically the completion of Health Grant Declarations and the new arrangements to verify proof of existence. I appreciate that this has required additional work for you and caused confusion in some cases so am grateful for your support.

Please remember that, going forward, we may have to ask you what you have spent your Health Grant on so do make a note of things that you are spending money on to meet your health and wellbeing needs throughout the year (no need for receipts – just a brief summary of what you've spent your Health Grant on and the approximate cost).

Communication Matters

As you will hopefully have discovered, our Trust website now has a fresh new look, a lot of new content and is now easier to navigate – and you can also now request payments online. We have also incorporated lots of opportunities for you to share your experiences with other beneficiaries so please consider sharing your story with us.

The new website has very much been a team effort – but I would like to particularly thank Katy and Lucy who led the process and put in many hours of work.

Beneficiary Events

There are a number of beneficiary events coming up over the next six months.

The first is our first ever '**Beneficiary Open Day**' at the Trust's office in **St Neots** from 10am to 3pm on **Monday 8 May**. This was one of the suggestions that we received from the Beneficiary Feedback Survey last year and we thought it was a great idea! It will be a very informal day - with beneficiaries able to drop in when it suits them – and will give you a chance to meet the staff team, see what our office looks like and ask us any questions that you have. If you plan to come along please let us know as soon as possible so that we have an idea of numbers and can ensure we have enough refreshments and parking available for everyone. The day will not only be a great opportunity to visit the Trust and put faces to all our names, but also a chance to meet with other beneficiaries in a relaxed and informal setting, so I really hope you will be able to join us.

Following the success of last year's 'Fit for the Future' event, we are planning another one. This year's event will be held in **Liverpool** on **6/7 October**. Further information will follow but if you are interested in getting fitter and more flexible, please pencil the date in your diary now or register your interest with Michelle Robinson as we will be offering an "early bird discount" for those that book early

And, in response to feedback that some of you would like the opportunity to meet staff and other beneficiaries but find the idea of the Annual Conference too daunting – and some of the distances involved in getting there too much - we are also planning a smaller **local event** in **Glasgow** in **early July**. The date and venue are still to be confirmed but we will let you know when they are fixed. If it proves a success, we plan to schedule more of these local events around the UK, so watch out for us coming your way.

And finally....

We always like to receive feedback from beneficiaries – whether it is positive comments or suggestions on how things could be improved. We have recently updated our 'Concerns & Complaints Policy' to make it easier for you to share any concerns you have with us and ensure that you get a quicker response. You can see a copy of the new policy on [the website](#) or request that a copy is sent to you.

The trustees and NAC will be reviewing our Major Advances Policy over the next six months, so if you have views on this, please let us know or get in touch with a member of the NAC.

With best wishes
Lebarah