

# The Thalidomide Trust

## Director's Update – December 2014

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### **Trustee changes**

As well as changes to the staff team, there are a number of changes to the Trust's Board of Trustees. Three Trustees are standing down – Mike Napier, Job Curtis and Professor Oleg Eremin. All of them have contributed an incredible amount to the Trust in the time that they've been Trustees and we will miss them.

We have already recruited one new Trustee with legal expertise - David Body - and will recruit another two (one with medical experience and one with asset management skills) early in the New Year.

Marlene Winfield has been appointed to replace Mike as the Vice Chair of Trustees.

The 'Scientific Committee' is being re-named the 'Research Committee' to reflect better what it does and it was also decided that going forward there will be three Board meetings a year – in January, April and September – instead of two. The April meeting will focus primarily on strategic issues.

### **Financial issues**

The Trustees approved the Annual Accounts at their meeting on 5 December and they have now been filed with the Charity Commission.

The Trustees also agreed the grant levels for 2015/16 and I can confirm that the Annual Grant is going to increase by 2.29% and the Health Grant is going to increase by 4.57% from the 2014/15 levels. The reason that the uplift in the Health Grant is higher than inflation is that the Trust has reduced the level of overheads associated with this funding.

The amount you will personally receive is now available on the Trust website. Please let us know whether you would like all or part of this money paid into your bank account in April by email to [keith.hammond@thalidomidetrust.org](mailto:keith.hammond@thalidomidetrust.org) or writing to Keith at the Trust's office.

These grants will be paid on 7 April 2015 – straight after the Easter break – and, if requested, should arrive in your bank account by 10 April 2015.

As previously notified, there will be no supplementary grant paid in 2015.

### **Beneficiary news**

We accepted one new beneficiary in July this year and a further two new beneficiaries this month. Sadly, three beneficiaries have died in 2014 – Anne Gallagher, Brian Orr and Stephen Kirby.

In July, Roz Hepple received an award from the Order of Mercy for her outstanding contribution as a volunteer.

## **Health & Wellbeing issues**

We now have a new Firefly report which is looking at the health needs of beneficiaries and the impact of Health Grants – combining both survey data and findings of in-depth interviews with 40 individual beneficiaries – which will be finalised in the next few weeks and will go up on our website. We are also going to produce a short summary which we hope to disseminate widely.

Ethical approval has now been received for the blood pressure study at UCL so recruitment can start early in the New Year.

At the December meeting, the Trustees had a discussion about the need for a clear policy around helping 'beneficiaries in trouble' to ensure that everyone is treated fairly. This is going to be discussed further in April but in principle it was agreed that there should be a 'support plan' in cases where beneficiaries find themselves in a very difficult situation and there will be an agreed ceiling on the level of funding provided by the Trust.

It was agreed that, on this basis, the Trust should continue to provide support for Mark Gizewski's welfare while he is in prison in New York up to a financial limit of £5,000 in 2014/15.

## **Other news**

We were sad to hear of the death, on 23 November, of Jean Bennett who managed Haighmoor House hotel in Jersey where many beneficiaries had holidays in their earlier years.

As some of you are aware Linda Patching, Health & Wellbeing Team Administrator, is retiring in February next year after 13 years with The Thalidomide Trust. We all wish her a very long and happy retirement.



**Best wishes for Christmas and New Year from all the staff team**