

# The Thalidomide Trust

**DIRECTOR'S UPDATE**

DECEMBER 2015

## People News

I am delighted to be able to advise you that we have appointed two new members of staff since September. Katy Sagoe has been appointed as our New Director of Health & Wellbeing (replacing Michelle Hodson-Curran) and Emily Bates will be working alongside Anne Horton as our new HealthLink Co-ordinator. Both Katy and Emily have quickly become valued members of the team. Some of you will already have met them as they were both able to attend the NAC Conference in Durham this year and they have also visited a number of beneficiaries at home.

However, I am sorry to have to report that, after almost five years with the Trust, Louise Bayliss is moving on to pastures new. Louise's is the first voice that you generally hear when you call the Trust and I know that she has got to know many of you over the years. She is very sad to be leaving but she is having to move house due to a change in her family circumstances and is using this as an opportunity to make other changes in her life ... including exploring the possibility of becoming a foster parent. Louise's last day is 31 December so she will not be returning to work after the Christmas break. We will start the recruitment process for her replacement at the beginning of January to take advantage of all the people making new year's resolutions to get a new, and more worthwhile, job!

Unfortunately Eddie Freeman has had to resign as a member of the NAC due to family commitments but we would like to thank him for the contributions that he has made in his relatively short time on the NAC.

This means that we will be appointing five new NAC members in the elections next year – so please do consider whether you could become a member of the NAC, particularly if you have an interest in health and wellbeing issues. If you're not sure, please let us know and we can put you in touch with one of the existing NAC members to talk through what's involved.

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## Research

Thank you to all of you who completed the Health & Wellbeing survey in September. We received completed questionnaires from over 75% of you – which provides us with the most comprehensive picture of your needs, experiences and concerns about the future that we've ever had. Firefly Research are currently analysing all the data and a preliminary report will be produced for the Board of Trustees meeting in late January. As soon as the report is finalised we will ensure that you can see a copy if you're interested in the findings.

In January, the NAC will be sending out their first ever 'beneficiary feedback survey' which is an important opportunity for you to tell them what you think about the Trust and what you feel the Trust should be doing (and not doing!) to support you going forward.

And finally – after a number of delays due to operational problems at UCL – the first beneficiaries have attended the specialist blood pressure clinic in London as part of the Trust's blood-pressure study. There are a number of appointments scheduled over the next few months and our Health & Wellbeing team will review how these have gone before inviting more of you, who have trouble getting reliable blood pressure results, to participate in the study.

## Health & Wellbeing issues

It has become increasingly apparent that the current IBR process requires reviewing and modernising to meet your increasing needs. We know that the health of all beneficiaries is deteriorating but less than one third of you have had an IBR since the process was introduced in 2001 and the feedback is that the current review process doesn't address many of the issues that are of real concern to you. The Trustees have set up a small group to look at new ways of ensuring that the Trust understands and can respond effectively to the increasing needs of all beneficiaries. You will be receiving more information about what is being planned soon and will have a chance to provide feedback on the proposals.

The Trustees and staff are really keen to ensure that the Trust is reaching out to all beneficiaries and that we provide you with the information, advice and support you need to make decisions about your own health and wellbeing. This is reflected in the forthcoming 'Fit for the Future' event which is being planned by a small group of beneficiaries and is going to take place in Loughborough on 15/16 April next year. The aim of this event is 'to empower Thalidomiders with knowledge, and tools to enable them to make informed choices in order to maintain or increase levels of independence and promote pain reduction' and it will include practical sessions and lots of useful tips to help you develop the healthier and more active lifestyle that many of you want.

Applications are now being accepted for 'Fit for the Future' and you can also book your place for the one-day hearing impaired conference which is taking place on 6 February 2016 at the Park Inn at Heathrow. You can contact Michelle-Jane on 01480 474074 for further information.

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## Media & Communications Update

Many of you will have seen the recent story in the Sunday Times about the German Government campaign. Whilst the fact that the German Government have acknowledged that the Thalidomide component of the drug taken by your mothers was manufactured in Germany is an important step forward, there is still a lot of work to do. They are recommending that individual UK beneficiaries apply for funding from the Contergan Foundation (which is the German equivalent of the Trust) however we do not feel it is appropriate for each of you to have to go through the complicated process of making a claim – and we have also had feedback that it can be very difficult to get funds from them. We therefore want the Germans to accept a single claim on behalf of all beneficiaries who have been accepted by the Trust which will take some time and a lot more negotiation by the Campaigns Team.

In preparation for the Thalidomide storyline in 'Call the Midwife' – which airs on 17 January 2016 – the Communications Working Group has developed clear processes for dealing with media enquiries and we are also in the process of producing a simple media pack for journalists.

We know that some of you have links with local media in your area so if you are speaking to journalists please let us know so that we can keep a record. We can also let you have a simple briefing that we are pulling together for all media spokespeople which identifies the 'key messages' that the Trust wants to get across (bearing in mind the current campaign against the German Government and our forthcoming negotiations with Diageo) and also provides suggested answers to some of the tricky questions that journalists tend to ask.

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## Financial matters

**Life Assurance:** The original Trust life assurance scheme only offered beneficiaries cover up until the age of 55 so many of your life assurance policies will have already ended or will come to an end in the next 18 months. The new scheme that replaces it only offers cover up to a maximum of £50,000 (which is very low in today's terms) and the premiums offered are higher than other providers so we do not believe it provides good value for money.

When the Trust set up the original scheme it was because no-one was willing to offer beneficiaries life cover, but the life assurance market has changed significantly in recent years and a number of beneficiaries have been able to get good deals on life assurance from mainstream insurers. We are therefore encouraging all beneficiaries who have a Trust policy that is coming to an end to get a quote from an external provider before making the decision to renew their policy.

**Major grants:** The number of beneficiaries who are applying for major grants (which are not really 'grants' but rather 'advances' on future grant income from the Trust) has increased very rapidly over the last two years as many of you are considering changes to your living arrangements. At the same time, the number of beneficiaries who have found themselves in financial difficulty because they have borrowed more from the Trust than they can afford to repay – especially when something unexpected and expensive happens – has increased. The Trustees have therefore been looking very carefully at this issue and have introduced a number of changes to the way they review requests for major grants and, in particular, are requesting more information from individuals so that they can assess the affordability of any advances that they make. This is in order to protect both individual beneficiaries and the Trust's financial resources (as the amount of money we lend to individuals reduces the amount we have to invest for the benefit of all beneficiaries). An updated Major Advances Policy will be finalised and circulated in the new year.

**Fraud:** Unfortunately one of our beneficiaries was recently subject to a serious fraud attempt after someone intercepted his email account (possibly when he lost his ipad which was not password protected). Luckily the Finance Team spotted that the email request for a very large payment to a new bank account looked strange and contacted the beneficiary to verify this so the payment was not made. However this highlighted the ongoing risk of fraud and we are taking a number of steps to reduce this.

We will now verify any changes to your bank account details or requests for payments to be made to new bank accounts by calling you. We have also been advised by our auditors that the risk of fraud is increased if people have multiple bank accounts for payments from the Trust so over the coming months the Finance Team will be in touch with you to identify one single bank account that will be used for all Trust payments. You will of course be able to transfer funds into different bank account or to third parties from your own bank account yourself.

We would also ask you to make sure that you password protect all your electronic devices to minimise the risk of your email account being intercepted.

**Wills and appointment of a Power of Attorney:** One of the highest-rated sessions at the NAC Conference was the one that looked at financial matters and, in particular provided advice on making a will and on appointing a Power of Attorney to make decisions (on both financial and health issues) if you lose the capacity to do this for any reason. You will be able to see a recording of the sessions on the Trust website in the next couple of weeks and the two external speakers, Jody and Natalie, have offered to speak to any individual beneficiaries who would like advice on these issues. If you are interested, just let us know and we can put you in touch with one or both of them.

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### And finally...

As the festive season fast approaches, all the staff would like to extend their best wishes for a Merry Christmas and a Happy and Healthy New Year.

Please note that the Trust offices will close at 3pm on Christmas Eve and will re-open at 9am on Monday 4 January. If you have any regular financial payments during the closure period, these will be made as normal. However if you need any payments to be made between 23 December and 4 January you will need to contact us by Friday 18 December to let us know.

