



# The Independence

Thalidomide Society Newsletter August 2017

---

## News from the Board of Trustees

2016-17 has been a year of change for the Board of Trustees of the Society as we welcomed new Trustees and said goodbye to our Chair of five years, Edward Freeman, and the Secretary's Line Manager and Chair of Events, Claire Freeman. Ed and Claire felt that it was time to move on, let others take the reins and devote more time to their family. We will miss their humour and dedication to the Society but they assure us they will be at next year's AGM and Conference, sitting in the front row! Vice Chair, Geoff-Adams Spink will be stepping in as Chair until the 2018 AGM. Sadly too, trustee Liz Lash resigned from the Board earlier this year. The good news is that we have gained two new trustees: Stewart Lee and Kath West, both very welcome additions to the Board.

## Thalidomide Society AGM and Conference 2017

At this year's AGM, Marie Pearse gave a moving tribute to Veronica Lennon (known to many as Roni), who sadly died on 12 February 2017.



"Roni was a stalwart of the Society and was truly instrumental in helping to organise the Society's Merseyside branch. She knew what our parents were going through and knew exactly how to solve problems. Roni and husband Kevin were "rocks" to the Society in the 1970s and 1980s and travelled many miles to other parts of the country attending regional meetings to help and support our families as we grew from children into teenagers and then early adolescents." Marie Pearse.

Trustee Geoff Adams-Spink introduced the Society's Srey Hang project, which aims to support a 14-year old Cambodian girl born with autosomal recessive terta-amelia which has left her with extremely shortened arms, no hands or fingers and an absence of lower limbs. (Please see below for an update).

Contact us: [info@thalidomidesociety.org](mailto:info@thalidomidesociety.org)

020 8464 9048

The afternoon conference focused on ***Thalidomide in the Media***, chaired by Geoff.



***Thalidomide in the Media*** began with a premiere screening of *When Geoff Met Harry*, Geoff Adams-Spink's interview with the Society's patron, Sir Harold Evans.



Mikey Argy talked about *A Campaigning Life* and answered questions about being in the media spotlight.



There was a screening of Mat Fraser's stage, film and television showreel, *Actor or Freak?* produced exclusively for the Society.

Visit the new [Thalidomide Society Channel](#) on You Tube to view *When Geoff met Harry* and *Actor or Freak?*

The second session featured presentations from Kevin Donnellon (who sadly couldn't be there but his words and video were introduced by Geoff), Rosaleen Moriarty-Simmonds and Louise Medus-Mansell who gave poignant and unique insights into life growing-up in the media spotlight.



Contact us: [info@thalidomidesociety.org](mailto:info@thalidomidesociety.org)  
020 8464 9048

In the evening, thanks to the excellent auctioneering skills of Stephen Simmonds, we sold an original quilt made by Geraldine Freeman and two signed copies of Harold Evans' autobiography. This was followed by our traditional raffle. All proceeds were donated towards the Srey Hang project. The Board of Trustees were overwhelmed by the outstanding generosity of this year's delegates, particularly those who bid and won the auctioned items – you know who you are! A huge thank you is extended to everyone who contributed. Over £2000 was raised to help Srey Hang meet her current and future challenges.

## Srey Hang project update



The proceeds from the AGM and Conference auction and raffle are being overseen by Anthony McGarel-Groves, the Society's Honorary Treasurer, whilst we decide how best to use them for Srey Hang's benefit. We have established good communication links with Sisary Kheng, Country Director for Exceed Worldwide in Cambodia and Munichan Kung who works for MJP Asia. We are currently looking into getting two bespoke designed chairs for Srey Hang to use both at home and

in the classroom where she struggles to use the traditional desk and chair that her school provides.

In the meantime, thanks to an extremely generous individual donation from a Society member, funds are assured for Srey Hang's close friend to become her carer, making school life, personal hygiene and travel from home to school a safe and secure reality for Srey Hang, who continues to show great promise academically.



## Call the Midwife and Tracey's legs ...

Towards the end of 2016, the Secretary, Ruth Blue, was invited to the *Call the Midwife* studio to observe and advise on the script. On a second visit, which featured the limb-fitting sessions for the character Susan Mullucks, Ed and Claire

Contact us: [info@thalidomidesociety.org](mailto:info@thalidomidesociety.org)  
020 8464 9048

Freeman were also invited so that Ed could share his first-hand experience of limb-fitting sessions at Roehampton. The episode screened in March this year.

Also invited on both visits was Society member, Tracey Baynam and her daughter, Kelly. By coincidence, whilst discussing the new episodes of *Call the Midwife* with the writers, Ruth had been contacted by Tracey to ask if the Society would like a set of five legs that she had discovered in her mother's attic following her mother's death. They were designed individually for Tracey and spanned her age from 18 months to 12 years old. Not knowing what to do with them, Tracey was about to throw them in the skip.

Thank goodness she didn't! After collecting the legs from Tracey, they went on to make a guest appearance on the set of *Call the Midwife* and are now in the process of being donated to the Science Museum to go on display for 25 years as part of their new Medicine Galleries display due to open in 2019 (more on that below). Ruth later interviewed Tracey about the legs and the display will include extracts from that interview.



Some of Tracey's legs on the set of *Call the Midwife*



## Society website

The overall re-design and drafting update of the Society's website is now complete and we are developing the file store that will include documents restricted to Society members only. Please do visit the website and sign up for access to these restricted documents. Go to: [www.thalidomidesociety.org](http://www.thalidomidesociety.org) and click on the tab, 'File Store' where you will see instructions on how to register. We would love to hear any suggestions, feedback or other comments you may have, either through the 'contact us' option on the website or directly to the Secretary at the usual Society email address.

Contact us: [info@thalidomidesociety.org](mailto:info@thalidomidesociety.org)  
020 8464 9048

## Science Museum – call for prosthetics and aids

Over the past 18 months, Ruth has been working with the curators of the Science Museum Medicine Galleries, where there will be a thalidomide exhibition on display for 25 years from 2019.

The Science Museum are very keen to collect prosthetics and any other devices that thalidomide survivors have used or found important in their lives. Some of these will be selected for display but all will be housed and catalogued as part of their growing thalidomide collection. ***Please do contact Ruth for more information on this and if you have anything you would like to donate.***

## 2018 AGM and Conference – save the date!

The next Society AGM and Conference will be held at Hilton St George's Park, Burton upon Trent on **Saturday 14 April 2018**. Booking forms and further details will be sent out towards the end of November but we have confirmed presentations from Dr. Neil Vargesson, Institute of Medical Sciences, University of Aberdeen on the latest research into the chemistry of thalidomide and his research into the recent Primodos scandal. Selina Hurley from the Science Museum will talk to us about the thalidomide exhibition in the new Medicine Galleries and there will be an amusing compilation of clips from our oral history projects relating to the lighter hearted side of prosthetics.

## Other news

- The Society's **Parents' Oral History Project** is now nearing completion. By the end of the year, we will have collected over 20 interviews. However, we can always extend the project if you know of anybody who is interested in being interviewed that we haven't been in contact with. So please do let Ruth know.
- The first anniversary of the unveiling of the **Thalidomide Memorial** in Cardiff took place on 30<sup>th</sup> June at 2pm. Many thanks to Rosaleen Moriarty-Simmonds, Stephen Simmonds and Ed Freeman for making this happen.

- **Membership subscription fees:** at a recent Board of Trustees meeting, it was decided that when the next batch of paid subscriptions expires, we will no longer be asking for a subscription fee from our members. Everybody will automatically be transferred to life time membership. New members will still be considered for membership by the Board of Trustees, but no subscription fee will be charged.
- **Paying for the AGM and Conference:** unfortunately, due to Department of Health regulations, members can no longer pay to attend the AGM and Conference directly from their Thalidomide Trust funds as the Trust can no longer make third party payments on this basis. This means you will have to pay the Society directly from now on.

## Support the Society, Play the Lottery!

The Society Lottery has been up and running for three years now and as the number of players increases, so do the chances of winning. Anyone can play – friends, family, other organisations and every time you play you are helping to raise money for the Society.

It is really easy to sign up to play – click on the logo above, or go to [www.unitylottery.co.uk](http://www.unitylottery.co.uk) and select Thalidomide Society from the list of charities. If you don't like computers then please contact Ruth for a form to sign up by post.

## And last but definitely not least ...



The Society has now been on Twitter for a year – if you are too, please give us a follow and check our feed regularly! @ThalSociety