



The Independence

Thalidomide Society Newsletter, September 2018

News from the Board of Trustees

This year we were very sad to say goodbye to two of our long-standing trustees: Marie Pearse and Louise Medus-Mansell. Marie has been involved in many aspects of the Society's work for over 30 years – she has been Chair, Vice Chair, was instrumental in finding accessible venues on many occasions for AGMs and in recent years set up the Society Lottery, for which she is still taking full responsibility. We can't thank her enough for her many years of dedication to the Society. Louise has also occupied a number of key roles for the Society – Chair, Vice Chair and, perhaps most notably, she organised the hugely successful 2012 50th anniversary event in London. Her enthusiasm and dedication to the Society will also be missed.

After seven years of invaluable service to the Society, our Honorary Treasurer Anthony McGarel-Groves has resigned from his post for personal reasons. He has provided sound investment advice, enabling the Society's projects to flourish, and has been a vital and much relied upon presence in Board meetings. His professionalism, humour, generosity and warm heart will be much missed. As you can imagine, he will be difficult to replace but work is underway to find a new Treasurer as soon as possible with minimum disruption to our work; Brian Payne, the Chair of Finance, has taken over Anthony's duties in the immediate interim period but we hope to advise you on the appointment of a new Treasurer as soon as possible. The registered company address of the Society is now at the Society office address.

As well as goodbyes, we are extremely happy to welcome onto the Board three new trustees: Catherine (Cas) Bulmer, Guy Tweedy and Tom Yendell who are already making their mark, as you will see from this Newsletter and the Society's website.

The Society's current chair is Geoff Adams-Spink; our Vice Chair is Stewart Lee and the Line Manager to the Secretary is Kath West.

Thalidomide Society AGM and Conference 2018

This year, the Society's AGM and Conference was held at Hilton St George's Park, Burton on Trent. At the AGM, as well as the usual business of approving the minutes of the last meeting and the accounts, we asked those present to consider the following two changes:

Firstly, members were asked to consider the possibility of trialling a joint annual event with the Thalidomide Trust's National Advisory Council. This has been a subject under discussion since Ed Freeman's days as Society chair but has recently gained momentum. Trustee Brian Payne presented the pros and cons of trialling a joint event and all members (including proxy votes and comments from those not present) were asked to respond to the proposal. Although the result was not unanimous, the majority agreed to trialling a joint event. We had considered this as an option for 2019, but are now aiming for 2020 to allow more time for both organisations to consider the logistics required to make this a great event for both organisations.

Secondly, we asked members to consider changing the Society's status from a Company Limited by Guarantee to a CIO (Charitable Incorporated Organisation). Anthony McGarel-Groves outlined the reasons for the change: simpler and cheaper accounting processes and the opportunity to update the language used in the current constitution. This initial move was met with no objections and we hope to have a new CIO Constitution to present to members for voting on at the 2019 AGM and Conference.

Over the lunchbreak, all those attending were invited to have a cuddle with 'Baby Susan', the prosthetic thalidomide

baby featured in the TV series, *Call the Midwife*.



Society members meeting 'Baby Susan' from *Call the Midwife*. Susan is sporting a hand-crocheted dress made from a vintage pattern by Society trustee Wendy Stubbings.

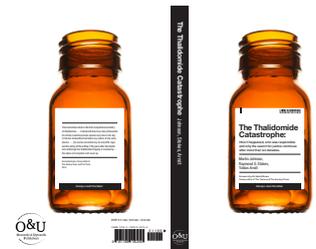
Photographs courtesy [Dave Laney](#), brother-in-law of Society member, Elaine Webb.

Our key afternoon speakers were Neil Vargesson (Senior Lecturer in Developmental Biology at the University of Aberdeen), Martin Johnson (former director of the Thalidomide Trust and author of the recently published book, *The Thalidomide Catastrophe*) and Selina Hurley (Curator of the new Medicine Galleries at the Science Museum). The conference day finished with an interactive discussion about prosthetic stories, led by Society trustees Stewart Lee and Wendy Stubbings.



Neil Vargesson's presentation, 'Thalidomide and the Forgotten Thalidomide: how did they do what they did?' consisted of a comprehensive look at the current research into explaining how thalidomide, and similar compounds, affect a growing foetus. Neil enjoyed meeting Society members and has said, after talking with some of us at the conference, that he has decided to undertake some new experiments - actual work in the lab to test out some ideas based on what he has been told by members at the Conference. He was particularly intrigued by the majority of survivors who have left-side upper limbs that are more affected than their right-side upper limbs – in many cases both limbs are damaged, but the left-side is more damaged. So he is now investigating this and seeking an explanation as to why this happens to the left side of the body. He has promised to report back on this.

Martin Johnson, in discussion with the Society's Chair, Geoff Adams-Spink, talked about his recently published book, [The Thalidomide Catastrophe](#), which was available for members to buy at the conference. They discussed his research and it is clear how much Martin's passion to unveil the true story of thalidomide has been driven by knowing and meeting thalidomide survivors - hearing your stories and understanding the desire for justice. The response of our members to Martin's book and presentation has been tremendous both in the qualitative comments he received and the quantity of book sales at the conference. If you'd like to order a copy of the book, you can now purchase it on [Amazon](#).



Selina Hurley gave a fast-paced, enthusiastic presentation about the plans for the new Science Museum Medical Galleries; showing, in particular, the role that thalidomide will play in these. This is largely through displays of prosthetics and everyday devices.

The icing on the cake was a fully interactive discussion led by Society trustees Stewart Lee and Wendy Stubbings with all members and speakers invited to participate.

They shared their own prosthetic stories and invited attendees to join in with theirs, which led to much hilarity and was a 'fitting' end to the day!

Throughout the day, trustee Wendy Stubbings collected bids for the new silent auction which featured original art works donated by our members. Thanks so much to Ed Freeman, Katrina Gardiner and Tom Yendell for their generous donations. We also held an auction after dinner for a weekend break in Flat Spaces, a crocheted throw made by Wendy and an exclusive trip to the *Call the Midwife* set. As with last year, we were astounded by the generosity of all members who participated in this. There was also fun with the Magic Mirror photobooth and casino tables.



Srey Hang project update



The proceeds from the auctions and raffle will again go to support Srey Hang and funds will continue to be overseen by the Society's Honorary Treasurer. Geoff and Ruth continue to liaise with Sisary Kheng, Country Director for Exceed Worldwide in Cambodia and Munichan Kung who works for MJP Asia and Brian is assisting with setting budgets.

We are so pleased to report that, with our help, Srey Hang has had a fantastic first year at High School and has come fifth in her class academically with an average score of 76%! The subjects she has learned include: Khmer, Morality, History, Geography, Maths, Science, Earth, English and Agriculture, with Khmer being her top mark and Agriculture her lowest.

With last year's money, we have covered the costs of accommodation and food for Srey Hang in a house close to the school, which is more appropriate for her and comfortable than the school dormitory. She stays there with two close friends (see photograph above), one of whom also assists her during the day. She has the light-weight wheelchairs we have provided for her as well as two specially adapted study chairs – one at home and one at school. The tuk tuk has been invaluable to her and her family.

In many ways, Srey Hang is a typical teenage girl and likes to 'fit in' with her peers so one of the challenges this year is to encourage her to start to use her mouth as a tool, so that strain and wear and tear on her spine and shoulders can be minimised. Her determination to do well, we are sure, will be her biggest motivation to try new things to make her environment more accessible for her.

Other news ...

Thalidomide Society wins Heritage Lottery bid!



We are so pleased to announce that the Society's bid for almost £100,000 from the Heritage Lottery Fund for our oral history project, has been successful. Our partners will be the British Library and the Science Museum and we aim to train up to 12 thalidomide survivors to interview around 50 thalidomide survivors. The completed interviews will be housed at the British Library sound archive and will provide valuable first-hand information for current researchers and for the future about the effects of thalidomide.

We will be looking for volunteer interviewers and interviewees, so watch out for more information on this very soon!

News from the Society's trustees ...

Skew-whiff: An Asymmetric Memoir by trustee Cas Bulmer

I have been working at writing my memoir for several years now and have attended several courses with the Arvon Foundation and The Guardian/UEA to try to improve my skills. My aim is to tell the story of the impact of three Distaval tablets on my whole family, particularly my parents. Whilst pulling in the bigger story, that is not my primary aim, as Martin Johnson's new book deals with the factual side/larger picture superbly well. Instead, I am going 'micro' to illuminate the 'macro.' As someone who 'only' lost one leg and a thumb, I am also well aware that I am only telling my own story and never trying to speak for anyone else affected by Distaval (thalidomide). We all have our own stories to tell.

I hope that you enjoy the extracts below and please do send any feedback to me through the Society. I am aiming to finish a final draft in the winter and plan to try and get Skew-whiff published. Thank you for taking the time to read on.

The first piece follows on from my early operations and eventual below-knee amputation. I have been going to Roehampton for several months and have learned to walk with my new prosthesis – Cas Bulmer, August 2018.

Extract from *Skew-whiff*, Cas Bulmer, Chapter 5: Seismic Shifts.



Soon I was back in Colchester and had a brief stint at St Mary's Kindergarden and Nursery School on Lexden Road. One summer's day, my parents took me to a strange building with two separate entrances marked 'Boys' and 'Girls'. We went into an office with a plaque on the door which declared that this was 'Miss Pritchard – Headmaster'. "Do come in and sit down," a small grey-haired lady with a bun and oval tortoiseshell-framed glasses ushers us into the room.

"Welcome to Hamilton Road Primary School," she smiles, "I assume this is Catherine?" She looks me up and down and I smile shyly. Looking around, the office seems very wooden – wooden shelves with lots of books; a large wooden desk and chair behind it. Somehow I am reminded of 'Wol' from the Hundred Acre Wood in my *Winnie-the-Pooh* books. My parents shift uncomfortably and I notice that we are all sitting on 'mini' school chairs made for six year olds rather than grown-ups. There is some talk amongst the adults and Miss Pritchard asks me if I like reading. I

enthuse about the animal books I enjoy. Then she puts both her hands on the desk in front of her and heaves her big wooden chair backwards, as if rising to her feet is a tremendous effort.

“Right. I’d like to see how Catherine manages the stairs now.”

Mummy holds her hand out to me and we all follow Miss Pritchard into the long main corridor of the primary school. We turn back on ourselves, towards the Girls’ Entrance, and, just inside the main doors, there are some concrete stairs that lead to the Juniors section of the school on the first floor.

“Catherine, I’d like you to walk upstairs now please. Just as you would at home.”

Ever eager to please, and especially keen not to annoy or disappoint my mother, I obey without a second thought. I am conscious that it is not ‘just like at home’ because my Mummy and Daddy and Miss Pritchard are all watching my every move. Very strange. The stairs are made of worn grey stone, uncarpeted so, again, nothing like the ones at home. Reaching up, I hold onto the dark wooden handrail on my left clambering up the stairs. I am quite nifty and can ascend one foot at a time on each step, placing my prosthetic limb carefully on the new level each time as Uncle Jack had taught me. I cannot grip with that foot so if I misplace it, putting my shoe on the edge of a step rather than flat onto the step itself, I might be liable to fall. Aged four and a half, I have no such qualms in my head and complete my first important ‘exam’ with flying colours.

Fortunately, I didn’t realise the ramifications of this seemingly simple task at the time. One false move, one slip, one nervous refusal or hesitation and I would not have been accepted into the best mainstream primary school in Colchester. My parents would no doubt have tried to get me into other primary schools but we would have encountered the same resistance and stair test. There was no legal requirement to educate disabled children at all until 1970; so the thalidomide affected children who had grown up in family homes were trail-blazers in the mid-1960s. Of course, my parents had made the most of their educational opportunities, they were both grammar school educated, and they wanted their young family to have the same chances.

Thalidomide Demographics - by trustee Brian Payne

There has always been some discussion about the geographical distribution of thalidomide-affected births in the UK and it’s been pointed out, by some members, that there was a prevalence of births in Liverpool and Scotland so I thought I’d do some research in the Society archives to explore this further.

Fortunately, we have an early Society membership book from 1967 and Ruth gave me an anonymised list of locations to work from. Of course, the location of Society members is not a 100% accurate guide to the distribution since some families did not join at all and it omits the birthplaces of those beneficiaries who have joined since these early lists. However, as a sample this membership list is not too bad an indicator.

So using the data from the 1967 book, I analysed the first address locations of the 454 member families and, based on a UK population of 55 million at the time, this gave a UK national average birth rate of 8.25 births per million of population (bpMpop). And yes indeed, Liverpool and Scotland do have a much higher than average prevalence of thalidomide births – 18.66 and 13.77 per million of population respectively. But they are by no means the highest. Amongst the nations of the UK, the highest rate is in Northern Ireland with 16.28 bpMpop and it is Bristol that just shades it as the city with the highest birth rate at 18.75 bpMpop. With regard to Liverpool, the nearby Wirral and the rest of Lancashire also have high birth rates, which is not the case around the Bristol. Oddly, this prevalence around Lancashire does not extend to Manchester, which is very low – only 2.92 bpMpop. Add in the rest of adjoining Cheshire, which is also very high and there are a total of 77 births – that’s one in six of the then entire membership.

What is very noticeable, and Harry Evans also noted it in his autobiography, *Good Times, Bad Times*, is that London is very low at just over half the national average – only 4.56 bpMpop. However, much of the surrounding ‘Home Counties’ – Surrey, Sussex, Kent, Essex, Hampshire, Berkshire, Buckinghamshire, Bedfordshire and Hertfordshire - have much higher rates than London.

Most strikingly are the extremely low numbers throughout all of the Midlands. Stretching from Lincolnshire, through the East and West Midlands to Gloucestershire, Hereford and Shropshire and including Derbyshire, there were only 37 births to members in this wide swathe of England. The entire area had a combined birth rate of only 3.66 bpMpop. Compare this to just Lancashire which alone had 59 births and Wales with 31. Yorkshire with a population similar to Lancashire, had less than half their rate – only 5.15 bpMpop. Meanwhile just further north, up the A1 in County Durham and Northumberland, the rate nearly doubles to 9.95 bpMpop. Over the Pennines, in the Lake District, it drops to a tiny 2.7 bpMpop.

Whilst there are such huge disparities between the areas of the UK there does not seem to be a single factor influencing these rates. Certainly there does not seem to be a relationship with poverty given that there are high rates in some leafy counties and shires and very low rates in some cities such as Manchester, Birmingham and London, where poverty can be high. The prescribing behaviour of GPs must be a key factor but why would it be so hugely varied? Did entire health districts adopt identical policies for wide areas of the country? And why did some cities have hardly any or no births e.g. Manchester and Middlesbrough and others so many e.g. Liverpool and Bristol?

The hotspot of Liverpool, Cheshire and the rest of Lancashire (excluding Manchester) begs to have some explanation as do the high rates in Northern Ireland, Scotland, Wales and the North East. I will explore further and anybody with any information, ideas or thoughts please do contact me through the Society office. I'd love to hear from you.

African Odyssey – My work with young people in Ghana by trustee Tom Yendell, based on an interview with the Society's Chair, Geoff Adams-Spink



When our son, Joe, was born 27 years ago, my mum worked as a volunteer in the local Save The Children shop and she encouraged us to take out a sponsorship for an African child. At that time, it was quite expensive - about £100 a year. We did this for about seven or eight years, and then I had a letter saying they were no longer doing individual sponsorship. We used to receive lovely letters and photos from our child every year, along with a report about how they were doing at school. That's why we did it: we wanted that connection with that particular child.

Then, the following week, I was doing an exhibition in Eastbourne. At the end of this very long hall there was a tall, white Englishman in an African chief's costume; in Eastbourne he looked so out of place! I later approached him and asked him what he was doing. He told me he was raising money to sponsor children in Ghana. I asked him how much it would cost and he told me, £10. I said, "No, I don't mean a month, I mean a year." He told me that £10 would sponsor a child to go to school for a year. This got me thinking about charity, and how large charities can waste such a lot of money. I put my £10 on the table and started sponsoring a child with Teabag. Teabag is the Education and Book Appeal for Ghana

This very tall white Englishman turned out to be an undertaker in Tooting, which is host to a large community of Ghanaians. Roger Gillman, the undertaker, had repatriated the bodies of many Ghanaians over the 30 years that he had been in the business. All he did though was send the bodies home - he had never actually been there. Then, in 2000, he had a knock on the door from a family whose grandmother had been buried by him. Their village chief had been over for the summer and he'd died in England. A group of villagers asked Roger to organise his funeral. He readily agreed before realising that the ceremony was to take place in Ghana and not in Tooting.

They wanted a top hat and tails funeral with him walking in front of the hearse. They told him that his expenses would be fully covered and, as he had never been to Ghana, he thought, why not? He did the funeral, and although he was pushed for time on his way back to the airport, he told his driver he'd always wanted to go for a swim in the Atlantic. His driver told him that they were very close to small village he knew with a beautiful, white sandy beach. So they stopped there, he stripped down to his undies and went in for a swim.

After swimming for a few minutes, he realised there were lots of children on the beach. As it was a Wednesday afternoon, he asked them why they weren't at school. They explained in broken English that, although there was a local school, they actually had to pay to attend. Although it didn't cost very much, most of them were from fishing families and they couldn't afford it. When he returned, being a rotarian, he persuaded people to start sponsoring children. And that's how Teabag came into being.

I would regularly receive a black and white newsletter which, to be honest, didn't look very professional. Eventually, I offered him my help. He told me he wanted to get Teabag registered with the Charity Commission. We set about doing that and I became a trustee and helped them with fundraising. Roger told me that I really ought to go to Ghana to find out how the charity worked in the field.

So, in 2007, I went to Ghana for the first time. It really changed my life. I'd never been to a poor, developing country before. I absolutely fell in love with the people and the place. I met the first group of 22 kids that we had supported through school. They were just about to leave to go off to college. I asked the headmaster what the future had in store for them. He told me that perhaps two of them might go off to university or college, if their families were able to afford or scrape the money together to do that. The majority, he said, would just go into the city and sell toothpaste or toilet rolls at the traffic lights. I just thought that was so silly after we had given them an education up until then.

I wondered where the nearest college was so that we could help the young people to complete their education. The headmaster explained that it was too far out of the village for them to go to. I convinced them to give me a piece of land and an old building and, ten years later, we have 160-170 students doing five different courses, graduating every year and going out to work. I go out to Ghana every January; I love it, it gets me out of the winter here in England and it's changing lives out there, which is wonderful.



Joel Acheampong; Ghana Mouth Painter who the Society supported this year with batteries for a new wheelchair



Roger Gillman TEABAG Chairman, Castro Amoah Principal of my College in Ghana and me

We are not stopping there - we have big plans for the future: our next stage is taking those students who are graduating and making sure they get into businesses, using the skills that we've given them. Whether it's getting them into jobs in the hotel industry, in a craft, or giving them equipment so they can start their own sewing business, or getting them the tools so that they can become builders, electricians, and so on.

At the moment, out of the 45 young people that graduated last year, 43 of them went into employment, but not necessarily into a job for which they had studied. We are going to get sewing machines and textiles for the seamstresses, equipment for the catering students or arranging interviews for them at the Holiday Inn. The next couple of years are going to be quite exciting.

I think my impairments give me a unique advantage when I'm dealing with officials in Ghana: when I walk into the room, people see a white, chubby man with no arms, they sit up and listen. Whether it's a government ministry or the Total garage head office or Coca-Cola's head office in Ghana, they pay attention because it's so unusual to find somebody who's unique like I am, standing up for their kids. I prostitute my disability, my uniqueness, as much as I

can in life, because I think that's why I'm here. I've never paid a bribe to anybody in Africa; I just say to them, "Look if you don't want to be involved, don't be involved. I'll go and find somebody else who wants to help."

To find out more about the work of Teabag, watch this YouTube [video](#) – (their website is currently under reconstruction).

Farewell to lifelong member of the Society, Heather Clark by Cas Bulmer

A Service to Celebrate the Life of Heather Alison Clark at The Pavilions, Harrogate, North Yorkshire 25th June 2018



Heather planned her own service during her eighteen months spent fighting terminal ovarian cancer. The Pavilions in Harrogate is a large venue, linked to the Great Yorkshire Showground where the annual Great Yorkshire Show takes place. Heather had appeared regularly here in happier times driving her pony, Barney, and trap. Originally, Heather drove as a member of the North East Driving Trails; but latterly she was a respected international paralympian-driver. Although Heather was Leeds-born and bred, the Pavilions in Harrogate was a beautiful setting for the service. The venue was light and airy on a blazing hot day and the room filled with about 300 people.

A smile was immediately raised by Heather's 'entrance music' – 'A Musical Joke' by Mozart, instantly recognisable as the music used for the BBC's show jumping coverage. The Rev. Jim Grebby spoke of meeting with Heather and of how impressed he had been with her spirit – the service was in a Humanist vein and The Eulogy was given by Gaynor Barnes, a friend and presenter from Heather's days working for ITV's local *Calendar News*. Heather's next choice of music was 'This is Me' by Keala Settle from the recent film, *The Greatest Showman*. An anthem for disabled people everywhere if ever I heard one and how refreshing for it to be sung 'loud and proud' by a female artist. An equally apposite poem entitled 'The Naughty Little Comet' was then read movingly by another friend and presenter, Christine Talbot. It was written at the start of the twentieth century by Ella Wheeler Wilcox. It captured Heather's 'I Can. I Will.' attitude perfectly.

The Tribute was read by Barry Hilditch on behalf of the North East Driving Trails. He charted Heather and Barney's meteoric rise through the Para-driving ranks. The trusty twosome competed in the 2004, 2008 and London 2012 Paralympics. The final Recessional Music was 'Who Wants to Live Forever?' by Queen.

Barney the skewbald pony was patiently waiting outside, in his showground finery, to bear Heather to her final resting place. This committal was reserved for family and close friends only but was followed by a buffet lunch and I had the pleasure of meeting Margery Anderson, 90 years young, who had been Heather's first school teacher. Margery told me how Tom Clark, Heather's Dad, struggled to find a school place for Heather. Margery happened to be manning the telephone on the day he rang her school and was instantly able to empathise and help as she was affected by polio, so disabled herself. Heather was then integrated without any problems and soon found roles for herself. Margery told me that, in all her years of teaching, it was Heather who made the biggest impression on her and she came back into her life a few years ago. The great news is that Margery is also now a member of the Society!



All the mourners enjoyed meeting Heather's wonderful pony, Barney. At 24, he is now being put out to grass, although a young friend of Heather's will continue to ride him every now and again.

Some will know Heather through her 'Wheels of Steel' blogs which were written during her recent time with cancer. Nine weeks ago, Heather was presented with an Outstanding Achievement Award at the Yorkshire Choice Awards and received a standing ovation.

Although I had only once met Heather back in 2002, I came to feel that I knew her through this very moving, personalised service and Margery's fond memories. Many tears were shed by the group of fellow thalidomiders who

were there to pay their respects. 'The Naughty Little Comet' poem's message is to live life to the full and eventually burn out, whilst those who are timid live on longer; but have seemingly less fulfilled lives. We can all take something from that. Shine on, Heather Clark.

Society website

Please do visit the website and sign up for access to these restricted documents. Go to: 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.

Our two most recent blogs are [Taking Control of the Narrative](#), Geoff's review of Martin Johnson's book and [Conferring – a Two-Way Process](#), Brian's review of the 2018 Conference and an extract from Chapter 7 of Cas Bulmer's [Skew-Whiff: An Asymmetric Memoir](#).

2019 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 6 April 2019**. Booking forms and further details will be sent out towards the end of November. In preparation for our joint event in 2020, we will also have some sessions from the NAC and Health and Wellbeing team at the Thalidomide Trust. More information and a full schedule will be available towards the end of the year.

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 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 three years – if you are too, please give us a follow and check our feed regularly! [@ThalSociety](https://twitter.com/ThalSociety)