

**NATIONAL ADVISORY COUNCIL**  
TO  
**The Thalidomide Trust**

**Newsletter**

**Autumn 2016**

Welcome to the Autumn 2016 Edition of the NAC's Newsletter.

I promised you a full edition last time, and here it is.

A pretty familiar recipe is followed, for our newsletter I focus on what we've been up to as a group, and this is interspersed with news from individual beneficiaries as well. There are numerous highlights, which include:

- We invested a lot of time and energy as a group into the "Fit for the Future" event, and there's a report as well as two articles from attendees.
- Health and Wellbeing Committee provide an update on their activities, there is feedback from the beneficiary survey, and an update from the campaign team.
- Call the Midwife ran Thalidomide as their storyline, and a thought provoking article (from an angle I haven't considered before) is also included.
- You'll also find an update from the Thalidomide Memorial - To remember is to care ceremony.
- An article from the Thalidomide Society on parents' oral history.
- Details of our forthcoming NAC Annual Conference.
- Plus more besides ..... 😊

If you wish to receive campaign updates by email, please let the Trust staff know by emailing [hello@thalidomidetrust.org](mailto:hello@thalidomidetrust.org) so that you are included in our distributions.

Thank you to Simone Illger who has helped source information for this edition, to ensure we could meet our publication deadline.

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Please enjoy reading..... AND,if you've something you'd like to contribute to the next newsletter please contact me.

**Karl Davies – Newsletter Editor**  
[DaviesKB@aol.com](mailto:DaviesKB@aol.com)



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# Chair's Update

Welcome to this latest edition of the NAC newsletter. I am so grateful to Simone and Karl for getting together this edition with the usual variety of articles – so well done to them both.

As ever, the NAC would love to hear from you if you have any questions or comments about our work.

## NAC – our year to date

It has been a busy year for me and indeed for the whole NAC. Although I've named some individuals, all have contributed to the overall efforts of the NAC, so apologies in advance if I have not named someone I ought to have.



We started off the year with the Beneficiary Feedback Survey with an extremely good response rate of 70%. I have presented the highlights of the survey results (for those who want just an overview) along with a link to the survey results in full (for those who want to see it all). I appreciate that I have taken a while to get the results to you and I know that maybe you were thinking this was going to be like the Chilcot Report taking seven years! The NAC and the Trustees have taken note of the survey results and I know from attending the Trustee Board Meetings that the survey results are taken very seriously by the Trustees.

We had an Awayday in June, when we covered three things:

- (i) the survey results out of which came a number of action points and these will be discussed further at the November NAC meeting;
- (ii) the Diageo talks – Nick Dobrik and I were given a mandate by the NAC for our main 'asks';
- (iii) and, lastly, we did a SWOT (Strengths, Weaknesses, Opportunities and Threats) analysis in which we focussed on our strengths and weaknesses.

On the Diageo talks, there is little I can say at this stage – we have met with Diageo on a monthly basis (except July) and we have further meetings in October and November, so hopefully it is a case of 'watch this space' towards the year end.

On the SWOT analysis, we identified that we need to think about aspects of conduct, governance, along with planning/inclusion to build on our existing skills, determination and commitment; and we will be working on these next.

We have been active on work in a number of areas of which I will highlight the following:

- Conflicts of Interest/Declarations of Interest policy – a Register of Interests for the NAC members and other beneficiaries in non-NAC roles (e.g. non NAC members of the Campaign Team) will be published shortly in the beneficiary area of the Trust website;
- NACAC planning (for Saturday 26 November), the working group has been led by Simone (many thanks);
- DH Audit Working Group – at the suggestion of Nick (Shadow Finance Team Leader), a working group has been formed to look at the issues of the PwC audit commissioned by DH. Mikey and Phil have represented the NAC on this group;
- The Communications Working Group continues to meet;
- Fit for the Future event – very much a NAC event with everyone contributing in one way or another being led by Simone (again many thanks);
- The Shadow Finance Team and Health & Wellbeing NAC sub-committee, joining up with the Health & Wellbeing Trustee committee, continues to work with the Trustees.

## NAC – vision/goals work ahead

A key area of work ahead for the NAC (working collaboratively with the Trustees and staff) will be developing a strategic plan to enable us to achieve the Trust's agreed Vision and Strategic Goals. In brief, there will be a five-year plan for each of five individual goals which will together form a jointly-owned strategic plan for the Trust. Each goal has a working group wherein NAC members will participate alongside Trustees and staff in a truly collaborative manner for the community. This work is starting in October with a view to produce a strategic plan by next May.



## Campaigning, and, Guy Tweedy

The members of the Campaign Team continue to work relentlessly on our behalf, and I thank all on the team, as well as others who help from time to time – Nick, Guy, Mikey, Craig, Stuart Kenworthy, and Liz Buckle. The latest Campaign Team update will give an update on their activities.

I want to take the opportunity to talk about a particular individual in these newsletter forewords (whilst I write them) and, this time, I want to pay tribute to Guy Tweedy. He has been involved in the campaigning for us right from the start.....

2002 – towards end of 2002, Guy met Nick for the first time, in Parliament, for a debate about the unfair tax treatment we received. Although neither Guy nor Nick had campaigned before, they decided to campaign for us.

2004 – the tax exemption that we all (in UK) enjoy was announced – it took just 18 months for this to be achieved – Guy was there right at the beginning.

2004 – around the same time in 2004, Guy with others approached Diageo to ask for more funds (despite sceptics in some quarters).

2005 – towards the end of, a new Diageo covenant was announced which marked the beginning of a new understanding between Diageo and the Trust – again Guy was involved.

2006 – 2008 Guy with others went to Germany several times and did much to improve things for the German Thalidomide survivors – again Guy was involved (we should remember that the travel expenses was self-funded and not from the Trust).

2008, the Campaign Team began to ask the UK Government for an ex-gratia payment and it is from this that the 3-year health grant pilot and the 10-year health grant extension resulted – again Guy was involved.

Over the last few years the Campaign Team, as you know, has turned its attention to the German Government – again Guy is involved.

Guy's other activities, which can't go unmentioned, are his campaigns for the release of two beneficiaries from prison overseas - one in the Philippines and the other in the US. This demonstrates his passion for others in difficult situations. Oh and lastly, Guy has got us eligibility for the Disabled Railcard scheme (I make lots of use of mine!).

Guy, ..... THANK YOU.

**Rowland Bareham – Chair**

# Beneficiary Feedback Survey

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Rowland Bareham

The last eight or nine months have seen plenty of activity as well as some changes for the NAC's Health and Wellbeing Committee

In January/February 2016, 467 invitations were sent for the Beneficiary Feedback Survey. The number of completed questionnaires received back was 326, including 200 by post and 126 online. There were 303 from the UK and 23 from the rest of the world. That means a response rate of 70.0% overall, 70.5% from the UK and 63.9% from the rest of the world.

Thank you to all who responded.

As promised, following the presentation of the results to the NAC and the Trustees (and further consideration at a NAC Awayday in June), here are both the highlights, followed by the full results for those who would like to know more.

## The highlights

### Questions about most recent contact with the Trust (Q1/Q2a/Q2b)

86% were either very or fairly satisfied with their most recent contact(s) with the Trust, with good comments in Q2a given as to why they were satisfied. A small number commented in Q2b on why they were dissatisfied – poor service, too business like /cost conscious or missed appointments.

### Question about use of Trust services/resources/events (Q3a)

Most beneficiaries seem to be aware of the various Trust services/resources with varying degrees of actual use or participation.

### Question about satisfaction of use of Trust services/resources/events (Q3b)

The percentages of satisfaction (very or fairly) with services/resources used/attended are very good.

### Statements of different opinions of the Trust (Q4)

There are two statements where there is not more than 2/3rd agreement (strongly/slightly):

- treating everybody fairly (62%);
- producing more written information (41%)

### Statements on thinking about the future of the Trust (Q5)

There are three statements where there is not more than 2/3rd agreement (strongly/slightly):

- continuing with the Volunteer Visitors scheme (52%);
- doing more to enable beneficiaries to keep in touch and share information (58%);
- considering arrangement group holidays (33%).

### Statements about the Trust (Q6)

There is at least 2/3rd agreement (strongly/slightly) for all the statements.

### Questions asking about changes/openness/ideas for the Trust or the NAC (Q7/8/9)

It seems that there is little call for the Trust or the NAC to change or be more open about or otherwise. Our social researcher has observed, that with these free text responses to the open-ended questions 'the opinions of beneficiaries are extremely fragmented. The majority of suggestions seems to come from only one or two people. Only a small number of suggestions seem to have more than half a dozen saying the same thing. This seems to reflect the fact that there is a massively diverse range of experience and circumstance within the beneficiary community'.

### Questions about NACAC (Q10/11)

It would appear that there is no particular strong view about having a national conference every two years or having regional meetings. When it comes to deciding on a venue for events, London, Manchester and Birmingham are the most preferred, with Newcastle, Edinburgh and Glasgow the least (with Bristol and Cardiff in the middle).

The NAC had an Awayday in June and had identified a number of action points. These will be discussed further at the November 2016 NAC meeting and I will report back to you further afterwards.

## The full report

For those of you who might wish to explore some of the feedback in more depth, you can see the report on the beneficiary website: <http://www.thalidomidetrust.org/wp-content/uploads/2016/10/Item-2.2-Beneficiary-feedback-survey.pdf> or alternatively call the Trust to request a hard copy.

# Health and Wellbeing (H&W) Committee

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The last eight or nine months have seen plenty of activity as well as some changes for the NAC's Health and Wellbeing Committee

## H&W Meetings

At the NAC's September 2015 meeting, it was proposed to combine the Trustees and the NAC's Health & Wellbeing (H&W) Committees to avoid duplication of work and to cut down on the number of committee meetings that the NAC's Chair of H&W attends and prepares papers for (currently around 8 or 9 a year). This merger is being trialled for a year initially.

## The NAC's co-option of Susan Kent

Since Sue Kent's retirement from the NAC in 2014, she has continued to work as part of the planning team on the organisation and delivery of Fit for the Future. During that time, she has also worked with Health & Wellbeing staff at the Trust on suitable exercise regimes to assist with the alleviation of pain for beneficiaries (Pilates). Following a presentation to the Trustee's H&W by Bjorn Hakansson, Sue was tasked with producing a video demonstrating the benefits of working on a one-to-one basis with a pilates instructor with commentary provided by a physio to describe what the individual exercises are achieving.

Sue's level of involvement has been formalised by co-opting her to the Health & Wellbeing committee where she'll be involved in all discussions relating exercise and pain relief methods suitable for our beneficiary cohort.

## Volunteer Visitor Role on H&W

Over the past 18 months, one of the Trust's beneficiary volunteers (Marianne Tharby) has been attending NAC H&W meetings as an observer. This allows for greater collaboration with our volunteers in H&W work.

## H&W Projects

### Neuropathy Study

The research report has been updated in the light of the independent review commissioned by the Trust. The study has been published and a copy of the article is on the [Trust website](#).

### 2015 Health & Wellbeing Report

As you will be aware, the finalised report produced by Firefly Research has now been published and a four-side summary of the key findings was sent to all beneficiaries. A shorter summary has been sent to the four UK Health Departments and Diageo – and so far a presentation of the findings has been given by beneficiaries to Diageo and to the English and Scottish Health Departments.

Some of the target audiences for the summaries include physiotherapists, disability media, Royal College of Occupational Therapists, and social workers. Katy Sagoe is making enquiries to ascertain what format would be preferred by these groups, and it is hoped that some of these groups will at least publish a link to the report on their websites.

A number of topics have been identified for further analysis. This will involve Firefly undertaking both further in-depth analysis of the data gathered in the survey and further qualitative research (i.e.: surveys, telephone interviews or focus groups). These include:

- Pensions and Loss of Earnings (now completed – see below)
- Social Care (access and use of services)
- Experiences of Healthcare services
- Housing
- Incontinence
- Emotional and mental wellbeing
- Falls and loss of balance.

### Pensions and Loss of Earnings

Ahead of the recent Health & Wellbeing survey, an “expert advisory group” was established working under the umbrella of the Research Committee. It enabled further questions about pensions and beneficiaries present and past employment status to be included in the questionnaire. Kevin Wesbroom and David Body (Trustees) are involved in this area of work along with Mark Tempest (who is a personal injuries lawyer) who has agreed to work with the Trust on a pro bono (no charge) basis.

A short survey was conducted amongst beneficiaries who agreed to be involved in further research and have changed their work pattern to identify the scale of the problem. Around 10 beneficiaries individual situations were be examined in much closer detail to work out specific losses. The findings of this research were presented to Diageo in August at one of the series of negotiation meetings.

### IBR review & development of a new assessment tool

Carolyn DesForges, Rowland Bareham and myself were part of the working group looking at the results of the IBR Review and also working with Katy Sagoe on a new assessment tool. The new Holistic Needs Assessment (HNA) tool has now been finalised, a group of staff and beneficiary volunteers have been trained to use it and it has been piloted with eight beneficiaries (four in England and four in Wales).

As you can see, the work of the H&W committee is vast. I hope to report continued progress over the next year, and I look forward to updating you in the next newsletter.

# Fit for the Future, 15th – 17th April 2016

The event took place at Burleigh Court Conference Centre, Loughborough, where a total of 27 beneficiary participants attended.

Around four of the participants who attended had never been to any kind of thalidomider organised event before.

Two participants had indicated they needed some support in order to fully participate and be away from their usual care giver and this support was provided.

One participant had never been into a pool before, but the support to assist them to get into swimwear meant that they were able to get into a swimming pool for the very first time! With support from the Thalidomide Trust staff, this participant has gone on to find swimming lessons locally so that they can continue with swimming.

Everyone who attended gelled really well and this was helped by the fact that there were four small workshop groups (9 or 10 in each) who remained together for the whole afternoon.

Feedback received during and after the event suggested that participants had thoroughly enjoyed the interactive workshop groups with the opportunity to try out exercises and exercise equipment, Pilates exercises, self-massage techniques, learning simple stretch routines, physio exercises and diet and nutrition.

In terms of diet, feedback was that participants would have liked more specific information – about BMI, the amount of calories they should be eating, the sorts of food they should be eating and portion control. This is something that we can look at as a topic for a future event – either a future Fit for the Future or perhaps at a NACAC.

Since the weekend, a number of information sheets have been produced:

1. Physiotherapy, massage & massage equipment
2. Other treatments and exercise for pain
3. Disability, obesity and weight Loss
4. Exercise, exercise equipment and personal trainers
5. Emotional wellbeing
6. Professionals list (list of physios, masseurs, pilates teachers, etc, with experience of treating thalidomiders).
- 7.

These information sheets are available on the beneficiary website:

<http://www.thalidomidetrust.org/?s=fit+for+the+future>

or by contacting Michelle Robinson at the Trust: [michelle-jane.robinson@thalidomidetrust.org](mailto:michelle-jane.robinson@thalidomidetrust.org)



A video showing the Genny Segway wheelchair being used on a sandy beach as well as another video of a beneficiary using his off road Genny generated a huge amount of interest. You can read more about the Genny here:

<http://www.gennymobility.com/uk>

The suppliers of the Genny will be at the NACAC 2016 event at Park Hotel Radisson, Heathrow (see more details of the event in the article 'National Advisory Council's Annual Conference')

A film made at the event was made and will be shown at NACAC 2016. The Trust can make available full footage of each of the speakers, along with written transcriptions and a copy of their PowerPoint presentations for anyone who would like this.

Ahead of the event, a Facebook Group was established for those registering for Fit for the Future. This enabled those subscribed to the page to share ideas on equipment, exercises, etc. Amongst the members of the group are around 5 or 6 very active members, three of whom have reported losing over a stone in weight since the weekend (6 months!) Others are sharing their weight loss, body measurements and the types of exercise that they have found to do and equipment that can help with this.

There are plans to have a second Fit for the Future event in 2017 – the Thalidomide Trust will let you have more details as and when these are available.

Take a look at the reports below by Geraldine Freeman, and Kath West, who share their experiences at this event..... It was fun, and we'd love to see you at future events!

**Simone Illger – Chair, Health and Wellbeing**

# Fit for the Future – Geraldine’s experience

Geraldine Freeman

Five years ago I got on the scales and was horrified at what I saw. I decided I had to do something which I did... I lost a stone in weight.

That changed so much for me as my movements and transferring from my wheelchair all became easier...pain was less and I found I was not as tired and sluggish I felt great... BUT then I stupidly allowed the weight to pile back on (and more). When I attempted to diet as I have done so successfully in the past, the weight just wasn't shifting.

I took on a personal trainer to see if the exercise might help, but although that helped me with aches and pains, the weight wasn't going down. I had to admit, begrudgingly, that perhaps my age just might have something to do with it.



When I was invited to join the Fit for the future weekend I jumped at the chance! Like many, I have been struggling with my weight for some years. I was seriously struggling physically, lifting myself ...transferring to and from my chair was becoming a real effort, even simple tasks like getting dressed was becoming hard work. I was fearful I was losing the bit of independence I had.

I thought it would be a good idea to invite my friend and personal trainer Rachel to accompany me on the weekend. Because Rachel has worked with me for some time she has got to know my body quite well, so we'd both derive benefit from attending the weekend

We all met up on the Friday evening which was quite a nice social gathering. It also gave us a chance to chat about our individual issues. For me it was nice to know I wasn't the only one struggling.

Saturday morning we gathered for a welcome talk. Our first speakers were Anne-Carin Lagerstrom and Hanna Isaksson who came over from Sweden especially for the weekend to talk to us about healthy eating. They spoke about food and diet and why what we ate and how much was so important. Our next speaker was Dr Nic Webbhorn who was really interesting. Nic specialises in helping people after accidents/illnesses to get moving again in sports or just any form of exercise. He talked about how any form of exercise was so important even if it was just a little was better than none at all.

The afternoon session was taken by our very own Sue Kent who talked about the benefits of regular massage and stretching. I found her talk very helpful and have since used her many suggestions and feel I have benefitted. Sue is one of us, so therefore very much understands our bodies. We also had an excellent physio, Carol Adkins who again specialises in helping people after accidents/illness and in some cases who have very complex physical problems.

We then had exercise sessions which were broken up into four different workshops, which I have to say was very enjoyable. Part of this session was taken by a Thalidomider's daughter who is a professional personal trainer. She also understands our bodies, growing up with a parent with physical difficulties. She tailor-made exercises that many of us could manage with the odd adjustment here and there.

We then had a chance for those who wanted to have a swimming pool session, which was simply unbelievable, virtually everyone took part. Someone who had never been in a pool even joined in, it was so much fun... there was a great deal laughter and it was noisy and crowded with us lot. Simply brilliant!

I feel I have gained a great deal from the weekend and since due to the Facebook page which was set up where we get a great deal of ongoing support.

I know I'm not the only one who enjoyed the weekend which was very well organised. I hope we can have a follow up weekend so we can share what we have achieved and maybe where we are still struggling. It would be good to have some newcomers. Don't be scared or self-conscious – you're not on your own and you will get a great deal of help and support. It was not just for weight issues. It was a WELL BEING weekend. Feel good about yourself.

## Fit for the Future – What did Kath West think?

Q&A with Kath West

Kath West, one of the participants in the Fit for the Future weekend, told us about her experience

### What made you decide to register for the FFF weekend?

*I knew I needed to take my diet and health in hand as I was getting seriously worried about future mobility and my back.*

### Did you have any worries before the weekend about what was planned? What concerns did you have about joining in the planned activities?

*Only that I knew very few people who were attending and that I might need some assistance. I didn't have any concerns about the activities planned.*

### What did you find most useful in the talks and workshops?

Pilates, self massage techniques.

### Can you tell me about some of the exercise equipment that you found useful / interesting?

Resistance bands and TRX

### Is there anything that you didn't enjoy?

The nutrition workshop (I was hoping to get more of an idea how many calories I should be eating, or the tools to work it out for myself).

### Did you come away with any plans to change your lifestyle?

Most definitely - dieting, more exercise, joining a health club.



*Kath tries out resistance training bands in one of the workshops*

**What changes have you made to your lifestyle resulting from the weekend?**

As above. I've not yet managed to achieve the last one yet!

**Have your family noticed any difference in you since you returned?**

Yes, that I'm moving better and not as tired.

**Would you like to attend a similar event if it was planned?**

Yes definitely – it was great fun.

# A diagnosis – HYPERTENSION

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Mandy de la Mare

In September 2012 I had upper eyelid surgery and it was at this time I discovered that I had high blood pressure. Before you have any surgery your temperature, pulse and blood pressure are all checked and my blood pressure reading was high. The anaesthetist suggested that I went to see my GP for a BP review.

I went to see my Doctor a week after surgery and told her what the anaesthetist said. The Doctor sent me to see the practice nurse who dealt with blood pressure because at that time my Doctor was unable to take the blood pressure herself, when it had to be taken during my pregnancies it was the midwife that took it.

I went to see the practice nurse shortly afterwards and she showed my mum how to take the blood pressure on my lower leg. The nurse suggested that I sat on a chair with my leg elevated for 10 minutes or so before taking the blood pressure, which she did and then took three readings, all were extremely high. The nurse went on to suggest that we borrow one of their blood pressure machines and take blood pressure readings in the morning and evening for a week and then come back and see her. This we did following the instructions that she gave us and this confirmed my blood pressure was extremely high. With this news the nurse suggested that we went back to see the Doctor to see what medication would be best to address this problem.

I went back to Doctor who agreed that I needed to be put on medication but because it was so awkward to get blood out of me she suggested that they treat my high blood pressure with beta-blockers and water tablets. These particular drugs avoid the need to take regular blood for testing purposes unlike other more conventional blood pressure tablets. I did start on the beta-blockers and water tablets which did lower my blood pressure to a more acceptable level but this did take quite a while playing around with the different strengths.

However, as I got more and more used to these drugs my blood pressure started to climb back up, I commented to Dr Dee Morrison at the Trust the problems that my Doctor was experiencing controlling my blood pressure. It was at this point that Doctor Dee suggested that I take part in the blood pressure project that the Trust were going to run at the University College Hospital in London by Prof Bryan Williams.

I attended a consultation to Prof Bryan Williams in February 2016 at the University College Hospital in London. The first thing that I noticed was that when taking my blood pressure in clinic they sat me on an examination couch. Immediately the readings were much lower than those experienced in the Doctors surgery and at home. The nurse also showed us exactly where to put the cuff for the blood pressure machine on my lower leg making sure that the sensor in the cuff was over the main artery in my lower leg.

Prof Bryan Williams took a comprehensive medical history from me and I showed him a current list of my drugs. He immediately noticed a couple of drugs that could have been exasperating some of my issues, i.e. high cholesterol, and not helping to control blood pressure. He stopped a couple of the drugs immediately and put me on a proper blood pressure tablet. I mentioned to him that my Doctor would not be happy having to take blood from me for testing on a regular basis. The Professor said “he would have to get over it and he would have to treat me” I have to say that pretty soon after I started to take the new drug my blood pressure was the best it has ever been and often reads normal which I have not had for a long time.

I think if there is something I have learnt out of all of this it is that you should not allow the Doctors to take the easy option just because it makes life easier for them, sometimes this could be detrimental to your own health. Just because things are difficult to do on us i.e. taking blood this does not mean that we should receive second-rate treatment.

Me - I'm lucky because my Doctor used to be an anaesthetist before he became a GP so he is willing and quite able to take blood from my groin which most GPs won't do. Before his arrival at my Doctors practice I had to go along to the local hospital and wait in A & E for an anaesthetist to come and take blood. I do understand that sometimes it is going to make more work for us to get the best or most appropriate treatment.

Maybe I should have been more proactive in my Doctors surgery and insist that I had the same opportunities as the other women patients in our practice who were all invited for regular health checks at certain milestones in their lives and which I was not, possibly because they all dreaded having to take my blood pressure and blood samples. This is quite worrying when you realise that the only reason I learnt about my high blood pressure was due to a chance surgical procedure and the anaesthetist involved telling me that my blood pressure was too high. I had no idea and was not experiencing any symptoms that might have made me think I had high blood pressure.

# Parallel London 2016 – 4th September 2016

On Sunday 4th September and after a day of rain, the sun was shining as four Thalidomide beneficiaries congregated at the accessible and iconic Queen Elizabeth Olympic Park in London.



Susan Kent, Simone Illger, Carolyn DesForges and Liz Buckle decided to participate in the very first “Parallel London” event after hearing about it from Sue Kent, who had been a big part of helping to organise and publicise the event. The group were accompanied by friends, family members and other supporters.



Parallel London was an inclusive push/run event, with participants being able to choose their own distance: 10k, 5k, 1k, a Super Sensory 1k and 100m. In the words of the event organisers “Run it, walk it, push it, be pushed. Anything goes.” The emphasis was on taking part, so was for people of all abilities and ages participated, with the emphasis being on fun. It wasn’t specifically for people with disabilities, although the inclusive nature of the event meant that many with disabilities could take part.

Although it wasn’t necessarily a competitive event, everyone was timed via chip timers. It was up to each individual to stay with a speed they were comfortable with and complete the course using a way that worked for them. Participants could choose to have a buddy to assist them to get around the track, for example, with a wheelchair, holding an arm, guiding or encouraging.



*Time for refreshment!  
Liz Buckle, Susan Kent, Simone Illger, Carolyn, James, & Alice DesForges*



*Simone, half way*

A Family Festival also ran throughout the day which included the Livability Community Zone, the Parallel Family Zone, the Toyota Lifestyle Zone and the Innovision Culture Zone. There was also a food and drink zone – very important for the participants!

Simone Illger, who did the 1k, explained “For most of us, it was the first time we’d taken part in anything like this. I absolutely loved the atmosphere and it was great seeing people moving around the course however they were able to. I’m definitely coming again!”

Thankfully the weather stayed dry and warm, so everyone was able to enjoy the free ice creams and cheese on toast on offer, as well as visiting all of the interesting and informative information stands.

This is likely to be an annual event, so next year, let’s see a few more joining in!

For more information, see [www.parallellondon.com](http://www.parallellondon.com)

# National Advisory Council's Annual Conference

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**Saturday 26<sup>th</sup> November 2016 at**  
**Park Inn by Radisson, Hotel & Conference Centre**  
Bath Road, Heathrow, Middlesex UB7 0DU

Book now to avoid disappointment.

Further information and a booking form are available on the beneficiary website:

<http://www.thalidomidetrust.org/nac/nac-annual-conference/>

or contact the Thalidomide Trust: email [hello@thalidomidetrust.org](mailto:hello@thalidomidetrust.org) or Phone 01480 474074.

Please return the booking form by 24 October 2016 to guarantee your place!

## NACAC 2016 – DAY EVENT

**WHEN:** Saturday 26 November 2016

**TIME:** Registration 8.45am – 9.15am.  
Ends 5.00pm.

**WHERE:** Park Inn by Radisson, Hotel & Conference Centre, Bath Road, Heathrow, Middlesex UB7 0DU

**COST:** Free

*Join us for a varied and informative programme with lots of opportunities to ask questions.*

### Choice of informative sessions including:

Applying for Personal Independent Payment (PIP)

Managing pain – how ergonomics and physio may help

Diet and Exercise

Supporting hearing impaired beneficiaries – what next?

### Talk by a Medical Expert

Stretching, relaxation and massage sessions

3D print – making innovative ideas a reality

### One-to-one 15 minute surgeries on:

- Finance including Health Grant
- Housing
- NAC matters

Meet up with existing friends - make new ones!

*The Genny Segway wheelchair – come and try it out!*



### Campaign Update

*Get the latest about all that has been happening – keep up-to-date and informed.*

## How do I book my place?

Complete the booking form and return it to the Trust Office by **the deadline 24 October 2016** to guarantee your place. (Note booking after the deadline means your place cannot be guaranteed).

*The event will be filmed so beneficiaries who can't attend can still benefit from the information shared, but there will be a designated area for beneficiaries who do not wish to be filmed.*

# Thalidomide Society: Parents' Oral History

Ruth Blue

In 2012, Professor Anne Borsay and I started Thalidomide: An Oral History; a Wellcome Trust funded project in which we interviewed thalidomide survivors in the UK. One of the things we were told emphatically by our interviewees was that we had to interview parents and we agreed: how could we let the memories of such key witnesses to the impact of thalidomide go unrecorded? With this in mind, last year the Thalidomide Society began its Parents' Oral History project and, to date, we have completed twelve interviews which are moving, direct, honest and utterly invaluable.

***"... the first words that the obstetrician said was, "She's not normal." And so I was lying there, on my back, expecting this horrific thing to come up and there was the most gorgeous baby you've ever seen in your life. Only five pounds, tiny, with little chicken wing arms and I was absolutely thrilled to bits. I mean I was over the moon and both my husband and the obstetrician couldn't understand."***

oooooOooooo

***"So she brought him in, gave him to me wrapped up and he started to cry and I said, "No wonder you're crying, you're wrapped up like a bundle of rags. Let's sort you out." So I put him between my legs on the bed, to wrap him all up again and of course he's wearing a stupid gown on and the sleeves were flapping and I says to him, "They haven't even put your arms in your sleeves." Then I look and there are no arms."***



The interviews cover some of the very traumatic moments so many mothers experienced when their child was born and whisked away from them, often without explanation. They also cover moments of hilarity (particularly relating to practical jokes with prostheses), heart-felt anger towards drug companies and prejudice, pride over their childrens' achievements, increasing concern for their future and fascinating insights into the everyday public perception of disability in the 1960s and 1970s. These first-hand spoken accounts, with their emotional inflection and maturity, provide a powerful historical testimony which has and will continue to help us with the many enquiries from researchers and the media

we receive each week. We hope to continue adding to the interviews and would love to hear from you if you think your parent(s) might be interested in participating.

Contact me at: [info@thalidomidesociety.org](mailto:info@thalidomidesociety.org) or phone 020 8464 9048.

Please visit the Thalidomide Society website: [www.thalidomidesociety.org](http://www.thalidomidesociety.org)

**Dr Ruth Blue, Secretary to the Board of Trustees of the Thalidomide Society and Assistant Curator at Wellcome Trust.**

# “TO REMEMBER IS TO CARE” THALIDOMIDE MEMORIAL

Rosaleen Moriarty-Simmonds OBE



On the 30th June 2016, a permanent ground-based memorial to all those affected by the Thalidomide tragedy of the 1960's was unveiled by Dr. Peter Beck, HM Lord Lieutenant of South Glamorgan at Alexandra Gardens, Cathays Park, Cardiff.

Following seven years of work, three Trust Beneficiaries - Rosaleen (Rosie) Moriarty-Simmonds OBE, Edward D. Freeman and Stephen Simmonds witnessed the unveiling of a memorial dedicated to remembering friends, loved ones and supporters who are, and continue to be touched by one of the greatest medical disasters in UK history.

The event was attended by Thalidomiders and their families from across the country;

Heidi Thomas McGann - the Writer and Executive Producer of the BBC's Call the Midwife series (which covered the Thalidomide story earlier this year) and her actor husband Stephen McGann. The organisers also welcomed the Officers of the Thalidomide Society, Civic Officials from the City of Cardiff, the Welsh Government Cabinet Secretary for Health (Vaughan Gething AM) and Lady Irene Morris (widow of Lord Alf Morris of Manchester). As the first Minister of Disabled People during the 1970's, Alf Morris (along with his life-long friend and parliamentary colleague Jack Ashley) was pivotal in bringing the Thalidomide story to the wider public through his passionate campaigning in support of the Thalidomide cause.



After those seven long years, it was a wonderful yet poignant occasion when the Memorial, sited in the heart of Cardiff's Civic Centre, in the shadow of the National War Memorial, the City Hall and the Welsh Office was dedicated. Rosie, Ed and Steve were as one in saying there was no better place for the Memorial than in the beautiful and tranquil settling of Alexandra Gardens. It is a fitting location to remember all those who have been and continue to be affected by a medical disaster which, but for the desire for profit, should never have happened.



*Memorial organisers and Dignitaries*

Running in tandem with the Memorial, is the Thalidomide Memorial website. With information on the history of Thalidomide, a comprehensive timeline and full details of the Memorial Dedication ceremony, the site also allows visitors to leave appropriate tributes to those we have loved and lost, and who were touched by the tragedy.

Alexandra Gardens (postcode for SatNav purposes - CF10 3AX - Museum Avenue, Cardiff) is open to the public all year round. With level access and ample parking in the immediate area, it is completely accessible and well worth a visit.

For more information about the Memorial, please visit: [www.thalidomidememorial.com](http://www.thalidomidememorial.com)

## The wording on the Thalidomide Memorial

### THALIDOMIDE MEMORIAL

This memorial is dedicated to  
All those persons and their families

who have been, and continue to be affected  
by the Thalidomide tragedy;

The memory of the children who did not survive to  
enjoy a full and rewarding life;

The memory of parents and loved ones  
who gave so much in the care of their children;

All who worked so tirelessly in helping and supporting  
those who sought justice from this episode in history

Unveiled by

Dr Peter Beck CVO KStj MD FRCP  
HM Lord Lieutenant of South Glamorgan

30th June 2016

TO REMEMBER IS TO CARE

# Call the Midwife: Dr Turner's Dilemma

Reflections of a Thalidomide Survivor and Doctor's Wife (edited) by Catherine Diwaker

I have read, and loved, all of Jennifer Worth's books so when Call the Midwife was televised it became our family's regular Sunday evening viewing. A drama that my husband, daughters and I could watch and enjoy together. We learnt from Sister Julienne's wisdom, laughed at Sister Monica Joan's antics and quoted Chummy's hilarious lines. We grew to love these characters and we involved ourselves in the everyday ups and downs of Poplar life. So it was that I remember watching the last episode of Series Four about a young mother, overwhelmed and hospitalised by morning sickness, who is prescribed a new drug, Thalidomide. With no prior warning, and knowing exactly what that prescription would mean for her unborn baby I felt a wave of grief, panic and horror flood over me.



Catherine Diwaker and her daughters meet Dr Turner (actor Stephen McGann)



Simone Illger cuddles the very life-like baby Susan, the prosthetic baby from the TV series Call the Midwife

But the emotion that gripped me most was sorrow about what the consequences of this decision, to prescribe Thalidomide, would do to the lovely Dr Turner? This kind, hard working family doctor who put himself out and worked tirelessly for his patients; this stalwart and respected member of the community whose character we had grown to love. What would it do to him?

Here was a young doctor affected by a war that had not been over for long. A war that had caused hardship and sadness and circumstances that were better forgotten. He is an optimist, a dreamer, an idealist. A man with a vocation who wants to build a better future for his patients. This is the 1960s. The NHS has been established, antibiotics are available and tackling many feared illnesses, attitudes to contraception are changing and the pill is available and becoming more widely accepted. Dr Turner, and many others like him, are dreaming of a better future - and then the devastation of Thalidomide hits.

Stephen McGann, who I had the pleasure of meeting at the Thalidomide Society AGM last year, plays his role as Dr Turner so well. You see his caring, patience and gentleness alongside his professionalism when Susan is born. Realising that there is life, and that Susan is going to fight to live that life, he stays true to the oath he has taken to preserve it and give her the best chance he can. But, later, as he realises the enormity of the effects of his 'wonder drug,'

you can also see his pain, his feelings of shock and horror and the sickness and guilt that he feels for prescribing it. You see his dream of making things better for his patients shattered.

I know that many of us, myself included, have had awful experiences with doctors in the past. But I know that there are many, many doctors out there who have trained in medicine because it is a vocation to them. They want to make people better and will do everything in their power to achieve this - my husband being one of them. They care deeply. Sometimes things happen - and doctors carry the weight of those things round with them. They are human. And when I see Dr Turner with his head in his hands

it makes me ponder how many other GPs and doctors lived with similar guilt and sadness for the rest of their lives? I know that my Mother's GP did.

Drama is an incredible medium for educating the public about many subjects. I think that the Call the Midwife team have been able to show the human cost of the Thalidomide scandal, not only to those affected physically by the drug but to those others mentally scarred by it through no fault of their own.

[campaigns@thalidomidetrust.org](mailto:campaigns@thalidomidetrust.org)

# Campaign update

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Craig Millward – on behalf of the campaign team.

## European Parliament Campaign Update

Since my summer update sent to beneficiaries signed up to receive emails from the Campaign team we have made two trips to Brussels for a number of key meetings with staff from the two main political groups sponsoring our motion.

We are getting feedback that there is widespread approval for our new position that the motion should focus on calling the German government to include the Spanish, Italians, Swedes and ourselves in the Stiftung fund, thus enabling us all to access the special fund they have set aside for health needs without having to go through the ridiculous process of applying individually which would necessitate new medical reports and x-rays and take years to complete.

The German Thalidomide Foundation Act is currently being amended to enable Germans to receive payments that are more adequate and this is proving a useful focus for everyone's attention. We all agree that the motion needs to be debated and voted on in Strasbourg before the end of the year.

We learned that the S&D group are appointing MEPs from all the affected countries to offer opinions on the wording we have suggested. By the time you read this all responses should be in and they will have held a meeting amongst themselves to agree on a position. They will then meet with the EPP group to decide how to move ahead together.

I also had a session with Martin Schultz' health advisor who tells me that the President has been seeking a meeting with Caren Marks of the Families Ministry in Berlin. In addition, there was a long meeting with Matthew Harpur who is a members of the British Representation to the European Parliament. He has promised to do what he can to support the representations made by the British ambassador in Berlin and talk with his German colleagues.

In the meantime, the WDR documentary on our campaign was shown in Germany on 28th September. You may remember that it was delayed following the publication of the NRW report into the role of the state in the suspension of the trial of Grunenthal executives, and the film maker wanted the documentary to address shortcomings in the report.

This is a link to the full documentary here:

<http://www1.wdr.de/fernsehen/die-story/sendungen/contergan-112.html>

We are going to get the documentary dubbed into English and we have plans to show it in the European Parliament, the UK Parliament and in Germany.

Things are moving fairly swiftly in Europe at present and I will send out further updates via email to those who have requested me to do so. If you want to receive campaign mailings please contact the Trust to add you to the list. I cannot do this myself and do not have access to your contact details.

## Contact Us

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We do hope that you've enjoyed reading this newsletter.

The next edition will be published in the Spring of 2017. If you've any feedback from this newsletter or would like to contribute to the next edition, please contact the newsletter editor, Karl Davies. [DaviesKB@aol.com](mailto:DaviesKB@aol.com)

Tel: 07790 492 967

If you need assistance to get your thoughts for an article into writing, then help can be provided!

## Mission Statement

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*"The NAC is a user led group that exists to represent the beneficiaries of the Thalidomide Trust by working in partnership with the trustees and the staff.*

*Our aim is to give the beneficiaries the resources to meet their increasing financial, health and other needs.*

*Its work is underpinned by a belief in justice, dignity and equality."*