

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

**Newsletter**

**Spring 2019**

## Welcome to the NAC's Newsletter

The format I follow, for our newsletter, is to focus on what we've been up to as a group, and to intersperse this with news from both the Trust and from individual beneficiaries.

In this edition, we have some sad beneficiary news..... since our last edition Louise Medus-Mansell has died. A moving tribute has been included in this Newsletter

We also have:

- Health and Wellbeing articles
- Information about projects the NAC is involved in
- Discounts we can get
- Geoff's thoughts on becoming chair again
- We introduce Gillian Sherwood
- Ramesh has written about moving back to the UK



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

Thank you to all who have contributed information for this edition, and a **HUGE** shout out to Simone and Carolyn, who have – again – not only been instrumental in sourcing articles for inclusion, but as I had to leave the country at short notice, Simone has finished the Newsletter for me – BUT – I'll be back.

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

**Karl Davies – Newsletter Editor**

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# Chair's Update

## Rowland Bareham, Outgoing Chair of the NAC

Firstly, many thanks to Simone and Karl for compiling this edition with the usual variety of information.

- You will have had the results of the NAC Elections. Congratulations to Karl Davies, Carolyn Desforges, and Craig Millward. Thanks, also, to the other candidates who stood for election – Anne Bancroft, Jacqueline Fleming and Bob Hepple.
- The next April NAC meeting will see NAC members in new roles. Geoff Adams-Spink as our new Chair, Carolyn Desforges as Co-Chair of the Health & Wellbeing Committee, and myself as Shadow Finance Team Leader. I wish Geoff and Carolyn well in their new roles.
- This means that Nick Dobrik who has served as Shadow Finance Team Leader and Simone Illger as Co-Chair of the Health & Wellbeing Committee retire from their respective roles. Thank you Nick and Simone. It has been a pleasure to work both yourselves alongside Mikey Argy, Deputy Chair to provide joint leadership of the NAC.
- We've had another beneficiary feedback survey and all the anonymous replies are now being analysed. The full findings will be going to the NAC and the Trustees for consideration and you will be getting feedback summarising what our community is thinking of the Trustees, Staff and NAC. Many thanks to Graham Kelly who has been the lead on this.
- The Campaign Team (Nick, Mikey, Craig and Guy) will be sending you a campaign update shortly. As I already said, when sending you the Annual Reports late last year, there is much to do before reaching the endpoint, so don't make new financial plans just yet! A round of applause to the Campaign Team, I say.



[Gillian Sherwood](#) joined the NAC in October to provide an essential administrative and support role to the NAC. This support has been especially useful to me in my role as Chair and is also making a very big difference to the smooth operation of the NAC and its work. It's been wonderful knowing that somebody else is able to undertake all of the things that myself and others were once doing - so organising meeting dates, taking notes of conference calls chasing up requests for information, keeping the on-line diary up-to-date, answering requests for information.... the list goes on and on! It's been a pleasure working alongside Gillian and I know that Geoff as incoming Chair will also appreciate this support.

This is my last newsletter update to you as Chair of the NAC. Having been in this role for three years (and having just about survived it!) it has been a pleasure to have worked with my NAC colleagues, trustees and staff. Thanks to all.

As ever, I wish you well.

# Remembering Louise Medus-Mansell

**Rowland Bareham**



**Sadly, on 7<sup>th</sup> November 2018 Louise died never fully recovering from a second kidney transplant.**

**For a full obituary, please see the Thalidomide Society page:**

**<https://www.thalidomidesociety.org/louise-medus-mansell-1962-2018/>**

**I'd like to share some memories and thoughts about Louise.**

Our paths crossed on many occasions over the years. I first met Louise at The Thalidomide Trust's hotel, Haightmoor, in Jersey when our respective families were young. I bumped into her on several other occasions and worked with her as part of the Volunteer Visitor team (as we once were) and as a member of the NAC. Louise was a delightful colleague and was very hard working in everything she took on.

Louise was my mentor when I first joined the NAC, spending time briefing me with background information and history to ease me into my new role. Louise also gave me guidance on what works effectively and what doesn't! Being my mentor, Louise enable me to quickly get up to speed with working as part of the committee and remained as someone who inspired me as a NAC colleague and hard-working and committed team member.

To provide you with an example of the determination shown by Louise when tasked with an assignment, I met Louise with Darren one sunny summer day at Heathrow Airport. We were there to carry out a reconnaissance visit to several Heathrow hotels to source a suitable conference venue for Trust events. Louise and Darren had travelled by coach and so we had no car to travel between hotels so we ended up walking miles from one hotel to the next, around each venue looking at the conference rooms, accessible bedrooms and gauging how well bathrooms would accommodate the variety of needs within our community. Louise's ability to negotiate favourable rates with hotels on our behalf was impressive. By mid-afternoon despite exhaustion on my part, in Louise's company I continued to be buoyed along by Louise's motivation and determination. That day with Louise and Darren remains a special memory for me.



Another example of Louise's motivation and determination I remember is when I visited Louise in hospital at Cheltenham in 2017. Louise had already been in hospital for over 100 days; her total stay eventually 176 days.

I will never forget her cheerful smile with such a positive outlook on life, despite all the medical issues that were going on.

I know besides myself, there will be many others who feel very honoured to have known Louise. Myself and fellow NAC members – past and present will definitely miss working with her.

There will be a tribute to Louise given by Stephen Simmonds at the Thalidomide Society's Conference on 6 April 2019.

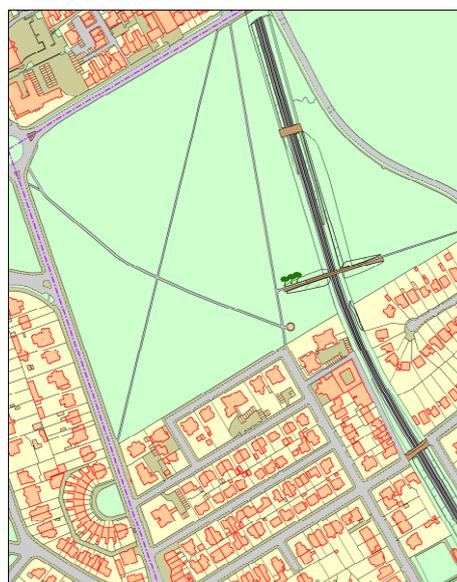
## Planting of 3 x cherry trees in Louise's memory

### Guy Tweedy

I've planted three cherry trees in Louise Medus-Mansell's memory on Harrogate's famous stray (shown in the planting plan below). They have been planted near the railway track and adjacent to the railway footbridge, close to nearby roads York Place and Leeds Road. I have to date planted over 50 trees in memory of people I know, including two babies.

The thalidomide memorial tree is planted at the top of Montpellier hill not far from Betty's tearoom.

Why not take a look if you are visiting Harrogate?



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These 3 cherry trees are planted in memory of  
Louise Medus-Mansell  
24rd June 1962 - 7th November 2018



*The three cherry trees in situ. A fitting tribute.*

# Engagement with beneficiaries on H&W issues

Carolyn Desforges

**So, how do we actually take notice AND take action on looking after our health and wellbeing?**



I'm sure many of you have noticed a proliferation of excellent articles on research activities such as the Cardio Vascular Risk project, articles in the "getting active" section of the website and case studies showing how some people genuinely are "getting active"!

How we support ourselves, as well as how the NAC / Trust can support us, to stay as fit, active and positive as possible, has been the focus of long discussions on the Health and Wellbeing committee. We have looked at national strategies, websites, blogs and role models (our own Simone Illger being one of them), and have made a plan - not another you might say...!

2020 will be the year of Health and Wellbeing. I, myself, reach the grand age of 60 in 2020, and, as many of us are, find aches, pains and arthritis spreading all over my body. I'm sure I will need various further joint replacements, but I feel there is too much life to live to give in to it. I really dislike people telling me what to do and not do, especially when it comes to food and drink, but I like the knowledge, do notice of our role models and little by little am making small changes, am trying to move / take exercise more, and if I have yet another hurdle put in my way (it is knees at the moment), I try to take stock and start again. When yet another part of our body shows more signs of wear and tear and pain, it can be difficult to keep a positive mindset - the Talk Together project has already begun to support those of us whose mood is low. We can't feel healthier without supporting both our minds and bodies, and we hope to have a future focus on both.....

So, be prepared to be nudged, challenged, and should you wish, be supported or be a supporter. We will have forums on the website to share recipes, share ideas for ways to be more active (Flex-it or Flop-it?), and have more information and case studies on managing balance, sleep issues, pain and dare I say it, the unmentionables such as managing our weight, personal care and sweating. I do feel that the best way to help ourselves is to be supported by peers, who perhaps are just one step ahead of us in a quest to manage their own health and wellbeing issues, so please keep an eye out for volunteering opportunities.



*Keeping fit so I can continue to do things like this!*

Any ideas and offers of help, please do contact myself or Simone – we welcome ideas on what has worked for you that others may also find useful, be it a piece of equipment that you can use or that you have adapted, an exercise, a lovely recipe, a piece of information / video you have found online - let's keep active and as independent as possible - I believe 60 is only "middle aged", in my mind I'm still in my 20's! We just aren't ready to grow old yet....

# The Cardio Vascular Risk research study

**Graham Kelly**

**If you are likely to be having surgery in the foreseeable future please tell the Trust (Cheryl Pinkney is the person to speak to). We can then tell you about the CV (Cardio Vascular) risk research and you can decide if you want to take part.**



If you decide to do so we can ask your consultant if you are having the right type of surgery to take part.

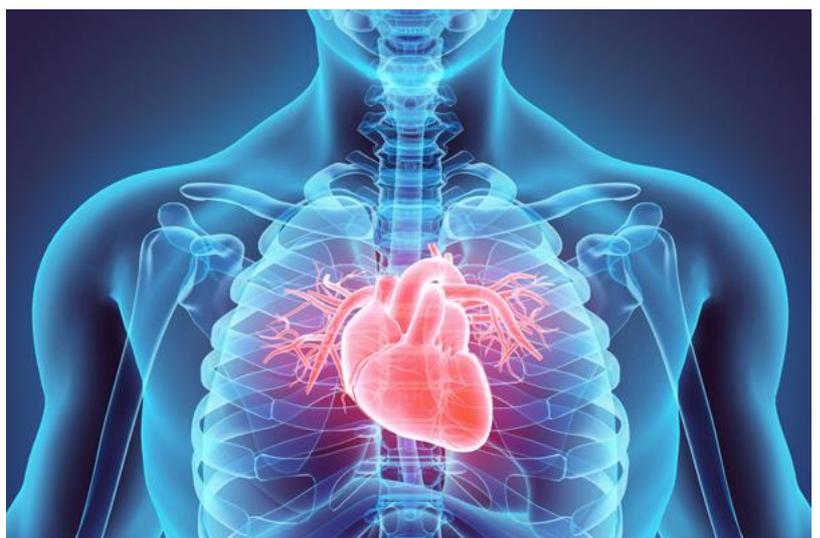
The purpose of the research is to discover how accurate blood pressure readings are for thalidomide affected people when taken via a cuff around a limb, as normally happens in a clinic or at home. Participants are given a report after surgery which tells them how close together the readings are from the cuff and arterial line which they can then show to their clinicians. This will help your doctors and nurses have a better understanding of the accuracy of your cuff measurements in the future.

We are looking for beneficiaries who are having surgery that will require the use of an arterial line, as happens in many operations. The plan is then to also place a cuff onto an arm or a leg during surgery, so that the blood pressure readings from the cuff can be compared with the readings from the more accurate arterial line.

If you do end up taking part you will not really know anything about it at the time, because the only difference it makes is that the Anaesthetist will place a cuff on your limb while you are under anaesthetic. Surgery normally requires a cuff or an arterial line, but for the purposes of this research participants have both.

In the future we hope to extend the research to Germany, in order to boost the numbers taking part. In the meantime, we need to include the maximum number of UK thalidomiders in order that we achieve robust, reliable findings.

So if you are going to be having surgery, please contact the Trust and alert Cheryl Pinkney. That will simply trigger a letter to be sent to you, and then I can explain things in more detail. If you do so, there is absolutely no obligation to take part until you have heard all of the information, had your questions answered, and of course, it's entirely voluntary.



We look forward to hearing from those of you expecting to have surgery.

# Welcome back

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## Geoff Adams-Spink

It's been rather a long time since I last chaired the NAC. So much has changed in that time - trustees, staff and NAC members - that it presents a fresh challenge to a role with which I was more than familiar.



Our Trust is now more proactive than ever before: you only have to look at the programme of events, the range of support services and the website, to know that there has been a sea change.

Each new director puts their own stamp on the Trust: I can remember Martin Johnson taking over at the turn of the millennium and introducing the organisation to ICT for the first time!

Deborah Jack has now been in post for more than four years, and she too has instigated a number of changes to make the organisation more responsive: the new holistic needs assessment (HNA), and the new peer support service are outstanding examples.

We are also working to a new strategic plan - and by 'we' I mean NAC members, Trust staff and trustees. Drafting it really was a genuinely collaborative exercise to which everyone contributed on an equal basis.

One of the strategic goals to which we all signed up was making the NAC more transparent and accessible. We are, after all, your elected representatives, and you should always be able to find out what we are doing and why.

The Trust has also adopted a whole series of policies including the one on safeguarding. Organisations in the UK have all recently responded to some pretty appalling revelations about behaviour in charities that have necessitated safeguarding policies. The Trust is no exception: some beneficiaries are at risk of abuse - emotional, financial and even physical. We have quite rightly made everyone aware of the need to escalate any concerns that are picked up in the course of, for example, a home visit.

The policy also applies to volunteers: members of the Council give up huge chunks of time to work for the good of our community and deserve respect for doing so. As Chairman of the NAC, I do not intend to sit idly by while any member is subjected to abuse and defamatory remarks simply for doing their job.

Social media is a brilliant way of staying in touch. However, the Government and others have significant concerns about people's online safety. In the next few months Facebook, Instagram, Twitter and other platforms will start to introduce more stringent controls on what constitutes appropriate behaviour.

So, while everyone has the right to question what the Trust and NAC are doing, as well as how and why they are doing it, the normal rules of decency and respect are not suspended; sharing the same range of impairments or knowing each other since childhood are no excuse for bad behaviour.

Being both Chairman of the NAC and the Thalidomide Society Board of Trustees is going to keep me pretty busy. I look forward to the challenge and to hearing from beneficiaries about what sort of Trust we should be creating for the future.

# Impact of Brex\*t! Will It Impact UK Thalidomide Survivors?

## Phil Williams

Brex\*t has almost become a swear word, amongst other things, so I thought it appropriate to use an \* in the word!

Several beneficiaries have posed the question in the title of this article.

The answer is firstly will or rather has Brex\*t even happened by the time this newsletter is distributed! Secondly, who knows!

I've no desire to be flippant about such an important and significant economic, political and social event, but frankly there is so much still up in the air.

You can rest assured that the NAC and I'm sure the Trust will do it's very best to mitigate against any problems that might arise. But, at this stage, I don't believe we should allocate financial or time resources to contingency planning for who knows what. In addition, there is little point in 'reinventing the wheel'. It's unlikely that thalidomide survivors will face unique problems that other impaired groups will have to deal with and other groups are already offering guidance or doing work in this regard.

We can think about;-

- will the economy slump - resulting in even harsher cuts to social welfare and benefits budgets at the national or local level or both? Is the UK government ready? A beneficiary kindly forwarded this interesting article;-

<https://www.disabilitynewsservice.com/ministers-block-release-of-no-deal-brexite-social-care-recruitment-plans/>

- will medicines we rely on be available? This does seem to be the one issue the government is prioritising and given the humanitarian element and potentially disastrous consequences of a shortage one feels that overseas governments would co-operate or bend any rules.

- will the UK leaving the EU adversely impact our campaign against the German government? I understand the campaign team have assurances this will not be the case but I'm sure there will more under separate cover at some point.

- will there be an issue obtaining parts/appliances related to specialist adaptations to home, car or wheel chairs? - many of which might come from within the EU or outside via the EU. For us, mobility is vital to our independence so delays in obtaining replacement parts would be beyond disappointing or frustrating.

In a nutshell, it's probably best not to worry and keep as calm as possible. Once we have facts about any adverse changing circumstances affecting individual beneficiaries or the whole cohort, please rest assured the NAC and the Trust will stretch every sinew to help.

In the interim, if you should have any questions or concerns please do not hesitate to contact the office, any NAC member or me, Phil Williams, on 07554016303 or [phil@philipdavidwilliams.co.uk](mailto:phil@philipdavidwilliams.co.uk)



# Future Money Matters 2

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## Phil Williams

On 1<sup>st</sup> March 2019 at the Radisson Blu, Stansted, the office and the NAC, working together, hosted the second 'Future Money Matters' event, designed to support beneficiaries look after, maintain and ideally improve their financial health.

In due course you will receive more detailed information, including how you can access new useful materials/resources on the website or on the telephone as well as videos of several sessions you can view.

It's fantastic that through the efforts of the campaign team, supported by the NAC and other beneficiaries, working with Trust staff and trustees that we have seen a steady rise in our incomes. However, we must all stay healthy enough to fully enjoy these long overdue monies, so the 'Fit For Future' events and related resources are invaluable. Please, please do look at these if you haven't yet had the time or motivation. Similarly, we must make the best use of our monies, so the 'Future Money Matters events and resources are equally useful.

The day was well organised by Jeff and the Finance team. Keith and Sarah did a great job as always. It was also lovely to have a trustee, Kevin - Chair of Finance Committee, in attendance.

Every attendee received a pack including their personalised timetable. There was a short opening group session followed by three consecutive small seminars with comfort breaks in between. A very social buffet lunch was provided before beneficiaries could have 1:1 sessions with the guest professional speakers of their choice, a member of staff or the NAC member. In addition, there was a large room where beneficiaries could mingle informally and talk to friends; old and new.

Topics covered were varied and included Universal Credit, Inheritance Tax, Savings and Investment, Pensions and Retirement Planning, Personal Trusts, Making a Will/Power of Attorney, Personal Budgeting and Mortgages/Personal Loans. I'm sure you'll agree there was something in there for everyone! The professional speakers were uniformly very good.

There will be plenty of detail to follow so please do look at the links and information available.

For me, three of the principal things I took away were:-

- 1) It was lovely to meet beneficiaries I hadn't met or even heard of before who were attending one of their first ever events.
- 2) historically, for various good reasons - many of which are now out of date - the Trust has been seen by beneficiaries as the lender of first resort; whereas it is often far cheaper and/or massively beneficial in cash flow terms to instead borrow money commercially! The Trust should arguably now really be seen as a safety net. Jeff at the office is fantastic at supporting us in this regard.
- 3) there are some fantastic members of staff at the office with quality recruits joining.

Pending the new resources becoming available, if you have any questions in connection with this event please do not hesitate to contact Jeff at the office or me, Phil Williams, on 07554016303 or [phil@philipdavidwilliams.co.uk](mailto:phil@philipdavidwilliams.co.uk)

## Discounts – thank you very much!

**Simone Illger**

Some readers may already be aware of these money changing passes which one can use on a regular basis. I make use of all three and I definitely visit the theatre and the Cinema far more often as a result!

### Mobility exemption for M6 toll road



Some Thalidomide beneficiaries may be entitled to a toll exemption when using the M6 toll road.

For beneficiaries who are Blue Badge holders, exemption will only be granted when producing an M6toll Mobility Exemption Pass which **ONLY** allows free passage for use on the M6toll when the registered disabled person is present in the nominated vehicle as stated on the application form.

To claim exemption in toll lanes, when requested please be prepared to show the M6 toll Mobility Exemption Pass to a member of staff at the toll booth or by pressing the call for assistance button to enable your exemption to be verified, CCTV is in operation to assist in verification.

To qualify for M6 toll exemption the applicant must be in receipt of one of the following:-

1. The higher rate mobility component of Disability Living Allowance;
2. Attendance Allowance;
3. Enhanced rate of the mobility component of the Personal Independence Allowance;
4. The War Pensioners Mobility Supplement.

If you think you may be eligible for the Mobility Exemption, you may apply to Midland Expressway Limited as only the M6 toll Mobility Exemption Pass can be accepted in toll lanes. Please send a self-addressed stamped envelope along with your completed application form (*which includes Terms and Conditions*) to the address on the application form. To speak to Midland Expressway Limited about Mobility Exemptions, please call their Mobility Exemption Team on 0330 660 0790.

### Access Tickets - accessing theatre performances



Do you enjoy the theatre? Might you be paying too much for your tickets?

#### What are Access tickets?

The title 'Access' refers to everything ATG does to enable everyone who needs support because of a disability or health condition to come to our theatres and have the best experience possible. If you have additional or Access requirements of any sort, there is likely to be something we provide that will improve your experience.

The ATG Access Membership Scheme offers a range of benefits. [Click here](#) to find out more and register.

### **At every theatre we do our best to provide the following services:**

- Wheelchair and Mobility Assistance ([find out more here](#))
- Guide Dogs ([find out more here](#))
- Assistance Dogs ([find out more here](#))
- Hearing Enhancement Aids ([find out more here](#))
- A Chill Out Area ([find out more here](#))
- At Seat Service ([find out more here](#))
- Theatre staff on hand to help ([find out more here](#))

### **Many productions have the following additional services:**

- Captioned performances ([find out more here](#))
- BSL-interpreted / Signed performances ([find out more here](#))
- Audio-Described performances ([find out more here](#))
- Relaxed performances ([find out more here](#))
- Touch tours ([these can be organised with the theatre's Access Champion directly here](#))
- Orientation visits ([find out more here](#))

### **Who can use Access services?**

Anyone who needs support because of a disability or health condition can use Access services. Please call our dedicated Access team on 0800 912 6971, or our typetalk number on 18001 0800 912 6971, or email the theatre's Access Champion here and a member of our dedicated Access team will be able to assist you.



### **Theatre staff on hand to help**

Theatre staff will endeavour to help you in any way they can. Please ask for anything you need and they will do their very best to assist you.

Additional ways you can be helped:

- With friendly and helpful advice and service.
- Booking taxis or assisting you into a taxi.
- Providing one to one sighted guiding.
- Showing you to your seats or facilities.
- Storing equipment and make sure it is available when you need it.
- Regular checks that you are comfortable.

# Cinema Ticket Concessions

The Cinema Exhibitors Association (CEA) Card enables a disabled cinema guest to receive a complimentary ticket for someone to go with them when they visit a participating cinema.



The Card is also one way for cinemas to make sure they look after their disabled guests. If you require an adjustment to visit a cinema because of your disability, cinema staff should make them for you whether you have a CEA Card or not.

The Card is developed by UKCA's Disability Working Group, whose members include film exhibitors and distributors, and national disability charities such as Action on Hearing Loss, the RNIB, Dimensions and Muscular Dystrophy UK.

If you have questions about the card and how it works read the Frequently Asked Questions or contact us. See full Terms and Conditions.

## Eligibility

You will need to provide evidence that the card holder receives one of the following:

- Disability Living Allowance (DLA)
- Attendance Allowance (AA)
- Personal Independence Payment (PIP)
- Armed Forces Independence Payment (AFIP)
- Blind Persons Registration

You will need to send a copy of the awarding letter from DWP or a statement confirming receipt of the allowance for the person requiring assistance (the card holder). This should be dated within the last 12 months.

Alternatively, if you are a Registered Blind Person then please send a photocopy of certification for the person requiring assistance (the card holder).

Please note that ESA (Employment and Support Allowance) or the Blue Badge on its own are not accepted as proof of eligibility.

## What does the card entitle me to?

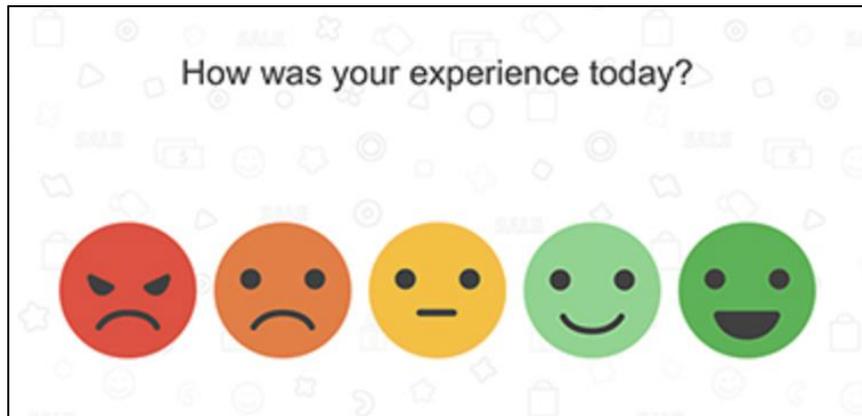
The CEA Card entitles you to ONE free ticket for someone to accompany you to the cinema to provide the assistance you may need during your visit. To get the free ticket, you will need to purchase a full price ticket for yourself for the same performance of the same film in the same auditorium.

The free ticket is provided on the assumption that the person who accompanies you can provide you with appropriate assistance, this might include

- helping you move around the cinema including finding and taking a seat;
- helping you leave the cinema in the event of an emergency;
- accompanying and/or helping you use the cinema's toilets;
- helping you buy refreshments.

# NAC feedback survey – operation and response

Graham Kelly



Thank you to everyone who completed a questionnaire for the 2019 beneficiary feedback survey. As I'm writing this, I've just received the news that 67% of beneficiaries took part, and that is an excellent response rate, providing a good quality representative sample of our beneficiary community.

The data is now being processed by the independent survey company and they will merge all of the individual questionnaires into one dataset before giving it to me. I will then analyse the results and produce a report. It has not yet been decided how that report will be communicated to everybody, but you will see the findings before too long.

Finally, I just want to reassure everybody that the survey was completely confidential, because a couple of beneficiaries did query this matter. They pointed out to me that the reminder communication sent to those who did not initially respond seemed to suggest that I had been told the names of non-responders. That was not the case, but I can see that the wording on the letter/email could be confusing, particularly since the letter had my name and signature at the bottom.

What actually happened was that I wrote that letter at least a month before the survey happened, and I gave them my electronic signature to print onto the letter/email. The survey company were then able to send that letter, with my signature, to those who did not respond after the first couple of weeks, and again later to those not responding after about a month. However please be assured, that I was 200 miles away from the survey company office, and I never saw any names or addresses.

That's all for now but there will be news about the survey findings later in the year.

# Diageo video project

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## Craig Millward

During the last set of negotiations between the Trust and the NAC, we brought a number of concerns to the table. The need for increased funding brought about the Capital Health Payment we all received soon after the agreement was signed. But a few other issues took a little longer to deliver but are also potentially very significant.

Our concern was that, if Diageo were to be taken over, or merged with another company or even broken up, this might affect their commitment to us in some way. The first thing we must always recognise is that we have a legally enforceable covenant with Diageo, and have established a very positive working relationship, both of which put us in a very strong position. But we wanted iron-clad security.



One of the suggestions we put to them was that it would be advantageous to both parties for their link with us to be communicated far more widely than their annual report. We suggested that Diageo staff, board members and shareholders could be far better informed about our needs, our partnership, and the difference the funding we receive makes to our lives.

We therefore agreed that a series of videos would be made featuring three beneficiaries who have stories to tell. Kevin Donnellon, Sarah Gaitely and David Tickell agreed to be filmed and Diageo agreed to commission Quite Frankly Productions, who they have worked with for many years, to produce the films. I was the NAC lead on the project and I had the opportunity to work with the three beneficiaries and film crew last summer. The films have now been edited and are nearly ready for release.

The films will be promoted via Diageo's intranet to all their staff, and we are working with them to explore ways of using them more widely. The three beneficiaries will be the first to see the clips in which they feature, and we then hope they will also be available for us to use more widely as well.

Finally, I want to thank Sarah, David and Kevin for their help, and I look forward to finding creative ways to use the stories to cement our link with Diageo in the minds of many more people.

# Moving back to the UK

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## Ramesh Lad

My name is Ramesh Lad. I am a UK Thalidomider, but have been living and working in Canada for the past 18 years. My wife and I are considering a move back to the UK and I have been invited to write a bit about myself and the reasons for the potential move as well as the practicalities, challenges and pitfalls of that move.

In 1999, which seems like a lifetime ago, I worked in Birmingham UK as a Careers Counsellor. At that time, the organisation I worked for was offering employees the opportunity to take a career break, which could range from 1 year to 5 years. I took a one year break with the option of extending my time away.

My goal was to live and work somewhere different and experience a life away from the norm, just like my parents had done in the 1950's when they emigrated to England from India. Their move had been to create a better life, while my move was born out of curiosity and challenge.

I decided on Vancouver, Canada as a place to move to. Vancouver had a more moderate climate all year round compared to the rest of Canada, so it is easier to get around in any season, especially with a wheelchair.

The immigration application process took about 2 years. I was able to get Landed Status in Canada (rather than, say, a work permit). Landed Status meant I could enter the country, legally look for work and be responsible for my own health care needs. It also meant I could apply for permanent residency and eventually citizenship after 4 years in the country.

My family and some friends thought I was crazy wanting to leave a comfortable and stable life, with a good job, home of my own, and family and friends, to head to a place where I did not know anyone and didn't have a job or anywhere to live. I tried to reassure everyone, while trying not to show my own doubts.

In 2001, I finally landed in Vancouver, British Columbia, Canada on a snowy, cold February night, alone. As I sat outside the airport, waiting for a cab, I looked over at my one suitcase and powered wheelchair at my side and thought of what was behind me, thousands of miles away. The doubts and fears, though, were soon overshadowed by excitement at the thought of being in a unique position, at the age of 38, of having an opportunity to start a new life on a blank canvas.

I arrived in Vancouver with about \$5,000, which wasn't going to last me more than four months, covering rent, food, transportation, etc. While I had more funds available to me in the UK, my goal was to become self-sufficient as soon as possible. Luckily, I found work within 4 weeks of arriving in Vancouver. Once I was offered employment, I was able to secure an apartment to rent and the idea of making a life in my new home became a reality.

Since then, I have had a varied career in Canada, ranging from selling concrete to counselling and supporting people with addiction issues and homelessness, to working with youth at risk, to now working for myself as an accessibility assessor. Of course, it hasn't been all work and no play. I have travelled extensively, including, in 2004, a solo three month road trip across Canada - just me and my trusty old Ford Focus station wagon. I zig zagged across the country from the West coast to the east coast and then returned to Vancouver through the northern states of



the US. I covered over 15,000 miles, round trip. It was brilliant! I had applied for Canadian Citizenship and really wanted to see most of Canada before I took my oath of citizenship, which I did in 2005. I now have two countries I can call home.



I met Julie a few months after returning from my travels. We've been together for more than 14 years. We got married in 2010. Since 2008, we have been living on Vancouver Island, in a small village called Cumberland. We have a family of three geriatric pets, our dog Ty (almost 15 years old), our cats Merlyn and Arthur (almost 17 years old) and our not so old dog Hanna, who is 6 years old.

The main reason for considering a move back to the UK is my 85 year old mum and my extensive family. There are a lot of things to think about and consider, such as Julie and I having our ageing parents in different countries and our pets (who are our family) being too old to travel. A move back to the

UK is certainly not as simple as my move to Canada 18 years ago. It is no longer just one man, one suitcase, two wheelchairs and a pocket full of dreams (a cliché, I know).

There are also quite a few practicalities to consider. We need to decide where in the UK we want to live and what we will do in the UK. As I haven't lived in the UK for such a long time, I'm not sure what rights I have around getting support like PAs or accessing the health care system. I also have concerns around the health care system in general, especially after reading about how the NHS is over stretched, with waiting lists and the level of service. I do get the impression, though, that there is a greater comfort level when dealing with the health matters in the UK, especially as the Trust Health and Wellbeing resources probably have greater credence with health professionals in the UK, which is something that certainly does not exist here in Canada.



Leaving Canada will be difficult. We will be leaving my in-laws. We have a varied circle of friends and interests, which we will both miss. I also have a brilliant set of PAs with whom we have developed great friendships and they have become like our family, which has made life easier for me. Alas these folks and our friends are not replaceable. I will certainly miss the open spaces, I've become accustomed to along with the natural beauty of lakes, ocean, and mountains, many of which are on our door step and also certainly not easily replaceable in the UK.

Finally, what am I looking forward to, if and when we come back to the UK? Decent meat and potato pies, mushy peas and good old British sarcasm, I'm still a Yorkshire man at heart. Seriously, though I am looking forward to spending more time with my mum, reconnecting with family and friends. Having Europe on the doorstep with easy access, is also another exciting prospect of returning and exploring places that don't require long flights or days of driving. We have also talked about the idea of maybe considering setting up a small business that Julie and I can work on together. I also feel that as I get older I have a greater desire to connect with and get to know my fellow thalidomiders and hopefully getting more involved with the group on a personal and social level.

## Welcome, Gillian Sherwood

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### Simone Illger

When I joined the NAC in 2013, I was struck by the amount of administrative work that was required to keep everything “on track”: conference calls, the newsletter, and communications – arranging suitable dates, venues, catering for everyone’s access requirements, overnight accommodation if required.

My career background involved working in various secretarial roles, including for the Estates Manager of Blue Circle Cement and Berkshire County Councils Finance Officer. It is therefore no effort for me to set up systems that enable myself and others to work collaboratively to tight deadlines, chasing other people for their contributions. Inevitably, it seems to be a role that I fall naturally into with any organisation that I am involved in.

All NAC members are volunteers – undertaking their roles in their spare time. Things like coordinating dates for the conference calls, sending out agendas, taking minutes and sending these around in a timely fashion, ensuring that everyone has carried out any tasks they have been assigned – inevitably falls to the Chair of the NAC.

In my view, the role of NAC Chair is a vital one! The role places a considerable workload on the position holder – just in terms of attending meetings, telephone conferences and keeping the show on the road! The Trust admin staff are brilliant – it is they who support the NAC as an “aside” to their main role at the Trust. But it always struck me that it would be so wonderful to have support of our own – much as the Thalidomide Society do – a person to take responsibility for all of these often small but crucial tasks that allow committee members to focus on the really important aspects of their work.

Eventually in the Summer of 2018 and following a committee decision, I started work with a small working group (myself, Rowland Bareham and Geoff Adams-Spink) in drawing up a role description, recruitment timetable and turning this much needed role into reality.

Of course, there was a little scepticism from some quarters – what difference will this make and what sort of tasks will the role undertake? It soon became evident once we started to compile the role description that there was plenty to do!

In October, we advertised the role and received over 70 applications! It was a huge amount of work to go through these and score them and come up with a shortlist, but we worked together and – surprisingly, it was fairly easy to decide on six people to interview.

Gillian shone out from everyone else at the interviews and we are very happy to have her on board. She has been able to hit the ground running. It is so wonderful to have a single person within the NAC who we can ask to undertake a specific task and know that it will be done. For once, I am the person being chased for progress updates on tasks that have been assigned to me!



***I asked Gillian a few questions by way of an introduction:***

***Can you tell me something about yourself?***

I'm the new Admin Support Officer for the NAC. I started the role in October 2018 and work 8 hours per week. I live in Urmston, Greater Manchester, with my husband and 9-year-old son. I'm originally from Scotland and still travel there regularly to see family.

***What sort of roles have you undertaken / worked in before this one?***

In a former life I was a head of department in museums in Staffordshire and Stockport and at The Lowry in Salford. I led teams using the arts as a tool to improve learning, employability skills and well-being for a wide range of people and ran outreach projects. In my student days I worked in shops, in a care home, a hospital, and on a conservation project in Northern Cyprus.

***What attracted you to the role of the NAC Admin/Support?***

The NAC Admin/Support role attracted me because I wanted to work for an organisation that was trying to improve people's lives. The joy of the role is that it is part-time, home-based and allows me to do the school run for the first time in my son's life. The role gives me a sense of purpose and a feeling that I am contributing in a small way to 'A Good Thing'.

***What have you enjoyed most about the role so far?***

I've enjoyed meeting the NAC members and learning about the work the NAC and the Thalidomide Trust do. I enjoy the coordinating nature of the role – keeping things running as smoothly and as efficiently as possible, whether that's by updating the diary, distributing minutes or supporting the delivery of events. I'm an organised person and, to be honest, I enjoy organising others!

***How is this role different to previous job roles you've held?***

It's not different in that I've always taken minutes, set up systems and procedures and project managed. It is different in that I've never had a home-based role before. Previously, I've led on strategy development, people management and been the person the buck stops with. It's a refreshing change to not have that level of responsibility but still feel I can make a positive impact. The improvement to my work-life balance is incalculable.

***Can you tell me what some of the challenges to the role are?***

Working part-time means that there is sometimes a time lapse in communication and I have to be careful that I'm up to date with the latest conversation before I plough in! The biggest challenge so far has been the monthly conference call and working out whose voice belongs to whom. The members have been very helpful by telling me their name before speaking.

I think because the role is new there is a lot of potential for it to grow and take on bigger challenges.

***Are you able to see how your role is making a difference to the NAC yet?***

This is a hard question! I hope it's making member's lives a bit easier in that I'm doing the basic admin they were having to fit in around their careers and other responsibilities. It's hopefully giving them some more headspace to work on the projects and campaigns.

### Contact Us

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

The next edition will be published in the autumn of 2019. If you have any feedback from this newsletter or would like to contribute to the next edition, please contact the newsletter editor, Karl Davies. [KarlBDavies@gmail.com](mailto:KarlBDavies@gmail.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."*