

NATIONAL ADVISORY COUNCIL
TO
The Thalidomide Trust

Newsletter

Autumn 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:

- Two top class Health and Wellbeing articles
- We introduce Suzanne Lluch
- An article on Home Automation
- A consultation paper the NAC has completed for the future of aviation
- There is an update on Campaign matters.



And more besides.

If you wish to receive campaign updates by email, please let Danielle at the Trust know, or email email@thalidomidecampaigners.com 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 – been instrumental in sourcing articles for inclusion.

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

Karl Davies – Newsletter Editor

KarlBDavies@gmail.com

Table of Contents

Chair’s update	3
Welcome, Suzanne Lluch	4
Appearing on BBC’s Pointless programme	5
Smartening up your home	7
NAC/Thalidomide Society Joint Event 2020	9
Administrative support – ten months in	10
Support for election to the NAC	11
Trials, tribulations, and solutions	12
Future care costs for thalidomide beneficiaries.....	14
Lands End to John O’Groats	16
Remap	17
Aviation 2050	19
Campaign update.....	21
European Parliament	21
The UK campaign in Westminster – the Health Grant renewal.....	21
And finally	22

Chair's update

Geoff Adams-Spink

Welcome to the latest NAC newsletter. Here, you will find useful and entertaining articles about what the NAC has been and is up to at the moment. Rest assured, we are losing no opportunity to improve the way we work and the way in which we communicate in order to make ourselves approachable, friendly and transparent.



Suzanne Lluch is one of the new arrivals at St Neots, and took up the post of Finance Director in March. Here, she introduces herself to the beneficiary community.

When he's not sifting through research data - both in his day job and on behalf of the NAC (looking at the feedback survey), Graham Kelly appeared on the BBC TV quiz show Pointless. What is it like to appear on camera to an audience of millions?

One of the things that has occupied a lot of my time over the past few months is planning the joint event - the first of its kind - between the Trust and the Society. A joint team is working on making this an extremely memorable get together, so please save the date now: April 25, 2020 at the Radisson Blu, Stansted is the place to be. Since I am currently Chairman of the Society Board of Trustees and the NAC, I have a vested interest in making this a resounding success.

One of the things that has changed since my first spell as NAC Chairman, way back in the noughties, is the amount of work that we involve ourselves in. Fortunately, we now have a part-time admin support person in the guise of Gillian Sherwood. Here she describes her role which is nothing short of essential from my perspective.

We really want to get members of our community who have not previously stood for election to the NAC to be involved in our work by standing for election. While this is not for everyone, we do have a plan to offer taster sessions - observing at NAC meetings - which will be open to people who are not sure whether the NAC is for them. I would urge everyone thinking about standing for election to dip their toe in the water.

NAC member Phil Williams - who is as sporty as they come - describes his recovery from injury (a skiing accident) and his new custom bike which he uses to stay in shape.

As we progress through our fifties and enter our seventh decade, our care needs and consequent costs are likely to increase. But by how much? Graham Kelly has been looking at the figures.

The fast-moving politics of the EU and at Westminster have kept our Campaigns Team on their toes. At the time of writing, we either will or won't leave the EU, with or without a deal. There will or won't be an election in October. So many variables, so many unknowns. The team are staying abreast of events and using the period of uncertainty to press home the message that we need our Health Grant renewed. You should all have received a letter to sign and send to your MP, and I would urge everyone to do this without delay.

I was hugely impressed to see Andrew Paddison on live TV, talking about his Lands End to John o' Groats fundraising extravaganza on a hand cycle. If you want to know more, have a look at Andrew's article.

Welcome, Suzanne Lluch

Suzanne joined The Thalidomide Trust in March 2019 to take up the role of Finance Director.



Tell us about yourself - family, previous employment

This is my first role in the charity sector, but I have worked in Finance for nearly 20 years, mainly in telecommunications. Prior to that, I worked in the hotel industry and have lived in Australia, Ireland and France (the latter for about 10 years). I live in a village about ten minutes away from the Trust offices in St Neots. My daughter is studying Psychology at the University of York, and I have a black and white cat called Boo. Outside of work, I love the theatre, the gym, and socialising with friends (not necessarily in that order). I read a lot of books, mainly fiction, and watch anything that makes me laugh. I have also just completed a counselling skills qualification.

What is your role in the Trust?

I look after all the Finance activities of the Trust. I ensure that the grant distribution processes run smoothly, oversee implementation of the Trust's investment strategy and monitor investment performance, and maintain all the financial management processes. And of course I ensure that beneficiaries have the support they need to manage their finances, both in the short and long-term. In addition to my finance-related responsibilities, I also contribute to the broader organisational management of the Trust as part of the management team.

What attracted you to the position?

Having worked in commercial businesses all my life, I was finding it hard to remain motivated by the endless pursuit of profits for wealthy shareholders. I realised I wanted to work for an organisation that wanted to improve the quality of peoples' lives. I happen to know someone who has worked for the Trust for a little while and who has always spoken so passionately about her role and the ways the Trust continually seeks to improve the support it offers to its beneficiaries. When the job opportunity came along, I jumped at the chance to be able to work for such a unique organisation. The fact that I would be able to personally help beneficiaries with their finances was a huge appeal.

First impressions about the work and your role?

Mid-September marked my six month 'anniversary', yet it feels like I have been here for much longer – in a good way! The Trust team is small but passionate about helping beneficiaries and it is great to be part of such a motivated group. I have been fortunate to have met many of our diverse group of beneficiaries already.

What kind of things have you been doing in the first months of work?

There has been a huge amount for me to learn but I have had tremendous support from the staff, trustees and NAC. I learnt a lot about the history of thalidomide, the battles our beneficiaries have had to go through, and some of the amazing successes too. As well as getting to grips with the day to day grant payment processing and financial reporting, I have attended several trustee meetings and the NAC meeting in April. I have met with our investment managers to understand the Trust's portfolio and ensure we are generating good returns. I have recently developed the

budget for next year and contributed to next year's workplan. I have reviewed and updated a number of policies and changed a number of internal processes to improve efficiency.

Can you tell us what sort of things you have managed to achieve (within the confines of confidentiality) to support some of our beneficiaries?

I have overseen the Annual Grant and Health Grant allocations and payments to ensure everyone received their money without delay. Along with Deborah Jack and a number of beneficiary representatives, I have visited all four UK Health Departments to ensure that our beneficiaries' needs continue to be fully understood and supported through the Health Grant. I have also visited several beneficiaries to help them with various matters. I attended the "Future Money Matters" event in Stansted in March, where we asked experts to present information about trusts, wills and investments to help beneficiaries with their financial planning. I was also at the "60 Years of Thalidomide" event in Cardiff where the Welsh Cabinet Secretary for Health and Social Services, Vaughn Gething, came to listen and talk to beneficiaries about their ongoing health needs.

Appearing on BBC's Pointless programme

Graham Kelly

On January 17, 2019 I appeared on the BBC Pointless programme, alongside my wife Nicki. Hopefully some of you were watching, for what I'm pretty sure was the first appearance by a thalidomider on a UK TV quiz show - though I may be wrong about that, so please do correct me.

I've been a fan of the show for quite a long time, so appearing on it was quite an experience. I've noticed that they often have people with disabilities, so I assumed they were disability friendly and would give me a fair chance if I applied.

Applying was fairly easy. You simply fill in a form on the website called BBC Shows and Tours, which has a special Pointless page. A few weeks after doing this we were invited to an audition. We went along to a hotel in London, but I imagine they have similar auditions in other parts of the country as well because the guests on the show come from all over the UK.

The audition consisted of filling in a paper questionnaire, then playing a mock game of Pointless around the table, with the scores simply put up on a blackboard. It didn't matter whether you did well or badly in this game, as I think they were just checking to identify any people who were super nervous and might freeze when it came to the real thing. They then did a very short video interview with each person, in which you are asked to say a few words about yourself, your interests and why you would like to be on the show.

We then waited again until we got a call inviting us to go to the studios in Elstree Hertfordshire on a specified date in February 2018. Much to our surprise we were told to bring at least five changes of clothing, but you were not allowed anything bright red or stripy because apparently those designs do not look good on the television. I only have about five respectable shirts so it was easy for me to choose! On the day you have to show your clothes to the wardrobe department and they tell you which ones you should wear on the show. I imagine they do this to avoid the risk of everybody turning up in the same colour shirt.

It's an early start on the day of recording. You have to be at the TV studios by about 7.30 in the morning. We live in London so that was not too bad but most of the other people had been put

up in a nearby hotel overnight at BBC expense. They film about five or six shows per day, so we were kept waiting in a chilly tent in the car park while we waited our turn.

My wife and I got our call after about three or four hours. Everything happens very quickly. There's just a quick introduction to Richard and Alexander (the hosts) and then it starts, in front



The moment Graham changes his mind on the answer to give. Nicki's face says it all!

of a small audience of about 50 people. Between each round there is about five or ten minutes waiting time as the losing pair say goodbye and the make-up artists check out whether you need fresh make up. I didn't need refreshing, so I can only guess that my complexion is perfect!

If you saw us on the show you will know that Nicki and I won the show and went home with the trophies, but we missed out very narrowly on the jackpot of £5250. We went home with the Pointless trophies and Nicki kept telling everyone that we only entered for the trophy not the money. However personally I would have quite liked £5250, but it was not to be. That's my own fault, because I knew the answer that would have won us the money in the final round, and I mentioned it three times but then decided not to put it on my final shortlist of three answers. That was frustrating, but it was a great experience and I would recommend it to anybody who loves the show and fancies having a go.

Smartening up your home

Geoff Adams-Spink

In the last couple of years, a quiet revolution has taken place in what's called the 'smart speaker market': the big tech companies - Google, Amazon and Apple - are all vying for our attention. As a group of people living with various degrees of impairment, this is something that should interest us.

Here's why: about four or five years ago, I met Carmel Daly, from Ireland, and she very proudly showed off her home control technology which was linked to an app on her iPhone. The entire system (everything from blinds to central heating and automated doors) cost upwards of £25,000. Now, because this technology is mainstream and not aimed at the older and disabled market, you can achieve similar results at a fraction of the cost.

Which system you go for depends on you. I have gone down the Amazon Echo route, and it doesn't make sense to mix Amazon with Google and Apple - that way confusion and madness lie. The Amazon devices are low cost and extraordinarily reliable and easy to set up. I did order a couple of the Apple HomePod speakers, but they were a nightmare to set up, and were soon packed back in their boxes and returned whence they came. I have no direct experience of the Google equivalent, but knowing that company's insistence on good usability, I don't imagine that they would give you a hard time. If you're not technologically inclined, I would suggest recruiting the services of a young person who can do the initial set-up for you.

So what exactly can you do with a smart speaker environment? At its simplest, your smart speaker can access music, news, podcasts and audio books and play them to you upon demand. If your smart speaker has a screen, you can see as well as hear the news. My Amazon environment is also extremely keen to help me to shop from - you guessed it - Amazon! So I can order a whole raft of things that are available from the company's website. Again, if you have a screen, you can actually see what you're buying, which helps a lot.



Rather like a smartphone or tablet, smart speakers can be enhanced by the use of apps: in the case of the Amazon Echo devices, these are known as 'skills'. One of the first skills that I installed was for Ocado. So whenever I suddenly remember that something is running low or that I fancy trying something new, I just instruct Alexa to "tell Ocado to add French beans to my trolley". You can do the same for to-do lists, reminders and so on. If you enjoy cooking, your smart speaker is really good at running multiple timers so that you can keep track of what is ready, when.

In order to get the best from this technology, I think you need a smart speaker in just about every room. I don't have them in the loos or bathrooms, but I do have them everywhere else. Then if you really want to make things interesting, you start to link your smart speakers to devices

around the house. One of my first acquisitions was Philips Hue lights. Now these are not cheap, but the price is coming down: so the initial investment is a little high when you consider that the white only bulbs are about £25 for a twin pack and the coloured ones are £62 for two.



Just to give you some idea, I have eleven coloured bulbs and thirteen white ones in my kitchen alone. So that's an initial cost of £520. You also need a Philips Hue Bridge, which connects to your Wi-Fi router. I have smart bulbs in pretty much every room in the house: in addition to being able to change the mood lighting, and turn them on and off by voice, I can also set up routines so that, for example, my outside lights come on at sunset and go off at sunrise. You can have endless fun setting up routines so that lights suddenly come to life at random times!

I've also linked my speakers to electric blinds and curtains, so that with one voice command I can open or close the blinds in a particular room or throughout the entire house. My smart thermostat (free from my energy provider) also has an Alexa skill so I can turn the heating up or down by voice.



Given that these devices are becoming ubiquitous, they are also incredibly useful as a communications hub. If you, and someone else who depends on you, enable a feature called 'drop-in' you can connect to them without them having to press any buttons or yell any voice commands. A good friend of mine has installed one for his elderly parents who love being

able to talk to him and actually see his face at the same time. Since I live in a three-storey house, the feature is really useful for me to communicate with my assistant, who might well be in the kitchen when I need her assistance two floors up. The alternative was yelling at the top of my lungs down the stairs. You can also make person to person calls outside of the drop-in environment, but in this case you have to touch the screen to answer the call.

So what does the future hold? Already, manufacturers of consumer electronics and white goods are building in smart speaker interfaces to their devices: we are, at the moment, in a Betamax vs. VHS situation; Bang and Olufsen for example only put Google Home interfaces in their audio and video products; other manufacturers build in more than one interface so that you can select which smart speaker environment you already have at home. When purchasing a new washing machine, for example, it's a good idea to check which devices it will pair with in your house.

And if you don't want to go as far down the road as I have, you could invest in a few smart plugs which are incredibly cheap (£5 and upwards) and will allow you a simple on/off control over any device that's plugged in. Just before writing this article, my tumble dryer started playing its endless tune which I was easily able to silence by telling Alexa, "dryer off".



NAC/Thalidomide Society Joint Event 2020

Gillian Sherwood

This Joint event which combines the Society's AGM and NAC's Conference will be held at Radisson Blu, Stansted Airport on Saturday 25 April 2020.

A combined team of Society trustees and NAC members have been sharing ideas and discussing logistics since summer 2018 and have chosen the theme 'Telling Your Story'.

A jam-packed weekend of interesting speakers, fun activities and entertainment is planned.



In the morning, the NAC session will include an interactive run through of the findings of the Holistic Needs Assessment as well as updates from the Trust. The Society will hold its AGM and a presentation on Thalidomide Stories: an oral history of thalidomiders.

After lunch the programme continues with the theme and invites presentations from members of the thalidomide community who have rarely, if ever, told their story to other thalidomiders as well as inviting a guest speaker (to be confirmed).

The second half of the afternoon will include workshops featuring Selina Hurley from the Science Museum updating us on the thalidomide element of the new Medicine Galleries, a music workshop from the OHMI Trust and more!

All parts of the day are open to everyone attending. All beneficiaries who are not Society members are eligible for free membership and so can attend the Society's AGM if they wish.

Throughout the day we are planning on holding an art and craft fair / break out area. If you feel you might be interested in participating in this, please contact Thalidomide Society at info@thalidomidesociety.org or on telephone number 020 8464 9048.

Following the positive feedback on Lith-tech wheelchairs, they've accepted an invitation to attend next year's event and there will also be a small number of stands available throughout the day with products, information and services that may be of interest and use to you.

In response to feedback there will be a breakout space available on the day for those who want to catch up with friends over coffee. We're also delighted that the Radisson Blu can provide an improved menu.

The evening should go with a swing, after an evening three-course meal, entertainment will be provided from comedian Laurence Clark, Daddy Cool, the DJ who attended the Society's event last year and is back by popular demand, a portrait photographer and some fun with large games including a giant Scalextric.

The Society will be coordinating the booking process for attendees and booking forms and full details will be sent out towards the end of December. Booking can also be done on-line.

In the interim, please pop the date in your calendars and diaries. It should be an interesting and enjoyable event! We're all very keen to make it inclusive and to bring people together.

Administrative support – ten months in

Gillian Sherwood

Doesn't time fly when you're having fun?! In November I will have been acting as the NAC Admin/Support Officer for one year. And what an interesting year it has been. It started last November with attending my first NAC meeting in London. What struck me immediately was how much is going on and how the Trust staff and NAC members work together to support the thalidomide community.



The purpose of my role is to support the members of the NAC in their work and ensure they have the systems in place to allow them to work efficiently and effectively. As well as taking notes for meetings I prepare the agenda for the monthly conference call for Members, ensure the NAC is GDPR (data protection) compliant and update their annual work plan. I also help coordinate this newsletter and ensure the Trust have up to date NAC information for their website. My role involves liaising with the Trust to coordinate diaries and schedules, update information and ensure timely and smooth communication between the NAC and Trust. I am also heavily involved in the planning for the NAC and Thalidomide Society Joint Event 2020 and helped to organise and run the NAC element of the 2019 event in April in Burton-on-Trent. It was lovely to meet many of you there and I hope to see you at the Radisson Blu next year.

I've learned so much about Thalidomiders through collating, summarising and building an NAC 'archive' of international government reports, conference papers and consultation documents alongside working with the NAC members.

In addition to booking meeting venues and supporting members who are leading on specific projects, my role involves a lot of 'herding cats'! The 12 NAC members are all incredibly dedicated to working on behalf of beneficiaries and work hard on this alongside juggling career, family, caring responsibilities, studying etc. This means it can sometimes be hard to pin everyone down at the same time, but I do my best and they are very patient with my 'gentle reminders' about deadlines and information required!

The role is what I hoped it would be - varied and interesting - and fits in well with my life and family. By setting up and running systems and being a central point of contact for all the NAC members, I hope I am making their lives a little more efficient and easier!

Chairman Geoff Adams-Spink adds:

I can't tell you how much difference it's made having Gillian to assist with the smooth running of the NAC: compared with my last spell as NAC chair, it's night and day. So many things I no longer need to worry about, so many things I've forgotten and am reminded to do.

We've also migrated our IT from the creaky old Yahoo group to the Google environment, where we have access to a shared drive facility and calendar. This makes collaborative working so much easier. A huge thanks to Simone Illger who introduced us to the right IT expert who then made this all happen.

Support for election to the NAC

Carolyn Desforges and Graham Kelly

Would you like to be an observer at an NAC meeting to learn more about the NAC?

Observational places on the NAC

We are really keen to have new people stand for election to the National Advisory Council to ensure we can support our community most effectively.

NAC members attend and contribute to NAC meetings and sub-groups, participate in telephone / skype conference calls, support Trust local events, and read and respond to documents and reports helping to shape Trust policies and developments. Key to the role of a NAC member is ensuring the liaison with beneficiaries and taking time to listen and feedback views.



Two observation places at NAC meetings are being offered to beneficiaries who are considering standing for election to the NAC in the near future. This will give applicants an insight into NAC working practices, including the joint working with Trust staff and trustees, and will support their manifesto.

Observation places are available for those applicants who:

- Have never attended an NAC meeting / Finance Committee/ Health and Wellbeing Committee in any capacity;
- Are willing to sign and adhere to the NAC/Trust confidentiality agreement;
- Are thinking about standing for election to the NAC in the next couple of years.

We can only offer applicants a place if they meet all the above criteria. Those offered a place will be invited to attend the formal NAC meeting with NAC members, Trust Directors, and trustees. There is a lunch prior to the meeting, with time for informal discussions and to ask questions of those attending the meeting. The costs of travel for successful candidates will be reimbursed in line with the Trust expenses policy.



Should there be more than two applications for an observation place, places will be allocated to those beneficiaries from “under-represented groups” on the NAC following analysis of all those who have stood and been members of the NAC. If there are more than two applicants from under-represented groups, then the successful candidates will be chosen by random selection.

We will establish a waiting list, with two people invited to the November 2019 meeting with others invited to attend later meetings.

If you wish to apply, please contact the Trust Office – there is a short application form to complete to allow places to be allocated.

Trials, tribulations, and solutions

Phil Williams

You may recall many years ago I did an article on losing weight, including a before and after photo on the beach which provoked much comment.

I was determined not to put that weight back on... but guess what. Yes, I did. It's very easy to make excuses and that's exactly what they were.

Many of you, or people close to you, sadly will have or have had serious ill health. Fortunately, I have not, but I have had a run of minor injuries, several totally self-inflicted so no sympathy please!



I've skied for 33 years to a respectable standard and never had an injury until I decided to teach my daughters to jump properly in Chamonix. An unintended somersault resulted in a fractured shoulder; ouch. It was very painful, truth to be told, and very inconvenient as it was my longer arm. I didn't want my girls to be put off skiing, so I jumped back up though my wife said my face was whiter than the snow. There was no way I was being stretchered off. Fortunately, it was near the end of the day, so I suggested a hot chocolate stop. We skied to a lift and went up even higher to a lovely mountain restaurant where I proceeded to take every paracetamol and ibuprofen in my rucksack. I then skied 2,100m down. There was little point in seeking medical help in a French ski resort where they have no experience of thalidomide architecture, so I bit the bullet for 2 days until we got home.

I went to Exeter RD&E for x-rays and care - they really didn't want to operate. The radiographers and consultants loved seeing me as at shoulder clinics they are usually all the same! When I was there, all 3 consultants on duty would pop in for a look. There was an amusing but alarming moment when they advised me to take a stronger pain killer and they offered me tramadol. When I declined and explained about Grunenthal they were aghast, but it was interesting they had very little idea about the company and our story. (As an aside, I really can't wait until we campaign full throttle against Grunenthal and I'll be very much at the fore-front of that- watch this space). I should mention that the H&W team at the office were incredibly supportive so a big thank you to Dr Dee and Michelle.

It took nine months to completely heal. I drank a lot of milk and took vitamin C & D supplements.

About a week later, my knee cartilage went. I was simply sitting on a bed in a hotel with my daughter who had a dance event. I was blameless, this time. My knee was completely locked. It wouldn't move for over a week. As you can imagine, mobility was a nightmare as crutches aren't practical with my upper limb impairment. I was pretty much hopping or sitting on a study chair on wheels to push backwards with my good leg but then getting twinges in my other knee which was frightening. I had to sleep downstairs. I'll spare you the details of having to fight my corner but I secured an MRI scan and an accelerated operation. Once again, the H&W team were invaluable.



Finally, when my knee was 100% better, I went back to Cardiff to watch my beloved Wales play rugby and in the final game, when they won the Grand Slam, I may have had a few diet cokes too many and fell over the seats in front celebrating.

Without longer arms to stop myself, my ribs took the impact on the seat backs so goodbye ribs; ouch. Not that I felt the pain until several hours later, for some reason, truth be told... It's amazing how much you need to bend and twist your torso isn't it when you have little or no reach with your arms.

What impact did all these back to back injuries have on me?

Firstly, I foolishly put on quite a bit of weight. I had previously given up running after an achilles problem but obviously I wasn't very mobile. The correct and obvious response was to do what I could – exercise-wise and eat/drink less. But no, I felt sorry for myself and comfort ate/drank, including lots of yummy carbs. Silly, silly boy.

Secondly, I had a rude awakening as to how fragile my independence was. All three injuries are pretty minor really for the majority of the population, but they were temporarily life changing for me.

Thirdly, with 2 young daughters it made me re-focus on the need to be as healthy and fit as possible.

So, it was time for remedial action including wise use of my Health Grant. I have taken the following actions:-

1. I'm looking after my nutrition - I hate the word 'diet'. I drink a lot more water again.
2. I bought a fit bit and set a goal of 20,000 steps a day with hourly targets too so it vibrates when there are 10 minutes to go and I'm behind. It's fascinating to look back and see how certain statistics or indicators have changed including my resting heart rate.
3. I bought a hot tub. It's fantastic for my emotional wellbeing and complements my mindfulness exercises. We often have a family session under the stars as there is little light pollution here the views are fantastic. In addition, it guarantees the girls have no electronic devices so we have a top chat. Finally, it's therapeutic for muscular-skeletal issues. **(editors note, I thank Phil for sparing us from Speedo shots, or worse).**
4. I looked around at many different models and I bought a static solid exercise bike for using indoors. It's in the snug, in front of the TV, so very handy. I average 30km a day across 2/3 sessions. No strain on joints or muscles as low impact and I set different programs depending on the work-out I want.
5. The major action I took was meant to be the thrust of this article. I had a road bike custom made for me! I wanted to ride in the fresh air and with my family. I didn't want a reclined bike or a trike. I wanted it to look like every other bike; at first glance anyway. I had four



meetings/fittings and now have a fantastic bike which I love though it cost a fair amount. I only use it on bicycle paths, but we have so many long ones here. Many roads locally are very narrow and hilly with the inevitable pot holes, plus I'm not sure any drivers would spot my arm signals! Since the idea of writing an article about getting my bike made I've seen really excellent footage on-line of our very own Sue Kent riding her bike and of course the outstanding long distance cycle from

Lands End to John O'Groats undertaken by Andrew Paddison. As such, I felt a fraud bigging-up my minor bike adventures. If you're interested, please do contact me.

6. Historically, I've resisted nearly all aids and gadgets as I've been very nervous about becoming (overly) dependent on them. We love travel as a family and I don't want to limit our options. I've also noticed that as many people age, their confidence in travelling even short distances and their geographic footprint becomes increasingly constrained. I didn't want this to happen to me allied to an over reliance on home comforts. However, all these minor injuries made me accept how fragile my independence is so I'm now exploring structural adaptations at home.
7. My experiences confirmed to me how much support and assistance is available at the office. I would urge you to contact both the finance and H&W teams if you need help.
8. I must remember I'm 57, not 27, so act my age on skis and at rugby matches!

I'm gradually getting back into shape and fully intend not to repeat my previous mistakes!

If you want to talk to me about anything above or indeed any other matter, please do not hesitate to contact me on phil@philipdavidwilliams.co.uk or on 07554 016303. I'm very happy to talk but prefer to use email, text or WhatsApp to set up a mutually agreeable date and time to do so.

Future care costs for thalidomide beneficiaries

Graham Kelly

The year 2022 will be a very important point in the next round of negotiations with Diageo and the UK Departments of Health for the next funding settlements. The NAC and the Trust agree that a vital factor in those negotiations will be making the case that Thalidomiders will have increasing and potentially expensive needs for additional care and support as they move into their 60s and beyond.

Most of us find difficulty in performing some tasks that would have caused us little trouble some years ago. We know that we will need more help with daily tasks as we get older. This is true of all people as they get older but is especially true for those who have had a disability from birth. All the information from the HNAs carried out with 90% of beneficiaries over the last three years provides evidence of deteriorating physical health and increasing levels of pain together with high levels of anxiety about how their future care needs will be met.

To prepare for the next Diageo negotiations, the NAC realised that we need to build up solid, detailed evidence on the cost of the future care we will need. Working with the Trust staff we have now commissioned the Future Care Costs study that uses a widely accepted legal approach to identifying future needs and costing them.

The project is being overseen by a steering group containing three beneficiaries, two trustees and the Director of the Health and Wellbeing team.

The first step in this process was for the Trust's Medical Advisers to carry out an audit of the recorded original damage of all beneficiaries to identify all the different patterns of impairments caused to members of our UK community by thalidomide. For the purposes of this study 15

different categories were identified (e.g. hearing impairment but no limb damage, upper limb impairment only, four limb impairment etc). This is important because people with similar kinds of impairments are likely to have similar types and levels of care needs.

The next step was to appoint a firm that specialises in assessing personal injury damages. This is the kind of independent assessment a person would have if they were making an individual claim for personal injury, for example after a car accident or medical accident. Following a competitive tendering process we have appointed Bush & Co, which is the country's leading provider of this type of service. They have put together a highly qualified team for our project, comprising of a Nurse, a Physiotherapist and an Occupational Therapist. This team will visit some of our beneficiaries to do a very comprehensive assessment of their current care needs, advise on how those needs are likely to change in the future and estimate the cost of those changing needs. They do this by identifying predicted changes across different age periods – from age 60-64, 65-69, 70-74 etc. For example, they will look at how care and domestic assistance is provided now and how that will continue to be provided in the future. Even the cost of help provided by family will be costed based on the market rate for employed carers.

Other topics covered in the assessment include things like support with pain management, exercise, travel, holidays, pet care, seeing family and friends, adaptations to the home or the purchase of new technology. As you might guess from this, the assessment involves a long list of all aspects of daily life that has been put together using what the beneficiary advisers tell us is important.

The third step in the project is for the Trust to identify 15 individuals who are willing to be visited and assessed by the Bush & Co team. These individuals will be chosen as being representative of the categories identified by the Medical Advisers. If you are one of those who has been or will be assessed in this way, then thank you very much for volunteering, because your involvement is crucial to the project.

The visits to the 15 selected Beneficiaries are taking place during 2019. Once all visits are completed and we have the individual reports from Bush & Co, these individual cost estimates will be reviewed by a Forensic Accountant with expertise in personal injury claims. This is to ensure that costs are not exaggerated, or any future care needs overlooked. We have appointed Hugh Gregory, one of the country's top Forensic Accountants and he will use the individual reports to estimate the total costs and likely care needs for the whole UK community of Thalidomiders over the rest of our lives.

The final report is expected to be completed ready for trustees to receive in September 2020, in good time to provide a really powerful piece of evidence for the negotiations.

Lands End to John O'Groats

Andrew Paddison

On the 12th July I managed to cycle 992 miles from Lands End to John o Groats to raise money for 3 cancer charities, namely Bloodwise, Macmillan Cancer Support and Prostate Cancer UK, all three close to my heart.

The main reason to attempt the challenge was for the charities, however it also coincided with the 60 years since the first thalidomide baby was born in the UK. I fully appreciate that thalidomiders have varied views and personally I have never been involved in any beneficiary, Trust or Society events, however I thought it appropriate to demonstrate to people that whatever your limitations, this should not prohibit you leading an active lifestyle which has huge health benefits.



Despite having 2 shortish arms, no elbows, right angled wrists, curved spine and no right leg, I have led an extremely active lifestyle, always via sport, ranging from swimming miles, table tennis, tennis, cricket, squash and golf, all to a reasonable standard and never within any para athletic group.

Cycling has always been in my blood, my father was an active cyclist and during my youth I cycled everywhere using an adult tricycle. A few years ago, I thought I would try hand cycling as after a hip replacement, normal cycling was slightly wearing. I loved it and 2 years ago purchased a road handbike, which I adapted for my needs, with a footbrake, automated gearing and a torque power assist, to ensure I could tackle the Welsh hills (as due to no elbows, leverage is only via the shoulders and back / stomach). It worked to such an extent 50 miles was achievable for a morning ride and I joined the local cycling club.

LEJOG was tough but enjoyable and I managed to persuade 6 other cyclists to join me, with only one with prior experience of LEJOG. Organisation was undertaken by a wonderful lady Emma Dyson of Mellow Jersey and she arranged the route, accommodation and provided the essential nightly massage. The hardest part of the journey were the first 4 days, traversing the narrow



Cornish and Devon lanes, with many a steep climb as our aim was to keep off A roads. The Lake District was glorious along with the Scottish Highlands. Amazingly amongst the team, there wasn't a day where there were crossed words, the support and morale was brilliant, with much banter along the way, even in adversity you must always find humour.

Interestingly, a few other cyclists joined us en-route to ride a few sections, some managed a whole day, others found the pace too quick - there was no time to dally, especially when covering 100 miles in day. There were many a high but no lows, even the wet days in their own way were challenging but rewarding.

With extreme fortune Susan Reid picked up the challenge and invited us to appear on Good morning Britain, which was great to raise awareness for the charities and the power of TV meant that in the 2 hours after the appearance, the fund increased by £5,000.00. Today we have raised just over £22, 400.00 and counting, which makes it all worthwhile.

Training is so important, I had trained for 3 months, juggling work and other commitments but the benefits meant I was fully prepared.

The challenge was only possible due to support of local business who covered the costs of the challenge, which I am eternally grateful.

A number of people have asked would I cycle LEJOG again, maybe, but I have completed that challenge, and there are other challenges out there! So, watch this space.

Remap

Simone Illger

Simone was delighted with her new electric wheelchair. It is lightweight and more manoeuvrable, with a better seat, and is easily transportable.

The only snag was that the controls were difficult to reach with her very short arms. She was forced to lean sideways and forward, and after a while this started to adversely affect her back and cause pain.

But where does one go to find someone to modify wheelchair controls to bring them within reach of someone with shortened arms?... Step forward Remap - the national charity dedicated to creating free bespoke gadgets for people with disabilities or special needs. Volunteer engineer Peter Kittoe - seven years a member of Remap's Berkshire branch - designed and built a unique bracket for the wheelchair joystick control - bringing it closer to Simone whilst allowing it to be folded away when not needed.

Now the wheelchair is spot on in every way.

To quote Simone, "I had got a local metal workshop to create me a bracket to help me with the wheelchair controls, but it was never satisfactory, took them ages to fabricate and cost me a fortune. Then I remembered Remap. Some years ago, they had created an accessible playpen to help me keep my baby daughter safe. They also assisted me in my journey to improve my fitness by installing a bar along the front of my treadmill - I couldn't reach the original ones at the sides, so the bar enabled me to use the treadmill safely.

"The job Peter did for me on my wheelchair is really great; it has made a real difference to me. I spend a long time in my chair, and the position of the original controls was starting to cause me real problems".



Peter - a professional engineer with a well-equipped workshop at his home in Reading - and the 21 other volunteers in Remap Berkshire are pleased to use their problem-solving skills to create gadgets and equipment where nothing suitable is available to buy. Previous cases he has handled include creating a four-wheeled outdoor buggy with a unique seat design for someone who lost most of her buttock to cancer but was keen to keep up with her gardening hobby.

The Remap Berkshire 'MakeAbility' service has assisted people in all age groups with a wide variety of issues and make no charge - the charity is financed through donations. Among the recent assignments have been:

- Electric grabber for a ten-year-old with weak muscles
- Long-reach window opener for a lady with arthritis
- Cornered ramp for a wheelchair user
- Steps for a child with dwarfism
- Safety bottle opening gadget

Due to an increasing demand, there is a need for more volunteers throughout Berkshire. Many MakeAbility are from an engineering background, but some have electronics and computing expertise, others are skilled with wood, or have a passion for model engineering, in fact anyone with a talent for problem-solving through making things can contribute. Some volunteers have their own workshop, others use community facilities or have a workbench and tools in the garage. Access to transport is essential.

Many volunteers are retired; others, like Peter, fit their MakeAbility assignments around work commitments.

Volunteers say that they get huge satisfaction from helping people overcome the practical problems they face and seeing how lives can be transformed by sometimes simple solutions. Enabling a person to become more independent is wonderful for everyone concerned.

Out of pocket expenses such as the cost of materials and travel expenses are paid. There is no obligation for volunteers to take on jobs unless they feel they have the necessary skills and enough time spare. Other engineers on the panel are always prepared to help when problems come up outside any individual area of expertise.

Remap Berkshire appeared recently on BBC Television. The feature can be viewed here:

<https://www.youtube.com/watch?v=H8tmxYSeHPE>

Remap Berkshire is one of 70 Remap branches throughout the UK who together helped over 3,000 people in 2018.

For further information about volunteering, or to discuss whether Remap could assist you or someone you know, please get in touch:

For National Office: please call 01732 760209

For Remap Berkshire: please call 07790 127123

To find a branch near you: please visit <https://www.remap.org.uk/contact-remap/>

Aviation 2050

The Future of UK Aviation: Consultation. A Response from the NAC

During the first quarter of the year, the aviation industry launched a consultation on the future of UK aviation including meeting the needs of disabled passengers. The NAC submitted a response on behalf of the Thalidomide Trust. The NAC response was based on the members' knowledge and experience and on general information provided by the Thalidomide Trust, based on their in-depth knowledge of the challenges faced by beneficiaries.

The Thalidomide community contains people with a wide range of impairments from blindness, deafness, mobility impairments to lack of limbs and shortened limbs. Upper limb impairments present a very specific set of challenges to an air passenger, affecting their dexterity, reach and ability to carry bags and navigate airport security.

The NAC noted that current aviation regulations state you can only fly unaccompanied (without support/an assistant) if you can:

- Understand the safety briefing
- Fasten/unfasten your seatbelt
- Take out and put on your lifejacket
- Leave your seat and get to an emergency exit
- Put on an oxygen mask
- Use the toilet on your own

For those who lack upper limbs, or who have issues with dexterity and reach, doing up and undoing a seatbelt or putting on a lifejacket or oxygen mask may be something they would require assistance to do. Older people and children would face similar difficulties. The NAC noted that, in practice, this regulation has rarely caused an issue as support has always been offered by a fellow passenger or member of the flight crew. The NAC are, however, concerned that an airline could refuse to transport a passenger travelling alone who is unable to do these things without support. Our belief is that this type of incidental support should be part of the special assistance that is offered to disabled passengers or that there should be a reduced cost for an accompanying assistant.

Whilst there are already internationally agreed codes for some disabilities (e.g. WCHC for those needing to be carried/hoisted aboard and WCHR for wheelchair users) and lanyards/booking pass stamps for hidden disabilities, the NAC advocates that the UK aviation industry takes the lead in advocating a new IATA code for people with an upper limb deficiency. The NAC feels this would have a significant beneficial impact, providing support for people who otherwise suffer significant muscular-skeletal and back damage resulting from performing activities their bodies are not designed to do, such as carrying/pulling luggage across an airport.

The NAC noted that passengers who are unable to mobilise or use an aisle chair, because of shortened or missing limbs, may not be able to access the toilet during a flight. It also noted that toilets are far too small for anyone who requires assistance. They are pleased to note that new airline standards specify that new and refurbished aircraft should have movable armrests, at least one toilet for PRMs catering for all kinds of disabilities and at least one on-board wheelchair.

There was strong feedback concerning the safe transportation of wheelchairs. The NAC felt that airport staff were too keen to take a powered wheelchair off a user well ahead the point of boarding causing discomfort and loss of independence to the individual. The NAC proposes allowing a user to remain in their own wheelchair until reaching the aircraft doors and that the industry looks to having the wheelchair put on board into a designated space as one's seat. This would also address the problem of wheelchairs being damaged in the hold; the financial and emotional impact of which the consultation document acknowledges.

The NAC requests industry-standard guidance on the transportation of lithium batteries used in mobility aids alongside other essential medical items such as oxygen, medication and catheters amongst others.

The NAC response was submitted in June and we will be keeping an eye out for developments.

Campaign update

The Campaign Team

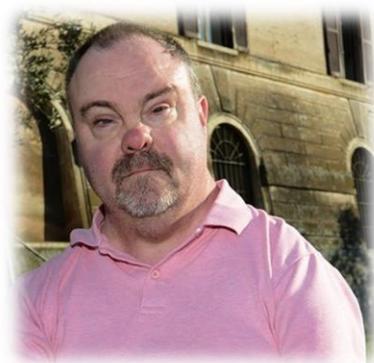
European Parliament

Since my comprehensive update earlier this summer there is not a great deal more to report given that the EU Parliament was busy establishing its political groups and then had a summer break.

The challenge remains working to establish a legal framework within a budget which is being debated currently and will not come into effect until 2021. The next step will be to try and engage the new German President of the EU Council and the Finn, Croatian and German Special Representatives as they prepare for their respective six-month presidencies.

We are re-engaging our main political supporters right at the beginning of this new session and are mindful that any Brexit deal we do, or do not get, will bring fresh challenges which we will do our best to overcome.

Craig Millward



The UK campaign in Westminster – the Health Grant renewal

Hi everyone

Thank you for sending your letter to your MPs in response to our recent mailings, and many of you also returned your postcards to the Trust. We cannot thank you enough for doing this as your actions enable us to make the phone call to your MP on your behalf and to speak with authority.

The letter you asked your MP to consider signing has received 139 signatures (as at 05 Oct) in the 6 chaotic days parliament was open in September. Even with Brexit many MPs found your letters a welcome distraction and have been more than happy to support us. Signatures are still coming in, and we expect to be able to present the letter to the Secretary of State for Health once parliament starts again. At the very latest it will be in the spring of next year.



On a final note we are planning an event in Westminster next year. Once we have a date set we will let you all know. If you hear anything about this event, or indeed anything about the campaigns from any source other than the NAC or the Campaign Team, please understand that our actions will always be shared with everyone via the Trust only.

Thank you all for your support, of each other, in this campaign.

Any questions please email us on email@thalidomidecampaigners.com

Thank you for your ongoing support.

Mikey Argy

And finally

Contact Us

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

The next edition will be published in the spring of 2020. 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

Tel: 07790 492 967

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

Mission Statement

"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."