

NAC NEWS

Autumn 2015

Newsletter of the Thalidomide Trust's
National Advisory Council

Hello, and welcome to the Autumn 2015 Edition of the NAC's Newsletter.

As well as more general news and information items, this edition brings you details about the proposed "Fit for the Future" event that will be taking place in April 2016.

Thank you to Carolyn DesForges who got stuck into her role as a newly appointed NAC member by offering to assist me in sourcing articles and chasing up contributors to ensure we could meet our publication deadline.



Also included is a progress up-date on the Campaign work, what is going on here in the UK as well as in Europe.

There have been many staff changes at the Thalidomide Trust and details of these follow. A number of beneficiaries have received Queen's Honours this year and we tell you more about their stories.

In the next edition, I'm keen to share reader's experiences of caring for their elderly parents. This can be a huge challenge for those of us who already struggle with so many aspects of daily living. Perhaps this is a time when you have found yourself closer than ever to your parents. Maybe you've just not been able to manage without a lot of additional assistance. Please do let me know if you are happy to share your story, which can be done anonymously if you'd prefer.

I've also got a few other ideas for articles up my (very short) sleeve – so watch out – I may be contacting you to ask for a contribution!

We will also bring you introductions to two new Trust staff members (with pictures!).



Finally, a thank you (once again!) to Karl Davies, who has helped me in formatting this edition. It's a substantial job to produce a newsletter but this time around we've enjoyed something of a team effort.

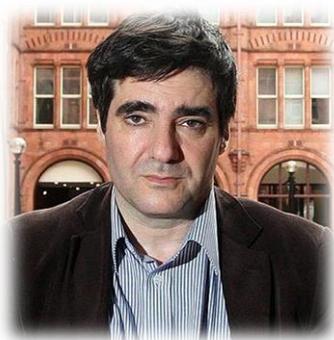
Please enjoy reading. If you've something you'd like to contribute to the next newsletter please contact me.

Simone Illger, Newsletter Editor

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Chair's Update



Welcome to the autumn edition of the NAC newsletter. We hope you find it interesting reading - and thank you to Simone & Carolyn for compiling it.

It is a few weeks until our NACAC 2015 in Durham. We very much hope you are planning to attend - and would like you to consider coming if you haven't yet thought about it. The programme will be packed, informative and fun. I also want to encourage you to seriously consider attending our first ever Fit for the Future event next spring. It will be an opportunity to take a look at various aspects of healthy living and exercise, and will be specially tailored to our needs.

It is also the season to give feedback. You will have already received your questionnaire sent out by Firefly Research. I hear that the early returns are very positive - over 40% received by Firefly in the first week alone and at the time of writing 75% of you have returned your forms! Well done. If you have not yet filled yours in it's not too late to do so. The data will be really important as we continue to remind the government we are alive and kicking. You'll recall that the government is due to assess our annual health grant after ten years and we need to be able to show them what our ongoing health needs are.

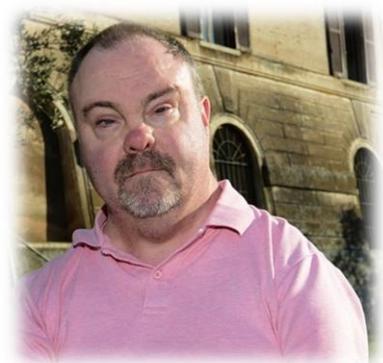
The Campaign Team had its first meeting with the German government in July. We will be writing more about this elsewhere but I want to assure you that we are doing our best to win this campaign. You should have by now have received another letter to send to your MP - thanks for helping us so far. It will be a while before we get a breakthrough but we remain confident.

Enjoy the last few weeks of summer.

God bless,

Nick Dobrik – Chair

Craig Millward – Deputy Chair.



Membership of the NAC – Up-date

By Craig Millward - NAC Deputy Chair.

The NAC is made up of twelve beneficiaries who are willing to serve the whole thalidomide community by taking on a variety of roles. In April of each year, three of our number come to the end of their four year term and have to stand down.

This year we said goodbye to Phil Williams, Stevie Sinclair and Karl Davies.

Phil served two terms on the NAC and contributed a huge amount during that time. He brought considerable financial experience to the role and was very influential on the shadow finance committee and in on-going negotiations with Diageo. Phil also served as Chair of the NAC and has contributed a massive amount to the on-going campaign to bring the German government to the negotiating table.

Stevie also served two consecutive terms and was instrumental in arranging a series of well attended events in each of the four national parliaments. These events gave us an excellent opportunity to thank parliamentarians for our health grants and explain our need for them to continue beyond the current ten year timeframe.

Karl has been involved with VTAG, assisting the beneficiary community to benefit from the wide range of technical assistance there is out there. He has also assisted with putting together the NAC's newsletter, with helping to organise the NAC's annual conference and with the recent revision of our Operating Guidelines. Karl has also served on the finance group.

Karl was one of six individuals who put his name forward for election to the NAC in 2015 and was re-elected. Along with him, Carolyn Desforges and Eddie Freeman were also elected to the NAC for four years.

Carolyn has joined the Health & Wellbeing committee and has jumped straight in to be involved with organising the Health and Wellbeing section of NACAC this year as well as assisting Simone in obtaining articles for this newsletter.

We thank all six who stood for election and welcome our new members to four years of hard work.

Sadly earlier this year Freddie Astbury had to resign due to ill-health.

EU here we come! A day trip to Brussels....

By Simone Illger

The idea to travel to Brussels for an event that was only likely to last a morning seemed rather crazy. Having previously undertaken the journey from London to Brussels via Eurostar once before, I knew it was an easy and fairly inexpensive trip.

Within a few hours of having received the email from the Campaign Team about the planned Press Conference on the 27th May 2015, I'd booked our Eurostar tickets and a hotel room in the Radisson Blu, just around the corner from where the press conference was being held.

Having organised similar events in the past – both for the campaign (the Germany Embassy demonstration) and for other disability organisations, I knew that for many, this short trip overseas would take quite a bit of organisation. One may think that Brussels, being at the heart of so many discussions on European law and equality debates may offer the perfect venue in terms of access and getting about, but sadly the reality is far from that.



I was very pleased to learn that there would be a number of us making the trip. I liaised with thalidomide friends to ensure that we would be staying close to one another and in the vicinity of the meeting. Then there were other arrangements to make, such as relaying details of our passports to Monika, Keith Taylor MEP's assistant.

News of a planned rail strike on the day we were due to travel did not deter me. Living less than an hours drive from London, I researched potential locations to leave the car should we need to drive in. Thankfully the strike was called off a week beforehand.

On the day itself, we had a fairly leisurely trip, travelling up to London in good time and enjoying lunch ahead of our train. Eurostar is definitely the way to travel for wheelchair users. One can book into Premiere Business for the same cost as

travelling standard class and the costs are reduced for wheelchair users and a companion. A one-way trip cost us just £37 each!

Even without the use of the Premier Business lounge and copious amount of free nibbles and drinks, Eurostar provides a VIP experience.

The carriage was virtually deserted and we enjoyed looking at the fields whizzing past the window as we tucked into our meal and sipped a glass of champagne.

On arrival At Brussels Midi, we had decided to walk the 1.8 miles to the hotel. This turned out to be a bit of a wrong move, as we managed to overshoot the hotel – and the walk that should have taken about 40 minutes took us over 2 hours... passing through some of the less desirable areas of Brussels. Thankfully I am able to stand and walk, as on several occasions I had to abandon my wheelchair whilst Andy, my husband, dragged it up and down high kerbs.

At the hotel, we were greeted by not just our fellow UK thalidomider friends, but by a number from Sweden who I have known for many years.



We were up early the next morning. We'd been instructed to be ready outside the Parliament building for 8.45am to meet with Monika (one of the MEP's personal assistants) so that we'd clear through security quickly. The building is enormous so it was good to have Monika escort

us once inside to the coffee bar we'd agreed to meet in.

Altogether there were about 15 thalidomiders from the UK, around 6 or 7 from Sweden and several from Spain and Italy. At this point, several MEP's came down to offer their support and encouragement for what we are trying to achieve.

Ahead of the planned start of the press conference, we were shown to the room, which was a large amphitheatre. Although the press conference was going to primarily be in English, translators had been provided and we all donned headsets so that we could follow everything being said. As 11 o'clock approached, the room quickly filled with journalists, cameras and MEP's. I was very pleased to hear that Meridian News were there – our local TV station.



The opening statement was delivered by campaign team leader Nick Dobrik who drew attention to the fact that the behaviour of a past German government fell well below the standards we have come to expect from modern Germany.

Ashley Fox (ECR), Esteban Pons (EPP) and Matthias Groote (S&D and a German MEP) called from the platform for the present Federal Government to 'put right an historic injustice and

ease the physical suffering of remaining thalidomide survivors before it is too late'. Herr Groote, spoke about ensuring that collectively we found a solution for all European thalidomiders – his attendance and participation in the event were welcomed by many there. Many other MEPs, both from the UK and other countries spoke quite passionately and emotionally from the floor of the conference in support of this call. It was excellent to see and hear such cross-country and cross-party backing. The EU was speaking with one voice in support of the campaigns aims.

At the conclusion of the event, we made our way back to the bar for a well-deserved coffee and to meet other MEP's who'd been unable to make the press conference itself.

Although I arrived home at 10.30pm that night, emotionally and physically exhausted, I felt that the effort for us to get there had been well worth it. Although I can report on this event and share pictures, it doesn't quite have the same impact as being there. The campaign team did a fabulous job – not just those who had travelled to Brussels, but others who I know work diligently behind the scenes Tweeting and keeping the campaign team up-dated with how the media are covering the event.

The trip was only marred by the fact that we left our passports hanging in the washroom on the Eurostar on the way out there. This may well have sabotaged our ability to enter the EU Parliament building – thank goodness for driving licences with photographs! Spending time inside the British Embassy in Brussels sorting out emergency passports so that we could travel back home was an experience we'd have been pleased to bypass....

I was very pleased to be invited to speak about the trip and the campaign to Anne Diamond who works for BBC Radio Berkshire. Anne spoke of her amazement that nothing had been paid by the German drug company to any of the thalidomiders. I ensured that the 10 minute interview also highlighted the fact that most of us are deteriorating rapidly – and whilst some of us are happy to be vocal and highlight our plight, there are many others struggling to live their lives in silence.



DUP = Democratic Unionist Party

S&D = The Progressive Alliance of Socialists and Democrats

EPP = European People's Party

ECR = European Conservatives and Reformists

International Thalidomide Congress, Tenerife 4th – 11th July

By Simone Illger

Having been one of the key organisers for the previous two international Thalidomide gatherings (Netherlands 1992 and Sweden 1998), I didn't need to give too much thought as to whether to join in the planned international thalidomider gathering in Tenerife 4th – 11th July 2015.

Tenerife is an island I have visited about 7 times before. I feel at home there and I know the area of Los Cristianos is particularly great for wheelchair users, boasting the very best accessible beach I have ever seen where – not only can one get into the beautiful sandy beach, but one can also get into the sea via a special beach wheelchair and trained lifeguards located on the Las Vistas beach.

I knew that for many of the group, this holiday would be a challenge. We are all almost 20 years older than the last time such an event took place. Comfort is much more important to us, as is reducing the amount of walking required. The choice of venue – Mar y Sol Hotel in Los Cristianos, turned out to have contributed significantly to the success of this week.



When I first heard about Mar y Sol from a fellow thalidomider, I thought it sounded like my idea of a holiday nightmare. A hotel with all sorts of facilities to enable disabled people to fully participate in every aspect of their holiday. Every

room is wheelchair accessible, the pool has hoists and chair lifts, the doors are all wide and every part of the hotel is accessible with lifts and ramps. A hotel which has on-site care facilities that one can hire out to assist with personal care. Physio and other treatments readily available. That would result in a disabled ghetto, right?



A fully accessible hotel with a disability equipment hiring facility right next door.... Who are also able to offer the hire of electric scooters and wheelchairs, fully accessible minibuses for airport transfers or visiting some of the islands attractions....

Suddenly this all makes perfect sense, especially when you are bringing together over 150 people with varying levels of disability, many of whom will travel independently and from destinations as far away as Australia and America.

Yes, we were going to be surrounded by a LOT of other disabled people. But these are fellow thalidomiders. My past experiences of enjoying a week together like this had been truly memorable and most enjoyable. These people are all friends – some who I have known for over twenty years and some of whom I have yet to become acquainted with.

My daughter Lois and I flew on an early morning flight from Gatwick. As previously organised, we were met in Tenerife Airport by LeRo, the company who work in partnership with the hotel with regards to disability and mobility equipment as well as accessible transport.

Our room was spacious – a large living area with a kitchenette, an accessible bathroom with a shower above bath AND a separate wheel-in shower. Separate large bedroom with plenty of storage space and a balcony. Ok, it was decorated in 80's fabrics, but spotlessly clean and meticulously maintained.



The organisers of the week (German) had thought of everything. Several excursions had been arranged which we could sign up for. There were also various workshops – jewellery making, photography, salsa dancing, singing and yoga. It was nice to know that you could join in as much or as little as you wanted to. The important thing was that we had all been brought together in one place.

Lois and I signed up for the whale and dolphin watching boat trip and the Spanish evening. The boat trip turned out to be quite eventful! A large boat laden with thalidomiders and a rather large sea swell! Soon there were people staggering about the deck and looking rather green about the gills. Having experienced sea sickness myself in the past, I did feel for these poor folk, as we sailed in search of sea life for over two hours. I soon started to feel rather queasy myself, but this was more as being a spectator to people experiencing varying degrees of sickness.

Once we dropped anchor for lunch, things started to calm down. A wonderful lunch of roast chicken, salad, rice and meatballs was served. Quite challenging as trays were provided, but these don't really work for those of us with short arms and no lap!

The pilot whales didn't make an appearance, however, we did get to see plenty of dolphins.

On the third day of our holiday, I travelled with others to see the centre of the island. I'm rather embarrassed to say that I've never been outside of Los Cristianos on the past because of the wheelchair - but with a hire car and someone else doing the driving we set off into the national park. The vista changed spectacularly with every bend in the road – pine forests, luna landscapes, volcanic lava beds, colourful layered rock strata... What was more striking was the perfect and absolute silence that one can experience once the car engine is turned off.

The Spanish evening was very hot. We drove up into the hills as the sun was setting, around several hairpin bends – very exciting as we were aboard a 52 seater coach! Sheer drops on one side accompanied by breath-taking views of the sea below. We where we were warned it would be much warmer and there would be mosquitos. It was hot! About 150 of us were seated in a large gazebo where we were treated to various local dishes such as tortilla, chick peas in tomato sauce, soup, sausage and cheese and a hog roast. The wine and sangria flowed freely – but to be honest it was so warm, that many of us drank large amounts of the soft drinks provided. The local culture group provided entertainment – dancing in traditional costume. There was also singing, a traditional band and flamenco dancing.

The evening's excitement was not over. Thankfully Lois and I decided to take one of the smaller wheelchair accessible coaches for the journey home. The largest coach set off first ahead of us. As we rounded one of the bends, we came face-to-face with the back end of the large coach. It had broken down! All the electrics had failed. There then began the exciting manoeuvre of all the smaller coaches inching past the large and now immobile coach, the wing mirrors of each vehicle just a few centimetres apart. We later learned that the smaller buses had to return to collect the stranded bus passengers.

I also had the opportunity to try out a "Mobility Cube". This is a segway-based wheelchair and belonged to German thalidomider Stefan Stoffel Keekamm. The man who designs these amazing "vehicles" was coincidentally on holiday in Tenerife and came over to the hotel so that several of us could try out the Mobility Cube and be adequately insured whilst we were doing so. I had seen Stefan on his Mobility Cube around the hotel and, like many others, was intrigued and interested to understand just how it worked! It's a very robust and solid piece of machinery that makes light of any terrain thanks to its two chunky wheels. No effort at all is required to remain upright and speed is controlled by moving one's body slightly backwards or forwards. Steering is done via the t-shaped handlebars that are moved left and right. It was fantastic to have the opportunity to try something like this – which otherwise would involve quite a bit of travel. <http://www.axperts.de/AX-MOBILITY-CUBE/en> and cost about £2,950 (for the basic model) but sadly it seems that you wouldn't be able to use one on a pavement or a road in the UK for the time being! - <http://www.bbc.co.uk/news/uk-england-south-yorkshire-12215326>. However, I am certain that Segway-based wheelchair design will soon be the norm....



The highlight for me of the whole holiday was spending time with other thalidomiders around the pool or in the bar, chatting over dinner. Sharing memories of past events and learning what was going on within one another's countries with regard to Thalidomide.



One evening we were honoured to see a screening of "50 Años de Vergüenza" (Fifty years of Thalidomide). This was an award winning documentary film made by Spanish film directors Javier Almela, Fernando Rodríguez and Ana Salar.

The film can be purchased (with English subtitles) here: <http://50adv.com/en/>

It was both powerful and thought provoking - featuring interviews with about 50 individuals from all around the world, including Martin Johnson (ex-Director of the Thalidomide Trust) and Fred Dove (German beneficiary living in the UK) and Craig Millward (UK beneficiary).

Our final evening arrived much too quickly. The group came together for a cabaret evening with performances from the hotel staff, workshop leaders, Germans, Swedish, English speaking

delegates. Although a little was lost in translation, there was a lot of laughing and applauding. The singing workshop shared their rendition of the Beatles song “Yesterday”.

In a corner of the hotel reception was a quiet corner decorated in red, yellow and orange material. Many candles burned here, alongside pieces of paper bearing the names of thalidomiders who are no longer with us. I added just some of the names of those UK beneficiaries who I was honoured to have known as good friends – Janette Cooke, Rob Moreton, Tina Gallagher, Veronica Packham, David Loughran... to name but a few.

Here in the UK, we thalidomiders sometimes take for granted that we are able to enjoy frequent contact with other thalidomiders, that we have access to the growing body of expertise and knowledge which is the Thalidomide Trust. Travel is easy within our small group of islands. Being able to meet thalidomiders from other countries and continents is an incredible opportunity and one I am very pleased to have been a part of.

Honoured in a wonderful day

By Rosaleen Moriarty-Simmonds

The 22nd November 2014 was the start of a truly special time for me.



On that date, I received notification that I had been awarded an OBE (in the Queen's New Year's Honours List) for "Services to the Equality and Rights of Disabled People".

I have been challenging perceptions of disability by overcoming barriers (whether physical or in attitude); campaigning and seeking to right wrongs; using my skills and knowledge to support, advocate for and mentor many people less fortunate than me; and through prolific voluntary work for numerous organisations, including as a school governor - for more years that I care to remember, and now, that work has been recognised.

The New Year List went "live" at 10.30pm on the 30th December, and shortly after, our phone line and my social media went into meltdown! However, my biggest regret is that my Mum and Grandmother could not share the celebrations with me. They were my biggest fans and role models, and I owe them a debt of gratitude that is difficult to articulate.

I received my Honour on the 17th July 2015 at Windsor Castle, and whilst it is not the most accessible place for disabled people, the staff and officials were wonderful. They really do make the Investiture day a truly memorable occasion.

All the excitement of that initial letter, the preparations for the big day and, the "pep" talk you have whilst waiting for the ceremony to start, pale into insignificance as you wait to be presented to the Queen. Her Majesty is a very gracious lady and shows a genuine interest in your work during the time spent in her company.

In December, I dedicated the award to my Mum, and in post-investiture media interviews, I expressed my intention to use the distinction of my OBE to ensure disability rights continue to figure highly in the equalities agenda.

As the first, but happily not the last Thalidomide impaired person to receive a Queen's Honour, I hope I live up to the expectation that having an OBE brings.

For more information on Rosie's Honours nomination and ongoing work, please visit the Blog and News pages at: <http://www.rms-consultancy.co.uk>

Lorraine Mercer MBE

When I got the letter telling me I will be awarded an MBE I was quite surprised and excited about it. I made little postcards for all my friends telling them my achievement and now have lots of congratulations cards all over my flat!



I have been working at the Princess Royal Hospital for about 8 years, helping patients with difficulties physically and mentally. It has been especially rewarding when they don't have any visitors and have been left feeling shut out, so I chat to them and help pull them out of their shell and encourage them, it makes them feel good and gives them a little boost in confidence.

I have also raised a lot of money over the years for charities such as the RDA (Riding for the Disabled Association) and Herons Ghyll who I have swam over 150 miles for, and for Operation Collingwood (former charity for engineering) for whom I have done a sponsored silence.

I am excited to receive the MBE and meet the queen. Being able to go inside Buckingham Palace and view the paintings will also be exciting to me especially since I have never been inside it before.

A friend is treating everyone after the day to dinner in the Shard, to congratulate me. We will be able to overlook the whole of London including the palace. I feel delighted to get this far, it has been an amazing journey but one I have yet to finish. I am privileged to be receiving this honour.

Campaign Update

By Craig Millward - on behalf of the Campaign Team

The aim of the current campaign is to force the German government to take responsibility for the fact that, when it conspired to bring the trial of Grunenthal to an end in 1971, this decision had serious implications for us. We believe that their actions broke the German constitution. We can also demonstrate that our current poor health is partly a result of long-term underfunding which is a direct result of this action.

The campaign is operating at three levels:

In the UK Parliament: We have over 280 MP signatures on an open letter to the German government. We are meeting MPs all the time and this number continues to rise. We have plans to send another letter to all MPs in September and meet with various key targets.

In the European Parliament: Following an open letter to the German government signed by the Presidents of all seven political groups in the EU parliament we have had meetings with the EU Health Commissioner and the EU President and hosted a very successful Press Conference. We are now following this up with plans for a Motion - something that will seriously embarrass the German government if we can pull it off. The procedure is long and complicated and we are beginning to seek advice and win the supporters we need. In addition to this we are helping the EU Commission celebrate the 50th anniversary of European drug legislation which was enacted following the shock of the thalidomide tragedy.

With the British Government: We have a huge amount of support in the UK government. Dave Anderson (Labour) & Simon Hoare (Conservative) from the Thalidomide All Party Parliamentary Group joined us the first meeting with the German government and George Freeman & David Lidington are the ministers who are aware of our campaign and in contact with German ministers. We also have a number of staff at the Foreign & Commonwealth Office working for us.

The first meeting with a representative of the German government was polite and helpful. We were promised a follow up meeting in the autumn and are doing our best to fix a date. We have delivered a great deal of evidence to them and are preparing more in advance of our next meeting. We will be well prepared.

In the meantime we are working with our Spanish, Italian & Swedish partners and helping them to put pressure on the German government from within their own countries.

We aim to win.

Thalidomide takes centre stage in Brussels: Can you help?

By Phil Williams

You may be aware that 2015 marks the 50th anniversary of the first EU pharmaceutical legislation and you can see more information here:

http://ec.europa.eu/health/human-use/50years/index_en.htm

Against this background, the European Commission (EC) has organised a program of commemorative events to celebrate the 50th anniversary of the adoption of the first EU pharmaceutical law. These celebrations, taking place throughout 2015, focus on past achievements while looking at the present and future role of EU pharmaceutical legislation in protecting the health of citizens in the EU and in the world and in promoting advance in science, innovation and public health.

The EC wanted to mark this important landmark with 10-15 testimonies of those that have contributed to shaping our system as we know it today. It intended to publish all the contributions in a booklet (paper and on-line version), which would contribute to explaining the defining moments of our history.

The Thalidomide disaster played an important role in deciding to develop legislation at European level; the first piece of legislation was adopted in the wake of the Thalidomide disaster to make sure that a similar tragedy would never happen again. This is the reason the EC believed it was important to recall the impact Thalidomide has had in general and on the lives of many families in the context of this booklet.

At the start of the year, a senior civil servant at the EC reached out to a personal contact on the Campaign Team to suggest the name of a person that could represent the Thalidomide survivors and share with them their experience. This was the remit;-

"The testimony should not be longer than 500 words. Content-wise, it does not have to be necessarily a summary of the whole history of the disaster (which will be difficult to do in 500 words anyhow). Instead, one may want to focus on certain aspects or share personal experience as a constant reminder of the effect a non-efficient control and supervision of pharmaceutical products may have."

As the deadline was very tight, we promptly provided 4 different stories and persuaded the EC they should use at least 2; one from each gender as their perspective might be quite different. A huge thank you must go to Geoff Adams-Spink, Simone Illger, Craig Millward and John for rising to the challenge. The final booklet is now available and can be viewed or downloaded here ;-

http://bookshop.europa.eu/en/50-years-of-eu-pharmaceutical-regulations-in-12-stories-pbEW0415462/?pgid=Iq1Ekni0.1ISR00OK4MycO9B0000KIsf6AyF;sid=ySGPiFAS_UePmAX0KjCRLzI3a-Lz2FfBz_I=?CatalogCategoryID=I1QKABstILsAAAEjCpEY4e5L

The introduction by the EU Health Commissioner mentions Thalidomide and there are 12 stories, of which we are the first and last. This demonstrates the profile we enjoy in the European political conscious at the highest levels.

Our written submissions were so well received that we were subsequently invited to attend the climax of the celebrations, which is a one day event in Brussels on 28th September attended by over 500 leading health professionals and policy makers. The Conference will be opened by the EU Health Commissioner and the very first speaker on stage will actually be one of our own, Kevin Donnellon, being interviewed by a medical Professor about how his thalidomide impairment has affected his life.

This is a fantastic opportunity to further raise the profile and awareness of Thalidomide with key decision makers and it should also be advantageous to our campaign. Many independent observers find it ironic that we are celebrating 50 years of excellent legislation, that has protected millions of EU citizens, but that there are still many victims of the original Thalidomide disaster, across the EU, whose health and independent living needs are incredibly still not being met by those responsible.

There are thalidomide survivors from various EU countries attending and you may recall an email went to everyone on the Campaign Mailing list inviting you to join us, although this was a big ask in terms of financial, time and travel commitment.

However, there is another far easier way you can contribute, share your story and support this Event and the wider Campaign. The original 4 stories that were submitted to the EC will be posted to our website www.fiftyyearfight.org and we are very keen to add your voice.

Please send your story or testimony, in less than 500 words, to Phil Williams or Stuart Kenworthy or via the office, but please be aware they will appear in the public domain so let us know what name you want to use; whether your full name or initials or just first name for example. There is a wonderful opportunity here to simply share our experiences amongst ourselves, if nothing else.

Craig Millward will be uploading the stories, attending the actual Event with Phil, and then talking to our supporters and advocates in Europe after the Event.

If you have any questions in connection with the above, or indeed any other matter, please do not hesitate to contact us.

Phil: phil@philipdavidwilliams.co.uk or 07554 016303

Stuart: stuartkenworthy@yahoo.co.uk

News from the research committee

By Professor Caroline Glendinning,
Trustee and Chair Thalidomide Trust Research
Committee

The Trust's Research Committee oversees all the research carried out by the Trust or by other researchers on the Trust's behalf. Members of the Committee include current and co-opted NAC members, Trustees and Trust staff. The Research Committee meets 2 or 3 times a year; reports from the Committee go to the Trust's Health and Wellbeing Committee and, in due course, to the full Trustee Board.



The Research Committee was set up because the Trust needs to make sure that all the research it funds will be of clear benefit to Thalidomiders and is carried out according to agreed budgets and timetables. For example, some research will aim to identify new treatments or other ways of helping Thalidomiders; much of our research will be useful to the Trust or NAC in discussions with Diageo or the Departments of Health (eg about the Health Grant).

We know that some Thalidomiders have taken part in many research projects over their lifetime, so any external researchers wanting to access UK Thalidomiders through the Trust must also get approval from the Research Committee.

As an example, the Research Committee commissioned Firefly Research to look at how the DH Health Grants are being used. Firefly's reports provided extensive evidence on how the Health Grants are helping by paying for housing alterations, new cars, extra help around the home or enabling some Thalidomiders to stop work or cut down their hours in order to maintain their health. We are certain this evidence was crucial in getting the Health Grants renewed for another 10 years. Another important study is the RECALL study, being



carried out by a team at University College Hospital London (UCL), to test alternative ways of taking blood pressure in people with arm impairments. The RECALL study is taking a while to get off the ground, but Dr Dee Morrison (the Trust's Medical Advisor) and the Research Committee are in regular contact with the UCL study team to ensure the project runs smoothly.

The Committee's big project at the moment is the survey of all UK Thalidomiders to find out what challenges and changes you anticipate in your lives over the next few years,



so the Trust can develop appropriate services to help you. (Again, we expect the study will also be useful in discussions with Diageo and the Departments of Health.) I hope everyone will have completed the survey during the summer, on line, on paper or over the phone! A report of the survey findings will be completed before the end of 2015. We plan to follow up the survey with more detailed discussions with small groups of Thalidomiders about specific topics of particular concern.

One of these may be the complicated question of pensions. As some Thalidomiders give up work early for health reasons, pensions may be affected. A group of Thalidomiders is working with the Research Committee to develop a future study aimed at measuring the financial impact of Thalidomide on pensions.

If you have suggestions for future research that the Trust should carry out, please talk to Simone Illger or Rowland Bareham, the current NAC representatives on the Research Committee.

A review of the Aquarius Porta-Bidet

By James McNally

I took delivery of my Aquarius Port-Bidet just ahead of an overseas trip to Tenerife for the International Thalidomider gathering in July this year.

Up until a bad fall when I damaged my right arm, I had always been independent in terms of going to the toilet and using toilet paper. Although I hoped that the damage that was caused to my arm was temporary, various surgeries to try and make the arm usable sadly didn't have the outcome I was hoping for.

At home I had a Geberit toilet – one that is plumbed in and operates as a regular toilet and as a washer/drier afterwards. The problem always came if I was travelling away from home. I travel over to Glasgow on a frequent basis following my football team Celtic. I'm fairly independent now that I've recovered from my fall, but personal toileting tasks are still something that I need assistance with, and there are some things you just really don't want to have to ask your mates to help out with!



When my Porta-Bidet arrived, I was immediately impressed by just how "portable" it appeared. It comes in its own smart bag, designed specifically to protect and house all the components. It comprises of a water reservoir, some plastic tubing, an electric switch with which to operate it, a small jug to make filling the water reservoir much simpler and a water jet arm that is attached just underneath the toilet set and held in place with two suckers. The unit is re-chargeable via

a mains electric three-pin plug, so there is no need to be near an electricity supply for it to operate. One charge is suitable for at least one weeks use.

I took the unit to Tenerife with me. Whilst the hotel we stayed in was totally accessible, I still needed my Porta-Bidet!

Other Thalidomidors who were holidaying alongside me in Tenerife were really interested in coming to have a look at the Porta-Bidet and were impressed by its portability and smart design. Of course, looks aren't everything, but I was able to reassure them that the Porta-Bidet is perfectly adequate for what it has been designed to do.

It's a piece of equipment that accompanies me whenever I am travelling away from home. The company which sells the Porta-Bidet have offered fantastic after-sales service and the unit has worked reliably and efficiently.

For more information, visit: www.aquariushygiene.com

Cost: £225.00.

You can now try the Aquarius Porta-Bidet in the comfort of your own home.

Simply buy the product from Aquarius' online store and if it is not suitable simply return it within 3 days and they offer a refund less £50 (the £50 consists of £10 carriage each way, cost of a new spray arm for hygiene reasons and £5 handling fee).

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

By Simone Illger

The Thalidomide Trust has advised beneficiaries that the date for this event has been brought forward by one week. This was to ensure that all of the hotel's 11 accessible bedrooms were available for us to use.

The hotel accommodation has now been reserved and work is well underway by the planning team to arrange the structure and other details of the weekend.

An interactive event, the Fit for the Future weekend will explore what delegates hope to achieve over the weekend, a session in the hotel's pool being shown some hydrotherapy exercises, looking at massage, learning about the benefits of pilates and other exercises and the very important part that diet and nutrition play in keeping our bodies healthy and moving.

This event won't just be about listening to people telling us what we need to do or how to change our lifestyle - it is not about a quick fix or setting unachievable goals. It is about understanding that taking small steps in managing health and fitness, in a way that fits each person's individual life and routine, can lead to long term changes and increased health, sense of well-being, empowerment and self-esteem.

The key speaker will be Anna-Carin Lagerstroem from Sweden, a registered physiotherapist, health educator and nutrition counsellor who has a lot of experience of working with people with physical impairments. Anna-Carin is the Author of the book "The art of healthy living with physical impairments" which is available in hardcopy or to download from this website: <http://spinalis.se/the-art-of-healthy-living-with-physical-impairments/?lang=en>

Anna-Carin played an integral part in the Swedish exercise project. A group of Swedish Thalidomiders and others with dysmelic impairments came together over three weekends to explore and learn about pain management, exercise, diet and lifestyle. Initial reports from the (on-going) project suggest that it has made a significant difference not only to the physical effects of Thalidomide that many of deal with on a daily basis, but also the emotional effects of living with long-term pain and the effects this has on mobility and independence.

Other speakers and experts we plan to have at the event are: **Ian Mulrooney**, Structural Integrator / Sports Injury Therapist, **Trevor and Jo Strutt** (Pilates osteopath and pilates instructor), **Carol Adkins**, Director off the Berkshire Physiotherapy Centre, **Nick Webborn**, Sport & Exercise Medicine Lead, Centre for Sport and Exercise Science and Medicine (SESAME), University of Brighton.

Two Personal Trainers will talk about their role in exercise, and work with individuals to find exercise regimes that are suitable and appropriate.

There are plans to have the Alter-G anti-gravity treadmill at the event for delegates to see in operation or even try out for themselves. Various other items of exercise equipment which can be used at home will also be available for delegates to look at or try out (wobble boards, gym balls, elastic resistance exercise bands, stepper, trampette, etc).

The final session of the weekend will concentrate on ensuring that delegates can share their feedback on the event, leave enthused, inspired and with firm plans about how to maintain their enthusiasm and to carry out any plans they have made in relation to diet/nutrition and exercise. A large part of this is expected to be through peer-to-peer contact and support.

We will hear from Thalidomiders who will share their own experiences and stories of things they have found to help them with pain reduction, weight loss and regular exercise. A network of support will also be established so that once the event is over, participants will be able to keep in touch and provide mutual encouragement and share ideas and progress up-dates.

The weekend is being funded in part by the Departments of Health for England, Scotland, Wales and Northern Ireland but beneficiaries will be asked for a £200 contribution towards the total cost of the event.

Two general personal assistants will be provided for the duration of the weekend for those who need some help with getting dressed, getting refreshments, opening doors and getting changed into and out of swimwear, etc.

Whilst the weekend is designed primarily for beneficiaries of the Thalidomide Trust, we recognise that some people may wish to bring along their own personal assistant or family members to assist them. Whilst we do not wish to discourage others from attending, there will not be a separate programme arranged for them, but they are welcome to join any of the sessions as observers.

A maximum of 32 attendees will be able to book to attend this event (excluding personal assistants), so keep a look out for the invitation letter that will be available at NACAC and sent out to all beneficiaries shortly afterwards via the Trust giving full details of the agenda and a booking form for you to complete and return.

If the event is over subscribed, a similar event will be planned to take place in a different part of the country on a later date.

Linda Patching's Retirement Party



By Roz Hepple & Giselle Cole, on behalf of the Volunteer Visitors

Linda Patching was invited to join us at the Volunteer Visitors Convention in Leicester on the evening of 13th May 2015. We chose to celebrate the occasion by way of a gift, and sharing fond memories of her time with the Trust.

We began our quest, as we have done with previous members of staff who have retired, to find out about the person we knew at work. We also wanted to learn about the person at home. We managed to contact Linda's daughter Sarah who shared with us some snippets of information on Linda's life away from work.



We decided that we needed a theme for the night. Retirement means, relaxing and time to chill out, so it was only natural that our theme was beach, sand, sun and sea!! To that end, we asked everyone to wear bright happy clothes that said "come on sun here I am"!

Linda was the last of the old and familiar faces of the Trust staff that we all knew and loved. We wanted to give Linda a night to remember!

One of the many things that we learnt about Linda is that she is a big fan of Justin Timberlake. So we put up a few posters of her heartthrob on the walls and put together a small quiz to test her knowledge on how much did she really know about Justin. A quiz is not a quiz without a prize for the winner....she got to keep the posters!!!

We also learnt Linda has 2 cats, called Smirnoff and Ice. Linda didn't name the cats, because if she had they would have been called Shiraz and Merlot as she is a lover of red wine. On the side in her kitchen, a half bottle of red wine can often be found.

Linda loves gardening, so this became the design we choose for her cake complete with a mini Linda sitting on her grass. What more could a girl want than to chill out in her garden with a glass of her favorite wine.



As we said goodbye, we reminded ourselves that farewells are not forever, nor are they the end.

They are simply words to say that we will miss you dearly, and we will remember you fondly.

As Linda moves on into the next amazing chapter of her life, she knows that she will be missed and that our very best wishes and thoughts go with her. More importantly Linda will be able to spend more time with her Mum who is in her 90s and her 3 grandchildren, soon to become 4, whom we're sure will command a lot of her free time.

Wishing you all the best Linda.

Michelle Hodson-Curran

18th February 1963 – 10th June 2015

As you will know, Michelle Hodson-Curran, the Trust's Director of Health & Wellbeing, died suddenly at home.

Michelle joined the Trust in October 2011 and since then she has been instrumental in increasing the level of health and wellbeing support that the Trust has provided to beneficiaries. She oversaw the introduction of the HealthLink service and has provided one-to-one support and benefits advice to many beneficiaries.

Michelle also provided ongoing support to the Trust's Volunteer Visitors and has undertaken Individual Beneficiary Reviews (IBRs) both in the UK and overseas over the last three years.



I, for the Volunteer Visitors, and Craig Millward, for the NAC, attended Michelle's funeral at Bramcote Crematorium in Nottingham (her home town) on 25th June along with three of the Trustees. It was an occasion where all the old and new staff who worked with Michelle met together (if only there had been a less sad reason for meeting up though) and we shared in some stories by her family and friends at the funeral and afterwards at the reception.

I will miss working with Michelle on issues of Health & Wellbeing, as will all the Trustees, Trust staff, other Volunteer Visitors, NAC members and also will many of you with whom she helped during her sadly shortened time with the Trust.

Rowland Bareham

Contact Us

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

The next edition will be published in the spring of 2016. If you've any feedback from this newsletter or would like to contribute to the next edition, please contact the newsletter editor, Simone Illger. simoneillger@virginmedia.com

Tel: 01189 670 218

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."