

Welcome to the Newsletter



Carolyn Desforges, Sue Gooding and Maggie Boyd - Newsletter Editors

Welcome to the NAC's Autumn newsletter.

In this edition, there's information regarding the Green Paper discussions on benefits and employment led by Carolyn Desforges; European and UK campaign news; a look ahead to the 2022

Beneficiary survey from Graham Kelly, news from my trip to Naidex and thoughts on what it's like observing an NAC meeting from Helen Shore.

We hope you find the content interesting and that it keeps you up to date with NAC activities. We welcome any comments or ideas for articles – by email or in our Facebook group on www.facebook.com/groups/ttnac! The next newsletter will be out in early 2022.

All very meaty stuff, we hope you enjoy reading!

Carolyn, Sue and Maggie- Editorial team

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Latest News from the NAC

Rowland Bareham - NAC Chair

NAC Awayday/Strategy Day

The NAC met face-to-face earlier this month (over two days) to discuss a number of topics, including ways of improving its representative role of the beneficiary community to the Trustees. I would like to report to you a few of the issues that we discussed.

Diageo Review

The Chairs of the Trustees and the NAC are meeting with Diageo next year for a review of the financing of the Trust (supported by others including Trust staff). The last review in 2016 resulted, for the Trust, in an increase in financial support and an improvement in financial security.

Currently, we have a working group (known as the Diageo Chairs' Review Working Group) consisting of three trustees, three NAC members and the three directors of the Trust. Ideas about the issues to bring to Diageo have been collated from the Trustees, NAC and staff. Now, it is the turn of the beneficiary community to give us ideas too. I will be writing to all of you to ask for your ideas, so that by the time we meet with Diageo, the NAC will have consulted with the beneficiary community.

Grünenthal Foundation

Whilst the NAC have had no contact with Grünenthal GmbH (the company), we have been in discussions with the Grünenthal Foundation to discuss our concerns about the fact that their current funding programme is neither transparent or fair to our beneficiaries. We are trying to secure significant improvements that will enable all beneficiaries to access funding if they have unmet needs. These discussions are ongoing, and I will keep you posted. As ever, please do let us have your feedback (email: feedback@ttnac.org).

Committee Highlights: Health & Wellbeing



Department for
Work & Pensions

Carolyn Desforges - NAC Co-chair of the Health & Wellbeing Committee

Shaping Future Support – Consulting on the Health and Disability Green Paper

During September 2021, the NAC led a consultation with beneficiaries on the government's proposals to review the benefits that support people with health conditions and disabilities.

Thank You!

We held three zoom consultations on the Meetup platform, gathered responses to the government's questions via the NAC Facebook group, and received emails with people's views.

Thank you so much to all the 37 beneficiaries who took part, sharing views and personal stories. We have really had some interesting and stimulating discussions.

How We Responded

In October, we submitted our collated response to the government. You can read the submitted NAC response here: www.thalidomidetrust.org/wp-content/uploads/2021/10/NAC-Response-Green-Paper.pdf

Throughout, we have been liaising with Trust staff. The Health & Wellbeing team have supported many of us whilst we have been applying for benefits and have gained knowledge and opinions on how the benefits and process of application could be improved.

We decided that it would be most effective to submit two responses on behalf of thalidomiders to ensure key messages are repeated on behalf of our community. Katy Sagoe has submitted the collated response from Trust staff. You can find the staff response here: www.thalidomidetrust.org/wp-content/uploads/2021/10/The-Thalidomide-Trust-Response-to-Shaping-Future-Support---The-Health-and-Disability-Green-Paper.pdf

What Next?

This consultation is part of a long government process, so it might be a while before we hear about what changes the government decides to propose. We will keep you up to date with any progress in future newsletters.

Committee Highlights: Campaigns Team



European Campaign News from Craig Milward - NAC Vice Chair and Campaigns Team Member

The last time we reported on the European campaign in the newsletter was in Autumn 2020. Since then, Brexit, the continuing pandemic and lockdown have made this a challenging time for campaigning. Here, we recap on what's been achieved so far and where the European campaign is heading next.

What's the Objective of the European Campaign?

To establish a mechanism by which the German Government could contribute to the health and wellbeing needs of thalidomide survivors in those countries where thalidomide was not directly supplied by Grünenthal: Italy, Spain, Sweden and the UK.

What's Been Achieved So Far?

After building a huge amount of ground-up support in the EU Parliament we secured a resolution which achieved unanimous backing, and an impromptu standing ovation in the EU Parliament. It called upon the German government to meet the needs of all thalidomide survivors. This led to a number of meetings with the German government.

Following the German Federal elections in 2017, those we had been negotiating with left their previous roles and we were forced to return to the EU Parliament to build up increased

support. Within a few years we had the top German politician in each political group supporting our cause and agreeing to make German money available to thalidomide survivors across Europe via an EU budget.

What Has Happened Recently?

The EU Health Minister decided that the most appropriate budget was the social inclusion element of the European Social Fund. We succeeded in establishing a mechanism through which all countries could gain access to ESF+ funds and the wording we drafted was included in the final text. The ESF+ budget was enacted in January 2021 and applications can now be submitted by the national governments on behalf of the thalidomide community in their country.

So, from the beginning of this year, the solution we successfully negotiated will be accessible by the Italian and Spanish – who have always been in a far worse position than any other group – and the Swedes.

So Is the Battle Over?

Unfortunately, the UK left the EU without a comprehensive agreement, so the UK government is not able to access funds on our behalf.

In anticipation that Brexit may not work in our favour, we began to reach out to influential members of the German Government via our EU contacts back in early 2020, with a view to making a formal request to the German Government that it should establish a special fund to benefit UK beneficiaries who are now unable to access the funds intended for our benefit. We were on the verge of speaking to Ursula von der Layen, President of the EU Commission, the day the EU Parliament locked down.

What Next?

Whilst a great deal of routine communication can be done online, we have always found that establishing new contacts and forming coalitions of supportive German politicians has to be done face-to-face. Not being able to travel and show our faces has been incredibly frustrating, but we intend to assess the state of play and move forward again as soon as it is safe to travel once more.

UK Campaign News from Mikey Argy - NAC and Campaigns Team Member

The good news we all know from earlier this year, is that the Health Grant has been awarded for life in England with reviews every four years.

This campaign had an extra side to it. Working together with trustees and NAC members in a working group, the Trust staff wrote a detailed 'Case for Support' showing how the Health Grant affects us. This, along with the fantastic support we had from the MPs, meant that the government was bombarded from all sides, and we received our outstanding result.

In the devolved nations, the Trust staff are continuing conversations to achieve comparable results. We have no doubt this will happen, however the Campaigns Team is watching closely and will be ready to take further action should any be needed.



In Focus: 2022 Beneficiary Survey – What, When and Why?

Graham Kelly - NAC Member



You may recall that in 2016 and 2019 you received a questionnaire asking how satisfied you were with the Trust and the different kinds of services and support it offers, as well as the NAC. The plan is to conduct these surveys once every three years, and the next one is due to happen in early 2022.

In mid-January 2022 you will receive the new questionnaire. In the past we had excellent participation by the beneficiary community with over two thirds of people completing and returning the questionnaire.

The Survey Is Completely Confidential

As previously, please be completely honest in the way that you answer the questionnaire. We use an independent survey company (called Marketing Means Ltd, based in Devon) to handle all of the completed questionnaires, so that Trust staff and NAC members never see any individual's answers.

If you do not reply in the first couple of weeks you may receive a reminder communication asking you to complete the questionnaire, but the Trust staff and NAC members never see a final list of who has responded and who has not.

If You Live In the UK

If the Trust has an email address for you, you will receive the questionnaire first by email, with a paper version arriving in the post a few days later for those who would prefer to use the paper version and send it back in the post.

If You Live Outside the UK

If the Trust has an email address for you, you will only receive the questionnaire by email this time. In the past we have sent paper copies to those outside the UK, but this has caused problems because postal delivery can be very slow in some parts of the world, both outgoing and return. If the Trust does not have an email address for you, you will receive a paper questionnaire through the post, which you can complete and post back to the Trust.

Check Your Spam Folder

Please remember that there is a risk that the survey invitation email may go into your spam folder, so please check this folder. You will have a reminder in January to do this check, about the time that the questionnaire is being sent.

The purpose of this article is to give everybody advance notice that this will be happening in January 2022, and there will be other reminders nearer the time.

Please Do Complete the Questionnaire

The survey is completely voluntary, but we hope that you take part, as the majority of beneficiaries have in each of the previous surveys. The results of these surveys are regularly used to help inform and influence discussions among staff, trustees and NAC members. They increase the understanding of beneficiary views, what is working well and where changes are needed. Thank you.

Our Stories: What Was New at Naidex 2021?

Maggie Boyd - NAC Member

On Wednesday 15 September, I got up early to get the 6.55am train from Knaresborough to the Birmingham NEC, arriving at 10.30am. Not too bad for a train journey – extremely quiet and no early morning rush.

The NEC is a huge complex – well signposted, easy access, and signing in was easy. There was a vast hall with lots of stalls, catering for all kinds of disabilities from robotics to high tech mirrors. It was like entering a sweet shop – disability heaven!

Wheelchairs and Motability



As a manual wheelchair user, it was great seeing a variety of wheelchairs – just like someone with feet going into a fancy shoe shop!

There was a good range of Motability vehicles with a variety of mobility equipment. Also, bespoke wheelchair accessible leisure vehicles which were luxurious and worth looking at if you don't want a caravan. They weren't cheap, but if you want the freedom to travel, it seemed well worth it.

Heating, Gardening and Dating

Adaptive heating technology was interesting, especially as we're now having to adapt to greener heating, as were the motorised blinds which can be controlled by your voice. For those of you who like gardening, they had Vegepod, a self-watering container with a protective cover, available in three sizes – such a great idea.

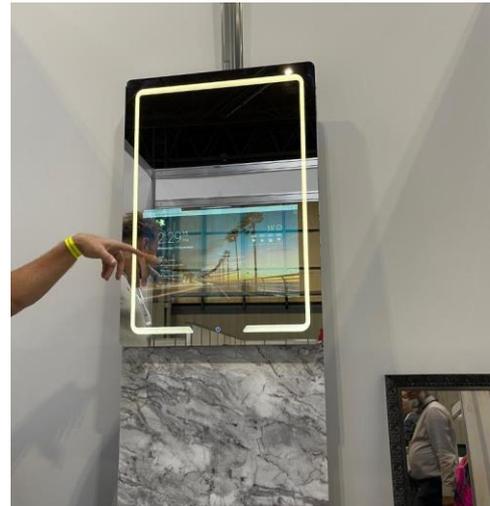
As well as lots of stalls, there were also live speakers at certain times. I listened to one about an online dating service called www.disabilitymatch.co.uk. It was set up by David Miller – who has been a dating coach for twenty years. Among other things, he explained how to write a great profile.



Smart Mirrors

One bit of technology that did stand out was My Smart Mirror. This has smart technology integrated inside, so you can write reminders whilst brushing your hair or cleaning your teeth. It has an inbuilt light around the outside. I just thought it was a great idea.

The toilet situation was lacking, at times there were long queues for accessible toilets, and the food wasn't brilliant, however I would definitely go again. It was also so good to meet up with other beneficiaries who made the trip. Next time, I think I would stay overnight and attend two full days. Even though this year there weren't as many stalls as usual due to Covid-19, there was still so much to take in.



Our Stories: Observing an NAC Meeting

What Are the Benefits of Requesting a NAC Meeting Observation Place?

Helen Shore - NAC Member

Since Autumn 2019, the NAC have been offering two 'observation' places at each NAC meeting. These are open to anyone who has not previously been on the NAC, but may be keen to stand for election, and give the observer a first-hand opportunity to experience the NAC at work. Helen describes her experience.



Why Did You Decide to Observe an NAC Meeting?

I heard about the observation places around the time I stood for election and was not elected into the NAC. It was suggested to me by another NAC member as they hoped I would consider standing again; they said that new people and perspectives were always welcome on the NAC.

They said that observing an NAC meeting, may change my mind – I would have the opportunity to see all the things that were going on behind the scenes that were helping our beneficiary community and I may feel that I could contribute to some of these.

After some thought and uncertainty, (I had stood for election three times and I felt maybe I wasn't the candidate the beneficiary community were looking for), I decided that it certainly couldn't hurt and better decisions are made when you have all the information. I therefore applied to observe the May NAC meeting.

What Was Your Experience of the Meeting Itself?

On the day, I was welcomed and included. I felt I gained a huge insight into the massive volume of work and commitment of staff, trustees and NAC members. That, along with the volume of documents I received to prepare for the observation, really cemented what an excellent job was being done. I decided then that I would stand again if the opportunity arose.

What Could Have Been Better About Attending?

It would have been helpful to receive the meeting documents a little more in advance – they were time-consuming to read – I needed to do this thoroughly as a lot of unfamiliar information was presented in a couple of hours.

What Did You Learn From Attending the Meeting as an Observer?

The experience helped me formulate my election manifesto when I stood again. I could see exactly what the Health and Wellbeing Committee were doing – this was the area that was my strength. We all need to know what a huge job is being done to help our community. The NAC meeting was an eye opener to me as I had not been involved with any of the inner workings of the Thalidomide Trust before. I would say to other people who might think of applying for an observation place – absolutely do it!

I am truly grateful to have observed. In the next few months Karl sadly passed away – I was brought on to the NAC as the next highest polled candidate. The observation place meant I felt that I had a tiny starting point and a feel for the workings of the NAC – very important when you want to get ‘stuck in’ and contribute!

Are you interested in taking up an observation place at the next NAC meeting in central London on Thursday 25 November?

Contact feedback@ttnac.org or phone the Trust office on **01480 474074** to find out more.

About The NAC

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

Get In Touch

We'd love to hear from you and include your stories and questions in the next newsletter in January.

Email feedback@ttnac.org if you'd like to write an article, suggest a topic or ask a question.

If you're on Facebook, look out for the NAC group on www.facebook.com/groups/ttnac – it's a place to catch up on news and information from your NAC reps, to ask questions and to discuss issues affecting the beneficiary community.