

NATIONAL ADVISORY COUNCIL
TO
The Thalidomide Trust

NAC Newsletter

Autumn 2022

Welcome to the Newsletter

Carolyn Desforges – Editor

Welcome to our Autumn newsletter. We have another interesting set of articles which range from experiences of a new NAC member attending Finance Committee meetings, updates from Health and Wellbeing, and some novel top tips for keeping warm as winter approaches. Rowland, Graham and our Finance Director scrutinise the facts as to whether in the beneficiary settlement of 1973, we lost out by not being awarded a 100% settlement, or if subsequent financial awards have in fact left us better off. Finally, Geraldine Freeman is campaigning for improved airline access for wheelchair users - read her story!



Any feedback and indeed any offers of contributions for the next newsletter would be greatly appreciated, please email editor@ttnac.org.

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Latest News from the NAC

Rowland Bareham – NAC Chair

I have mentioned to you in previous newsletters my thoughts on the seasons and which of winter, spring, summer, or autumn I prefer most. For me, it changes between both spring and summer being my best seasons. So, I reflect that sadly summer is now over but nevertheless I have been blessed with a lovely sunny day today in writing this as I take a retreat in Wales (alas, no doubt that my expectations of lots of rain in the following days will materialise!). Oh, well, whatever the weather, I wish you all well for the remainder of 2022, for Christmas and into the New Year.



Talks with Diageo – an update: I do get calls about what is happening with the talks with Diageo and I appreciate that you are all waiting for the outcome of these talks.

As a reminder:

- The NAC consulted with the beneficiary community late last year and received responses from 29% of beneficiaries with their ideas and experiences. This has had more impact for us in being able to put a strong case to Diageo this time round, as we were able to give Diageo comments, ideas and details about needs that were strongly supported by many of you.
- A small working group of trustees, NAC representatives and staff (known as the Diageo Chairs' Review Working Group - DCRWG) was formed to prepare for the discussions with Diageo, with the consultation results being central around the 'Asks' for Diageo.

Meetings have taken place with Diageo in April, June, July and earlier this month (October). Whilst we cannot provide a running commentary, we can confirm that we put to Diageo, a summary of the feedback that you all provided in the above consultation, so that Diageo is fully aware of your input in respect of your needs.

There will be a formal meeting between the Chair of Diageo, the Chair of the NAC and the Chair of Trustees which is now scheduled in December. News of the outcome of this final meeting with the three Chairs will be released as soon as possible.

Again, any announcement on the outcome of the Diageo talks will be simultaneously made by Diageo and the Trust.

Annual Grant RPI Announcement - The increase in the Annual Grant each year is linked to the Retail Price Index (RPI) measure announced for the September preceding the payment of the Annual Grant in April 2023. This has recently been announced as 12.6% for September 2022.

Increases in fuel and energy prices and the general cost of living will be reflected in the RPI measure. However, we appreciate the effect of further increases to RPI between September and April not being reflected in the April Annual Grant payment (this is the same sort of thing experienced by pensioners with index-linked pensions).

The NAC is keeping a watch on this and gets monthly reports on movements of the RPI measure. The NAC will advise trustees accordingly if hardship is being noted by the beneficiary community. Apart from our own experiences on the NAC (as beneficiaries), it would be really helpful if you could keep us posted with your own experiences regarding the impact of fuel/energy/cost of living increases. The best email address is feedback@ttnac.org.

Finally, a reminder. The next NAC meeting is on Wednesday 23 November. We offer two observation places at each meeting for those who are interested in standing for the NAC giving an opportunity to see first-hand how we work, and how you might use your skills to support our community. Please email feedback@ttnac.org if you are interested in being an observer at this meeting.

The Finance Committee - A Newbie's Perspective

David Alexander – NAC member

I was elected to the National Advisory Committee (NAC) earlier this year for the first time. As well as being involved in the usual NAC activities, I am also one of the NAC's representatives on the Trust's Finance Committee. I thought it might be helpful to share some information about NAC involvement in the work of the Finance Committee.



What is the Finance Committee responsible for?

The main purpose of the Finance Committee is to look at how the money-related aspects of the Trust are managed and controlled. Their key task is to ensure that the costs of our Annual Grant and Health Grants are met in the short, medium, and long term.

NAC members are involved in the section of Finance Committee meetings which involve reviewing the following areas: how investments are performing and any additional income generation activity. These are the areas which directly influence the Annual Grants we receive.

Who attends the Finance Committee?

The meetings, held every three months, are attended by representatives from the NAC, trustees, and staff from the Trust. Other people outside of the Trust may be invited to the meeting to present information. For example, from the investment brokers: the companies tasked with investment Trust monies.

One company has been asked to independently review the reports from all investment brokers and to provide a single summary report. This has been really helpful as it provides an overall perspective and puts things into plain English!

What happens at Finance Committee meetings?

Each meeting has a well-managed agenda. The Finance Committee reviews the recent financial data to maximise investments. There is a great deal of financial expertise in the meeting, but everyone has the freedom to express an opinion or ask questions. As NAC representatives, we are encouraged to contribute - I do feel our views and opinions are taken into account.

The past year has focussed on ensuring all four UK nations give a lifetime commitment to providing the Health Grant. This commitment has been given in England, Scotland and Wales so far - which is great news. The committee is also supporting the team involved with the four-yearly discussions with Diageo.

How can you help?

At the last meeting, we heard about beneficiaries' experiences of dealing with independent financial advisers. If you have any positive recommendations about advisers you have been in contact with, can you let the Trust know? We thought it would be good to share these recommendations with everyone. Thank you!

I hope you've found this article helpful and if you have any questions please don't hesitate to be in touch.

More information about who does what on the NAC can be found on the [website](#).

Committee Highlights: Health and Wellbeing

Carolyn Desforges – NAC Health and Wellbeing Committee Co-Chair

It's been a busy summer responding to Scottish government consultations. In May, Helen Shore was involved in supporting a Trust response to the Scottish consultation on community equipment and housing adaptations and more recently, the National Care Service consultation on the introduction of a National Care Service (Scotland) Bill going to the Scottish Parliament. In August/September, Helen myself and five Scottish beneficiaries contributed their ideas on the Scottish government consultation on a future Mental Health Strategy for Scotland. This was completed through Meetup zoom, email and 1:1 calls - some doing all three! Thank you so much to everyone who participated. Should anyone wish to see a copy of the response, please do contact feedback@nac.org.



Helen, in her role as website liaison for the NAC, has reviewed articles on "[Managing your weight for a healthier lifestyle](#)".

She has also contributed to the [Private Referral Scheme factsheet](#).

Along with volunteers, we have taken part in a focus group to make the Emergency Card, (developed specifically for beneficiaries to let medical staff know about your thalidomide damage and medical conditions in the event of an emergency) more user-friendly. More information about the card can be found on our [website](#).

Coming up on Thursday 17 November at 2.30pm, is the next interactive health webinar looking at staying safe over Christmas and New Year. Alcohol is a way of life for many of us, but is there a way to stay healthy and drink the right amount? Come along and find out how to drink in a way that is not going to hurt your body or your mind. Joining details can be found on the [Meetup platform](#) or contact the Trust for further details.

Finally, a reminder! The cardiovascular risk research is still ongoing - If you know that you are likely to be having surgery in the next 12 months, you could participate in this Trust research on cardiovascular risk among thalidomide affected people.

The research only involves the collection of blood pressure data while you are anaesthetised on the operating table. It doesn't require you to do anything, other than give consent to your data being collected. Afterwards, you will receive a personal report about your blood pressure from the Consultant Anaesthetist leading the research.

Please do let the Health & Wellbeing team know about any upcoming surgery, so that they can tell you more about this important research. Please email hello@thalidomidetrust.org or call **01480 474074**.

In Focus: Top Tips for Keeping Warm in Winter

Helen Shore – NAC member

Whilst chatting to other beneficiaries about the energy price rises, we found that a few of us had different strategies to keep warm in winter, especially those of us that struggle with being cold. And please don't worry, we have another piece due in the spring to help those who struggle to stay cool.

These tips are not suggested to replace heating in our houses and the web links don't promote items, they are just suggestions that some of us use. First off, can I say that if you are struggling to pay for heating then please contact the Trust to see what can be done to help.



- **Ponchos** or **hoodies** - to go over ordinary layers of clothing just to give that 'wrapped in a blanket' feeling. Very handy if you're sitting in a wheelchair or at a desk all day.
- **Electric/battery powered gilet** – if you're sitting all day, a heated gilet allows arm movement but keeps your core warm. Argos do one too but there are lots on the market.
- **Hot wheat bags** (Microwavable) - or hot water bottles which can also be microwaveable.
- **Cashmere wraps** and **jumpers** – although they are more expensive, they allow you to regulate temperature more easily than synthetic fibres and they are light and soft too – like putting on a hug! And eco-friendly as they last for years.
- **Electric overblankets** - I am sure a lot of us will have wrapped ourselves up on the sofa with one of these. They help with sore joints too without being too heavy or restrictive.
- **Down duvets** - some of us need more covers or more heat at night-time in bed. Down duvets are light and warm especially if you have the two weights that you can put together so you can choose which tog you need as the seasons change.
- **Heat holder socks** – these are a godsend for me. And for those of you with little feet they come in children's sizes too.

Keeping warm isn't all about sitting and layering. One of the best ways to help stay warm is to move around at least every hour and to drink warm drinks or even cuppa soups and hot food. Maybe an insulated mug or flask like a **Contigo** can help.

Our mental health can also be affected when we are cold, and we don't move around much. It might be worth asking yourself: "Am I more motivated to get up and do something when my environment is warmer?" If so, pop that heating up a couple of degrees.

And if you find yourself at a loose end sitting around, you can always find a warm welcome at our Meetup groups so come along and say “hi”.

In Focus: The 40% Settlement

Graham Kelly - NAC member

There has been some discussion on social media suggesting that we have been disadvantaged by settling with Distillers for just 40% of the total claims against them and so we have notionally ‘lost’ out on the other 60%. The NAC researched these claims to clarify the issue and state the facts.



There are two things to bear in mind when considering a scenario of our parents pursuing their claims in court and winning 100% of their claims:

1. Courts rarely (if ever) award a full 100% of claims, and
2. More importantly, if the parents had achieved a better than 40% award in court, then the Thalidomide Trust would not have been set up in 1973 through the continued campaigning instead of the court action.

Keeping these two points in mind, there are two scenarios to compare. The first (on the left below) which is what has **actually** happened with the acceptance of the 40% award. The second (on the right below) which is what **could** have happened with the rejection of a 40% award and a successful court award of 100%. The analysis has been based on an average beneficiary’s Annual Grant (which was £41,810 in 2022).

In short, it has turned out that we are much better off than if our parents had pursued 100%.

40% Scenario	100% Scenario
What an average beneficiary has received since 1974.	An average beneficiary’s possible full settlement back in 1974.
In 1974 an average beneficiary* would have received a lump sum of £17,556 (40% of the total sum claimed) from Distillers. This is equivalent to £220,029 today (using RPI as the inflation measure). Since 1974, an average beneficiary would have received a total of £632,971 (at today's equivalent value) from Distillers/Diageo. This is made up of their Annual Grant payments and any additional payments (e.g the CHP).	An average beneficiary would have received a lump sum of £43,890 from Distillers. This is equivalent to £550,073 today (again using RPI as the inflation measure).
Total received: £853,000 (today's equivalent value)	Total received: £550,073 (today's equivalent value)

This means that an average beneficiary has already received **£302,927 more**, in real terms because of the establishment of the Thalidomide Trust rather than pursuing for 100% settlement prior to 1973.

Of course, Diageo has committed to continue to make Annual Grant payments (adjusted for inflation) to each beneficiary for as long as they live, so this sum will continue to increase over their lifetime.

Furthermore, if all cases with Distillers had been settled in full, then the Trust would not have been established in 1973 to provide ongoing support to beneficiaries. The payment of Health Grants since 2009 would not have happened without the Trust being in place.

Remember, the Health Grants came about because of the effectiveness of the Campaign Team that lobbied Government via MPs. It would have been far less likely for individual campaigners to have gained the momentum they did in lobbying the Government without a ready database held by the Trust for effective letter writing to the MPs of beneficiary constituents.

Finally, thanks to Suzanne Lluch (Finance Director) for the number crunching and Rowland Bareham for also working on this.

Our Stories: Travel Traumas

Is the world going backwards in terms of disability equality?

Geraldine Freeman shares her experiences

In 2019, the aviation industry launched a consultation on the future of UK aviation including meeting the needs of disabled passengers. Both the NAC and the Trust staff submitted a response on behalf of beneficiaries. Unfortunately, since lockdown, disabled people's experiences of flying seem to have worsened. Geraldine tells her story....



In July, I was scheduled to fly to Tenerife with Jet2 from Bristol airport. Several weeks earlier, I tried to book my assistance. Unable to get through on the phone and 5 emails later, I finally got a response which said someone would contact me in due course. 2 days before I was travelling, I received a call from "Heather" from Jet2, who asked a few questions about my electric wheelchair and ability to walk to the aircraft. I have no legs.

Arriving at the airport in plenty of time, we booked in our luggage and were taken to the assistance desk. I was told my wheelchair couldn't go on the aircraft, as at 91cm, it was too high to get into the hold. I had received no indication until then this would be a problem. With the help of "Andrew" on the help desk, an airport engineer came to dismantle my chair - something I've never had to do before with any other airline.

It was so stressful! I was eventually helped onto the aircraft which had already been loaded with passengers. This is very difficult for any disabled traveller and being watched whilst transferring and manoeuvring into such a small space is embarrassing, humiliating and very uncomfortable.

My stress levels (which were already through the roof) were made even worse when my wheelchair was left sitting on the tarmac waiting to be lifted into the hold. The pilot, furthermore, announced (3 times!) that an electric wheelchair waiting to be put into the hold was causing further delays. I felt so humiliated.

Then an air hostess approached me to say, "In the event of an emergency to let you know we won't be able to come back and help you..." At this point I couldn't even look at her...

My return trip was the same - my wheelchair was dismantled, I was, yet again, helped on the aircraft with passengers already boarded. I found this simply unacceptable and back at Bristol, those who needed assistance had to wait a further 45 minutes to disembark. My wheelchair had to be relocated as it had not been prioritised. Obviously, whoever made this decision didn't think the person needed it that badly!

Why in the 21st century are airlines not improving things for disabled travellers? I know I'm not the only disabled person to be suffering such sub-standard treatment, there are high profile disabled people who are receiving the same poor treatment.

Please share your stories of travel experience, good or bad by contacting feedback@nac.org. The NAC will forward your experiences to me as I am collating them for future campaigning.

You can also listen to my radio interview about my appalling treatment on the following link: www.bbc.co.uk/sounds/play/p0cs4f9p

About the NAC

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

If you have any feedback from this newsletter or would like to contribute to the next edition (help to get your thoughts for an article into writing can be provided), please email editor@ttnac.org

Get in Touch

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

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