

NATIONAL ADVISORY COUNCIL
TO
The Thalidomide Trust

NAC Newsletter

Winter 2023

Welcome to the Newsletter



Carolyn Desforges - Editor

Happy New Year and best wishes to you all for 2023. Whilst the days are getting longer, it is still very chilly - we hope you enjoy our news and articles whilst staying warm and cosy! It is NAC election time again, please do consider standing, David Alexander lets us know his experience of the election process and becoming a new NAC member. Trust staff are busy planning 2023 Open Day and Local Events - it's a great opportunity to hear about what's new in the Trust and have time to chat to other

beneficiaries - Julie Beveridge tells us about her first Local Event. We have our regular slot "You said...we did" which lets you know how your queries and ideas influence the NAC's work. We also have information on bidet toilets, using a financial advisor and what to do about muscle spasms.

And finally, you might be interested in what some of the Trust staff have been doing in their spare time. Katy, Hannah, Claire and Sally have recently taken part in the BBC quiz show 'Bridge of Lies' which will be broadcast on BBC 1 at 16:30 on Monday 20 February 2023. Tune in to find out how they did.

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

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Latest News From the NAC

Rowland Bareham - NAC Chair

This is my last newsletter update as NAC Chair. I remain Chair until the eve of the April NAC meeting. I wish my successor, Geoff Spink, well as he takes over at the April meeting. Although I will be stepping down as Chair, I will continue to work as a volunteer NAC member until 2024.



Craig Millward has been my excellent Vice-Chair and he too will be standing down and as he has stood for the maximum number of terms, he will not be able to stand again in the next elections. I would like to take this opportunity to thank him for all his hard work over the years. I wish his successor, Mikey Argy, well as she takes over at the April meeting.

When I was on the NAC as a young adult (decades ago), the NAC just met twice a year with the meetings led by the Director and that was it! The NAC has evolved to what it is today doing much, much more, so that in addition to the two annual meetings we have monthly zoom calls to keep up to date with what is going on. So, I will take the opportunity in this last update to reflect on what the NAC does now for the beneficiary community.

Diageo Discussions

By now you should have received your individualised letters giving details of the lump sum payment which has been agreed to enable you to meet big one-off costs and to help you make the most of your 'golden years'. I'm pleased with this outcome which was achieved by the Diageo Chairs' Review Working Group (DCRWG) of which I was a member (along with two other NAC members – Nick and Craig). However, we must not overlook also the additional funding for a number of health and wellbeing activities which include:

- the creation of an additional 'funding pot' to pay for essential medical treatment in the UK that is not available on the NHS in a reasonable time, together with associated rehabilitation, if required. And, for overseas beneficiaries, a contribution to private medical insurance; and
- funding for additional staff for the Health & Wellbeing team so that they can continue to meet the demand for information, advice and support on a wide range of issues including health, care and carers, benefits and emotional wellbeing, plus additional support for people who experience cognitive decline.

Improved Communications

During my time on the NAC, we introduced the beneficiary feedback surveys and we had a consultation exercise with you all prior to the Diageo discussions. These NAC initiatives have been an important part of improving beneficiary engagement (both of which I initiated). Thanks to Graham, our internal social researcher, for his time and skills with the surveys and consultation.

The NAC now has a Communications Officer (Paul Randall), who has led on improvements to the NAC Newsletter and other communication channels such as our Facebook group page and the Meetup sessions that we have after our April and November meetings.

Strategic Planning

The NAC were part of the strategic planning process that took place last year to develop the next five-year Strategic Plan, working with staff and trustees from an initial Awayday with them, through to the subsequent working groups which each focussed on one of the five agreed strategic goals.

Beneficiary representation on the Board, Health & Wellbeing and Finance Committees.

Following the last Governance Review in 2007, beneficiary engagement has improved with the NAC having its Chair and Vice-Chair taking part in the Board of Trustees meetings, along with NAC members taking part in the Health & Wellbeing and Finance Committees.

Governance Review

Last but not least, the NAC asked for a Governance Review to ensure that the governance arrangements for the Trust (trustees and NAC) is going to be ready for the next 10 years of our lives. The NAC is represented on the Governance Review steering group by myself and Craig as Chair and Vice-Chair. A report is awaited later in the spring.

Finally, the NAC Elections

You should have had a letter from me about the NAC elections. Please refer to that and I encourage you to think about standing for election as there are five vacancies for 2023.

As ever, please do let us have your feedback (email: feedback@tnac.org).

NAC Elections: We Need You!

David Alexander - NAC member

As you will have seen from the Trust email recently, NAC elections are about to take place, and I've been asked to share a few thoughts as someone who has joined the NAC for the first time after last year's elections, hopefully to encourage more people to stand for election.



After retiring from full-time work, I felt that as I had some more free time to spare, I should think about stepping forward and stand for election. I had watched from afar and benefited, as all beneficiaries have, from the hard work that the NAC has put in over many years and wanted to see if I could contribute to the ongoing work of the NAC.

The election process is painless. It involved putting a manifesto together, detailing why I wanted to join and what skills and experience I could bring to the table.

I actually got elected at the second time of asking. In 2021, there were four places up for election and I just missed out. However, I was not put off, and I reapplied last year and was successful.

I would encourage you to consider stepping forward to join the NAC in these upcoming elections. Getting new members onboard can only be a good thing in that we can always benefit from new ways of looking at things and new ideas. I have been made to feel very welcome by the rest of the NAC and encouraged to get involved in lots of different areas.

So, if you were elected, what can you expect to get involved in and how much time would being a member take up? Well as you may have seen in the email regarding the elections there are two full-day face-to-face meetings held in the spring and autumn. There are also monthly NAC meetings held online via Zoom – so no travelling required!

There may be subgroups to get involved with in between meetings too. For example, I am involved in a group looking at how we can encourage beneficiaries to get more involved even for short, one-off activities.

Once you are an NAC member there are two areas you can be involved in: Finance or Health and Wellbeing. You may be aware of the work the Health and Wellbeing Committee does as this involves working closely with the beneficiary community.

I joined the Finance Committee as I felt it would be a better fit for me. This committee meets four times a year and you have the option to attend in person or online via Zoom. As I am based in Scotland, I have taken advantage of online attendance. There is quite a bit of reading to do in preparation for these meetings but in my opinion it's worthwhile. I appreciate finance isn't everyone's cup of tea, but I do enjoy it.

So how have I found my first year on the NAC? I have to say that it has been busy, but enjoyable nonetheless. Like most things, the more you put in, the more you can get out of it. At the end of the day we are all part of the beneficiary community, so we all benefit from the work done. Despite being the newbie, everyone on the committee has been very encouraging.

I hope this may have encouraged you to consider putting your name forward, and as a reminder the election timetable and process notes are included below. Good luck!

Election Timetable & How to Apply Notes

If you wish to stand for election, then you should inform Charlotte at the Trust office of your interest by 5pm on Monday 6 February 2023. You can do this by emailing her at charlotte.black@thalidomidetrust.org or calling 01480 474074. There are also dedicated NAC members who will support you should you want it.

2023 Timetable

6 February	Deadline for expression of interest to stand
16 February	Deadline for receipt of supporting statements/manifestos & declarations
22 February	Ballot papers despatched
22 March	Deadline for receipt of ballot papers
31 March	Announcement of the results to all beneficiaries

In Focus: Trust Local Events

Carolyn Desforges and Julie Beveridge

Whilst the NAC hosts question and answer sessions after each NAC meeting via Zoom, we have been asked on occasions, when beneficiaries can meet NAC members on a face-to-face basis. In 2023, there will be three event opportunities to listen to updates from Trust staff and NAC representatives. There are also opportunities to ask questions and book 1:1 sessions with Trust staff and NAC representatives at these events.



Local events are held in different areas of the country in different years, so that beneficiaries have the chance to attend an event nearer to where they live, however, any beneficiary can travel, and attend any event should they so wish. The last local event was held in Durham in October. The event began with a presentation from Deborah Jack, our Executive Director, and Carolyn Desforges NAC member. This was followed by a health quiz led by Katy Sagoe, Director of Health and Wellbeing which gave us all insights into our beneficiary community and our health needs. In the afternoon, Dr Susan Brennan, Medical Adviser, presented useful tips for staying healthy and managing pain. This was interspersed with plenty of time for mingling, exchanging ideas with other beneficiaries, and of course, drink breaks and lunch! 1:1 sessions were available to book over lunch and through the afternoon.

Julie Beveridge, a beneficiary from Newcastle attended – Julie says:

“I wanted to attend a local event as I felt the Trust had put a lot of effort into organising them. I was looking forward to catching up with old friends and becoming more informed on how things were going at the Trust.

“I enjoyed Deborah’s presentation. I understood why she didn’t want questions until the end of the presentation. However, the presentation covered a lot of subjects and I think it would have been better to have broken it up into sections and taken questions at the end of each section. There was a lot to take in.

“I particularly enjoyed Susan’s presentation about health and wellbeing. I took a lot of tips away with me. For example, if your grandma ate it then it’s good for you! Also, if there are more than ten ingredients in a product it’s too processed. I eat healthier as a result.

“It was lovely seeing old friends again and I enjoyed having lunch with the lovely ladies. The food and beverages were very nice.

“I didn’t feel that it was correctly described as a ‘drop in’ event and possibly that was misleading. As there was definite structure and timings to the event. I felt like the folk who turned up late missed out.

“Thanks for organising the event and for your company. To conclude I really enjoyed the day and would definitely attend future events.”

The plans for events in 2023 are:

- The Open Day at St Neots - late April 2023
- A Trust Local Event in North Wales (Wrexham area) - June 2023

- A Trust Local Event in East of Scotland - September/October 2023

There may be some flexibility around dates if it is difficult to find suitable venues but research into this has already started so we hope we can keep to this schedule. More information nearer the time.

In Focus: Bidet Toilets – Clean Machines

Geoff Spink - NAC member

Many of us, for many years, have been using bidet toilets. I got my first [Clos-o-Mat](#) when I was in my teens. It seems that our community is split between those who favour Clos-o-Mat, and those who prefer its more sleekly designed rival, [Geberit](#). However, this is a developing market, and other models and manufacturers are becoming available.



Since I own both, I thought I'd share my thoughts in case you were thinking of replacing your existing Clos-o-Mat Samoa, which is shortly to become obsolete because the servicing agent in the UK will no longer be able to get the parts.

Clos-o-Mat has always been a more medical device – its principal market being care homes, hospitals, and so on. As such, the device is robust, but insufficient attention has been given to aesthetic appeal. One fellow thalidomider describes them as the Land Rover Defender of bidets – strong, reliable workhorses. The Clos-o-Mat gets serviced once a year and any adjustments to water pressure or temperature have to be done by an engineer. Although in recent years, the company has paid more attention to user appeal, the device remains largely unconfigurable by the end user.

Geberit on the other hand, was targeted at those who want one as a lifestyle choice, rather than an access requirement. There is no servicing, but you have to top up the cleaning fluid and change the carbon filter occasionally.

The device can be operated by a remote control, or it can be triggered by an infrared switch, which I have mounted at floor level. It has an impressive array of user configurations and even separate user profiles. You can alter the water and drying temperature, the pressure and spray pattern. There is even something called a ‘lady shower’ which, for obvious reasons, I don’t make use of! My friend with the Land Rover metaphor describes the Geberit, as a Ferrari: flashy, appealing, but less robust.

My Clos-o-Mat is a Samoa, so I’m now wondering which way to jump. I think ultimately, I am drawn to the Clos-o-Mat because of its reliability and durability. That said, and perhaps a bit TMI, when I had a rather painful haemorrhoid issue a year ago, the Clos-o-Mat was just too powerful for comfort. I had to stop using it until a surgeon intervened.

There are other devices out there: Toto is a popular choice in North America. My Canadian thalidomide friend, Susan Wagner-White recently had one installed and is extremely pleased with it. She says:

“I purchased the Toto toilet in 2015 as well as the washlet seat to go with it. It has a nightlight, the seat automatically goes up and down, five minutes after standing up,

automatic bowl spray to disinfect and clean the bowl, with UV light, heated toilet seat with varying levels of warmth, heated water spray with many multiple levels and angles of spray from the wand, heated air to blow dry your bottom, again, with varying levels of warmth, there also is a fan that sucks in air and deodorises it with a filter.

"A remote control to program up to two users' preferences that can be attached to the wall or held, also, this goes along with buttons on the side of the seat which I can't reach- but that does not matter to me, as I have the remote close on the wall."

Preliminary research here suggests that the Toto can be obtained in the UK and that the pricing seems to go from the sublime to the ridiculous: one model sells for around £3K while another can be yours for an eye watering £12K. I guess it depends just how important it is that you have the ultimate wash and blow dry.

Michelle Robinson from our Trust Health and Wellbeing team comments on models beneficiaries are buying: "Although the Clos-o-mat and Geberit are still the main models beneficiaries are going for, a few folks are opting for different models. One which is creating a lot of interest, is the Japanese self-washing toilet, where the toilet seat converts any standard toilet into a self-washing toilet, at a fraction of the cost. These include the Comfort Cleanse system which has different options - a bidet toilet seat, a Japanese toilet seat and a combined system. More information can be found [here](#).

"There is also the Vovo system which is useful as the toilet lid automatically opens and closes. See the [Vovo website](#) for more information.

"Further information can be found on the [Trust website](#)."

If anyone would like to share their views about making life easier in the bathroom, we would love to hear from you at feedback@nac.org

In Focus: You Said, We Did - Cost of Living

Concerns

The NAC listens to beneficiaries and acts on your concerns

In October 2022, the NAC received beneficiary feedback regarding the impact of the recent cost-of-living increases. Following these concerns, the NAC decided to write a report to present to Trustees to highlight this issue and to ask them to consider a special payment to beneficiaries.



To support this paper, the NAC requested feedback from the community and received 11 responses from beneficiaries who were concerned about the impact of rising costs. The paper was then presented at the NAC meeting in November (as highlighted in the meeting notes circulated in December 2022).

At the meeting, staff explained that the Trust has received very few enquiries (only four) regarding this issue and beneficiaries have not highlighted this issue at HNAs or in their regular ongoing contact with the Health & Wellbeing Team.

The Trust's view is that the need for urgent financial support is not universal – a significant number of beneficiaries still have large financial balances held at the Trust - and support is available, if needed, on a case-by-case basis, for example through an Emergency Advances and the Exceptional Needs Fund. Trustees do not have the freedom to make additional payments across the board to beneficiaries - the Trust has to operate within an agreed funding framework and any funding over and above the Annual Grant payments needs to be based on clear evidence of needs.

Based on the feedback provided, the NAC updated the report and presented it to Finance Committee in December for further discussion. Finance Committee did not agree to the request for additional funding for the reasons outlined above, and because beneficiaries are due to receive an uplift in their 2023 Trust grants above the current level of inflation and Diageo have agreed to provide a lump sum – of at least £20,000 - to every beneficiary as part of the Chairs' Review process. However, the Health & Wellbeing Team is working on a 'Cost of Living Update' to signpost beneficiaries to sources of additional financial support which will be published soon.

If you are struggling to pay your bills or are worrying about your finances, please do not hesitate to contact the Finance Team for advice and support.

Our Stories: Do You Really Need a Financial Adviser?

Darren Mansell shares his experiences

Louise (my wife, who is unfortunately no longer with us), and I first considered our finances back in 2014. With Louise's health issues, we had already gone through the legal things like Wills and Lasting Power of Attorneys. These turned out to be very important.

It so happened that our solicitor recommended a financial advisor company, Caple Banks. We arranged a meeting with Jody Banks. Jody spent time understanding how the Thalidomide Trust worked. We went through a thorough review of our finances and more importantly our future needs and desires. We both had balances in our Trust allocations, and these were not doing anything in terms of growth. Taking out the Health Grant each year increased the amount of cash that was available for us to invest.

Louise also received Direct Payments and contributed some of her own funds to achieve the level of care she needed. This meant she needed a pot of funds readily available should the Direct Payments change. This was built into the review together with the need for a new vehicle. This information all painted a picture for Jody to work with.

We were asked to consider the level of risk we would accept given the potential volatility of the stock market. This was all explained in a simple way.

An investment proposal was put together for both of us, and inheritance tax and income tax were considered and 'wrap around' Trust portfolios were set up for us both. These are Trusts in our names not the Thalidomide Trust.



The most obvious benefit was that our Trust money was now working for us and generating growth rather than sitting in the Trust doing nothing. The investments allowed us to plan for the future with a new van, holidays and feeling safe in the knowledge our funds were being looked after. It also meant things were easier to deal with as part of Louise's estate when she passed away.

The downfalls are that shares and funds are subject to the markets but despite recent downturns, the funds have mostly recovered – you do need to have faith in your advisor and go with their recommendations.

I have been with Caple Banks for nearly nine years now and having gone through the process of dealing with Louise's estate, it was good to have sound advice and access to solutions. My advisor is both professional and a good friend. It is important to have an annual review and to take note of any recommendations proposed.

In summary, you need to decide what you want to do with your money. If there is no urgency in needing cash, then look to get your funds working for you. From a simple ISA through to wrap around fund portfolios, there are investments available for everyone.

I am not endorsing any one Financial Advisor as there are many out there, but finding one that you feel confident to talk with makes a big difference. Please make sure they are registered with the Financial Conduct Authority which offers you further piece of mind.

Trust Resources

Don't forget that the Trust has lots of financial information on its website including videos about financial topics in the [Money Matters](#) section. Also, if you have used a Financial Adviser, the Trust would really like to hear from you, whether it was a positive or negative experience.

Our Stories: Muscle Spasms

Michael Brear asked this question via our Facebook Group

"Hi. Does anyone get truncal muscle spasms when twisting? Most of us twist more when dressing or doing normal daily functions but lately these annoying sometimes painful spasms seem to happen with greater frequency. Maybe no other reason than I'm getting to be an old git!!"

We contacted the Trust and received the following reply from Dr Susan Brennan:



A spasm can be felt as sudden tightness and pain in your muscles in a particular area. Muscle spasms can be caused by poor posture which can develop if you have short arms and have to compensate for reduced reach, or when you have to twist the body more when getting showered or dressed. From our experience most of the beneficiaries carry a lot of spasm because of this overuse of muscles caused by performing everyday tasks of daily living. The overuse and load on muscles then sends some muscle sets into spasm. The continuous spasm of the muscles then shortens the muscle and makes it less flexible. This then makes it less able to do things and the pain develops earlier in the performing that particular task or action.

The things that we know can help are regular massage, heat and good posture in everyday tasks.

- **Massage** - we think works by stretching and lengthening the muscle back into its normal length and improving the blood supply to the area. If this isn't done, then over time the muscle becomes shortened and can do less before it is irritated. The Trust can help find you a suitable massage therapist and we know many of you find benefit from regular massage therapy.
- **Posture** - Maintaining good posture is important but we also know it's a balance between using your body for everyday tasks or the action causing pain and spasm. If the task causes severe pain, consider asking others for help to reduce strain on these muscles. Try to avoid lifting or carrying heavy bags and keep loads light if possible. A physiotherapist assessment may be helpful if you are looking to improve your posture and move in a way that puts less strain on your muscles and joints.
- **Heat therapy** - heat therapy can be helpful. This probably works by the heat improving blood flow to the muscles involved that are spasming. Again, we know that many of you use Jacuzzis, saunas and heat packs for this reason.

The Trust is also holding a webinar with a physiotherapist, Fraser, who has helped a number of beneficiaries. This will include information on things like posture, gait and good sleeping positions. More information to follow soon.

Muscle spasms are common but if you find them coming on with increasing frequency or severity, it's worth having a chat with one of the Trust's Medical Advisers. Likewise, if you need help finding a massage therapist or physiotherapist, please contact the Health & Wellbeing team on **01480 474 074**.

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