

Welcome to the Newsletter

Carolyn Desforges - Editor

Welcome to the Summer NAC newsletter. It seems incredible that we are halfway through 2022 as winter seems like yesterday! It's been an action packed few months and you will read about the Campaigns Team update, the development of the Trust's five year strategic plan, the Beneficiary Feedback Survey results, ongoing MeetUps/webinars and we properly introduce Paul Randall, our new Communications Officer. There is also information about the amazing jubilee celebrations of the Thalidomide Society (so good to actually see so many of you in person again), and a Motability update. Enjoy!



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 was thinking about the seasons and which of winter, spring, summer, or autumn that is the most preferred. For me, it is the summer, of which today is a lovely summer's day to write my update.



Diageo Discussions

We have had three of our scheduled meetings. As I have explained before, it is not possible to give a running commentary on the progress of these meetings until we have concluded them at the end of the year. I can tell you that we have been guided by the outcomes of the beneficiary consultation we held with you at the end of last year, ahead of the Diageo talks. These were to improve funding for us, for Diageo to understand our changing needs and for the provision of funding to help with our health problems. These are growing and becoming more complex in areas such as mental health, pain management and cognitive decline.

Many thanks to all those who took part in the beneficiary consultation, which has proven to be an invaluable resource for our discussions with Diageo. We will be undertaking two more discussion meetings with Diageo from September onwards. The final meeting (in November) will be the one where the Chairs of Diageo, trustees and NAC meet. Any announcements can be expected after November.

Grünenthal Foundation

In the recent beneficiary feedback survey, around 53% of you were aware of the Grünenthal Foundation but 42% of you were not. Given the level of awareness of this source of funding is so low, a factsheet is being prepared about the Foundation. Interestingly, around three quarters of those who were aware of the Foundation have applied for funding or would consider applying for funding in the future.

Strategic Planning

The NAC has been working with the trustees and staff on the next five year strategic plan with members sitting on the five strategic goal working groups. There has been good progress so far and you can read more about this later in the newsletter. I think it is fair to say that if you don't plan then you are effectively planning to fail, which is why this development work on the Trust's strategic plan is so very important.

Finally, have a great summer.

Regards, Rowland

Committee Highlights: Campaigns Update

Craig Milward - NAC Vice Chair and Campaigns Team Member

We have always argued that the German government bears some responsibility to assist all thalidomide survivors, for reasons we have explained many times in previous campaigns updates. But it is one thing to establish a communication channel to our own government who are obliged to engage with us, and another thing entirely to do the same thing with a foreign government which sets its own rules and believes it has no case to answer.



We therefore believed that our best route to communicate with Germany was via Germans in the EU Parliament. Through our hard work there over a good deal of time we eventually won over German MEPs from every political group and achieved unanimous support for a Resolution calling on the German government to communicate with us. This led to

discussions and an agreement to make it possible for thalidomide survivors to receive assistance through an EU Social Fund budget.

National governments are now able to apply for funds from the EU to assist thalidomide survivors in their country. Unfortunately, the route by which the UK left the EU made it impossible for us to benefit from this breakthrough. We therefore began lobbying our contacts in Brussels just before the pandemic hit, asking them to treat us as a special case. However, due to travel restrictions we were unable to achieve the necessary traction to mount a new campaign.

Over the last two years there have been two major developments. The first was the death of David Sassoli, who was President of the European Parliament and a big supporter. This was a big blow.

The second was far better news - a change of government in Germany. Members of the CDU/CSU parties had been supportive in Brussels, but not in Berlin. The Social Democrats and Greens are now in coalition together in Berlin, and they have been much more supportive of our case. We are therefore in the process of renewing contact with both groups in the hope that the new government will be willing to begin a dialogue with us.

The process of engaging the necessary supporters is at a very early stage, but we have begun positively and will do our very best to push our claims. If we are to get the breakthrough we need, it will be necessary to amend German law. We will do all we can to push for a solution.

We will keep you updated as and when we make progress. Thanks for your support.

Committee Highlights: A Plan for the Future

Carolyn Desforges - Health and Wellbeing Committee Co-Chair

Whilst it might seem that the work of our Trust staff is routine, in fact, it is guided by a strategic plan. Strategic planning is important because it provides a sense of direction and outlines measurable goals. The plan guides day-to-day decisions and allows for evaluation of progress to ensure the Trust is achieving the goals necessary for supporting beneficiaries' needs. Our last plan began in October 2017 and completes at the end of September 2022. Each plan lasts for five years.



The Trust management team, trustees, and NAC members met for a joint awayday in February 2022, to begin developing the strategic plan which will run from October 2022 through to September 2027. Deborah, Katy and Suzanne have also involved all their team members in the process through their respective team meetings. It is important to include all those working for and with the Trust so that we can think about how our activities and responsibilities fit into the larger picture, so we can contribute to outcomes most effectively.

At last February's meeting, we began with ensuring the "vision" and direction of work is appropriate for beneficiaries' current needs and we also agreed on the five goals that we want to achieve in order to make our vision a reality.

Our Updated Vision, Ethos and Strategic Goals

Our Vision is that each and every beneficiary of the Trust has access to the resources and support they need to live their best life for the longest time.

Our Ethos (the way we work)

We put the beneficiary community at the heart of everything we do. We are supportive, non-judgmental, inclusive and fair - and are committed to beneficiary empowerment and maintaining effective two-way communication with beneficiaries.

Our Strategic Goals

- To ensure the Trust's income is secure, financial risk is effectively managed and adequate funding is available to meet the increasing needs of beneficiaries as they age.
- To apply the Trust's resources strategically, effectively and equitably (in order to achieve our vision).
- To ensure that all beneficiaries have access to the best possible information, advice, advocacy, services and support – both within and outside the Trust – as they age and their physical and mental health needs increase.
- To ensure effective (two-way) sharing of knowledge and learning for the benefit of the beneficiary community and for wider public benefit.
- To ensure that the individual beneficiary's needs remain paramount, even when third parties (families, carers, representatives) have a role in acting on their behalf.

In addition to our five strategic goals, we identified two cross-cutting aims:

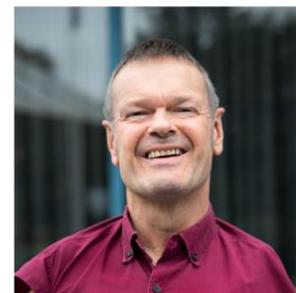
- To ensure we have the right people, structure and decision-making processes in place to deliver our vision and goals.
- To continue to build the best possible evidence of beneficiaries' evolving needs and the cost of effectively meeting those needs.

Since then, five working groups have been established – one for each strategic goal - to give careful thought to developing specific objectives and milestones needed to ensure goals are met. We are ensuring that these are realistic, thoroughly researched, and quantifiable so that progress can be measured. The plan will be completed by September 2022, to begin in October 2022 (though some elements of the plan may be dependent on additional funding from the current discussions with Diageo). Once finalised, our strategic plan will be available for everyone to see.

In Focus: What the Beneficiary Feedback Survey Shows Us

Graham Kelly - NAC Research Committee Member

All beneficiaries were invited to complete a questionnaire and 65% did so. This is an excellent response rate that compares very well with other surveys that we read about. Thank you to all who took the time to do this.



UK residents were given a choice on whether to complete the questionnaire on paper or online, and just over half chose online.

Overseas beneficiaries could only complete the questionnaire online this year, due to previous postal delays, but the overseas response rate was slightly higher than 2019, suggesting that most are happy to do it online.

You will have received a separate letter giving you an overview of the survey results and letting you know what the Trust and the NAC will be doing in response to them, but here are some of the headline survey findings.

Trust Staff

- Satisfaction with the most recent contact with Trust staff has increased again, and 91% were satisfied with the last occasion
- People were very positive on all measures relating to Trust staff, for example:
 - 89% agree that the Trust staff “are caring”
 - 86% agree that “if I needed help the Trust would do all it can”

The NAC

- Most beneficiaries have positive views about the NAC, for example:
 - 75% agree that “the NAC is a good way of ensuring beneficiary views are heard”
 - 65% agree that “I feel I can trust the NAC”

Trustees

- 72% agree that “I feel I can trust the Trustees”

The NAC Newsletter

Encouragingly the newsletter was considered useful by the great majority - 52% thought it was “very useful” and another 33% thought it was “fairly useful” - that means that 85% regard it as “useful”.

Services Provided by the Trust

Beneficiaries continue to support the Trust’s Health & Wellbeing services, with 92% agreeing that the telephone support from health professionals should continue, 89% supporting the development of specialist clinical networks, and 84% agreeing that the Trust should continue to research our health needs.

There is also continued support for the Trust's expenditure on campaigning, with 80% agreeing that this should continue

The Trust provides a range of services and runs physical and virtual events for beneficiaries, and our use of these is increasing. In the first feedback survey in 2016 we found that the average beneficiary used (or attended) 3.37 services/events, and in the 2022 survey this figure had increased to 4.17. That's a 24% increase in beneficiary use of Trust services/events and reflects the increased levels of contact noted by Trust staff.

The Trust services most commonly used in the last three years were written information including factsheets (69%), the website (68%), support from Trust health professionals (58%) and benefits advice (38%).

The Trust Website

Satisfaction with the Trust website is increasing. In 2019 36% of us were "fairly satisfied" and 41% were "very satisfied". Those figures have now gone up to 41% and 51%, meaning that 92% were satisfied with the Trust website. Importantly, 78% now agree that they know how to find the financial information on the Trust website. Only 2% did not agree. The remaining 20% mainly said that they didn't know, or neither agreed nor disagreed, suggesting that they haven't tried to access the financial information on the website.

In Focus: MeetUps and Webinars

Helen Shore - NAC Member

When Covid came along everything had to go online. It helped us to keep in touch with people, it helped reduce isolation, we learned a lot and we had a lot of fun.

Now that the Covid restrictions are much reduced and lots of people are getting out and about and back on with their lives, at least to some extent, I want to highlight the fact that there's still a lot happening online with MeetUps and webinars.



Here's a selection of some of the meetups.

- [How do you garden?](#) - ideas to enhance your gardening 'know-how' and your outdoor space creativity.
- [Weigh To Go](#) - help and support to lose weight and get your health in good order.
- [Chill & Chat](#) - come and have a coffee with people that you haven't seen for a long time or meet some new friends.

In addition to the meetups are our webinars. Here you can learn a new skill like foreign cookery or focus on health-related topics such as [Men's Health](#). Recently we held our [Future Money Matters](#) series which included a wealth of relevant financial information. These events are often recorded so that you can watch them at another time if you are busy or even if you are shy!

If you're interested in finding out what's going on, visit our [events calendar](#). It contains all the details and links with new events being added all the time.

All our meetups and webinars are free and new faces are always welcome. So please come and join us and feel free to share something of your life, successes and struggles with us. If Covid has taught us anything, it is that we need community and your community is here for you.

In Focus: Thalidomide Society Anniversary

Geoff Spink - NAC Member

Putting the Sparkle into the Jubilee

This year may well be the Queen's platinum jubilee, but for some of us an even more important jubilee is being celebrated: the Thalidomide Society was founded by the parents of thalidomide survivors 60 years ago.



Having already celebrated our golden jubilee in 2012 – spectacularly pulled off by the late, great Louise Medus-Mansell – we knew that the bar had been set very high.

The event at the Heathrow Marriott felt like a great coming together after all of the lockdowns and restrictions – a real reason to celebrate being together. Call the Midwife, Mat Fraser as compère, presentations about oral history and the latest thalidomide research as well as our collaboration with the Science Museum were high on the agenda.

We remembered those of us who are no longer here – a respectful and sobering moment – and we heard from thalidomide associations around the world who wished us well.

Our new patron, Baroness Jane Campbell, came and spoke to us all and stayed for dinner. Tina Brown, the widow of our late patron, Sir Harry Evans, gave us an interview by Zoom and has subsequently accepted our invitation to replace Sir Harry and is now a second patron of the Society.

There was a film show running all day in a separate room – among the highlights, Attacking the Devil and Niko Von Glassow's brilliantly self-deprecating film, Nobody's Perfect.

There was a craft stall that did brisk business, selling items made and donated by our members; Gerry Freeman made a commemorative quilt which fetched £1,000 by silent auction, and the Kate Rennie Thalidomide @50 portraits were once more on display, much to the delight of many.

In the evening, honorary Trustee and founding member, Margaret Hogg proposed a toast to all of us. We had a fabulous dinner in the beautifully decorated dining room (thanks again Gerry) and were entertained by poets, magicians, an improv band and the obligatory seventies and eighties disco.

The next day, people looked tired but incredibly happy: the number of people who came to say 'well done' and 'fabulous event' was a joy to hear.

Let's hope that in ten years' time, we too will be going platinum.

In Focus: Motability - Join the Queue

Geoff Spink - NAC Member

If you drive an adapted vehicle or, like me, you're a member of the Motability Scheme, you may be in for an unpleasant surprise when it comes to renewing that vehicle.



Supply chains the world over have been stretched to breaking point and one of the items in extremely short supply is computer chips, many of which are now used in the automotive industry.

Motability customers have been told that waiting six months will be the norm and probably extending their lease for a year would be advisable.

Many of us prefer to go our own route, finding the Motability scheme too restrictive. But here again if you talk to your local dealer they are likely to remind you that the pipeline is running dry.

What's more, manufacturers are stripping out some of the very useful assistive features from their vehicles because of the shortage of semiconductors: things like reversing cameras, parking assist and lane assist are being dropped from some vehicles because again, the components just aren't there.

It's very likely parts for a vehicle adaptation will also be scarce. This should even out eventually, but for now we just have to bide our time.

You can read more about this on the [Motability website](#).

Our Stories: Introducing Paul Randall

NAC Communications Officer

Our new Communications Officer, Paul Randall, started working part-time for the NAC in April. We look forward to working closely with Paul over the coming months but took this opportunity to get to know him a bit better.



Can you tell us a bit about yourself?

I live in Nottingham with my partner, our two teenage kids and two crazy spaniel dogs. I've worked in various communications roles with a range of different charities for over 30 years almost always working with volunteers. In my spare time (before we had children) I enjoyed the outdoor life and motorbikes and now that the kids are getting a bit older, I'm hoping to spend more time in the hills or on two wheels.

What is the role of a Communications Officer?

I think it's all about making sure communications are as effective as possible. The goal is for people to be fully informed and feel connected to the organisation. But it's also about listening. When I worked on the radio, I quickly realised that you need to get to know your audience, otherwise they'll just switch channels. So it's very important to me to get to know

the beneficiary community better and find out what you want from the NAC as well as supporting the NAC with its communications.

What attracted you to working with the NAC?

I had a couple of days in the week to spare and I wanted to put them to good use. The role really appealed to me as I've been interested in disability issues for a long time especially through my professional work. I'm in the same age bracket as beneficiaries and NAC members, so I could see a lot of synergy there too.

How will you know the most appropriate way of communicating with our beneficiary community?

There's already been a lot of work done in this area by Sarah, who was the previous Communications Officer. I think it's important to look at what's working and do more of it, and also what isn't working and find ways to improve. These days there are multiple ways of communicating using print, online, phones, events... the list just keeps growing. It's really a question of meeting the needs of each individual and finding ways to connect.

What do you hope to achieve in your first year of working with the NAC?

I want to continue to improve the link between the NAC with the beneficiary community. If I can see progress within 12 months then I know we're on the right path.

I'd really like to get to know beneficiaries better, so please email me at paul@ttnac.org if you're happy to have a chat.

My perfect weekend

Early riser or night owl? I'm an early riser - best part of the day!

Wine or water? Wine is fine. But beer is better!

Dog or cat? I spend a lot of time with our two dogs, Hugo and Oli, and have always enjoyed hanging around our canine friends.

Cook at home or eat out? I do a lot of cooking at home and have recently started making my own pasta, which has been a real surprise at how much better it is than the shop stuff. But it's nice to eat out every now and again.

Park run or countryside cycle? My first choice of transport is my bike.

Football or rugby? Neither. Cricket is where it's at.

Rock or pop? Either. I used to work on the local BBC's music programme and enjoy all sorts of music.

Staycation or holiday abroad? I do enjoy popping over to France when I get the chance.

Cinema or theatre? Cinema for me, ideally with some popcorn and a Kiara orange.

I couldn't get through the weekend without..... A cup of tea.

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