

Welcome to the Newsletter



Carolyn Desforges, Sue Gooding and Maggie Boyd, Newsletter Editors

Welcome to the new-look NAC newsletter. It might be surprising to receive this hot on the heels of the Spring edition, but our recent communications review showed that our newsletter needed to be shorter, but more frequent.

We are aiming for four short newsletters each year and will be sharing the full newsletter stories on the Thalidomide Trust website. We hope you find the content interesting and that it keeps you up to date with NAC activities. We welcome any comments – by email or in our brand new Facebook group on www.facebook.com/groups/ttnac!

In this edition, we continue with headlines from the NAC Chair, interview new NAC member Sue Gooding about her perfect weekend, feedback on the joint NAC / Society conference, and review the NAC MeetUp Q&A session.

We also look back at the Future Money Matters online workshops and, finally, hear from Craig Millward (NAC Vice Chair) about his experiences as an interviewer for the Thalidomide Society Oral History project – yes, he does have a life away from the NAC!

We hope you enjoy the read!

Carolyn, Sue and Maggie - Editorial Team

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Latest News from the NAC

Rowland Bareham, NAC Chair

NAC Q&A follow up for the May meeting – held Friday 11 June 2021

As part of the communication improvements being implemented by our excellent Communications Officer, Sarah, there was an NAC feedback meeting via Meetup to give beneficiaries an opportunity to put questions to myself and Carolyn, following the NAC's May meeting.

Previously, only one or two people joined the conference calls that we set up following NAC meetings (May/November). However, this time we had 15 people come along to the 1 hour Meetup session (10 of whom were not NAC members and six of whom asked questions or made comments).

We will hold a Meetup session again after our November meeting and hopefully even more of you will join us to ask questions and get answers. As ever, we'll be looking at how we can improve things even further to improve interactions between the NAC and the beneficiary community it represents.

Awayday / Strategy Day

The NAC has been functioning principally through the Zoom conference facility for its main Meetings with the trustees and staff, its monthly conference calls and other meetings. With the relaxation of Government restrictions, the NAC are hopefully going to be meeting up face-to-face early in October to discuss ways of improving its representative role of the beneficiary community to the Trustees. I'll report back to you in our next newsletter.

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

Committee Highlights: Health and Wellbeing

Carolyn Desforges, Co-chair of the Health and Wellbeing Committee

To scan or not to scan? That is the question!



During the June NAC Q&A, concern was raised that some beneficiaries, when undergoing surgery, were discovering evidence of internal damage that had been there since birth. It was suggested that all beneficiaries should be offered a full body scan to identify any internal abnormalities.

I was aware that deciding to have a body scan is a complex decision, not

to be taken lightly, so I contacted our Trust Medical Advisers, and Katy Sagoe (Director of Health & Wellbeing) for their opinions. I thought you would be interested in their response:

“As we have become more involved with beneficiaries having surgery – in particular through the Private Referral scheme – we are more aware that some beneficiaries are finding evidence of internal damage that has been there all along. This may not cause any problems on a day-to-day basis, but can be unexpected when performing surgery and so make it more complex.

Therefore, we have amended our advice to the clinical teams performing surgery on beneficiaries. If you are going into hospital, we can provide a letter flagging any potential issues to ensure the surgeon has all the information they need in advance of the operation.”

But should everyone be offered a full body scan?

The Trust Medical Advisers said:

“We wouldn’t recommend this for several reasons:

- Current medical advice is to avoid unnecessary scans and x-rays to reduce exposure to potentially damaging side effects.
- There is a high risk of over-diagnosis leading to potentially unnecessary medical treatment and associated worry. Many abnormalities that are detected by screening will never go on to cause any harm. There is **increasing concern amongst the medical profession** about the implication of over-diagnosis.
- Screening is limited in what it covers. It can never really provide a clean bill of health – there are false negatives as well as false positives – so it may not actually give you peace of mind.
- Identifying a reputable private provider (as this screening is not available on the NHS) and having an objective interpretation of the results is problematic. Some of the tests offered by private companies are not recommended by the NHS, because it is not clear that the benefits outweigh the harms.

At the moment, our advice to beneficiaries is:

1. Screening is not for people with symptoms. If you have specific health concerns or new symptoms, speak to your GP. If they feel a scan is necessary, they will refer you to the NHS. You could use your Health Grant to access this privately if you feel the wait is too long.
2. If you are having planned surgery, then ask for a letter from the Trust that explains the possible complications a surgeon may find.
3. If, despite this advice, you still want to use your Health Grant to pay for a private screening scan, use a reputable provider. It is a legal requirement that all providers of screening services are registered with the relevant care regulator, so check this is the case.”

Read more about the pros and cons of screening here:

<https://senseaboutscience.org/wp-content/uploads/2016/11/Makingsenseofscreening.pdf>

Committee Highlights: Finance

Phil Williams, NAC Finance Lead

Future Money Matters 3: A Virtual Event held in June 2021

You may recall that there have previously been two Future Money Matters (FMM) events face-to-face in Birmingham and Stansted. Given the pandemic, we didn't want to put off FMM3 indefinitely – so we took the decision to hold it as a zoom webinar.



What is Future Money Matters?

These events are designed to help beneficiaries with any aspects of money-related issues. The Trust cannot legally give financial advice, of course, but can share knowledge and signpost us to solutions.

If you were unable to attend – or did attend and need a recap – the great news is that the videos are now available online; edited with subtitles. You can watch whichever short sessions interest you:

<https://www.thalidomidetrust.org/news/events/future-money-matters/future-money-matters-2021/>

The presenters included representatives from professional firms on various topics and there was an excellent session on Trust investments by two trustees, Kevin Wesbroom and Mark Benstead. I would urge every beneficiary to watch that one as they bust a few myths and clearly explain the position. It's fantastic to see our trustees getting involved; thank you both.

So what was the feedback on Future Money Matters 3?

- All webinar sessions were rated highly with an average score of 9.28 (out of 10) recorded from 55 responses on this question.
- The overwhelming majority of the beneficiaries who signed up had not attended either of the previous Future Money Matters sessions.
- Initial feedback from beneficiaries showed that they will be taking positive action as a result of information obtained.
- 93% of beneficiaries said they prefer an online event (or had no preference) over an in-person event.

What next for Future Money Matters?

It's fantastic the event was well-received and interesting to see that the online format was so popular. This is maybe a sign of the times! It also meant that many beneficiaries were able to choose just those one-hour sessions on the topics that were interesting or relevant to them, rather than travel to attend sessions that weren't.

The detailed feedback is being analysed and includes some very good ideas on topics that could be dealt with in another Future Money Matters event, should this be the way forward. May I say a huge thank you to Jeff Prevost (Finance Co-ordinator – Beneficiary Support) who worked so hard before, during and after this very successful event.

If you have any questions about Future Money Matters or other finance matters, please do not hesitate to contact Jeff Prevost at the Trust (jeff.prevost@thalidomidetrust.org) or Phil Williams on the NAC (using phil@ttnac.org).

In Focus: Telling Your Story Joint Event

Sarah Hagger-Holt, NAC Communications Officer



“Moving, informative and inspiring”: Your thoughts on ‘Telling Your Story’

In May, over 100 people took part in the first ever NAC and Thalidomide Society Joint Event. This was not the only ‘first’. It was also the first major event that either group had run entirely online.

The two-day event, ‘Telling Your Story’, included both business and pleasure: the Society AGM and Trust updates, as well as breakout rooms to chat to old friends and new ones, gasp at some amazing magic and create our own spontaneous poems with the help of Judge, our resident poet.

The theme of storytelling threaded through the whole weekend. Fred Dove and Sureshi Thakkar shared their powerful life stories in words and images. The oral history presentation sparked a heated debate about cold baked bean sandwiches, as well as keeping us on the edge of our seats - and the verge of tears - as we listened to many moving personal experiences.

Not everything went entirely to plan, and we learnt a lot for future events. However, overall the weekend was a success.

Here's what some of you had to say about 'Telling Your Story'

"Fun, informative and professional! Was lovely to see all my friends."

"I loved hearing other people's stories formally on presentations and informally in the breakout rooms."

"I felt it was good to catch up with old friends and good to see the Society, Trust and NAC working together."

"I found the event moving, informative and totally inspiring."

"Given the current circumstances, it was very well organised. However, you cannot beat attending these things and meeting up with others in person."

"I was made very welcome and I met new people. It was great to hear their stories."

"To everyone who made it happen, well done, we all have a story to tell."

And in the closing words of Judge the Poet...

It's been a beautiful weekend, joining every heart and mind;

Everyone feeling the warmth - and everyone being so kind.

You are heroes of history and victors over doubt and pain,

As you declare: What a result! And WE'LL MEET AGAIN!!

What next? Tell us what you think

Thanks to everyone who completed the feedback survey after the event. Whether or not you were able to come along this time, we'd love to know your thoughts about the role of NAC and Society joint events in future, the balance between real life and online events, and what you'd like us to plan for next year.

Email feedback@ttnac.org with your ideas and comments.

Our Stories: Introducing Sue Gooding

Sue Gooding, NAC member



As a child, Sue went to a boarding school in West Sussex and made loads of friends in her time there. Sue never had the opportunity to live at home with her parents as they were unable to look after her, but she feels this has given her a lot more independence during her life.

Sue lives with Vicky and her daughter Hannah and their new adopted kitten called Maisie (pictured overleaf!). She loves holidays, mostly cruises, as this gets her to places that she may never have been able to visit due to difficulties with wheelchair access in some countries.

Sue enjoys going to the theatre, sewing, arts and crafts, the challenge of growing orchids and keeping her mind active.

Sue tells us about her perfect weekend...

Quiet night in or night on the town? Night out on the town.

5-minute pasta or fine dining feast? Fine dining feast.

Netflix box set or reality TV? Reality TV.

Who or what is your screensaver? My screensaver is a bunch of pink flowers.

Dog or cat? Likes both but has a cat.

Wine or water? Wine on special occasions, but mostly water.

What's your signature dish? Chilli Con Carne with brown rice and nachos and grated cheese on top, yuummmmyy!!

I couldn't get through the weekend without... Visiting family and friends and having a good time. Having a laugh is so important for my mental health.

And for those longer breaks – Cornwall or the Caribbean? Caribbean of course, silly question LOL, somewhere warm and hot.



Our Stories: Reflections from an Oral History Interviewer

Craig Millward, NAC Vice Chair



(Picture above from the Thalidomide Society)

Stories are fascinating – from the stories we tell ourselves about ourselves, to the things we learn about ourselves from the stories told by other people. But it is not often that we get the opportunity to sit and talk, without being interrupted, challenged, contradicted or criticised, for as long as we like, about our own life.

For the last couple of years, I've had the great privilege of going beyond my usual NAC and campaigning role and doing something completely different.

A few years ago, the Thalidomide Society applied for a grant from the National Lottery to give every one of us the opportunity to tell our story to a trained interviewer and have it recorded, transcribed and eventually stored in the British Library. The complete archive will then be accessible to future historians, and anyone else who is interested.

Telling my story

The very first experience I had of the project was sitting in my own front room with a microphone clipped onto my shirt, whilst Ruth Blue asked me a series of questions that enabled me to unpack my unique history. It was a few years ago now, but I still remember the experience as if it were yesterday.

I had decided in advance that I was not going to hide anything. Beginning with what I'd been told about my birth and my early battles as a premature and disabled baby, through the traumas of school, dating, my discovery that I'd been damaged by thalidomide and the challenges of marriage and fatherhood.

One memory led to others I had forgotten. I found myself connecting themes as I talked. I came to appreciate people who I'd maybe taken for granted when I was younger. I still find myself connecting some of the threads today.

Listening to others

Just as profound is the tremendous privilege of sitting listening to others having the same life-affirming experience. I've completed six interviews now, and each one was special in its own way. The format we've adopted, and the simple list of questions we've refined into an order that seems to make best sense, just enables a story to flow so naturally.

Some parts of the stories have clearly been told before and are full of detail. At other times, it feels like riding a rollercoaster – one thought leads to what may seem to be a random recollection that veers off in a completely unexpected direction. My role is simply to guide a fast-flowing stream whilst making a mental note to explore a tributary or backwater when the next opportunity comes to throw in a question.

What next for the oral history project?

We are coming towards the end of the project now, but the hope is that we still have time to enable a few more of our parents to take part. There is also an idea that some of our siblings or children may be interested in contributing to the archive from their own distinct angle, but that may depend on securing more funding.

Read about and listen to the oral history interviews:

<https://wellcomecollection.org/articles/YIBmoBAAACgA1TRE>

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 October.

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 new 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.