

NATIONAL ADVISORY COUNCIL
TO
The Thalidomide Trust

Newsletter

Autumn 2018

Welcome to the NAC's Newsletter.

The format I follow, for our newsletter, is to focus on what we've been up to as a group, and to intersperse this with news from both the Trust and from individual beneficiaries.

In this edition, we have some sad news..... our last edition featured an article on Heather Clark. Sadly, Heather has since lost her battle with cancer.

We also share thinking on NACAC, a regional event, and a joint event with The Thalidomide Society.

There is an update on Campaign matters, information on support for individuals, as well as useful apps.

On the Trust news there is an article on how HNAs are supporting individuals; new staff; and one about a new survey on Prosthetics.

If you wish to receive campaign updates by email, please contact the Trust office (email: hello@thalidomidetrust.org) so that you are included in their distributions.

Thank you to all who have contributed information for this edition, and a **HUGE** shoutout to Simone who has – again – been instrumental in sourcing articles for inclusion.

Please enjoy reading..... AND if you've something you'd like to contribute to the next newsletter please contact me.

Karl Davies – Newsletter Editor

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Chair's Update

Rowland Bareham

Firstly, many thanks to Simone and Karl for compiling this edition with the usual variety of information.

The NAC is working co-operatively with the Thalidomide Society and we look forward to being at their AGM event next April with a NAC session on Health and Wellbeing.

We had our Awayday in June – this was not a ‘jolly’ but a day in which the NAC members worked together to look at the Milestones that were specific to the NAC in the Trust’s Strategic Plan. I’ll highlight just three of them here:

- We’ll be producing an ‘annual report’ by video at the end of every calendar year (this is going to be filmed at the next November NAC meeting);
- Another beneficiary feedback survey will be conducted next January including questions on the level of engagement with the Trust staff/NAC, barriers to engagement and the quality of communication; and
- Whilst not quite around the corner just yet, we will be starting to plan for the Health Grant Renewal working with the trustees and staff in jointly approaching the Health Departments – please be assured this is on our radar.



We are looking for an Admin Support person for the NAC to ensure that we better stick to what is outlined in the Strategic Plan - especially with regards to communication with and involvement of beneficiaries. The advert is out now.

I am in my third year as Chair and there will be an internal election at the November meeting to elect my successor, whom (whoever it will be) I wish well in taking over.

As ever, I wish you well.

Campaign update

Mikey Argy – on behalf of the Campaign Team

European Parliament

Meetings have been held with a couple of very important and strategic people within the European Parliament. Manfred Weber, President of the EPP (European People's Party) and a CDU German MEP; and Jens Geier, Member of the S&D (Socialists and Democrats Party) and Leader of the SPD German Delegation of MEPs. They are both working together, and with us as well, in writing a joint letter to the German government supporting a solution in Germany.



UK Parliament

Before the parliamentary summer recess in July, the drive in the UK parliament was to get a letter signed by MPs that was written by both our APPG (All Party Parliamentary Group) Chair Simon Hoare and the Thalidomide Trust, and to get as many signatures from MPs as possible in the four weeks we had between writing the letter and getting it signed. We ended with 122 signatures on the same day our Prime Minister had her cabinet reshuffle, so we lost a few names and ended with 114 signatures. More MPs came forward after the deadline date but we were unable to add their signatures as the letter was by then delivered to the Foreign Office. The Foreign Office agreed to take the letter to the German Ambassador in London who would hand deliver this letter to the German government in Berlin. This was delivered on the 23rd July 2018.

We are now awaiting a response from the German government.

See below the letter that was written to the Chancellor of Germany for your information.

Thank you all for your continued support.

Any questions please email us on email@thalidomidecampaigners.com

Or call Mikey Argy on: 07875 084320



SIMON HOARE MP
NORTH DORSET

HOUSE OF COMMONS
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Dr. Angela Merkel
Chancellor of the Federal Republic of Germany
Bundeskanzleramt
Will-Brandt-Straße 1
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Germany

10th July 2018

Dear Chancellor

As Chairman of the House of Commons All Party Thalidomide Group, and on behalf of the Director and Leader of the UK Thalidomide Campaign Team, we want to press the case for your Government to make good on those verbal commitments made to the UK Thalidomide campaigners in relation to financial support prior to your recent elections.

Our Group has met regularly with my colleague, Sir Alan Duncan MP as the Minister for Europe and he, and our Foreign Office, remain committed to facilitating a German-authored and funded outcome for those UK survivors of Thalidomide.

There is concern in the UK that the proposal to provide readily accessible funding for UK survivors is not contained within your Coalition Agreement. I have raised this with the Prime Minister at Question Time.

We are presuming that the Agreement does not limit the actions of your Government to its content and that, in the general scheme of things, and not least as the issue affects UK citizens, the issue was not deemed necessary or of sufficient scale to be included in the Agreement. You will be aware of the strength of feeling for justice to be done, not least as expressed by the European Parliament.

Our Government stands ready to provide whatever reporting/accountability requirements your Government may have and to engage with your Officials to deliver them. We remain of the hope that your Government remains reconciled to the proposition that financial support should be provided to those survivors living in the UK and that the fund is best administered in English and from the UK. The current arrangements are onerous and cumbersome, placing, as they do, an unfair burden on those who 'live' with Thalidomide.

Your Chancellorship has the hallmark of doing what is right for people. We hope that will be true for finding a speedy solution to this issue which has, in all conscience, gone on for too long. Now is the time for firm and swift action.

We look forward to hearing from you and would be happy to meet any of your officials in Germany.

Yours sincerely
Simon Hoare

Simon Hoare MP
Chairman Thalidomide All Party Parliamentary Group

Mikey Argy

Mikey Argy MBE
Director UK Thalidomide Campaign Team

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Where's NACAC?

Phil Williams

Many of us will know the game 'Where's Wally?' but some beneficiaries might be wondering what is happening with the NAC's Annual Conference (NACAC) as there hasn't been one since 2016.



If you recall, this is the annual event run by your NAC which moves around the country each year and features presentations on lots of the hot topics from guest speakers with Q&A sessions. The recent events have been recorded and are available on the Trust website if you want to see a particular session. If you're reading this digitally you can [click here](#).

The NAC recognises this format does not work for everybody. Some beneficiaries come every year but others are not so keen for various reasons; some of which were identified in the Feedback Survey. Action has been taken based on your input.

There was no NACAC this year in 2018 and there will not be next year in 2019 either; but more on a very exciting development later in this article.....

As you are aware there has been an increasing number of smaller events that are regional and/or have a specific theme.

The Trust have held two 'Open Days' in May 2017 and in March of this year at the Trust offices both of which attracted beneficiaries who haven't ever attended a NACAC. There have been regional events in Glasgow and Belfast which have received a very positive response. If you haven't attended one yet and are near the south-west then please seriously consider coming to Bristol on Tuesday 9th October; [link here](#) for digital readers. There are NAC representatives at all these meetings and plenty of opportunities to talk one to one to them or staff/directors about anything and everything.

Co-chair of Health & Wellbeing, Simone Illger, has run two fantastic 'Fit for the Future' events to help all of us improve our health. Hopefully you've attended or read the features including testimonials from attendees in newsletters or elsewhere. NAC member, Phil Williams, helped the finance team, who ran 'Future Finance Matters' in Birmingham earlier this year. This was designed to help beneficiaries with managing their finances & financial planning. It was a real success & another will be held in London in 2019 so please keep an eye out for your invite but do sign up quickly as places will be limited given the interactive nature of the day & the provision of booked one to one slots with the financial professionals there after lunch. Once again, there are [videos here](#).

There is one other significant innovation your NAC is trialling. As you know there are principally two organisations for thalidomide survivors -The Thalidomide Trust & The Thalidomide Society. These are actually different and at a future point maybe we should clearly set these out for everyone but, essentially, they both exist to support us all. The Society also has non-thalidomide members which is a key difference.

The Society has an annual event too. So, the intention is to hold a joint NAC and Society event in 2020 to see how that works for everyone!

In the interim, the NAC will have a formal presence at The Thalidomide Society event on 6th April 2019. There is an article about this elsewhere in this newsletter.

Fit for the Future – What next?

Simone Illger

Life style changes – what's stopping you?

You may recall that in the last newsletter (Spring 2018) we reported on the last Fit for the Future event which took place in October 2017. The article also touched on whether there were plans for any more of these events.

Some of those who are keen to attend a future event are from a small but keen cohort of beneficiaries who have embraced some long-term life-style changes.

But what about the remainder of our beneficiary community?

We know that when a Holistic Needs Assessment takes place, many individuals report that they are experiencing pain, wish to lose weight, give up smoking or find a regular form of exercise that they are able to do and enjoy.

The reality is that many do nothing more about making any lifestyle changes to address these things.

At the Health and Wellbeing meeting planned for 6th November, part of the meeting has been set aside for committee members to indulge in some lively discussion and ideas sharing about how to encourage our beneficiary community to engage and start to make change happen.

Many of those who have made changes – either through one of the Fit for the Future events or on their own - are enjoying some positive (and sometimes unexpected) results!

Annie Bates recently shared some information on Facebook which sparked huge interest and debate.

Annie's experience



Recently my deteriorating mobility issues got a lot worse and consequently I put on weight which turned into a horrible trap and downward cycle. Not being able to exercise because of my condition did not help at all. Dieting didn't work because it meant eating nothing, almost literally, to lose weight. I am 5 foot.

I then saw the programme on BBC1 called [“The Big Crash Diet Experiment”](#) which mentioned the diet was ideal for people with disabilities and mobility issues.

I followed the diet up by researching swimming exercises which strengthened my spine and joints and have now lost over two and a half stone and counting.

My mobility changes are short of a miracle. I did not think it was possible to be as healthy as I am and I'm still improving.



The diet is backed up by an Oxford Professor who also reports that this diet also has unique effects on blood pressure and blood sugars.

Whilst I have to put in hard work my regime isn't that unpleasant.

Part of these specific diets is re-education of food and readjusting technique to changing food requirements as you grow in age. I have full hope I won't put it on. I was very, very anti these types of crash diet until I saw the research and this programme.

With the (Cambridge) Diet which is the meal replacement diet I used, you do 9 weeks on low calorie meal replacements which do suppress the hunger pangs.

After 9 weeks you go to phase 2 in which you add a real meal per day which is based on healthy protein and veg. Then there are 3 other phases until you are on a maintenance programme.

I am finding coming out of eating normal food for a while is psychologically easy and has given me a chance to reassess how I approach eating in the future.

I never used to over eat but I now know because I have lost height, am older and less able to move with the bounce of youth I am like most other people in this thread that I must now eat child portions or smaller portions than most 'normal' people for the rest of my life which I'm okay with. I accept this.

I've lost two and a half stone in total now.

It wasn't just the diet which has helped me it is how I have used swimming and specific pool exercises to control my lack of mobility and pain. The difference in pain is a miracle - truly a miracle.

My local (Council operated) swimming pool offers "Ability Sessions" which are aimed at people who need support to get into and out of the water. I'm not sure if other Councils operate similar sessions, but it may be worth others making enquiries with their local Council.

As an aside, because of my diet and exercise regime my knee surgeon has postponed surgery that was planned for the end of August as I now have much more movement. I have to back to him in November to that he can assess how things are going.

Read more hear about Total Diet Replacement Programmes:

<https://www.phc.ox.ac.uk/research/diet-plans>

The Holistic Needs Assessment (HNA)

Katy Sagoe

The HNA Process

An HNA (or Holistic Needs Assessment to give it the full title) is simply a structured conversation that takes place between you and a trained member of staff. HNAs were introduced by the Thalidomide Trust to help us make sure that we understand and can respond to the changing needs of our beneficiaries.



An HNA takes place in your home and gives you some time to talk to us about any area of your life and your health, although you don't have to talk to us about anything that you don't want to. From the HNAs we can identify any support that you as an individual might want from us, as well as finding out what issues affect lots of you. For example, we will ask you about your health, so that we can build a picture of the main health issues that are developing for everyone. So, even if you feel you are doing well at the moment and don't need help it's important for us to see you and learn from your success.

As well as helping the Trust make sure we are providing the right help, the HNA information helps the Trust and the Campaign Team make a strong case for continued and increased funding from Diageo and the Departments of Health (although of course personal details are never shared).

So far 252 people have had HNAs and we plan to have seen everyone in the UK by the end of 2019. We have had really positive feedback from beneficiaries who have had an HNA including –

“I was delighted to see the staff from the Trust and know that I have the support from them”

“I made an immediate connection and found it very easy to open up”

“overall it was very useful and so easy to talk - I felt I could talk about any and all of my concerns”

96% of beneficiaries who have had an HNA would recommend it to another beneficiary. So if you have not had one yet, we very much look forward to meeting you over the next year or so. One person has kindly agreed to share his HNA experience and you can read his story below:

Ian's experience

Ian's HNA took place in April 2018 with Cheryl Pinkney and Dr Susan Brennan, who had recently started work with the Trust.

Were you a bit apprehensive before the HNA took place? Did you know what to expect?

I wasn't at all apprehensive in fact I was looking forward to it. As far as knowing what to expect – not really. But I'd had several conversations via email with someone at the Trust ahead of the visit so I knew what sorts of things would be covered.



How did you find the process?

Straightforward... Emotional... It was an extremely valuable experience and it was nice to be listened to. Cheryl Pinkney and Dr Susan Brennan carried out my assessment. It was good to express some of the struggles I was having emotionally and psychologically. There was excellent pre-appointment communication ahead of the HNA day which really helped with the process.

Did the HNA make you aware of anything that the Trust may be able to help you with?

We covered all the bases and there was nothing new there for me. The only thing the Trust identified was that I wasn't claiming Personal Independent Payments (PIP) and I was gently encouraged to make a claim. However, I feel that I wouldn't qualify for it, and I don't need it. There was no pressure to apply – the Trust staff just wanted to ensure I knew about it.

Did the HNA help you to identify things that you wanted help with or to change?

I was signposted to Information that I could forward to my GP on how to take blood pressure in the leg and using a thigh cuff. To be honest I feel well informed about the Trust and the services they offer. Communication has really improved under the new director. Martin Johnson was fantastic, but the Trust has gone from strength to strength under Deborah Jack. I feel I'm more connected with the Trust than I have been before.

Since the HNA, how have things changed for you?

I feel more allied to the Trust having met Trust staff face to face and this makes calling them much more personal. Proof of Existence video calls have been a great way to connect with beneficiaries as well.

What would you say to any beneficiary who's unsure how an HNA can be of help to them?

It's valuable to connect. The trust is there for our wellbeing and to ensure that we are given all the support that is there and available to us.

I found it a pleasant experience and would encourage others to have one! For me, the HNA was timed just ahead of my decision to retire from full-time work and a job I loved and enjoyed. I was able to talk through my fears and concerns and the Trust staff provided me with the reassurance I needed. It came just at the right time.

LifTS – Low-mood improvement for Thalidomide Survivors

Simone Illger

This exciting new project has been designed with the University of York in response to the findings of the 2015 Health and Wellbeing study which showed how many of you are feeling low and anxious some, or all, of the time.

The project involves:

- A "Mood Survey" of all beneficiaries to build a more detailed picture of how widespread low mood and anxiety has become
- Testing a short programme that has been specially adapted for beneficiaries to see whether it can help people make changes to improve their mental health.



- Training a small group of volunteers to support others through the programme
- Assessing how well the programme works to see if it can be rolled out more widely.

You should have received a copy of the “Mood Survey” recently sent out to all beneficiaries. Please make sure you complete this and send it back – the more responses that York University receive, the better informed the Trust will be about our beneficiaries.

The survey also has information about volunteering to take part in the study – this could be the beginning of a more positive you.

Joint NAC / Thalidomide Society Conference Weekend

Simone Illger

A team from the NAC has been working closely with a team from the Thalidomide Society over the past year to form a working group to discuss the idea of trialling a joint weekend event. The aim is to combine the Thalidomide Society’s AGM and Annual Conference with a NACAC event.



There are many benefits to the Society and the NAC joining forces – on a practical level, pooling the administrative task of organising an event, having a shared budget (which would hopefully make it slightly cheaper for those attending) and sharing the workload of organising speakers and sessions. From the point of view of those attending, there would be a saving on travel across the UK (which isn’t getting any cheaper or easier – many Beneficiaries regularly attend both events) and an opportunity to meet some of the people who usually attend one event rather than the other, therefore expanding contact amongst thalidomide survivors.

At the Thalidomide Society’s AGM on 14th April, a vote was held in relation to trialling a combined event and there was overwhelming support in favour of it.

The working group have since agreed that the trial event should take place in 2020. In the meantime, the NAC will have a greater involvement and presence in the Thalidomide Society’s Conference due to take place on 6th April 2019.

Plans are already underway for the NAC to host a session that will be interesting and valuable – possibly concentrating on health and wellbeing issues which are becoming ever more important as we age with a focus particularly on dieting – we will be asking those present what has worked for them, what has failed, and generally sharing experiences.

In the meantime, the Society and NAC are really keen to find a new venue. Ideally it needs to have good transport and road links and have at least 12 accessible wet rooms and the option of walk in shower cubicles rather than showers over a bath. The Conference area must be able to comfortably seat up to 120 attendees, preferably in cabaret style, with space for up to 15 wheelchairs. Needless to say, the more accessible bathrooms any venue has, the better.

If you would like to suggest a potentially suitable venue, we would love to hear from you!



The NAC would like to encourage as many beneficiaries who are not already Society members to come along to the 2019 Conference and to consider becoming a member of the Society, which is free for anyone who is Thalidomide impaired, their friends and families or anyone who has a similar impairment. You can find out more about the Society on their website:

<https://www.thalidomidesociety.org>

by email: info@thalidomidesociety.org

or by telephone: 020 8464 9048

TalkTogether

Simone Illger

The Talk Together contact service

TalkTogether is designed to put beneficiaries of the Trust who feel lonely or isolated in touch with another beneficiary who will be there to offer a friendly ear each week in a confidential telephone call.

From conversations we have with beneficiaries, during HNAs and telephone calls we receive at the Trust office, the Trust has become aware that many beneficiaries of the Trust feel isolated and lonely at times.

This may be due to changes in life such as losing a loved one or a lack of close family or friends or it may be that deteriorating health and confidence mean beneficiaries can no longer go out and about like they used to.

Although TalkTogether is not an advice line, talking to another beneficiary means being able to share problems and concerns with someone who understands and may have faced similar worries.

Who can use this service?

Any beneficiary who feels they would like someone to talk to on a regular basis.

How does it work?

Tell the Thalidomide Trust you would like to receive a call from TalkTogether and they will match you with a trained volunteer and arrange for them to call you each week for a chat. The Trust do all the work for you – all you need to do is answer the phone!

The Trust will arrange for you to receive a weekly telephone call on a day and time that suits you. The call will be set up for the same day at the same time each week and the Trust will ask about your availability when you join TalkTogether.

The Trust will try their hardest to match you with someone who has similar interests to you, so hopefully your conversation flows and over time you will build up trust and feel able to talk about anything that is important to you.

It is hoped that you will find it easy to talk to the person who calls you and enjoy your conversations, but from time to time the matches might not work. In that case let the Trust know and they will do their best to find an alternative.

All Talk Together calls are free

TalkTogether volunteers will make the call to beneficiaries. They do this through a special system that means they will not have your phone number and you will not see theirs. The cost of the calls will be paid for by the Trust – they are completely free to you.

All Talk Together calls are confidential

The volunteers are all trained in confidentiality and sign a confidentiality agreement not to discuss your conversations with any other beneficiaries. If the volunteer is seriously concerned about someone's safety, in that case they may tell Michelle or Katy at the Trust so that they can consider whether safeguarding action is required.

Find out more if you think Talk Together would help you

If you are interested in finding out more TalkTogether, please contact Michelle Robinson by calling **01480 474074** or by completing the form on the Trust website: <http://staging.thalidomidetrust.org/health-and-wellbeing/talk-together/> Michelle will then contact you to explain how TalkTogether works and will be able to help you decide whether it is for you.

If you decide to go ahead Michelle will arrange a time to talk to you in more detail about your experiences, hobbies and interests and anything you want the Trust to take into account. This will help the Trust to match you with the right person to talk to.

Being a Talk Together Volunteer - Marnie

Marnie (not her real name) – tells us a bit about being a Talk Together volunteer.

Can you tell me a little about yourself?

I'm 58 years old and a recent widow. I have a grown up son living in London. I live on my own but have a good network of friends and family. I enjoy going to see films and love travelling. I have recently returned from 6 weeks of travel to various European countries.

I teach secondary school age children in food and nutrition.

Oh – and I was a Master Chef finalist in 1991 – but there's no point in looking for archive footage as I know none exists!

What made you decide to put yourself forward as a TalkTogether volunteer?

I'm quite inquisitive and this was something new and completely different; something I'd never thought of. It's not dealing with knife edge situations like the Samaritans – and I enjoy the continuity, so being able to talk to the same person regularly. I like chatting, I can chat to anyone. It's interesting and a way of giving something back. It's easy to put money into a charity box - but giving something of yourself on a regular basis is sometimes more valuable.

Having been through a lot of recent tragedies (bereavements) I have come to realise that I am very resilient and can use this valuable skill to assist others.

How was the whole experience?

I had to apply for the role, which understandably makes one feel a little vulnerable. I felt I was putting my neck on the line and wondered how I'd feel if I was rejected? I had to accept that I may not be good enough or that there might be others better qualified than I for the role.

The next stage was a telephone interview with two people interviewing me. I quite enjoyed this as I was on the way home from work on my hands free! It made the journey home go really quickly.

Then there was the formal training. This was a very interesting 2 hours on the phone. I did the training whilst I was on holiday. It was quite an unusual process, being "virtually" trained - as I couldn't see any one and they couldn't see me – I could only hear them. There were around four of us in total and one person leading the training session. It was a little daunting and quite competitive as there were several of us, all competing for a role. The whole training session was very thorough and intense.

Then I had to wait to hear whether I'd been successful – it was great to learn that I had!

For the next part, I had to wait again until I was paired with a match.

Have you started to support any beneficiaries yet?

Yes, I've been speaking to someone for 5 or 6 weeks now.

Do you receive support from the Trust to help you with your role / any difficult or distressing calls?

The Trust have made it clear that they are there to help, advise and give guidance. There is fantastic back up from the Trust should I ever need it.

A big part of the training was understanding that clear boundaries are important and exist to safeguard both the volunteer and the caller.

What would you say to anyone who might be considering getting in touch or joining the TalkTogether service?

The great thing about this service is that you are paired with a volunteer who you have something in common with, who can empathise with what you want to talk about.

I thoroughly recommend it. As a concept, it's a wonderful model. It's safe, bespoke and dependable. Keeping it tight knit – just for the beneficiary community – ensures maximum confidentiality.

Who better to speak to than someone who absolutely understands the issues that we share and the experiences that we have lived?

Do you think you've benefitted through volunteering for the TalkTogether service?

Absolutely. I look forward to the calls. It's a regular and manageable commitment that fits into my life.

It's something that I need to prioritise for and it's making a difference to someone else's life.

A Tribute to Heather Clark

The last edition of the NAC newsletter featured an article by beneficiary Heather Clarke about her battle with ovarian cancer.

Sadly, Heather lost that battle on 2nd June 2018.

Her close friend Debbie shared the following tribute to Heather.



It is with a heavy heart that I update this blog to let you know that our lovely friend Heather Clark passed away just before midnight on Saturday 2nd June 2018. In the end her death was peaceful and she was surrounded by her close friends and her beloved horse Barney in the field outside her window.

For those of us lucky enough to know Heather – she was a wonderful and truly inspirational woman. Born with no limbs after her mother took the anti-morning sickness drug Thalidomide she always managed to live her life to the full working as a TV reporter and producer for ITV Calendar for over twenty five years.

She was also a champion carriage driver competing at national and international level and never one to shy away from a challenge she took to the skies and completed a twelve and half thousand parachute jump.

Heather was diagnosed with Ovarian cancer eighteen months ago and during that time has campaigned for the charity Ovacome to raise awareness of the symptoms. She recently appeared on our television screens in Yorkshire to talk about her illness and at the time of her death she was busy organising a charity ball, tickets sold out within days and it will take place in September.

Just seven weeks ago Heather was given the Special Recognition Award at the Yorkshire Choice Awards for which she received a standing ovation. Her belief was that nothing was impossible in life and she lived by that philosophy. She will be sadly missed by all her family, friends and colleagues at Calendar.

Heather's funeral was on Monday 25th June at the 11.30 am at The Pavilions in Harrogate. It was followed by a private committal service for close family and friends at 12.20. There was a funeral buffet for all at the Pavilions afterwards.

Donations in Heather's memory can be still be made to Yorkshire Cancer Research, Ovacome and St Gemma's Hospice.

Heather worked hard to raise £5,000 on her JustGiving page – this target was achieved (*editor's note – stands at £5,612.82 at the time of writing*) but the page is still open for anyone wishing to donate.

<https://www.justgiving.com/fundraising/HeathersOvacomeAppeal>

Heather will be sadly missed by everyone who knew her but she will always be fondly remembered.

Several beneficiaries attended Heather's Fundraising Ball in Leeds on 28th September 2018.

Heather arranged the event with support from her friends but she always knew she'd not be there. Everyone believed that with Heather's determination, demonstrated throughout her life, she would have achieved that one last goal. The ball raised £21,959.32.

Life won't be the same without her.

NAC engagement with the beneficiary community

Simone Illger

In 2016, the Thalidomide Trust created its first 'vision' for the charity. You can find the Strategic Plan in its entirety here:

<https://www.thalidomidetrust.org/wp-content/uploads/2017/12/SUMMARY-Strategic-Plan-2017-22.pdf>

The Plan is made up of five strategic goals:

- GOAL 1 To ensure a beneficiary-centred approach in all Trust activities - with an emphasis on equity, empowerment and support.
- GOAL 2 To ensure sustainability and security of income for the Trust and manage financial risk - in order to effectively meet the needs of existing and new beneficiaries for the whole of their lives.
- GOAL 3 To apply the Trust's resources effectively and equitably.
- GOAL 4 To ensure that all beneficiaries have access to the best possible information, advice, services and support – both within and outside the Trust – as they age.
- GOAL 5 To inform and educate those decision-makers and service providers who have an impact on the quality of life of beneficiaries.

These goals were developed jointly by the trustees, NAC and staff team working in partnership. Over the last 24 months, a key priority has been to translate these agreed goals into a clear five year Strategic Plan which sets out how the trustees, staff and NAC will work together to focus our energy and resources and help make our vision a reality for the beneficiaries of the Trust.

As part of the work to ensure that Goal 1 is achieved, one of the linked Milestones specifies:

Beneficiaries are able to engage easily with all aspects of the NAC and its work.

The NAC have started work on ensuring that this will be achieved.

- Beneficiaries see the agenda and are given the opportunity to feed into discussions in advance of every NAC meeting.
- Have a standing agenda for NAC meetings. Ensure some narrative is included with agenda headings to clarify subject matter for beneficiaries for distribution of agenda to beneficiaries prior to meetings.
- Have a standing statement on the agenda template stating that if any beneficiary wishes to raise a topic at NAC meeting, they contact an NAC committee member to discuss the topic and the most appropriate means of raising it during the meeting.
- include NAC agendas and how beneficiaries can contribute to the agenda in the NAC newsletter

It is also planned that the NAC will provide feedback to all beneficiaries within four weeks of each NAC meeting and provide some sort of mechanism for an interactive discussion involving at least two NAC representatives. It is looking increasingly as though this will be an on-line / video discussion and plans are underway for this to be trialled in the coming months.

As you can imagine, this is quite a process to get up and running – but it is hoped that it will be effective in enabling beneficiaries to engage easily with the NAC and its work.

We will keep you up-dated with progress.

Welcome, Susan Brennan

Medical Adviser

Susan joined on 5 April, as a Medical Adviser, alongside Dee Morrison.

Tell us about yourself - family, previous employment

I've been a GP since 2012, trained as a GP at King's College Hospital, London. I live in South East London, with my partner and 2 resident moggies. I've worked in a variety of roles as a sessional NHS GP in and around London and the South, as well as for a private weight loss clinic in Cambridge. I'm interested in lifestyle medicine too – how healthy diet, good quality sleep, low stress, and staying active, can have a real impact on people's health.



What is your role in the Trust?

My role is as a Medical Adviser for the Trust, helping to support beneficiaries with medical issues, helping to build a clinical network of specialists to work with the Trust and also to produce medical information for beneficiaries and health care professionals alike.

What attracted you to the position?

As much as I love being an NHS GP, it is so time pressured. Often you feel you don't get the time to spend with patients to really get to the bottom of concerns- 10 minutes per patient is simply not enough, whereas in my role for the Trust I have the time to both listen and help where I can.

First impressions about the work and your role?

It has been a great first few months- getting to know the organisation, the staff and beginning to get to know the beneficiaries too. There is a lot to learn and I'm really enjoying the role.

What kind of things have you been doing in the first months of work?

I have completed a thorough induction with the Trust when I started. The first couple of months were very much getting to know how everything worked and getting to know the people and how the different elements of the Trust work together.

Very soon after starting I began assisting beneficiaries with medical issues, trying to identify new specialists to work with and producing some factsheets that will be on the website soon.

Can you provide some examples of the sort of things you have managed to achieve (within the confines of confidentiality) to support some of our beneficiaries?

I have provided advice and support for a variety of medical issues such as pain, weight loss, arthritis and diabetes management to mention but a few. I have been able to advise on appropriate consultants to be referred to when someone has needed secondary care to help ensure beneficiaries see the best person for their condition.

I have written medical support letters to help with PIP and ESA and I've contacted beneficiary GPs when someone has had a particular medical issue, to help facilitate the appointment and to ensure the beneficiary gets the most appropriate and best outcome.

How does your work at the Trust differ from your role as a GP?

The biggest difference is with the Trust you have the time to really be able to talk to beneficiaries, research problems and the time to help to find solutions. It's a great organisation full of people that really want to help and make a difference.

Welcome, Sally Sheehy

Health and Wellbeing coordinator

Sally joined on 13 June as Health & Wellbeing coordinator, for health and social care.

Tell us about yourself - family, previous employment

Hello, my name is Sally Sheehy (an Irish surname that came from my husband's father). I have 3 children who vary in ages 14, 26, 29, so I'm rediscovering the "joys" of teenagers again!



I trained as a general nurse in both Lancashire and North London where I moved to when I married in 1986. I have worked predominantly as a community nurse but also did a short spell in an ear, nose and throat ward, worked (frustratingly) as a patient capacity manager managing timed discharges from hospital, was a staff nurse on a geriatric rehabilitation unit and completed 18 months in a busy A & E department. I worked in adult social care for 12 years, assessing and care planning with working age adults and then older persons aged over 65. The last 3 years with the local authority, I worked for a team to identify people's entitlement to free NHS funding through the Continuing Health Care system. (Both contentious and frustrating)!

What is your role in the Trust?

My role will hopefully benefit those who may need support to navigate the systems of the NHS and social care. I am passionate about promoting at whatever level someone can achieve.

What attracted you to the position?

I became a little frustrated at the fragmentation between health and social care when supporting people, especially when they had been discharged from hospital. It is often one type of care, one patient but two systems. I decided to find out about "the other side" (social care) to utilise my experience and skills in an attempt to reduce the inconsistencies and poor journeys that I felt were happening to those during times when they were at their most needy due to poor health.

I have always tried to make a difference to support and help those who may be unable or not know how to navigate the often complicated, difficult and frustrating systems of health and social care. I felt a need for a change in my work and began searching for an alternative way to use my experience and promote knowledge. I focused on health and wellbeing as a search engine and was excited to find the position within the trust!

First impressions about the work and your role?

Since I joined the Trust, I have found a refreshingly positive culture where everyone is determined and focused to do the best they can to maximise the potential of all the beneficiaries.

What kind of things have you been doing in the first months of work?

I have already carried out a number of Holistic Needs Assessments, attended a health and wellbeing event in London and have visited and supported several beneficiaries in times of crisis.

How does your work at the Trust differ from your role as a GP?

My role in the Trust has, in some situations, included the need for similar support that I provided in my past employment. Hopefully this has and will, benefit beneficiaries to enable them to move forward, to feel more confident and allow them to maximise their life quality and independence.

Welcome, Jane Darlington

Financial Director

Jane joined in July to take up the role of Finance Director.

Tell us about yourself - family, previous employment

I have worked in the charity sector for the past 14 years and prior to that I qualified with an international firm as a chartered accountant. I have worked in both London and Cambridge and I live about 10 miles outside Cambridge with my husband and our 10 chickens. Our two sons are in their early twenties and have homes of their own, one locally and one in London.



I enjoy cooking, gardening and have recently returned to dressmaking. I am on a mission to complete a handmade wardrobe, but progress is a little slow as there is a lot to learn.

What is your role in the Trust?

My four main areas of activity at the Trust are to lead on the Financial management, planning and reporting for the Trust; to provide support and leadership of the Finance Team; to contribute to the organisational management of the Trust as part of the management team; and to provide support to beneficiaries, primarily about financial matters.

What attracted you to the position?

The role at the Trust was of interest to me because I wanted to work for a charity that has close links to the beneficiaries it serves. Previously I had run a grant making charity that offered funds to a wide range of community and voluntary groups. In that role I had very little opportunity to interact with the beneficiaries, so the Trust is very different in this respect.

I liked the people I met through the interview process and was encouraged that beneficiaries took an active part in my recruitment.

Importantly to me, the Trust is small enough to allow everyone to know each other, financially stable and still evolving the support it offers.

First impressions about the work and your role?

I have enjoyed my first three months. There are a good variety of projects for me and I have been made to feel very welcome by all I have met. The systems and processes are strong, but there are areas where I feel I can make a valuable contribution.

What kind of things have you been doing in the first months of work?

My induction process has been rigorous and through this I have had the opportunity to meet and interact with a number of beneficiaries, trustees, and the staff team. I have attended a range of meetings – including my first Finance Committee meeting – and allowed the time to get up to speed with day to day operations, and to contribute to plans for the next 12 months.

Can you provide some examples of the sort of things you have managed to achieve to support some of our beneficiaries?

I have been involved in ongoing activities, such as the processing of payments and the review of advance requests, as well as developing the budget for the next year and contributing to new factsheets and policy documents. I am working with the Finance Committee on how the Trust manages the cash it holds, looking at our future office space needs, working with external consultants to review the IT security of the Trust, and am preparing for the forthcoming audit of the 2018 financial statements.

Trust Website

Your Stories

Why not visit the Trust website and see all the fantastic information available there which is always being up-dated and added to?

[Your Stories](#) provide lots of personal accounts from the Thalidomide Community about their lives. Might you be prepared to share your story about something which has made a difference to your life and might help other beneficiaries?

It might be a piece of equipment, a house adaptation, a new kitchen... whatever it is, we are keen to know about it! Please contact the Trust at hello@thalidomidetrust.org or the newsletter editor Karl Davies at DaviesKB@aol.com

Here are a few examples of what our beneficiaries are sharing with the community:

[David](#) explains how his dental implant surgery has changed his life.

[Ramesh](#) talks through swimming exercises that he developed for a workout while supported in water.

Ramesh Lad is a Trust beneficiary who regularly shares the exercises he has developed to help keep himself fit.

In this video he explains how he has adapted standard flotation equipment to help posture and to provide resistance while exercising in a pool. This helps to isolate muscle groups that are not used regularly, especially for a wheelchair user. His workout then targets different areas of his body helping to maintain his fitness while being supported in the water.

Take a look at his video to see these amazing techniques.

<https://www.thalidomidetrust.org/swimming-workout-techniques/>

Prosthetic Legs – [Glenn's](#) Story. Getting new legs wasn't without trials for Glenn but they have totally transformed his life.

App Corner

Contact the newsletter editor to share any Apps that you find invaluable.

Found an App which has made a huge difference to your life? The Trust "Apps Corner" shares useful apps which can be downloaded to your phone, and could make a real difference!

It's Accessible

<https://www.iaccessibility.com/apps/mobility/index.cgi/product?ID=176>

"It's Accessible" is a community-based parking app. Users of the app recommend parking locations and share their accessibility with other users.



FuelService

<https://fuelservice.org/en/>



Simple, Easy Refuelling for Disabled Drivers. Helping disabled drivers find and get assistance refuelling their cars. Use the app to ask a petrol station for assistance with putting petrol in your car then notify them via the app when you have arrived.

Calm

<https://www.calm.com/breathe?from=/>



Explore Mindfulness techniques and helps to break bad habits. Uses meditation for sleep and stress reduction. Calm is the perfect meditation app for beginners, but also includes hundreds of programs for intermediate and advanced meditators and gurus.

Voucher Cloud



<https://www.vouchercloud.com/>

Voucher Cloud gathers vouchers for all sorts of shopping in one place to help you save money on every day spending.

And useful websites:

<https://bluebadgeparking.com/view/55.814168%2C-4.345149%2C55.905498%2C-4.174861/sat>

Find the location and details of Blue Badge parking spaces anywhere in the World – including Blue Badge parking bays with details on access and time restrictions.

Prosthetics Survey

Mitch Lambert

You may well be approached by the Trust in the coming months to take part in a survey around use of prosthetics.



Why the survey is happening?

We don't know for sure exactly which beneficiaries use prosthetics, or which type they use because the information the Trust holds is out of date.

From the contact we have had with beneficiaries who use prosthetics – including arms, legs and ears - we know that a lot of people have problems getting good quality services and equipment.

We would like to be able to do more to help and to do this properly, we need to collect more up to date information.

What it aims to achieve?



To improve our understanding of prosthetic use amongst beneficiaries to help us provide better advice and support to improve the experience of using prosthetic services. Also, to collect and share good practice, tips and advice between beneficiaries who use prosthetics.

An idea of how those beneficiaries using prosthetics will be involved.

After we have looked at the results of the survey we plan to run a couple of focus groups with beneficiaries who use prosthetics to explore the issues in more detail. If anyone is interested in being involved – please contact mitch.lambert@thalidomidetrust.org

Northern Ireland Local Event

Katie Sagoe

The Thalidomide Trust's local event for Belfast was held at the Clandeboye on 4 July 2018 from 10.30am until 3.30pm.

The informal day gave those attending a chance to meet staff members and other beneficiaries and find out more about the topics beneficiaries have told the Trust are important to them.

With talks from Trust Director Deborah Jack and the NAC (Carolyn DesForges and Craig Millward) attendees also had the opportunity for a short private 1:1 session with a staff member, NAC representative or external expert (Physiotherapist, Solicitor) as well as a chance for a complimentary massage therapy session.



The agenda for the day left plenty of time for people to socialise and catch up with their colleagues.

Sara Bunting who attended the event provided the following overview of the event:

“July 4th 2018 saw one of the first Northern Ireland Local Event by the Thalidomide Trust, under Deborah Jack’s watch. It was a great opportunity to catch up with fellow local Thalidomiders and meet Trust staff, in the relaxed surroundings and professional care of the Clandeboye Lodge Hotel.

Representing the Trust were Katy Sagoe (Director of Health and Wellbeing) and Director Deborah Jack. Deborah talked about the challenges surrounding the first few years in post and the Trust’s projection into the future. Carolyn Desforges and Craig Millward both spoke of their role in the NAC, of possible future events and on the continuing German campaign. A number of visitors were also in attendance, John Martin Director of Arches Physiotherapy Belfast was available for consultation. In addition, a number of delegates took the opportunity of a massage from John Quigg Physiotherapist also from Arches Physiotherapy, and by all accounts all emerged feeling rejuvenated – both are recommended! Thompsons Solicitor Laura Henderson, was on hand to discuss with individuals the private - and rather depressing - pertinent subject of Wills and Power of Attorney.

Whilst some of us from Northern Ireland have travelled across the pond to attend Thalidomide meetings, a regional meeting meant little, or no travel stress, was less tiring and resulted in a higher percentage of delegates - an attendance rate of 63%.

These local events will assume importance in years to come. A fun, relaxing informative day.

Thank you!”

Local Support

Simone Illger

Find local support with pain, exercise and more.....

More and more beneficiaries are asking the Trust about finding a suitable professional to help them with exercise or pain control. Finding a physiotherapist, personal trainer, Pilates instructor, sports masseur - with experience or knowledge of treating “the thalidomide body” is much easier if you know of one who is used regularly and recommended by someone who has found someone!

A database of individuals who have or who are treating other beneficiaries was compiled following the first Fit for the Future:

<http://www.thalidomidetrust.org/wp-content/uploads/2016/10/Professionals-List-Word-Apr-16.pdf>

And can be viewed on the website or sent to you by the Trust’s Health and Wellbeing Team.

Alternatively, go to the bottom of the Thalidomide Trust’s website Home page: <https://www.thalidomidetrust.org/> where there is an interactive map to enable you to locate a service or provider in your area.

Similarly, if you have found someone who has made a difference to your health, your wellbeing and your pain control, please forward details to the Trust so that we can continue to populate the map with this crucial information.



Contact Us

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

The next edition will be published in the spring of 2019. If you have any feedback from this newsletter or would like to contribute to the next edition, please contact the newsletter editor, Karl Davies. DaviesKB@aol.com

Tel: 07790 492 967

If you need assistance to get your thoughts for an article into writing, then help can be provided!

Mission Statement

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

Our aim is to give the beneficiaries the resources to meet their increasing financial, health and other needs.

Its work is underpinned by a belief in justice, dignity and equality."