

NATIONAL ADVISORY COUNCIL
TO
The Thalidomide Trust

Newsletter Spring 2020

Welcome to the NAC’s Newsletter for Spring 2020. I’ve taken on the task of editing this edition of the NAC Newsletter. Simone has been sourcing items for the past 5 years for 10 newsletters and Karl has been editor for just as long. They are both, now, having a well-deserved rest. On behalf of us all, I would like to thank both Simone and Karl for their hard work over the years.

This is an unusual time as everyone in the country (and around the world) struggles to cope with Covid-19. For the next edition, it would be good to report back stories of how you have coped and are coping. I hope you enjoy this Newsletter. Any feedback and indeed any offers of contributions for the next Newsletter would be greatly appreciated, please email editor@ttnac.org.

In the meantime, stay safe.



Rowland Bareham

Editor for Spring 2020 Newsletter

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Chair's update

Geoff Adams-Spink



Welcome to the latest NAC newsletter.

These are probably the strangest times that many of us will ever experience. In years to come our children and grandchildren will ask us how we coped, how people behaved, how on earth the world got itself into this situation and how it survived.

It would be great to speak from that perspective - of a time already past. Unfortunately, as I write this, we are into the fourth week of lockdown: we are either at or just approaching the peak of Covid-19 infections. All over the world, behaviour in almost every sphere has been radically changed.

I'm really pleased that our Trust had the foresight to prepare for a lockdown scenario. The work of supporting beneficiaries has been able to continue and none of our staff members have contracted Covid-19 up to now. Our annual allocations were all paid on time and our Health Grants will also be released on schedule. Life goes on, but not as we once knew it.

The NAC is also part of this new online world where meetings have to take place virtually. That said, we were very used to having conference calls every month to discuss business. For us, Zoom has probably improved what used to be an old-fashioned telephone conference. We couldn't see the expression on anybody's face, we couldn't tell whether they were paying attention - now we can. We will be going a step further though by holding our May NAC meeting via Zoom. This will be a lot more challenging: more people in the room, more discipline required so that we don't all talk at once, more papers to read and digest and have relevant questions ready for.

I read in the [Guardian](#) only today that some disabled people are no strangers to lockdown: depending on the level of impairment, many disabled people are not able to access what others take for granted. A virtual trip to an art gallery or watching a National Theatre performance on YouTube are the preferred option for some. We can perhaps teach our non-disabled peers some of the best survival strategies. Disabled people are incredibly resilient and think creatively - these are qualities that are needed in spades right now.

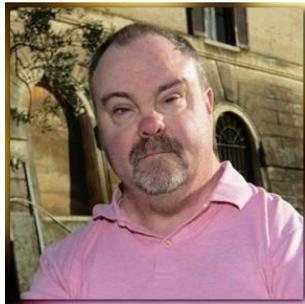
I won't repeat what others have already written about the Trust's finances. Suffice it to say that we are in a very privileged position thanks to the covenant with Diageo. Unlike many millions of people all over the world, we are fortunate in that we enjoy a stable, gently rising, tax-free income.

I hope that everyone reading this is coping in the best way that they can, staying sane, healthy and enjoying some of the simple pleasures of life: birdsong, a morning lie in, freshly baked bread and a walk with the dog. These are some of the things that give my day direction and purpose and for which I am extremely grateful.

By the time I write the next Chairman's Update, I hope the world will have returned to some semblance of normality, or a new and improved normality. [Return to Table of Contents](#)

How I'm coping with lockdown (1)

Craig Millward



Who would have imagined, at the start of the year, that within just a few months much of the world would be in lockdown?

Incredible. I had a full diary from March until May, but, within a week, everything was cancelled. As it became clear that things were not going to return to 'normal' for some time, I realised I had a choice - either to resent the missed opportunities or to view my empty diary as an opportunity.

I decided early on that the key to survival was to take control of each day. To view lockdown as a gift rather than a curse and set myself some goals. I have a pile of books I'd been recommended but not yet read, so I began by making a commitment to myself that at least two hours a day would be spent reading. I've done pretty well so far and have five books of different styles on the go. Two are intellectually challenging - one on neuroscience and the other a study in social psychology, a fascinating collection of essays by Emmanuel Carrere, a novel my daughter gave me for my birthday and a book of cartoons. I have no excuses - I have a book for every mood!

Before Coronavirus I'd barely have time to read the News Statesman and The Week news magazine each week. It is now such a luxury to surround myself with a range of books, read a chapter of whichever one shouts to be read and then sit for a few minutes thinking about what I've just read. I have a notebook next to my chair and find myself connecting ideas and storing them for later. I used to enjoy writing to sort my thoughts, and I've rediscovered that pleasure.

Humour is also becoming a lifeline. I currently live alone and I miss the banter. So, I've downloaded some comedy boxsets and am unearthing some gems I missed when life was so busy. I'm discovering Gavin & Stacey for the first time and have found that an episode of standup comedy is great before bed. And then there's the extended series I missed - The Wire, Westworld & Babylon Berlin - that I'm looking forward to immersing myself in over the coming weeks.

Maybe the most important thing I've learned is to cultivate an attitude of gratitude. At our age there are so many regrets or thoughts of missed opportunities just waiting to intrude into our thoughts. I just realised last night that I have not spoken to anyone apart from Alexa for the past 5 days, and a wave of loneliness began to sweep over me. After a few minutes I saw what was happening and realised that I was faced with a choice. I was on my own, so only I could fill my mind with something else. I began to think of things to be thankful for and the gloom gradually lifted.

This season is a challenge, but it will pass. I hope it doesn't last too long and that it will be a season of growth rather than stagnation - and I'll get to listen to the whole Classic FM Hall of Fame without interruption!

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How I'm coping with lockdown (2)

Rowland Bareham

As I'm putting together this NAC Newsletter for the first time, in place of Simone and Karl, we are just into the second three-week period of lockdown. This has and continues to be an unusual time, a time of adjustment and enforced change.

Firstly, I've been working from home instead of going into the office (I work for a Government Department). For me, fortunately, the change has been relatively easy as I already had a work mobile phone and a work laptop - this coupled with changes such as hotdesking in the office meaning that I had no papers, no filing cabinets and nothing to tie me physically to anything in the office. If anything, I've been working harder with more video meetings so there hasn't been any time spent on collecting people from reception for meetings, time spent in moving from one meeting room to another, and so on. So, for me, working from home has been easy. The main changes are in the social interactions with colleagues - but even then, my team has been having daily meetings by video for a five-minute catch-up for this kind of interaction.



Rather, for me, it has been the little things - like not being able to go into Waterstone's bookshop in Trafalgar Square or the more specialised bookshop like Church House Bookshop in Great Smith Street (both near the office). I miss the flicking through the pages of new novels and theological books alike. I miss other shops too like the clothes shops (no more looking in Marks & Spencer for the summer tank tops!) and the department stores for birthday gifts and cards. The lockdown has changed so much.

I'm going to tell you a secret now - I like Duran Duran from the eighties! It was with sadness that I learnt that their new album will be put back and no signs of a tour date for this album which would have been announced by now. You see, John Taylor (the bass player) has been ill with the Coronavirus and in any case the recording studios have been closed so new songs can't be recorded. You can be sure that, ordinarily, I would have had tickets on order for their tour by now. The lockdown has changed so much.

Another change for me is that I'm not grabbing sandwiches and fast food for lunch and for tea on the way home from work as I often do for timesaving and for convenience. Rather, I am now cooking more healthily at home and at much less cost. Another thing also that I've been doing less is the mileage in my car - I have barely done 20 miles in the last three weeks. My electricity bill will be much less, especially as the little charging I've done for my electric vehicle will cost me nothing, from the solar panels I have on my roof, because the car will be parked at home during the sunny days rather than being parked at the office. The lockdown has changed so much.

Lastly but not least, I am a lay minister at my local church. This has been a complete challenge in keeping in touch with my church friends despite the church doors being locked. Again, technology has come to the rescue with telephone and video conferencing as substitutes for the Sunday services. However, there is going to be a knock-on effect on churches' financial reserves when churches eventually reopen having had few collections

during the lockdown. Throughout all this, I've hinted at costs - many costs being less (fewer books, concert tickets, clothes and transport) and for some costs being more. I'd be interested in hearing from you your stories of how the lockdown has affected you, financially and otherwise.

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William Wordsworth predicted Covid-19!

Graham Kelly



Amazingly, it turns out that William Wordsworth predicted Covid19, in one of his lesser-known poems (updated by Graham).

I wandered lonely avoiding crowds
That flock in parks and shopping malls,
When all at once I heard aloud,
A host of sneezing nostrils;
Beside the supermarket doors,
Coughing and sweating in the breeze.

Continuous as the stars that shine
And spurting in the hanky's way,
They stretched in a never-ending line,
Trolleys spaced 2 metres away;
Ten thousand saw I at a glance,
Would they find loo roll perchance?

Small kids beside them danced, but they
Danced more as they grabbed eggs in glee;
A poet could not but be gay,
In such bored witless company;
I gazed and gazed at my mobile phone
And found a delivery slot for home.

For oft, when on my couch I lie
In mindless channel surfing mood,
More Kirsty Alsop than Steven Fry,
Embarrassed to tell what I have viewed,
Escape to the country - today in Bude!

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Covid-19 poem

Sue Kent



I'm in the house wondering what to do
I consider my options as I look at the loo
The virus Covid-19
Means there is no toilet roll to be seen
I can't go to work or see my friends
Or go to the pub for a drink at weekends

I trawl the shops and live in hope
The supermarkets will restock the soap
I've become a bit smelly
So I'll just watch the telly
The rain will stop soon
Spring flowers will bloom

This is all so extemporary
But everything is temporary
Don't hold hands hold your nerve
Together we can reshape the curve
It won't help to blame or to moan
Be grateful for the small things
Let love rule your home

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Viva Video

Geoff Adams-Spink

Having worked in BBC radio and television news for more than two decades, using audio and video to inform, educate and entertain people is pretty much in my blood. The thing that has changed in the last twenty years has been the democratisation of broadcasting. Now, all you need is a smartphone and some sort of internet connection and you can become the next YouTube sensation. Making audio podcasts is even easier: many can and do start on people's kitchen tables and gradually become more sophisticated as the newbie broadcasters get their wings.

Thanks to the foresight of one of my NAC colleagues, we started using video to give people access to our then annual conference. If you couldn't attend in person, you could watch a video of a particular session via the Trust's website.

The social media revolution made the creation, curation and dissemination of audio and video even easier: throw a custard pie in the Prime Minister's face in the middle of the afternoon and you will have gone viral by teatime. I hasten to add that I'm not condoning this light-hearted form of abuse directed at a man who is still, as I write, recovering from COVID-19.



How can we at the Trust best use video to the benefit of our community? For a couple of years now, Deborah and her fellow directors have been offering a video version of their regular update; very informative it is too. The NAC produces an annual video so that we can report back to members about the work we've been doing both individually and collectively (available when you log in to the Trust's [website](#)). There are also thoughts about having prospective candidates for the NAC produce a one-minute video manifesto as an alternative to the written page of A4.

Given that we have spent several decades solving problems, I think this is where video really comes into its own. The sharing of ideas, new technologies and existing life hacks means that we don't all have to sit at home reinventing the same wheel. My vice chair and colleague, Simone Illger recently made just such a [video](#) on her kitchen adaptations and one about her [exercise regime](#). In the past, I have made videos for the Trust on how I use my [CPAP equipment](#) (the breathing machine that you need to use if you have sleep apnoea) and about my [smart speakers](#). These now control everything from the house lighting, the blinds and curtains and my central heating.

Most recently, living with lockdown, I've been highly entertained by what people are getting up to and entertaining others in the bargain. For example, the wonderful [David Carter](#) strums his guitar and sings, his dog [Millie](#) always getting into the shot.

It would be great to hear from others about how they would like to use video going forward. What sort of content should we as a Trust be producing (home and vehicle adaptations for example) and what sort of videos do you want to share with us about the way you live your life?

It's an exciting time to be around because we can now share things with each other as never before. Please let us have your thoughts either by emailing feedback@ttnac.org or by using the Trust's forum.

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The Diageo Covenant - A Reassurance

Phil Williams - I've split this article into two sections - a brief bullet point take-away menu for everyone then a more detailed sit-down main course for those who are interested.

The Take-Away

- Your Annual Grant (AG) is safe and guaranteed
- It is NOT linked to stock market performance
- It goes up with inflation (by the Retail Prices Index - RPI).
- Diageo is a strong wealthy company

- The Trust and Diageo has a Covenant reviewed every six years
- This Covenant is a legally enforceable arrangement
- Diageo provide for the Trust's costs with no impact on your AG

The Sit-Down Main Course

Why does my annual grant only go up by 2% to 3% each year when I see investments averaging over 10% long-term growth on our investment portfolio?

NAC members, including myself, often get asked this question and similar. I'm quite fortunate that I trained as a chartered accountant with Price Waterhouse Coopers (formerly Coopers & Lybrand) specialising in international personal tax before running my own business as an Independent Financial Advisor. This background has been incredibly useful sitting on the finance subcommittee but, please understand, one does NOT need a professional background to join the NAC, as support and training is provided.

Myth Busting

Sadly, there are many myths, misunderstandings and misconceptions about how Diageo funds the Trust. There is also information circulating that may have been true years ago, but is now out of date as the Covenant - **the legally enforceable arrangement** - between the Trust and Diageo is reviewed every 6 years and amendments made.

These long-standing issues were recognised a while ago and the solution I suggested was that at Future Money Matters 3 (FMM3) in Manchester this autumn, we run a session on the Covenant explaining, in detail, how it works and then take questions from beneficiaries. This session would be filmed and available on the Trust website for everyone.

You'll be aware that this event along with so many others will be rescheduled but please do keep any eye out for FMM3 and book your place as soon as the new details are announced. Almost every attendee has benefitted financially, either directly or indirectly, using something they have learnt at previous events.

Given the delay and the current economic uncertainty, in the interim, the NAC finance team wanted to offer some reassurance to you. I won't use many numbers here as credit ratings, share prices etc. are constantly changing so I don't want to provide inaccurate information. This will be a big picture explanation.

Our Annual Grant (AG) is NOT linked to investment performance

It won't have escaped your notice that share prices have fallen massively this year, as a result of the Coronavirus pandemic. Compared with a +10% long-term growth rate, it is now down 25% this year. But your grant is NOT affected. **The payments due to beneficiaries are 100% guaranteed.** They increase in line each year in line with inflation. There are several measures of inflation, but the Covenant still uses 'Retail Prices Index' (RPI), which is one of the better ways of measuring inflation for us as it's traditionally the highest index!

After negotiations with Diageo, a schedule was put in place with Diageo to double everyone's AG over period of years to 2022 - a Long Range Plan (LRP).

You may recall that we all worked together over a 2-year period to create the 'Securing Our Future' Report for the Department of Health to support the Health Grant pilot scheme being renewed and made permanent. We then took that same Report to Diageo immediately, rather than waiting until the next 6 yearly review. As a result, **of seeing this hard evidence**, we secured a one-off lump sum payment and the acceleration of the LRP 2022, so every beneficiary saw a large jump in their AG.

Your NAC is always looking to increase money for beneficiaries from all sources to meet our increasing needs and **evidence-based requests are the best way forward**. Please rest assured this is very much ongoing work in progress; more in due course.

So, the annual payments to beneficiaries are fixed and guaranteed.

The Trust has a large amount of money under investment. Or so it seems... some of this money is still owed to beneficiaries who have not drawn down their available balances for various reasons. ALL of the balance is earmarked to pay all of us the guaranteed payments referred to above.

Diageo make an annual payment to the Trust every year. This payment is less than the total distribution the Trust makes or is due to make every 6th April. The shortfall is made up from the investments.

As a charity, given our liabilities and beneficiary age profile, one would ordinarily expect the Trust to have had a very conservative attitude to investment; predominantly cash, fixed interest and governments bonds (gilts). However, the investment approach has always been agreed with Diageo and is periodically amended. As a result, the Trust - almost uniquely - has been able to authorise our fund managers to invest in shares (equities) that over the medium to long term historically have outperformed fixed interest investments or bank deposits. The reason for this is that Diageo offer a guarantee or an 'underpin'.

Actuarial Reviews

Every 3 years actuaries review how much money the Trust is due to pay out to every beneficiary over our remaining lives. They look at how much money there is invested and the future annual payments due in from Diageo. This exercise involves lots of assumptions, not least about inflation, investment growth and how long we beneficiaries will live.

When there is a 'shortfall' of more than 10%, the Covenant requires Diageo to make 'top-up' payments. So, there will always be enough money in the fund to continue to make Annual Grant payments for as long as there are beneficiaries.

I trust this makes things slightly clearer until FMM3 when I and others, including possibly a finance trustee and/or our fantastic Finance Director, will go into more detail and take all questions on film.

Obviously, Diageo are very important to the Trust. They are a very strong company with a good credit rating and cash reserves. Your Finance Committee keeps a watching eye on their finances. I see no reason the Coronavirus pandemic will materially affect their business in the medium term.

Trust Running Costs

The final point, for now, is also important. **As part of the Covenant, Diageo underwrites a ring-fenced amount for the running of the Trust.**

These expenses are continually monitored, and decisions are carefully made. As long as we stay inside the limits agreed with Diageo, there is no expense by the Trust that negatively impacts on the annual grant of beneficiaries - that's simply impossible. However, the range of advocacy and other support activities, including research, has immeasurably improved beneficiaries' lives. In the past, much campaigning was funded out of campaigners' own pockets but in more recent years the Trust has supported some campaign expenses. You've all seen the increased benefits that have accrued.

As an aside, you might be interested and reassured to hear that over the last two years, I was involved in recruiting a new Finance Director for the Trust. As part of their preparation, they obviously review our accounts. I've heard so many candidates express astonishment or surprise at what a tight ship the Trust runs and what is achieved off so little overhead.

More Information?

If you can't wait for FMM3 or are unsure about anything above, please do not hesitate to contact me by email (phil@ttnac.org), text (07554 016303) or WhatsApp to agree a mutually convenient time to have a chat on the phone.



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Feedback Survey

Graham Kelly

You may remember completing the Trust/NAC Feedback Survey at the start of 2019. This was the second such survey (the first was in 2016) and it was done to find out what beneficiaries think about their dealings with the Trust, Trust services and activities, and their views on Trustees, staff and the NAC.

As in 2016 we sent a questionnaire to everyone and we had an excellent response with 67% of beneficiaries giving us their views - down just slightly from the 70% who responded in 2016. This is a very good response rate, compared with other surveys, and it means that we can be confident that the findings are representative of the opinions in our community.

Interestingly just over half of beneficiaries chose to complete the questionnaire online in 2019, reflecting a growing preference for online communication in our community.

If you would like more details about the research method and the survey results, then please get in touch with Danielle or Charlotte at the Trust Office and they will be able to give you these.



The main findings

The report below describes the proportions giving positive and negative opinions about various aspects. Please bear in mind that these figures will normally not add to 100% because some people gave neutral answers to some questions, or said “don’t know”, or simply gave no answer.

The Trust’s staff and Trustees

In 2016 we found that beneficiaries were generally satisfied with the Trust and its staff, and the same was true in 2019. In fact, the proportion of those “very satisfied” with their most recent contact with the Trust went up from 66% in 2016 to 73% in 2019. Only 5% said they were “very dissatisfied” or “fairly dissatisfied”, and that figure was down from 7% in 2016.

The great majority of beneficiaries responding to the survey had a positive view of Trust staff when asked if they were “friendly and approachable”, “caring”, “open and honest” and that they “treat everybody fairly” and “deal with financial requests efficiently”. However, a small group of beneficiaries reported dissatisfaction on these questions. On average about 4% (one in 25 survey respondents) said that they disagreed that Trust staff were “friendly and approachable”, “caring”, “open and honest” and that they “treat everybody fairly” and “deal with financial requests efficiently”.

About 80% agreed that they “trust the Trustees”, and this figure was the same in 2016.

83% agreed that “If I need help the Trust would do everything it can to help me”, and this was an increase from 78% in 2016.

Trust services, events and support

At least 80% of beneficiaries were aware of each service/event provided by the Trust, and in several cases, awareness was over 90%. Only 6% of those responding to the survey had not used or attended a Trust service/event in the last three years.

Awareness of Trust advice on benefits had increased significantly between 2016 and 2019, presumably due to many beneficiaries having to go through a PIP assessment.

For each Trust service or event, we asked if people had used it, and if they answered “Yes” we asked them to tell us how satisfied they were with it. Satisfaction levels were generally high, and particularly high for Fit for the Future, Talk Together, Health Professionals telephone support and the St Neots Open Day.

Opinions were more mixed for questions about the Trust website. Only two thirds (67%) said that they were satisfied that they knew how to access their financial information on the website, and only half (50%) said it was easy to find what they were looking for. One of the reasons for these disappointingly low figures was that around one quarter of survey respondents replied “don’t know” or left the answer blank on each of the questions about the website. This might indicate that around one quarter of beneficiaries do not access the Trust website, or at least do not do so regularly and as a consequence, they are not familiar with it.

Trust activities

The 2019 survey found a big increase in support for the idea of the Trust providing health professional support over the telephone - 91% agreed that this should be provided, up from 79% in 2016.

There was also strong and growing support for the Trust to develop a network of specialist clinicians - 90% in favour in 2019 compared with 75% three years earlier. Note that the 2016 questionnaire asked about this in a slightly different way, referring to “centres of medical excellence” and this was changed in 2019 to refer to a “network of clinical specialists”. This may partly explain the increase in support.

Support for the Trust continuing research into beneficiary health needs remains steady - 82% agreeing with this in 2019, compared with 83% in 2016.

Support remains strong for the Trust’s campaigning activities. Only 4% of beneficiaries disagree that Trust money should be spent on campaigning. Support for the German government campaign is particularly strong, with 90% agreeing with Trust involvement in this campaign (from 89% in 2016) and only 3% disagreeing.

Three quarters (77%) of beneficiaries agreed that the Trust should continue to hold a range of beneficiary events. Opinion was less strong on whether the Trust should continue to provide AA group breakdown cover (54%) and group car insurance (49%). (Note that these questions were not asked in 2016).

NAC

Just over 8 in 10 agreed that the NAC “is a good way of ensuring that beneficiary views are heard”, with 81% agreeing in 2019, down slightly from 84% in 2016. Around two thirds of beneficiaries agree that “I feel I can trust the NAC”, with a figure of 66% agreeing in 2019, down from 75% in 2016. This drop was mainly due to a slightly higher proportion answering “don’t know”, but also due to an increase in the proportion who disagreed - 9%, up from 6% in 2016.

In 2019 we included an extra question suggested by a beneficiary, asking whether people agree or disagree that “it’s difficult to raise an issue if you have a minority view in the beneficiary community”. Two thirds of people were non-committal (“don’t know” 35%, or “neither agree nor disagree” 29%, or no answer at all 3%) presumably because they had not tried to do so and perhaps not thought about it. About one in five (22%) people agreed with this suggestion and one in nine (11%) disagreed.

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Together but Not Together

Geoff Adams-Spink

Being the Chairman of both the NAC and the Thalidomide Society brings with it, not power, but great

responsibility. One of the things I really wanted to do while holding both of these roles was to draw the two organisations into a sort of 'ever closer union' given that we have common interests, though distinct and separate cultures.

What better way than to organise the first ever event hosted by both organisations? It was to have been a spectacular coming together: brilliant speakers, giant games including Kerplunk and Scalextric, seventies snacks, and the unfailingly funny [Laurence Clark](#) to entertain us after dinner.

We spent months planning, batting ideas backwards and forwards, getting the buy-in from the respective organisations. Our Society secretary, Ruth Blue, put her shoulder to the wheel to make sure that everyone got the room that they wanted. The hotel acquiesced to our myriad demands.

Of course, I don't need to tell you what went wrong - we are living with what went wrong on a daily basis. In fact, cancelling what was to have been an important and exciting event is probably the least of most people's worries.

However, I want to reassure everyone who was looking forward to meeting their extended thalidomide family that all of this meticulous planning has not gone to waste: we will be back! We will be stronger and even better organised than before. There will be Angel Delight, giant games, important discussions, the raffle and the raucous laughter.

From this distance - I'm writing this in mid-April - our best guess is that the phoenix version of the joint event will happen roughly 12 months hence. There is an awful lot of uncertainty involved, but if we are clear of the virus and people feel confident to travel, there's no reason why we can't meet again (in the words of Vera Lynn) some sunny day next April.

Until then, stay safe and well. Be kind to each other. Don't take any unnecessary risks. See you all this time next year!

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A Life-Changing Decision & Using the Health Grant

Phil Williams

In addition to my upper limb impairment, I was born profoundly deaf with both of my ears affected and my right ear missing.

When I was 3 years old, I spent around 9 months in hospital having reconstructive and plastic surgery to move my inner ear and rebuild it, though I have no outer ear. I have subsequently resisted advice to have an artificial one or surgery to construct one.



Part of the original operation as a toddler was a skin graft where a patch was taken from my bottom, so I always have a little smile to myself when anyone kisses my right cheek! I still have a little white square on my bottom, but I'll spare you a photo of that!

The outcome was that I had about 55% hearing in my right ear and 45% in my left, so this was marvellous. Through a combination of coping strategies, including lip reading and trying to always have everyone on my right - so sitting myself at the end of a table - I've always managed.

A few years ago, I had to accept I was really struggling, particularly where there was a lot of background noise, like a pub/restaurant, or in larger boardrooms when at NAC/Trust or other meetings. It was adversely impacting on my social and professional life.

I'm bad with health issues and tend to wait until something is critical before I seek help. A typical man, in other words. My wife and I like watching shows that are dialogue based rather than 'Bish-Bosh' but increasingly I needed the TV volume quite high - so high that my daughters used to come downstairs saying they couldn't sleep. I bought a brilliant set of wireless headphones that allowed the wearer to set the volume to suit you, whilst anyone else in the room set the TV volume to suit them! A brilliant short-term solution. In addition, other family members would wear them with TV on mute. But we soon realised that, obviously, wearing them is quite isolating.

I finally went to my GP for a hearing check and my hearing had definitely significantly worsened. Part of this was the normal ageing process but as I was starting from such a low base the impact was quite debilitating. I was referred to Exeter RD&E hearing clinic. It was so frustrating as each trip was around a 3 hour wait plus 45 min drive each way and the usual parking issues. The final advice was to have a Baha system on one ear. I was unhappy as I didn't want an operation. With my upper limb impairment, it would have been a real struggle screwing/unscrewing it for showers, swimming & sleeping. Then, they talked about a magnetic plate under the skin instead of a protruding screw thread. The NHS would only do the one ear so I suggested the other should be done at the same time, but I would pay for that. Apparently, this was impossible, and they wouldn't know how much to charge me! As an accountant, I found this rather startling as how on earth can they budget?

The final nail in the coffin was how big the unit was. I like to wear my hair short for sport etc. and have no ear lobe on one side then a tiny one the other. The unit on the side of my head would not be concealed by anything so I'd look like Frankenstein's Monster, truth be told. I said I'd pass and carry on coping.

I spoke to Mark Spofforth at the next trustees meeting who advised me of some options he was aware of and to go private! As a Welsh working-class boy, that was a slight anathema to me and I hadn't ever considered it. Doh.

I booked at a private clinic in Exeter - WOW! What an exemplary service. I arrived 5 minutes before my allotted time with ample parking and entered a smart reception to be offered a proper coffee; latte, thank you very much. I sat down and pulled out my iPad ready for a long wait. How naive was I, I was seen exactly on time.

The examination and testing process were excellent. I think the chap really enjoyed it as something quite different to his usual cases. He was imaginative, empathetic, and creative. I

had three visits there before he identified several solutions. I opted for an in-ear, digital, titanium aid in my left ear custom made and moulded with a longer wire on for me to access it independently.

The day I received the hearing aid was scary, and hilarious. I sat in the chair and he inserted it the first time then popped to reception. I was sitting on a swivel chair and thought.....what's that sound? I realised I could hear the seat squeaking then my feet rubbing on the carpet. Then I heard Sam talking to the receptionist outside! WTF. My hearing wasn't simply restored but instead it was actually was better than it had ever, ever, been in my entire life! Amazing. He offered to turn down the volume, but I preferred to have a maximum setting initially.

When I got in the car to drive away, I'm thinking what's that noise; is the car broken? I soon realised I was hearing the keys jangling, the indicators etc. for the first time. I was then hearing so many sounds that many of you may be fortunate to hear and simply tune or screen out. It took me many months to adjust!

My daughters aren't sure they like me being able to hear them plotting and planning and whispering! On my next train trip to London, I was trying to concentrate and work but about 3 rows away were two young ladies chatting excitedly about organising a hen weekend in Ibiza for £300 per person. It was entertaining, but incredibly distracting!

My home, social and professional life has improved immeasurably. For example, I went to Rome on an annual rugby trip with a regular group of twelve, watching Wales - we usually alternate Dublin/Paris - and on arrival at a restaurant went straight to the bathroom. When I got to the table, the boys had left a usual seat on the end with everyone else on my right but it was awesome I no longer needed that. I can hear (sometimes too) clearly in social situations and at meetings.

It wasn't cheap as all in all, including a contract for regular check-ups, wax clearing, free batteries etc. for 2 years, I paid £2,200. But it was money well spent; invaluable in fact.

Given my wife and two younger children I might not have taken this option but having access to the Health Grant made the decision incredibly easy.

I don't know if this story has any practical relevance to you but, if nothing else, hopefully it's made you smile.

However, if you are having any health issues whatsoever, please don't put things off or be as blinkered as I was about going to your GP or even private if the NHS can't meet your individual unique needs. I'm sure the staff at the office can signpost you to relevant and appropriate support whether it's hearing aids or any other adaptations or equipment or procedures.

If you are interested in my detail or information, please do not hesitate to contact me on 07554 016303 or phil@ttnac.org.

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Future Learning Online Courses

Simone Illger

Especially whilst we're all confined to barracks, why not check out some of the FREE Future Learn on-line courses?

I've done a few of these around health, healthy eating, the importance of exercise and a few on Dementia and Dementia care and would thoroughly recommend them.

The courses have been designed by top universities and specialist organisations, are often interactive and feature lots of visual learning aids (film). They are different lengths (usually a few hours for a few weeks) and you are able undertake learning at your own pace. There is also the opportunity to interact with your fellow learners.



The following courses are all free - and if you're not enjoying your learning experience or find you don't have enough time, you are able to leave the course at any point.

The Musculoskeletal System: The Science of Staying Active into Old Age

(3 weeks @ 3 hours)

<https://www.futurelearn.com/courses/musculoskeletal>

Food and Mood : Improving Mental Health Through Diet and Nutrition

(3 weeks @ 3 hours)

<https://www.futurelearn.com/courses/food-and-mood>

Food for Thought: The Relationship Between Food, Gut, and Brain

(5 weeks @ 4 hours)

<https://www.futurelearn.com/courses/food-for-thought>

Nutrition and Wellbeing

(4 weeks @ 3 hours)

<https://www.futurelearn.com/courses/nutrition-wellbeing>

The Role of Personal Assistants in Disability Support

(4 weeks @ 2 hours)

<https://www.futurelearn.com/courses/personal-assistants-disability-support>

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And finally

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.

Contact us

Here are the contact details of the NAC members if you would like to contact any one of them:

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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."

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