

# HEADLINE

## news

SUMMER 2021

SUPPORT & INFORMATION FOR THE ACOUSTIC NEUROMA COMMUNITY



INSIDE



**BANA AWARENESS DAY**

**SURGERY DURING A PANDEMIC**

**SUPPORT GROUP MEETINGS**



**BANA**

British Acoustic Neuroma Association

[www.bana-uk.com](http://www.bana-uk.com)

# About BANA

## BANA is established to:

- a) Assist and support people who have been diagnosed as having or who have been treated for Acoustic Neuroma (Vestibular Schwannoma), and other related conditions and others affected by such conditions.
- b) Promote and support research into medical, surgical and other procedures likely to lead to the prevention, early detection and successful treatment of such conditions and any such procedures assisting in the rehabilitation and quality of life of people affected by such conditions.



## Contact details

Tapton Park Innovation Centre, Brimington Road,  
Tapton, Chesterfield, S41 0TZ

**Tel:** 01246 550011 **Email:** [admin@bana-uk.com](mailto:admin@bana-uk.com)  
[www.bana-uk.com](http://www.bana-uk.com)

## The BANA team

**Julie Dixon** Chief Executive [julie@bana-uk.com](mailto:julie@bana-uk.com)

**Heather Trueman** Community Support Administrator [heather@bana-uk.com](mailto:heather@bana-uk.com)



# BANA

British Acoustic Neuroma Association

Registered Charity No:  
1165065

The 2021 Headline Magazine was created and set up with the help of GB Creative [www.gb-creative.co.uk](http://www.gb-creative.co.uk)

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*BANA does not endorse or recommend any commercial product, medical practitioner, management or treatment programme or medical institution.*

*The views expressed by contributors should not be taken to be those of BANA unless this is expressly stated.*

*Any advertisements are not endorsed by BANA.*

# A warm welcome

As I write this our national football team in England lifted everyone's spirits despite losing out to a superb Italian team on penalties. The double edged sword for me is as well as lifting our gloom the crowd numbers from lockdown have grown massively. We have seen crowds gather at similar events, Wimbledon and The British Grand Prix, which was massive with 140,000 spectators and I do wonder if this is helpful or right so soon after we were in total lockdown to try and stem the spread of Covid 19 and all before freedom day as it's dubbed 19th July!



You can rest assured that at BANA we are doing our best to stay safe and maintain the charity and the work we do and we hope you are all staying safe too.

In 2020/21 there have been some wonderful stories of support for BANA (some of those shown in this magazine) and I am pleased to say that we remain strong for the future. The stamina and determination of our eventers', is just incredible. Thank you! It is also with thanks to the efforts of Julie and Heather in the office (they were not there much in 2020 being furloughed or working from home much of the time) and all of our wonderful fundraisers and donors. Thank you all so much.

Wear Blue for BANA on July 1st was a great success and I saw lots of lovely photographs of you all on Facebook. We received some donations to recognise this special annual event too and events to raise money continued, which is fantastic. We are ever grateful.

With no government support for our charity, we rely heavily on the support of our friends, charitable trusts and individuals to support the revenue from membership, so if you value BANA and our information and services and what that provides for those with an Acoustic Neuroma and their families, perhaps if you can afford it, you might like to make a donation. You will be making such a difference and helping our work continue.



# A warm welcome

Finally, I send my personal best wishes to all involved with our charity, whether as a staff member, volunteer, AN patient or survivor, family member, friend or medical professional. Until next time, come on BANA people, look forward to your next celebration!

*Karen Frampton - BANA Chair*

## BANA – behind the scenes

As we gradually move forwards with a more familiar way of living our day to day lives, we at BANA hope we can begin to start up our face to face support groups again. Heather has already planned one for September that we are hopeful will go ahead. She is also planning for future group meetings and will be contacting Support Group Hosts to work together to ensure we are all happy with the direction we take. We know lots of members have enjoyed the virtual groups. There have been lots of positivity around them, with opportunities to meet others from different parts of the country and share experiences. We will continue to run the virtual groups alongside face to face groups. These create opportunities to have speakers reach out to more people with Acoustic Neuroma; with this in mind Ivan Munkley, CAB advisor has agreed to speak about benefits including PIP on Tuesday 14th September – so please look out for details.

Some of you are aware that the website forum has been out of action for a while. We are very sorry about this situation. We have taken a long-overdue decision to update the website. We are, therefore, working with a company that has lots of experience of working with small charities like BANA. The forum although not well used will be part of the new website and hopefully will be up and running within the next few weeks. So please pop across to the forum and see who you can connect with. We are sorry for any inconvenience caused to you.

We will also be re-vamping our Listening Ear programme (peer-to-peer support). Anyone who is on the registrar will be receiving an email from me soon. If anyone would like to join the Listening Ear registrar, please get in touch for further information.

# BANA – behind the scenes

I would also like to say a BIG thank you to Genette Bodsworth for the amount of support she is giving BANA with the graphics for our Awareness days and the help in pulling together the Headline News. Genette and Heather have worked closely together; I know how grateful Heather is for her support.

We will once again be running our yearly conference as a virtual conference. We took the decision to do this in early 2021 and will be sticking with this decision; the date for your diary is Saturday 16th October. So please keep a lookout for more information nearer to the date.

Lastly but certainly not least good luck to our London and Chester Marathon runners. All running on Sunday 3rd October. Sarah Rawlings in the actual London Marathon on behalf of member Valerie Ellwood, Ione and Phoebe Hansford (you can read about Ione's journey on page 23) and Ryan Turncross whose dad is a member are doing the virtual London Marathon. Andrew Reed is doing the Chester Marathon as part of his 12 in 12 (12 marathons in twelve months) along with champion fundraiser Mark Leadbeater and our fabulous Ambassador Sara Crosland – as ever thank you all. You are all winners for BANA! Enjoy the rest of summer.

*Julie Dixon - CEO*

## MAGAZINE CONTRIBUTIONS

Send your articles to [admin@bana-uk.com](mailto:admin@bana-uk.com). Please ensure images are high resolution, preferably 300dpi and supplied as JPEGs.

*Please note: Material sent for inclusion in Headline News may be subject to editing. Consideration will be given to all readers and conditions. BANA reserves the right not to print any item deemed inappropriate to the ethos of BANA. Headline News magazine aims to provide support and information for all members.*

# Managing single sided hearing loss

A BANA Member shares their experience



Losing your hearing in one ear is startling. I lost the hearing in my left ear completely and very fast – almost overnight. I had been warned this might happen, but I had assumed that if I could hear in the other ear it wouldn't make much difference. I was unprepared for the huge change that it made to my ability to process sound and particularly to understand conversation in lots of different conversations.

In one way I was really lucky – some years previously I'd done a foundation course in British Sign Language (BSL), just out of interest, so I had learnt something about deafness – including that there is a large deaf community in the UK who use BSL as their first language and who welcome and embrace their deafness as part of their identity and culture.

Knowing that gave me the confidence to tackle my single-sided deafness head on. The first thing I did was tell all my immediate close family, friends and colleagues.

# Managing single sided hearing loss

We worked out together what worked and what didn't. We found out that I could hear some people better than others and that it was easier to hear outside than in. I couldn't hear the questions in the pub quiz, but one of my friends sat on my 'good' side to repeat them to me. In a restaurant it was best to have a table next to a wall, with me sitting with my deaf ear to that.

Once so many of my colleagues knew, it was a small step to telling my employers formally. That made a huge difference and made life much easier in the workplace. I do a lot of training, and this was all moved to rooms where I find it much easier to hear. When I take part in an event where there is a lot of noise, people are happy to move into a quieter environment – which is actually easier on many people.

I'm now happy to say to anyone – whether I know them or not – that I don't hear on one side. If I can't hear something or someone, I tell them – whether it's shop assistants, waiters, doctors, people at the gym. I tend to say that I'm partially deaf, because people often don't realise the impact of single-sided hearing loss, but do understand difficulty in hearing. Very occasionally I've had an odd reaction, but I can count those times on the fingers of one hand. Overwhelmingly, I've found that when people know I can't hear on one side, or in certain contexts, they're really happy to accommodate it. I think this is partly because I'm so unembarrassed about it myself. It makes my life much easier and takes a lot of the effort out of hearing and listening.



# AN 20 years on in 2020

Chris Parker (age 74)



Lying on my back, my head was propelled backwards into the chamber of the Leksell Gamma Knife machine. As I stared at a metal bar just two inches from my nose, the equipment locked into the correct position with a loud clunk that seemed to echo the full length of my body down to the tips of my toes. Almost immediately, in complete contrast, the most soothing music washed over my head and as I closed my eyes my mind was transported to another world, whilst 201 gamma rays were concentrated with pinpoint accuracy onto my tumour. After five minutes the machine stopped and I was propelled back out of the chamber in order for the radiographers to make several programmed adjustments and after resecuring the frame on my head to the machine's frame the process started again.

This point in my treatment at Sheffield's Weston Park Hospital was the culmination of hundreds of measurements by a dedicated team of neurosurgeons and radiographers and twenty years later I can remember their names as if it was last week.



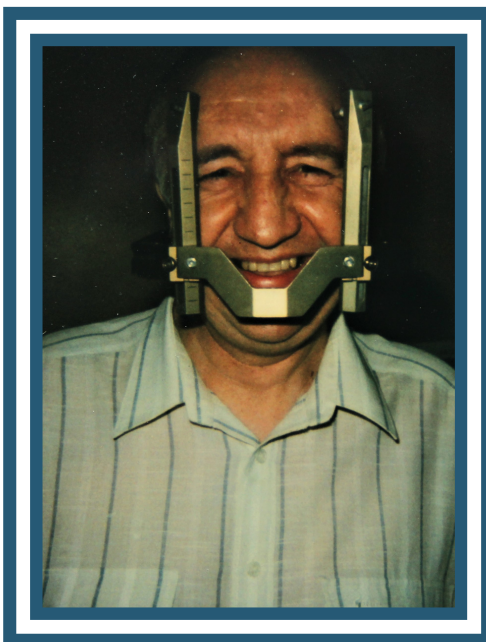
# AN 20 years on in 2020

Today stereotactic radiosurgery is much more common but then the centre at Sheffield was the only place in the U.K. and only the third in the world, where patients could experience this new treatment for brain tumours. Coincidentally my elder daughter trained as a diagnostic radiographer at Sheffield two years before my diagnosis and mentioned the time she spent on the amazing Gamma Knife equipment: little did we realise that I would be treated there myself just two years later! I felt extremely privileged at the time and fortunate today that I am so well and able to cope with the deafness and tinnitus that afflicts most acoustic neuroma patients. So much so that as 2020 approached I planned to celebrate my 20th year since diagnosis with a trip to New Zealand.

Instead 2020 became the year of the mask: the loss of my travel paling into insignificance as the COVID-19 pandemic grew and many people lost loved ones and many others were unable to visit family members in care homes or hospitals. Generally, at first, people seemed to struggle with wearing a mask but I remembered from visits to the Far East how easily the population used them every day.

I particularly remember my first visit to Japan in 1999 where I found many people wearing masks as I travelled the length of the country, learning that they wore a mask out of respect for their neighbour, a phenomenon I also witnessed when visiting other Asian countries.

*"Instead 2020 became the year of the mask: the loss of my travel paling into insignificance as the COVID-19 pandemic grew."*



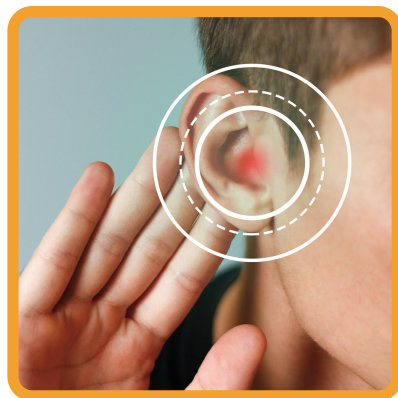
# AN 20 years on in 2020

Numerous older people, including myself, find hearing to be worse when wearing a mask. Particularly in noisy surroundings and more guidance from research would be helpful as to the best materials for masks when considering hearing. Also masks do not allow for lip reading and even the loss of the ability to read facial expressions is a disadvantage. Another point is that sign language is used for television announcements in some countries, but not all.

However I cannot help but be inspired by the wonderful community spirit that has been on display throughout the pandemic. The claps of support for the NHS and the amazing exploits of Captain Sir Tom raising millions of pounds, has brought the country together in a manner of comradeship not seen since the end of the war in 1945. I am in awe of the heroes of communities throughout the nation who have given time and help so selflessly to the needy in remarkable acts of kindness.

Personally I was pleased to be included in the CROSSSD study ([www.nottingham.ac.uk/go/CROSSSD](http://www.nottingham.ac.uk/go/CROSSSD)) researching single-sided deafness which turned out to be a fascinating experience. Enthusiastically and professionally led by PhD student Roulla Katiri, the original meeting day had to be cancelled due to travel restrictions but Roulla and the team organised a web-based meeting surmounting all the difficulties with great efficiency. I was enlightened to meet participants who had suffered single-sided hearing loss overnight presenting difficulties I had not experienced before with my contacts through BANA. BANA certainly helped me twenty years ago to come to terms with my illness and today I look forward to the future very positively.

*"BANA certainly helped me twenty years ago to come to terms with my illness and today I look forward to the future very positively."*



# Ultra Marathon – Lake District

Sara Crosland

100 km

If you would still like to support this fundraiser along with Danielle and Sara please go to this link:

[www.justgiving.com/fundraising/teamanwarriors](http://www.justgiving.com/fundraising/teamanwarriors)



Still coming back to earth...

Well, we finally did it! The build up seemed to go on forever, thanks to a certain pesky virus messing with our plans. The silver lining of course, more time to train! I'm Facebook friends with many of you on here, and don't want to repeat myself, but just wanted to say thank you so, so much for your support. We didn't take the easy option of the 25km section, the 50km or even 100km over 2 days, we jumped in at the deep end. Saturday was incredibly hot. The terrain was, for want of a better description, foot-shreddingly brutal, but beautiful.

For two individuals who, as you know, have just one vestibular nerve, experience balance issues and fatigue, it really was a challenge. These are the hidden things that people don't see, and we are both committed to raising awareness of this. We're also both deaf on the same side so there was a lot of "what was that??" going on throughout the 27 hours we were competing.

To put the event in context, 1270 started the event. 230 withdrew; we witnessed one of them being put in a taxi by a medic at around 70km. Of the 423 competing in the continuous 100km, 127 withdrew. We were placed 226th and 227th. 64th and 65th female finishers. I am so proud of us both for getting over that finish line.

I think I speak for both of us when I say how proud I am to belong to such an amazing community as BANA. Your support has been incredible.

# Ultra Marathon – Lake District

So many of you were following our progress online, even throughout the night. You cannot begin to understand how much your posts/comments/messages meant to us, particularly as we were going in the dark. I was exhausted due to virtually no sleep the night before. However, I'd done quite a good job of putting this to the back of my mind until, at 3:30am, Dani reminded me that I'd now been awake for 24 hours – little did I know we still had another 8 to go! Covering approximately 30km of uneven, rocky, overgrown, slippery, dewy terrain in darkness with poor balance was... well to be honest I can't think of a suitable description.

When we stopped at 'Camp Doom' at around 70km, greeted with 'the medical tent is on your right' I can honestly say I was taken aback at just how broken other athletes looked. As we stuck our feet back together and tried to stretch out rock hard muscles, we read through every single message and checked the increasing fundraising total. It really boosted our resolve to keep going.

As we passed through Cartmel, our attention was drawn to a lovely lady sitting alone under a street light, clapping and cheering us on. When she asked if we knew Sara and Danielle I realised it was our very own BANA member, Kirsten. She had been waiting there for one and a half hours hoping to see us – and for all she knew we could have passed through already! During that time she had been cheering on others who had passed by. To see a friendly face at that point was like being sent our very own angel! Thank you so, so much for the hot chocolate, the biscuits and a hug... And also the BANA banner! That was such an incredible moment and an act of kindness I don't think I'll ever forget. This is what the BANA community is all about. Kirsten personified that.

In the early hours of the morning, we began to receive messages about just how many people had withdrawn. I was an emotional wreck already by this point (delirium was setting in and we went from laughter to tears in seconds) and I think that was the point at which it dawned on us on just how much we had achieved – in spite of our own physical challenges – in what really was a tough event.



# Ultra Marathon – Lake District

As we crossed the finish line, hearing the words, "Well done to both of you – it's all over" momentarily tipped me over the edge... this was rectified of course with a medal, finisher's t-shirt and a glass of prosecco!

I hope that by doing this we have inspired others in a similar position to push beyond fears and attempt those things that you think you'll be unable to do. Whether personal or physical challenges, I truly believe that with a positive mindset (and believe me, I have been to hell on earth and know that it's not always easy) and surrounding yourself with the right people (the wrong ones usually disappear of their own accord anyway!) you really can continue to achieve, despite the barriers and obstacles that may come your way. Find someone to help you – I'll never say no to a challenge!!

If you've read this far, thank you! Anyway, I'm off to dream up my next challenge, and I hope to hear more about yours!!

## 'Never give up!'

Andrew Read

### 12 Marathons in 12 Months

None of this I'm doing would have even entered my head if it wasn't for the three incredible charities that have helped me on my journey of recovery, all the inspiring people that have given me fuel and confidence to push my boundaries to the absolute limit, 'Never give up!'.



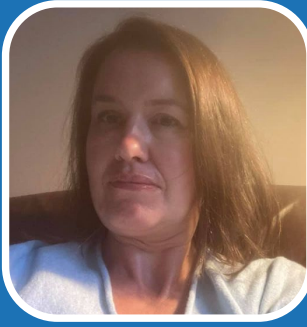
<https://uk.virginmoneygiving.com/AndrewRead12>



# THANK YOU



# For wearing Blue for BANA on July 1st for BANA Awareness Day



# Q & A with Andrea Wadeson



Specialist Skull Base Nurse,  
Salford Royal

**Q. BANA Member** – *Could you explain the difference between a 'Middle Fossa' approach and 'Trans Labyrinthine' if any?*

**A. Andrea** – Middle fossa is best for smaller tumours and can be used for hearing preservation in selected cases. The incision is usually above the ear. There is a small window of bone cut out and the brain is retracted to gain access underneath the brain and to come at the tumour from above.

The Translabyrinthine route, common in the U.K, will ultimately sacrifice the hearing but offers benefit for larger tumours and allows the course of the facial nerve to be followed from the inner ear to the brain which some surgeons feel is an advantage compared to the middle fossa approach. It also gives better access to an area of the brain called the cerebellopontine angle which larger tumours protrude into. This route also involves very little brain retraction. It tends to be a longer operation as the access takes longer.

Routes are determined by many things, treating the hospital's preferred way of operating/approaching the tumour, size and configuration of the tumour, potential for hearing preservation and other medical issues that may mean longer anaesthetic is an issue.



# The Giving Machine

Why not join the Giving Machine and **earn commission for BANA every time you shop online**. It is quick and easy to sign up and you can download a desktop reminder to help you remember to **support BANA whenever you are shopping**.



## How it works

Set up a Giver account on TheGivingMachine and then just click to shop via TheGivingMachine website, desktop reminder or mobile app every time you shop online. Purchases generate a donation which will show on your account summary once processed by our Machine.

## How is it free?

Every year online shops pay millions in sales commissions to other websites that direct shoppers to them (e.g. search engines and voucher code websites). At TheGivingMachine we turn these commissions into donations for your favourite schools and charitable causes, at no extra cost to you.

## Eight reasons to sign up and start earning for BANA...

- It's completely free to join as a Giver and as a Cause
- You can choose up to 4 causes to support
- It's easy – just remember to click via TheGivingMachine every time you shop online
- You can download a free desktop reminder and mobile app
- You'll find over 2,000 top retailers
- Choose BANA from thousands of good causes to support
- As a charity, TheGivingMachine can give away more than commercial alternatives
- Join a growing Giving Community!

It's easy to join...

Go to this link: [www.thegivingmachine.co.uk/sign-up/](http://www.thegivingmachine.co.uk/sign-up/)

## Hassle free membership renewal

We are now able to offer members the option to pay subscriptions by Direct Debit using GoCardless. A safe and simple enrolment process to register your bank details and your payment will be taken automatically when due. If you would like to pay by this method email us at: [admin@bana-uk.com](mailto:admin@bana-uk.com)



## Gift Aid

Donating through Gift Aid means BANA can claim an extra 25p for every £1 you give. It will not cost you any extra. As a Charity we can claim Gift Aid on most of your donations.

### What you need to do

- You need to make a Gift Aid declaration for the charity to claim. You usually do this by filling in a form – contact us if you have not completed a GA form.
- You can include all donations from the last 4 years. But must tell us about any tax years where you did not pay enough tax.
- Paying enough tax to qualify for Gift Aid
- Your donations will qualify as long as they're not more than 4 times what you have paid in tax in that tax year (6 April to 5 April).
- The tax could have been paid on income or capital gains.
- You must tell us if you stop paying enough tax.

### Higher rate taxpayers

If you pay tax above the basic rate, you can claim the difference between the rate you pay and basic rate on your donation. It's the same if you live in Scotland. Do this either:

- Through your Self Assessment tax return
- By asking HM Revenue and Customs (HMRC) to amend your tax code

Example You donate £100 to charity – they claim Gift Aid to make your donation £125. You pay 40% tax so you can personally claim back £25.00 (£125 x 20%).

**Using Gift Aid is a great way to support your favourite charity.**

*giftaid it*

# Spend and donate



## How does AmazonSmile work?

When first visiting [smile.amazon.co.uk](https://smile.amazon.co.uk), you will be prompted to select a charitable organisation. Search for British Acoustic Neuroma Association. Amazon will give 0.5% of the net purchase price (excluding VAT and other shipping fees) of eligible AmazonSmile purchases to the charitable organisations selected.

## Text Giving

Text BANA to 70085

### Text BANA to 70085

An easy way to support BANA. Or share with your family, friends and supporters to help you along with your fundraising campaigns.

Texts cost £5 plus one standard message charge.

**Text Giving** enables your community to instantly support your cause by texting BANA and the donation amount, which will then be added to their phone bill or deducted from their credit.



# Fundraising roundup

## Events completed

Thank you to  
James Taylor  
BANA Life Member, for  
raising awareness on the  
1st July and raising a  
fantastic...

£7,460.78

Sara Crosland  
and Danielle Gibbons  
completed 100km Ultra

£3,428

*AN Warriors! WOW!!*

## Events ongoing

Ione Hansford  
and friends  
900 miles in a month by  
walking, jogging and  
running.

£920

Sarah Rawlings  
London Marathon 2021

£480

Andrew Read  
12 marathons in 12 months

£945



# Fundraising roundup

Pay Pal Giving Fund

**PayPal**  
Giving Fund **£1,053.86**

Ongoing fundraising



**£13.04**

Easyfundraising

Thank you to everyone who uses Easyfundraising to raise funds for BANA when they are shopping online. Your support is very much appreciated.

**amazon**smile

You shop. Amazon gives.

Amazon Smile

Thanks also to those who shop at Amazon and do so via the Amazon Smile site to raise funds for the charity.

**£103.21**

Grants recieved

Card factory  
community fund **£900**

Catherine Cookson  
Charity Trust **£600**

Sir James Roll **£1,000**

Douglas Arter  
Foundation **£500**

What amazing fundraisers BANA has. You really rose to the occasion on our National Awareness Day. We heard so many positive stories of how you were raising awareness by wearing Blue for BANA and telling others why. Along with doing mini fundraisers and not so mini by some. As ever we thank you from the bottom of our hearts.

*Julie Dixon CEO*

# Fundraising – we need you!

## Would you like to help us with our fundraising?

BANA was formed in 1992 by a group of patients and their partners. In 2016 BANA became a CIO registered charity and has come a long way. Providing support for many, but this can only happen with fundraising, donations and grants.

## Where will your funds go?

▶ **£5** pays for 47 copies of our 'Here to help you' leaflet

▶ **£20** funds 1 hour room hire for support meetings

▶ **£100** will print 76 copies of Headline News

The support from BANA helps 100's of members, their friends and families. All of the great work continues to raise the profile of BANA and the awareness of Acoustic Neuroma and every penny counts to help change a person's life for the better.

## What activity can you do to fundraise?

There are many ways to raise money from holding an auction to running a marathon – there is something to suit all ages and abilities. We have an A-Z of ideas in the Fundraising Resources section on our website but please follow Covid-19 Government guidance at all times. We are happy to help support your event by sending you collection boxes and advertising your event in the magazine and on social media.



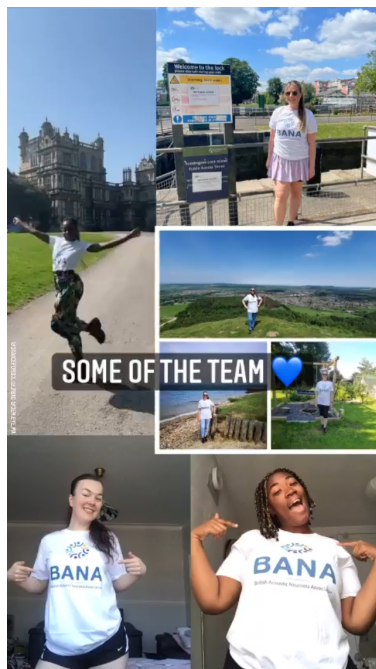
If you would like to fundraise for BANA, please contact the office on  
Tel: 01246 550011 or Email: [admin@bana-uk.com](mailto:admin@bana-uk.com).

# Surgery and a marathon

Ione Hansford

In April 2020, at the age of 21, I was diagnosed with a 4.5cm Acoustic Neuroma. Six weeks later, I had a 19 hour operation to remove the majority of the tumour.

Single-sided hearing loss and severe imbalance led me to be (incorrectly) diagnosed with Ménière's disease in February 2020. Two months later, I had an MRI scan, as simple movements became increasingly difficult to do on my right side. I was soon diagnosed with AN and told that surgery was my only option if I wanted to live. After the operation, I spent one week in hospital learning to walk again (as I had fat and gristle removed from my thigh). My right eye didn't close completely, meaning I had to tape it shut and cover it with an eye patch for the majority of the day and night.



A physio would practice facial exercises with me, mainly to get my mouth and eyebrow moving. I am now completely deaf in my right ear (as a result of the surgery) and suffer from constant tinnitus. I have therapy to help with my facial palsy and will consider using a CROS aid in the future. Thank you to the team at St George's Hospital (honourable shoutout to Dr Martin, Dr Patel & my fairy godmother, Vicky Barnes... especially as I couldn't have any family or friends with me in the hospital during lockdown!).

Throughout the month of June, I & 12 friends walked, jogged and ran 900 MILES collectively to raise money for BANA and awareness of AN! I'd like to thank my friends for participating whilst doing exams, working and surviving a pandemic. I will also be taking part in the 2021 Virtual London Marathon on Sunday 3rd October!

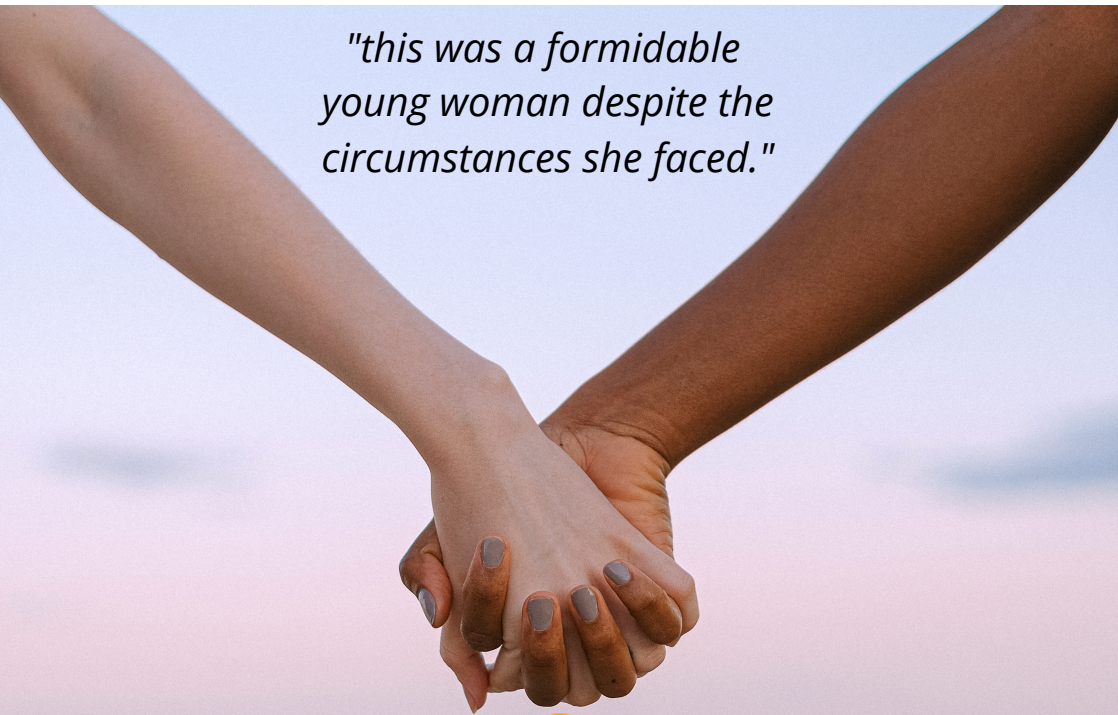
<https://uk.virginmoneygiving.com/ioneHansford/1>

# The Indomitable Storm (my surrogate niece)

Vicky Barnes  
Skull Base Nurse

I met up with the very determined Lone Storm Hansford on her day of surgery just over a year ago in June 2019. It was that time when our hospital was getting over the 1st wave, and Lone was the second patient our team operated on since the trust went into lockdown for elective surgeries. Before this, once I learned of her upcoming surgery, I had initiated contact via several telephone calls.

Lone was apprehensive, she tried to show a brave face, but the raw vulnerability showed. At 21 years old, to be told you have a sizeable vestibular schwannoma which requires removal very shortly after being diagnosed. Lone then faced numerous team members on the morning of surgery, devoid of any family members. I think this indicated to me there and then that this was a formidable young woman despite the circumstances she faced. I again reminded her of what to expect at different stages pre and post-op. Lone agreed to my 'tough love early rehab plan'.

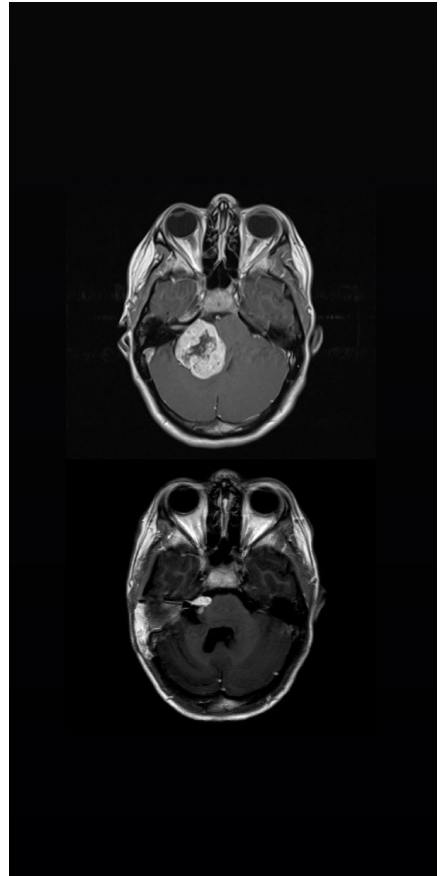


*"this was a formidable young woman despite the circumstances she faced."*



# The Indomitable Storm (my surrogate niece)

The theatre team were very supportive, as were the consultants and anaesthetists. Theatres were still trying to regulate the new normal of how things would flow once patients were present and waiting for this possible 8-12 hour surgery. I spent all morning with Lone to know a bit more about her, and I accompanied her to the anaesthetic room. We had a bit of a wait, so we chatted and laughed and then she asked me the most unusual question... she asked me, 'if I were a believer... a person of faith'. Initially taken aback, as nurses, we are admonished not to impart our beliefs to our patients. I said 'yes' she said 'good so am I, I feel better now. I held her hand until she was taken over by the theatre team and reminded her that I would see her in the morning. I then contacted Julie (her mom), updated her found the physio team and made them aware of Lone and my plans for very early rehab; of course, they were positively on board.



Lone's surgery began at 10:00 and finished at 04:00 the following day, 18 hours! She spent that day intubate in the ICU and a further two days there before going to the ward. As promised, I visited her every working day. Walking on to the ICU on the 1st day after extubation, her nurse LC informed me that she had been asking for me as soon as she could communicate clearly.

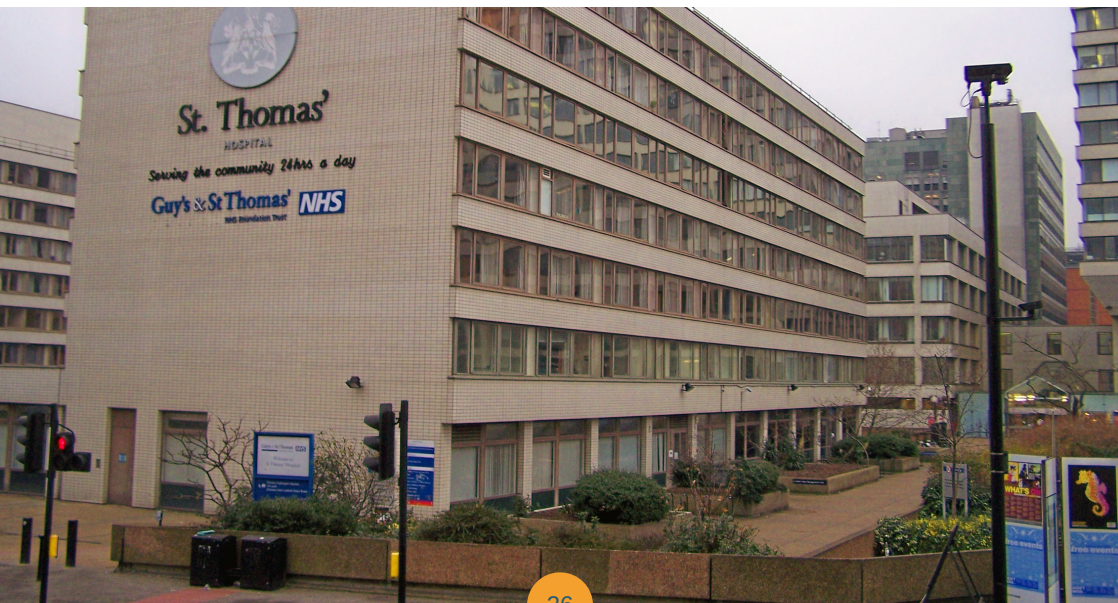
Her post-op complications included some facial weakness.

# The Indomitable Storm (my surrogate niece)

House Brackman scoring of 3-4, nystagmus, numbness to the left side of her face, dizziness and nausea. I referred her to the Speech and language for swallowing assessment as well as the Occupational Therapist.

She had issues with nausea, and we addressed that early. She had partial closing of her eye. I commenced early independence with her instilling the eye drops. I would visit her four times a day; we would go for walks and chat to distract her from the obvious additional physio I was giving her. With this added input, she was able to do so much more with the actual Therapists. As her family could not visit, I would sometimes get her little treats to help get her appetite back.

She did have periods when she was low in mood, and I would sit and speak with her and encouraged her to communicate with her family and remember what the goal was...to get home safely. I continued to keep Julie updated as well, and this helped immensely to ease the family's anxiety. On the day of her discharge, the entire family came to pick her up from the hospital; it was a beautiful moment. We have kept in close contact ever since. I gave her my phone number to stay in touch as I knew she was feeling apprehensive post-surgery with facial weakness etc., and we have kept in contact since. She is a beautiful soul and such a humble young woman. I felt blessed to have been a part of her journey.



# Forthcoming meetings

Further details including venues available from BANA HQ. All members are welcome to attend any BANA meeting (virtual support or face to face) and are encouraged to take along a guest – either a family member or friend – if they wish. It is important that you confirm your attendance with Heather (heather@bana-uk.com or 01246 550011).

Area	Date	Time	Meeting type
<b>South Wales</b>	Saturday 11th September	10.00-12.00am	<b>Virtual meeting</b> with Deepak Rajenderkumar - Consultant Audio Vestibular Physician <i>'Hearing Rehabilitation in Acoustic Neuroma'</i>
<b>UK wide</b>	Tuesday 14th September	10.00-12.00am	<b>Virtual meeting</b> Citizens advice caseworker Ivan Munkley discussing benefits, including PIP. All welcome.
<b>South Normanton, Derbyshire</b>	Saturday 18th September	10.00-12.00am	<b>Face to face social meeting.</b> All welcome (limited numbers). Guest speaker Ann Sullivan, Operations Manager, Deaf and hearing support for Chesterfield
<b>Belfast</b>	Monday 20th September	10.00-12.00am	<b>Virtual meeting</b> - Social
<b>UK wide</b>	Wednesday 29th September	7.00-8.30pm	<b>Virtual meeting</b> 35 and under - social



*"I find the information invaluable and the Facebook group very supportive and inspiring" - BANA Member*

# Data protection

## General Data Protection Regulation 2018

### Data Processing Statement

As a charity that has a membership and provides services to people BANA requires certain information from you to fulfil that provision. All data is governed by the General Data Protection Regulation 2018 in how we use and keep your information. It is our responsibility to explain this to you.

- When you join BANA we ask for information to be able to contact you and to provide the services available to BANA members. By you not providing information may affect the services we can provide.
- Your information will only be used by BANA with governance in place for how it must be used and disposed of.
- Your details will only be held on BANA networked computers.
- We will apply security to our electronic systems and use locked cabinets where applicable.
- If you leave the membership, we will retain your contact details on a record of ex-members to assist with accountability enquires for a maximum of two years. Any medical specific information will be deleted. All financial data relating to your membership will be stored securely for six years as required by HM Revenue & Customs it will then be securely deleted or destroyed.

We will not use any information for any other purpose. However, it is your responsibility to advise us of any changes to your personal details. BANA abides by its Confidentiality and Information Policy which is reviewed annually.

If you do not wish to be contacted by a certain means, or wish to be removed from our databases, you must inform us and you may unsubscribe from a database at any time.

We will always do our very best to ensure we manage our services and your information in the most appropriate way. Please contact the BANA office with any concerns and we will take any necessary actions to rectify the issue.

# Are you a BANA member?

## There are many benefits to becoming a subscribing member of BANA

- Access to local support groups (subject to availability) run by volunteer host members  
Headline News magazine
- Free information sheets
- Access to our online forum in the members-only area on our website
- Access to our closed Facebook page
- Hire of Trophic Stimulators (use under medical supervision) for treatment of facial palsy
- Access to the Medical Advisory Panel
- Access to support for fundraising
- Volunteering Opportunities around the UK
- Our Telephone & Email Support Register, made up of volunteer patient members willing to speak with others in a similar position, to share mutual experiences and give support from a place of understanding.
- Subsidised Annual Conference with prominent speakers and trade stands.

## Here's how you can join

### Sign up online

Log on to our membership section of the website.

[www.bana-uk.com/membership](http://www.bana-uk.com/membership)

Here you can register and pay online (single membership only) or download an application form.

### By post

Fill in the form opposite and enclose a cheque payable to 'British Acoustic Neuroma Association' or 'BANA'.

Post to BANA HQ – address is on the form.

## Ensure your membership stays activated and hassle free by setting up a Direct Debit

If you set up a Direct Debit your membership subscription will automatically come out of your bank each year. Please contact the office for further information.

# Membership/Donation form

**Title**                      **First Name**                                      **Surname**

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**Home Address**

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**Postcode**

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**Tel**                                      **Email**

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I enclose

**Membership (23 per year)**                      £ \_\_\_\_\_

**Joint Membership (30 per year)**                      £ \_\_\_\_\_

**Donation**                                      £ \_\_\_\_\_

**Total**                                      £ \_\_\_\_\_

## Gift Aid Declaration

**(please sign in box if appropriate)**

*giftaid it*

I confirm that I am a UK tax payer and I want the charity to treat all subscriptions and donations I make today and in the future, until I notify you otherwise, as Gift Aid donations.

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax for each tax year (6 April to 5 April) that is at least equal to the amount of tax that all the charities or Community Amateur Sports clubs (CASCs) that I donate to will reclaim on my gifts for that year. I understand that other taxes such as VAT and Council Tax do not qualify. I understand the charity will reclaim 25p in tax on every £1 I give.

**Signature** \_\_\_\_\_ **Date** \_\_\_\_\_

### **Please note: Gift Aid cannot be claimed if someone else pays on your behalf**

Please notify the charity if you: 1.Want to cancel this declaration. 2.Change your name or home address. 3.No longer pay sufficient tax on your income and/or Capital Gains.

If you pay income tax at the higher or additional rate and want to receive the additional tax relief due to you, you must include all your Gift Aid donations on your Self Assessment Tax return, or ask HMRC to adjust your tax code. If you have any questions about Gift Aid please visit HMRC website – [www.hmrc.gov.uk](http://www.hmrc.gov.uk)

**Please send your completed membership form to** British Acoustic Neuroma Association  
Tapton Park Innovation Centre, Brimington Road, Tapton, Chesterfield, S41 0TZ

**Tel:** 01246 550011 **Email:** [admin@bana-uk.com](mailto:admin@bana-uk.com) **[www.bana-uk.com](http://www.bana-uk.com)**

**Registered Charity No:** 1165065

Cheques should be made payable to 'British Acoustic Neuroma Association' or 'BANA'.



# BANA

British Acoustic Neuroma Association

Meet, Share, Relax, Support



Connect with others  
on the same journey.

Join us at our virtual and face to face  
support groups

To find out when the next meeting  
is and to book your place contact...

T: 01246 550011

E: [admin@bana-uk.com](mailto:admin@bana-uk.com)

[www.bana-uk.com](http://www.bana-uk.com)

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