

Winter 2020

# HEADLINE NEWS

It's what we do.....



Connect, Support, Share experiences



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

# Headlines

*By Jackey Weightman*

Well this is my last issue as Editor of BANA's magazine, Headline News and what an edition to go out on! Thank you for the support from everyone over the past few years. I have thoroughly enjoyed my time producing the magazine but health problems have now made me call a halt.

A big thank you to the members who have shared their AN journeys with us and to all the donors and fundraisers who have kept BANA afloat in these trying times. As I am sure you are aware all charities are struggling at the moment and it is especially hard for smaller charities like BANA who rely so heavily on donations and fundraising. Thank you one and all.

I am sure many of you are missing the Area Support meetings but I do hope you are enjoying the virtual meetings held on Zoom. My children introduced me to Zoom when the pandemic began and I soon got to grips with it – well to be honest it took a while for me to master turning on the sound and video but I got there in the end – and Alan and I now enjoy weekly meetings online with our daughters and granddaughters. We have to do whatever we can to stay in touch these days.

Finally, I would like to wish you all a happy and above all, healthy, Christmas and may 2021 be a better year for us all.

## Merry Christmas

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.

## Our new Patron– Richard Ramsden

*It's a great pleasure to have Richard join us as Patron and we very much hope he enjoys being part of our community. Below is a little about Richard's career.*



I am delighted to have been invited to be a Patron of BANA, to follow in the footsteps of my dear friend David Moffat. I graduated in Medicine at St Andrews University in 1968 and trained in ENT at the Royal National Throat Nose and Ear Hospital, and the London Hospital. I was appointed Consultant at Manchester Royal Infirmary in 1977 and developed the Acoustic Neuroma and cochlear implant services. Over the course of my career I managed approximately 1800 Acoustic Neuroma cases and carried out surgery on 1200. I developed special interest in NF2, its diagnosis and management and carried out the first auditory brainstem implants in Britain. I was appointed Professor at Manchester University in 1994, and MBE for services to Otolaryngology in 2015. I retired to Oxfordshire, reading extensively and writing on the history of medicine. I serve as a trustee of a number of charities and play golf very badly.

## Not happy with your Care?

More often than not we are all very satisfied with our care from the NHS; unfortunately, sometimes things go wrong. You have the right to make a complaint about any aspect of NHS care, treatment or service, and this is firmly written into the NHS Constitution as well as the core requirements for NHS complaints handling laid out in legislation.

The NHS encourages feedback because it's used to improve services. If you wish to share your views and experiences, positive or negative, simply speak to a member of staff. Many service providers have feedback forms available on their premises or websites.

# Not happy with your Care?

Sometimes the NHS will ask for your feedback. If you're unhappy with an NHS service, it's often worthwhile discussing your concerns early on with the provider of the service, as they may be able to sort the issue out quickly. Most problems can be dealt with at this stage, but in some cases, you may feel more comfortable speaking to someone not directly involved in your care.

Considering making a complaint but need help? Many issues can be resolved quickly by speaking directly to the staff at the place where you received care or accessed a service.

Some people find it helpful to talk to someone who understands the complaints process first and get some guidance and support. You'll find a Patients and Liaisons Service (PALS) in most hospitals. You can speak with a PALS member, who'll try to help you resolve issues informally with the hospital before you need to make a complaint. PALS can be particularly helpful if your issue is urgent and you need action immediately, such as a problem with the treatment or care you receive while in hospital.



If you're making, or thinking about making, a complaint, someone from the independent NHS Complaints Advocacy Service can help you. An advocate will also be able to attend meetings with you and review any information you're given during the complaints process. You can seek advice from an NHS complaints advocate at any stage of the process.



If you decide you need some support, it's never too late to ask for help. Your local council will be able to tell you who the advocacy provider is in your area. Your local Healthwatch can also provide information about making a complaint.

# Office Talk

*By Julie Dixon*

Hello and welcome to our Autumn/Winter Headline News. Gosh, there have been some changes haven't there since our last magazine? I very much hope you have, in your own ways, stayed safe and have had some support across the late spring, summer months and in the months to come through winter.

Here at the office we had to change our ways of giving support to the members of BANA. Our support meetings were wiped out and the launch meeting for our first group in Ireland was cancelled a week before it was due to run.

As many of you will know we have moved support to online using Zoom, which has worked out amazingly well. We also decided to extend our AN Awareness Day from one day to three. We ran our 'Wear Blue for BANA Day' followed by running a webinar each day for three days and these were an outstanding success with over 140 people logging in across the three days; we also welcomed people from Canada and Croatia.

It was a huge disappointment to have to cancel our yearly conference in 2020, which we were planning to hold in Cambridgeshire. However, following on from the success of the webinars we ran two presentations on Saturday 10<sup>th</sup> October which should have been the conference day, again with wonderful success having over 180 people tuning in, and, again, not just from the UK.

For the first time BANA put out an appeal to its members and supporters asking for donations as we lost all our summer funding events; like many charities this is our season to fund raise for the rest of the year. The response was amazing and we are so very grateful to all our members and supporters who dug deep to help us. Thank you.

Unfortunately, Ayodele decided to leave BANA after a short period with us and we wish him well for the future.

You may recall we had to announce the sad loss of our patron David Moffat earlier in the year. It is with great pleasure we welcome Richard Ramsden who has agreed to become a Patron of BANA. Richard knew David well and is delighted to follow on.

## Office Talk

As you will see in the magazine, we have lots of the fabulous fundraising efforts from individuals who were able to get out. It was great to see and be involved mainly via Facebook and Twitter in some small way.

As many of you will now be aware, we are again running the BANA Raffle this year. It's a great opportunity to give a little and, maybe, win a lot.

Once again many, many thanks for your continuing support in these difficult times and hopefully we will get back to some sort of normality in the coming months

Stay safe

## 2.6 Challenge

*By Simon Hunter*

I was diagnosed with an Acoustic Neuroma in 2018. I had initially booked a hearing test with Specsavers because of concerns over hearing loss and tinnitus in my right ear. This led to audiology and ENT referrals before an MRI confirmed the presence of an Acoustic Neuroma. I am fortunate to be on Watch & Wait and have recently been moved from 6-monthly to annual scans.



While the AN is not impacting my life too dramatically at present, I know that for others the effects can be challenging on a daily basis and, in some cases, life-changing. For my part, I have found BANA's support and resources invaluable since diagnosis.

The 2.6 Challenge was a great opportunity to provide BANA with some support in return, by raising money to help keep the charity afloat while so many fund-raising events are being cancelled due to COVID-19.

## 2.6 Challenge

By asking friends and family to sponsor me if they could, it also gave me the opportunity to raise awareness about Acoustic Neuromas and BANA in a more informal way.

For my 2.6 Challenge, I chose to cycle 26 miles on my indoor cycle trainer for each of the six days of 2.6 Challenge Week – 156 miles cycled in total, all from the comfort of my garage! I was thrilled to exceed the fundraising target of £260, with friends, family & kind BANA members raising a total of **£389**. I should also thank my friend Andy, who did the rides ‘with’ me in his own garage for moral support, via WhatsApp!

Since we have been less restricted in time spent exercising outdoors, it has been great to get back out on the bike again. Road cycling is a little more nerve-wracking these days as I become more aware of my balance issues, so I love being able to take my mountain bike off road into the North Downs and Surrey Hills, away from traffic and concrete! I also find mountain biking helpful in challenging and training my balance in a (relatively) safe way.

Thanks again to everyone who supported my efforts and enabled me to support BANA – it is very much appreciated.



# BANA Christmas Hamper Raffle 2020

*Thursday 22 October – Friday 4 December*

## The BANA Christmas Hamper Raffle is back!

**A £5 donation = 1 entry to the draw**

**For every £30 raised a new item will be added to the Christmas Hamper**

**A WINNER will be drawn on Friday 4 December**

***Helping to support Acoustic Neuroma patients and their support networks***

*To purchase tickets please telephone the office on **01246 550011** or send a cheque to **BANA HQ** (address on back page) Alternatively you can follow this link:*

<https://uk.virginmoneygiving.com/charity-web/charity/displayCharityCampaignPage.action?charityCampaignUrl=BANACHristmasHamperRaffle2020>

# My AN Diary

*By Ben Jackson*

## **November 2016**

One morning, after 3 years of feeling periodically dizzy and numerous inconclusive trips to ENT surgeons, I was referred to a neurologist. After a test, involving me sitting in a chair, with my head covered in dozens of small electrodes, the neurologist told me that all the results were 'normal'.

"Do you work long hours?" he asked.

"Officially 40 a week, but more often 60. I have been on the phone nightly for a year negotiating a contract with a Californian customer",

"Have you been in Germany long?"

"A year."

"Before, you were in the UK?" he enquired.

"No, 6 years in the US and also a year in France."

"Hobbies and sport?" he asked.

"No time for those. I like skiing and singing however."

"Are you in a relationship?"

"Single."

"Living abroad is tough. You work long hours. It places a lot of stress on you. You should slow down; do more hobbies. The tests show your brain function is normal." He closed his laptop. I took one week off work, felt a bit better, joined a choir and was content that the issue was resolved.

## **May 2017**

After a cold I noticed that I could not understand speech on the phone very well. I got a recommendation for yet another ENT consultant and went to see him. I was prescribed a steroid nasal spray and told to be patient.

# My AN Diary

## Late September 2017

The issue had not resolved; after more tests at the hospital one morning I was ushered into a room to get the results. My German was poor and unusually for a German doctor his English was rough. I decided to be direct, "How were the tests?"

"The tests are normal. I think the reason for your hearing loss is a brain tumour. They are often not bad ones."

"You mean benign?" I asked. "Benign. Not cancerous?"

"Yes, no cancer, we need to have an MRI scan to know for sure."

The rest of that day was a blur.

## Early October 2017

The MRI scan showed I had a 30mm Acoustic Neuroma that was also pushing into the brain stem. I met with the surgeons at the university hospital in Munich. The specialist surgeon was flanked by two junior doctors. Suddenly things felt very serious.

"It is a big operation, but you should be back at work in about 6 weeks". This would turn out to be hugely over optimistic.

"We have a 95% success rate but still in about 30% of cases we can't preserve the facial nerve causing your face to drop, and you will be totally deaf in your left ear after the operation."

"Will I make a full recovery? Will I be able to ski again?" I have no idea why I asked if I could ski again, but it seemed to me to be a reasonable benchmark. I thought if I could ski, I should be able to do most things!

"You will be able to ski again, but not this season." Sounds promising, I thought.

"You will however never feel normal again," he continued. "You will have to get used to a new normal. This could take a few years."

"How long can we wait before doing the op?" One half of me wanted to have the operation that very moment and just get this thing, this foreign

## My AN Diary

object, out of my head, the other half wanted to postpone this operation for the rest of time. After all, despite the hearing loss and the odd bit of dizziness I didn't feel that bad.

"We can wait 6 or 8 weeks, but not 6 months, the tumour is rather advanced. If it is left longer it will be much more serious"

A few days later I called the university hospital in Munich and booked the operation.

### **Mid November 2017**

Four days before surgery an email arrived from the hospital; the operation had been postponed by 2 weeks due to nursing shortages in the ICU.

Two weeks later I was admitted to the hospital on a freezing Thursday morning. My op was scheduled for the following day. Thursday was filled with what seemed like every possible test; MRI and CT scans, an ECG, blood and hearing tests. Finally, at 8pm we had the pre-op briefing with one of the doctors. But there was a big question that nobody could answer - would the operation actually happen the following morning, or would there be another postponement?

Waking up on Friday morning it was confirmed that surgery would be postponed. The sense of disappointment and desperation was unbearable. I was sent home and told to come back on Sunday night.

### **26<sup>th</sup> November 2017**

As I walked to the underground station on Sunday evening to head into the hospital it started to snow heavily. On the deserted platform the whole situation hit me hard; I was desolate. My mother, who had come to support me was stuck in my apartment alone in a country she didn't know; my elderly father who was unwell, was waiting back in Cheshire; and here was I, hoping to have brain surgery tomorrow. Wanting everything to be over, but with no certainty of what permanent condition I would find myself in.

# My AN Diary

## 27<sup>th</sup> November 2017

I woke up the next afternoon in the ICU. 90% of the tumour had been removed and there was no apparent damage to the facial nerve. In my left ear there was loud tinnitus, but I was utterly elated – the waiting was over and the outcome was the best that had been predicted!

What then followed was a week in hospital, recovering, resting and watching the snow falling outside. Within 24 hours I was out of my bed and within 48 hours I was climbing up and down stairs. I was amazed that I was not sick and not dizzy than before the op. It seems that after years of bad balance information from my left ear, my brain was not too shocked by the new situation.

On the eighth day a doctor took my stiches out, and announced I could go home, live normally and come back in 3 months for a check-up. Critically in the meantime I should not do any boxing or contact sports.

Needless to say, boxing was not on my 'to do list' but it was good to have this clarification.

## December 2017

I now realise that I did not give myself enough time to rest in the days after getting out of the hospital. It also became apparent that being alone was not helpful for a good recovery. It was great to have visitors, but just holding a conversation for 20 minutes was draining, yet when I was alone, I would worry about next steps. It was a difficult balance.



## My AN Diary

After a week I got up one morning and poured myself a glass of water, as I swallowed water came out of my mouth. Looking in the mirror I could see the issue; my face looked normal, but when I smiled only one side of the mouth moved. The left eyelid would shut, but lethargically compared with its neighbour on the right-hand side. Over the course of the day the symptoms became more pronounced and by the end of the day I could not close the left eye independently of the right.

The next day, back at the hospital, doctors were relaxed about the partial facial paralysis and assured me this was common in about 5% of cases where the facial nerve was not damaged in the operation, it gets inflamed and has reduced functionality for a while. Indeed, the surgeon was pleased, as this was an indicator that they had got as close as possible to the nerve without damaging it. I was given a week's course of steroids and a sheet with about 20 facial exercises on it. I was advised to 'exercise the nerve with high frequency' and that in 2-3 weeks the movement would come back.

I started to follow the instructions, standing for hours in front of my mirror trying to do the exercises. It was a bizarre experience; the right side was normal but literally nothing would happen on the left. It felt soul destroying, but I did my best to ignore my feelings and follow the instructions. I developed a routine of spending 20 minutes after each meal in front of the mirror doing the exercises.

A week later I had finished the course of steroids but there had been no change, not a millimetre of improvement in the face. However, I had settled into the exercise routine and, at least, the symptoms had not got worse.

Despite reassurances from the doctors about it being safe to fly home for Christmas, the engineer in me thought the train would be safer. Eventually on the 19<sup>th</sup> December I got up early and took the 7am train from Munich. By that evening I arrived in London.

# My AN Diary

Learning to not 'over-do' things, the following morning I wanted to take a taxi to Euston. On getting into the taxi, the driver told me to get out; he didn't want a short fare. For the first time in the whole ordeal, I had a 'sense of humour failure'. I removed my hat – pointed at the missing area of hair on my head and told him, "I know it is not far, but I've just had brain surgery!" I told him what to do with his taxi and walked to Euston.

Back at my parents' home and two weeks after the onset of symptoms, the partial facial paralysis very, very slowly began to improve. This gave me a massive morale boost, and seeing the positive impact of the exercises encouraged me to continue. It confirmed that the rate of my recovery was somewhat in my control. By New Year my face was back to normal.

## January 2018

With my parents' support, I continued to recover. I took a regular walk, adding 100m each day. I also sought advice for special exercises to manage the dizziness. In mid-February, 8 weeks after arriving in the UK, I flew back to Munich. A few weeks later I had my 3-month MRI and check-up. All was fine and I returned to work.

## February 2018

Getting back in the office was easily the best day of recovery; I was so happy to be back and be 'normal'. I planned to return to work over an 8-week period. "That's an athletic pace", my GP told me when writing out the note to my boss. Sure enough, we had to extend it to 12 weeks.

## March 2018

I took advantage of only working part time and drove into the mountains. I knew I had been told not to ski for a year, but the snowfall that winter had been excellent, and I was determined to do a 'little test' to see if I could still get down a mountain. I ended up skiing all day every day for 3 days. I could still do it! Bizarrely I also found then and on many subsequent ski trips that skiing helps reduce my dizziness.

# My AN Diary

## May 2018

Over the following months I realised that the recovery was still on going. I was fitted for CROS hearing aids, which while not as good as having two ears, are helpful. I started working with a trainer to improve my fitness and my balance. I found concentrating for long periods in meetings hard, and often I felt the need to lie down in the afternoon. Work was gruelling with me pushing for, and getting, a promotion in the weeks after I came back. This might seem crazy, but I felt like I had climbed a massive mountain professionally in the years before surgery. It felt as if the AN had pushed me to the bottom. Now I was determined to not walk, but to run, back up the mountain to get to where I was before the AN.

## March 2019

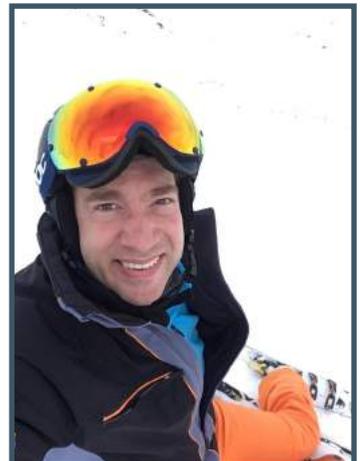
Waking up one morning I felt awful. I was beyond tired and was much dizzier than I had been in a while. After tests the doctors informed me that everything was normal.

I had to face that this time the issue was me. The original neurologist I saw, while missing the AN did get one bit of the diagnosis correct - I was pushing myself too hard and my GP warned me I was on a path to burn out. It was time to get the rest of the recovery on track.

I resigned and moved back to the UK; the sense of relief was overwhelming.

## February 2020

I am currently putting work on the back burner and prioritising my health, my family, my friends and my interests, like skiing and singing as I explore new professional directions. While admittedly still adjusting to the 'new normal' I feel much healthier and happier than I have in years. I have finally learnt that there is more to life than work. We should relish and enjoy our life, especially when you get a second chance.



# 12 in 12

*By Andrew Read*

I was diagnosed with an Acoustic Neuroma on 25 April 2017, the same year I turned 40 – nice birthday present NOT!

I had just got into running in the January then it all came to a sudden halt after diagnosis. I eventually got back running very steadily in September 2018. It was like starting all over again but this time I had more determination and stubbornness and a drive to succeed and nothing was going to stop me!

In 2018 I was also introduced to this brilliant incredibly supportive group called BANA. It was a massive relief to hear other stories that all AN warriors can relate to and to realise that this thing in our heads is real and not just made up as others may think.

2020 has been a very testing year for everyone but for me being able to get out running a few times a week really has been the best tonic and setting goals to keep my mind distracted from what's going on in the world right now.

So, while out running, drifting off in my little world thinking of ways to help the charity closest to my heart, I came up with this massive but interesting (or bonkers) challenge of '12 in 12'. Twelve marathons in 12 months – not all organised events – but I will run 26.2 miles on one day every month next year, somehow. This is definitely my biggest challenge to date.

This is my way of saying a massive thank you and giving my little bit to BANA for all the incredible support and encouragement, not only for me but for every AN warrior pre/post treatment. Positive Thinking Positive Outcome.

***Thank you Andrew for thinking of BANA. If you wish to sponsor Andrew please follow this link or contact BANA HQ.***

***<https://uk.virginmoneygiving.com/fundraiser-display/showROFundraiserPage?userUrl=AndrewRead12&pageUrl=1>***

# Fundraising while you shop

## Give as you Live

Do you use an iPhone? @Giveasyoulive's app is the easiest way to raise donations for us as you do your online shopping. Simply sign up, visit your store via the app and make your purchase. The retailer will pay a free donation to us as a thank you!



Find out more > [https://www.giveasyoulive.com/join/british-acoustic-neuroma-association-cio/1165065/0utm\\_source=charityfr&utm\\_medium=post&utm\\_campaign=FRBacktoSchool&utm\\_content-17aug2020](https://www.giveasyoulive.com/join/british-acoustic-neuroma-association-cio/1165065/0utm_source=charityfr&utm_medium=post&utm_campaign=FRBacktoSchool&utm_content-17aug2020)

## Smile.amazon.co.uk



Sign into smile.amazon.co.uk and nominate British Acoustic Neuroma Association as your chosen charity. In future when shopping use smile.amazon and BANA will receive a percentage of the cost of the goods you purchase.

## The Giving Machine



Set up a Giver account on TheGivingMachine and then just visit TheGivingMachine website, desktop reminder or mobile app and click on the retailer link you want to shop at. Purchases generate a donation which will show on your account summary once processed by our Machine.

# Wearing Blue for BANA—AN Awareness Day



# Wearing Blue for BANA—AN Awareness Day



# Using ZOOM

## Instructions for Joining a Zoom Meeting

*We know lots of you will not have used Zoom before; hoping this will be helpful to you should you wish to join an online group.*

### **Wi-Fi and sound**

Ensure you have Wi-Fi and you are connected to the internet.

Check your sound is activated and working.

Look for the sound icon at the bottom right on your screen. Click on the icon to adjust the volume or use the relevant F (function) keys at the top of your keyboard to turn the volume up or down.

### **Join the meeting**

When you see a Zoom meeting you would like to join, there will be one of two ways to join. You may be asked to register (this is usually for the bigger meetings or webinars). A link will be available when the meeting is advertised. Once you have registered you will be sent a link for the day and time of the meeting. With smaller meetings let us know you wish to join and we will send the link to you. Again, on the day, click the link and you will go directly to the meeting. You do not need to sign up to Zoom you can simply join us at the time on the day of the meeting.

Zoom has been made a lot safer now with more security and features, and we encourage you to join us.

### **Basic functions within Zoom**

Familiarise yourself with the few simple icons and features as below:

See taskbar at bottom of Screen: (Please ignore 'participants' 'record' and 'invite' icons)

**AUDIO:** Bottom left is your microphone so when not on mute you can be heard.

**VIDEO:** Bottom left - one icon in - is the video icon which you can click on to turn off if you wish not to be seen temporarily.

# Using ZOOM

## CHAT:

1. You can ask questions using the Chat function – As an attendee, **Chat** will be in the controls at the bottom of your screen.



2. When you click on Chat, the Chat window will appear. It will be on the right if you are not in full screen. If you are in full screen, it will appear in a window that you can move around your screen.
3. Type your message and press **Enter** to send it.

You can also select who you would like to send the message to by clicking on the drop down next to **To:**.



**REACTIONS:** Please do use the 'reactions' icon to give thumbs up or applause if you'd like to show that you are learning something useful and enjoying the session.

**LEAVE THE MEETING:** You can leave the meeting when you want. Bottom Right.

**BREAKS:** You can leave and re-join the meeting whenever you wish.

# Walking for Charity

*By Jamie Carson*

"There's a big gap between your ears," she said. Hahaha. Something I'd heard before? "I need to refer you to the NHS." Fast forward two years of appointments, tests, watching and waiting and the operation to remove my AN was scheduled for the 1st July 2019.

Highly delighted, my surgeon reported the complete removal of my AN. He wasn't the only one highly delighted. So now to recovery and the thought of the sun on my face, walking my Jack Russell around the local beauty spots spurred me on. It wasn't going to be that simple. Two CSF leaks led to further operations and combined with other complications, this resulted in almost a month in hospital.



But soon I began to walk just a few metres, and then a few more. The wife, the sunshine and my little pooch willed me on. Before long, I was gently achieving a couple of miles and that's when 'The Charity Walk' was born.

Aiming high was always a thing with me. I've been a racing cyclist most of my life and I've always loved pushing myself and competition. So, a big challenge was in order. I chose to walk the length of the Leeds Liverpool canal (127.5m) in the week coinciding exactly a year to the date of my last week in hospital.

Preparations and training began. But so too did COVID-19. Social distancing was almost impossible on the canal towpaths as were the scheduled overnight stays. So, a new route was hatched. I would walk 18.5 miles per day for seven consecutive days. Friends volunteered to join me and the momentum grew.

# Walking for Charity

Sponsorship came in thick and fast as I launched my intentions on social media. As BANA relies heavily on subscriptions and fundraising events, it was important for me to do something to help and say thank you. Including a second charity, seemed to me, to widen the resonance with sponsors. The Alzheimer's Society was close to my heart, so they were chosen to share the proceeds 50/50.

The week dawned. I had spent a king's ransom on blister care, foot powder, special socks and new boots. Nothing was going to scupper me. And so, off I went, 6am every day and back in time for a latish lunch and to post "today's walk low down with pics" on social media. Posting every day kept up the momentum as someone new stumbled across my post and pledged cash.

Day seven. My feet were so sore. The fatigue was beginning to get the better of me but I pushed on. Walking the last few hundred metres towards the pub car park finishing line, I could see in the distance, a crowd cheering and waving, a banner, bells ringing and some kind soul had bought me my first pint. As I broke the blue ribbon stretched across my path and took my first gulp, the feelings of elation were overwhelming.

Total raised: **£5,577.80**. Thank you to everybody who supported me.



# BANA Webinars

*We are very grateful to BANA member Chris Richards for this article based on the BANA webinars which took place to mark Acoustic Neuroma Awareness Day. Chris attended two of the three webinars and reports below. If you are a member of BANA and would like to watch them, they are available on the BANA website.*

## "Management of AN in Covid-19 Pandemic"

*Professor Simon Lloyd, Salford Royal Hospital.*

Professor Lloyd is a consultant at Salford Hospital Manchester and talked about the way they had been managing their patients during the COVID-19 pandemic.



He started with a description of the COVID virus and the timeline of the pandemic as it developed over the last 6 months, highlighting that at this point in time the number of cases going into hospital is low and they are beginning to resume some of the more regular activities. While he did suggest that the ear may possibly be affected by the virus due to the lining of the middle ear being the same as that of the respiratory tract, he said there was no real evidence for this and certainly no reason why anyone with a Vestibular Schwannoma should consider themselves at more risk for COVID-19 than anyone else, unless they had any of the recognised risk factors.

Professor Lloyd said that the pandemic had changed the way they do everything at the hospital, however this has not affected the management of Vestibular Schwannoma in any way although there has been some impact in relation to decision making and timing, as the average age of VS patients is 56 and many are older, and this, along with any co-morbidities, needs to be taken into account when making decisions about treatment.

There has been an emphasis on 'virtual' clinics where patients have consultations over the telephone or by video.

## BANA Webinars

This works very well for patients who do not need to be examined, which is usually the case for follow up consultations. When patients do visit the clinic, they will find staff will be wearing 'blues' plus masks and gloves, and if any procedures need to be carried out, particularly if they involve generation of aerosols into the atmosphere, full protective equipment (PPE) is required and consulting rooms are cleaned after each patient. Professor Lloyd did also comment on the difficulties PPE can cause for those with hearing difficulties. He reported that at Salford scanning has resumed, but the process is slower as here again cleaning needs to be carried out between each patient.

In Salford, surgery resumed at the end of June, and this also raises some issues, such as working out how to use equipment such as microscopes and drills effectively and safely. They are learning to develop strategies to make things work. Radiotherapy has also resumed, although this will also be impacted by the need for protection and cleaning. Decisions around all treatments need to be made in relation to priorities, and in relation to this, Professor Lloyd did emphasize the slow growth of Vestibular Schwannomas and that a delay of a few months is unlikely to make any difference to the eventual outcome.

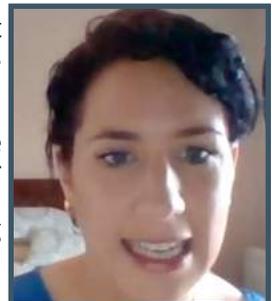
Professor Lloyd's talk was very interesting and he answered questions from the audience at the end.

### **'Facial palsy in Acoustic Neuroma'**

***Shaunagh Farragher, Speech and Language Therapist working in Belfast***

Shaunagh works as a speech and language therapist and has a special interest in treating stroke patients and facial palsy.

She began her talk by describing the facial nerve which is the 7th cranial nerve, responsible for movement of muscles in the face controlling facial expression, speech and articulation, eating, drinking and taste, production of saliva, eye closure and blinking and eye watering.



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The nerve has many branches and recovery in different areas of the face may be variable. There are 43 different muscles in the face, all producing very subtle and intricate movements- it takes twelve muscles to smile, eleven muscles to frown.

She said that 10% of Acoustic Neuroma patients report a degree of weakness usually following surgery; this is much less than twenty years ago when the number was nearer to 48%. This is because, although during surgery for removal of Acoustic Neuroma the facial nerve is rarely directly implicated, it does sometimes become 'insulted' or mildly damaged as it is 'in the way' of surgery. This often causes a loss of use, but this will often recover slowly and full recovery can occur in 3 – 4 months post-surgery. For this reason, early treatment is not advised.

### Early management

In the early days patients are recommended to undertake eye care using drops as often as necessary and gel at night, exercises are discouraged, but it is important to support and protect the face through use of glasses and scarves, resting of the facial muscles for some time during the day is important and gentle massage and heat are helpful in maintaining a good blood supply to the muscles. If the mouth is affected it is important to maintain oral hygiene and be very careful to keep the mouth clear of trapped food.

### Eyecare

Care of the eye is extremely important and patients must protect the eye as much as possible, being vigilant about any possible damage or infection and getting help from opticians or emergency department quickly if you have concerns. Strategies such as taping of the lower lid and taping the eye at night may be helpful (Facial palsy UK video <https://www.facialpalsy.org.uk/support/patient-guides/how-to-tape-eye-closed-adults/>). Using a bubble or eye patch can also be helpful and eye drops should be used as often as needed, along with gel at night. Manually closing the eye frequently to mimic the blink reflex is also protective.

## Synkinesis

For those who have a slower recovery synkinesis may develop. This results from the signals between the brain and the nerves becoming mixed leading to incorrect direction by the nerve. This can lead to unwanted movement and tightness due to the muscles being constantly innervated. Commonly the switch in response will be between the oral and ocular muscles, or the ocular/oral muscles such as eyes watering when you chew food. This process cannot be prevented, but can be helped using 'dissociation' exercises to try to tune the brain to reduce muscle activation, stretching muscles to relieve tightness and facilitate movement. Use of massage and heat, and Botox can maximise dissociation, but must be administered by a trained clinician who understands synkinesis.

### ***Therapy and assessment.***

When patients are first seen a formal assessment is carried out using a scale which measures resting symmetry, volitional movement and synkinesis. Surface electromyography (sEMG) is used to check nerve function; this is a pain free and instant test which provides an objective measurement. It is also important to take progress photos to show how the condition has improved.

As stressed above in the early days therapy is related to care rather than treatment. Measures such as massage and heat to relax muscles and stimulate blood flow, taping, gentle facilitated movement which aims to keep the balance between both sides of the face, are all important and some people find acupuncture helpful. It is important to celebrate small successes.

During recovery the aim is to guide the nerve and optimise movement, building on all of the small movements emerging. It is very important to maintain balance between both sides of the face, monitor for synkinesis and build strategies to help deal with the situation.

sEMG is a process which measures the behaviour of nerve activity. It can be used to provide a baseline measurement to provide biofeedback to

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help patients see what balance looks and feels like. For cases where the facial nerve is severely damaged there are some surgical options which may be considered after a year, and these include protection for the eye and various forms of reanimation.

### Therapy

Counselling to assist acceptance is very important as in the early stages it can be very difficult to imagine that acceptance may be possible. Patients are encouraged to feel that 'this too will pass' and to remember they are more than just their face. It is important to maintain pre surgery routines and stay connected with friends and family. We should all be aware if we look around that nobody is completely symmetrical, (despite what social media may suggest) – the two sides of our face are 'sisters not twins'.

Shaunagh spent a lot of time answering questions from the audience, emphasising the importance of care in the early stages, relaxing the face and taking time to 'switch off' the muscles through rest, along with the benefits of health and massage and gentle stretching, in a balanced way.

## Sandstone Trail Challenge

*By Sara Crosland*

8 a.m. Saturday 25<sup>th</sup> July, 2020. A warm, cloudy, humid morning with a forecast of mixed sunshine and showers. I was feeling happy. I was feeling confident. I was about to start running the entire length of the Sandstone Trail, 55 kilometres in length, 1,268 metres of ascent; an undulating path following sandstone ridges, made up of 225-million-year old Triassic sandstone. It runs from the ancient market town of Frodsham in Cheshire, to rural Whitchurch in North Shropshire. I had decided to run from south to north, as this would mean I would finish closer to home. I couldn't wait to begin. In October last year, I had the brainwave of running an ultra-marathon. Not just any ultra-marathon, but a hilly 100km one in the Lake District. I wanted to raise funds for BANA and Brain Tumour Research. Fundraising was going well.

## Sandstone Trail Challenge

At the start of the year, on the recommendation of a friend from my high school days, I enlisted the help of Jon Fearne, an endurance athlete coach. I hesitantly told him of my plans and received nothing but support and great guidance; he felt that my plans were within reach. I was nervous about working with him; he has worked with some awesome endurance athletes, and I feared I would drag his credibility into the mud! I seriously doubted myself. I'm hardly Paula Radcliffe and still battling fatigue, I was struggling to complete three 30 minute runs a week. However, with Jon's help I soon found myself training 5 to 6 days a week, whilst also working on core strength and balance. Quite honestly, I'd never felt better.

Then Covid-19 happened, and this event along with so many others, was cancelled. I felt utterly lost. I was still out training every day, but without having a focus and no goal, just stepping out of the door each day became incredibly difficult.

I decided to devise my own event, the Sandstone Trail Challenge. So, in July, I found myself at the stone archway in Whitchurch, that marks the official start of the trail. My good friend Cerries was meeting me at certain points. My long-suffering husband Neil was planning to meet me at roughly the half way point, for some moral support. I knew it was going to be tough, both mentally and physically. It would be the furthest I've ever run in my life. I would also be running alone. Just me alone with my thoughts for hours. Was this a good idea? Of course. Would I be capable of it? I think so; no, scratch that, yes, I was perfectly capable of it. You see, once you've been through the ordeal of a brain tumour diagnosis (or any other life changing illness), everything else by comparison is perfectly doable and really not so scary.

The route took me alongside waterways, through fields (some a little muddy, a few full of maize that was as tall as me, others filled with inquisitive cows!), along lanes, through farms, up hills, onto sandy trails, and along paths that were overgrown, or strewn with rocks and tree roots. It was a warm day, for the most part, except for the torrential downpour I encountered during the first half; this left me running with soaking wet feet for about 8 miles until I reached halfway, where I could change. I also endured insect bites and nettle stings, too many to count...

## Sandstone Trail Challenge

The second half was much harder psychologically. There were many miles of not seeing a single person. Paths were hidden beneath undergrowth, and navigating my way through some sections became a little tricky. My trail shoes were great on trails and fields, but as I ran some sections along narrow lanes, the lack of cushioning meant I felt every single impact with the ground. I pushed those negative thoughts to the back of my mind and picked a spot in the distance to aim for. Then another. Then another....



At one particularly low point, only a few miles from the finish, I read through the messages of support I'd received throughout the day. They really gave me the boost I needed to continue, and the final few miles were fuelled by thoughts of how I had felt as I lay in my hospital bed, throwing up and unable to walk unaided. How I would've given absolutely anything to be doing what I was doing now.

I crossed the invisible finish line in Frodsham 11 hours 26 minutes later, to be greeted by Cerries, Neil, my two sons Daniel and Alex, and of course, Hugo the dog. It took a little longer than I'd hoped, as I added an additional mile by missing a turn and had to navigate my way around herds of cows, extreme mud, fallen trees and climbing a very slippery Jacob's Ladder on my own on Frodsham Hill, which I was a little nervy about given there was absolutely no one else around; the alternative route was blocked due to a fallen tree! I felt strong.

In the process I had raised just over **£2000** for both BANA and Brain Tumour Research. I felt on top of the world and an enormous sense of achievement. Once more I had given the finger to fatigue and all the other issues I still suffer with as a result of my tumour and again proven people wrong. That gave me great satisfaction.

## Sandstone Trail Challenge

I loved the whole experience and I fear the endurance, ultra-running bug has bitten! But what would have happened if I'd just accepted the hand that fate had chosen to give to me? If I had accepted the balance issues and lived my life within the anticipated limitations? If I hadn't taken any risks or set goals and worked towards them? Well, I wouldn't have been running the Sandstone Trail, that's for sure. Life is all about choices. You can make your life whatever you want it to be. It all begins and ends with you.



I still suffer with the after effects of my Acoustic Neuroma, more than I want, less than it could have been. The thing is though, my future is bright.

You can watch my challenge at <https://www.youtube.com/watch?v=fJITvExBEqs&feature=youtu.be>

## Aerial Adventure

*By Amanda Hussey*

My grandson Jacob was due to turn 9 and with the world in lockdown we decided to book a family holiday as a party with friends wasn't going to happen. We chose a venue with lots of activities and started booking them:

- a birthday meal out
- mini golf
- trip to the pool
- and Jacob desperately wanted to do the aerial adventure - a walk through the trees 40 foot up in the air.

## Aerial Adventure

None of the available adults were keen to do it, so I said I would. I'd seen him do something similar last summer at the local lakes and had been toying with the idea of secretly having a go and then surprising him. My thought was if a 9-year-old can do it, then why not me? Now I can always find a reason to get out of doing something until a later date (procrastination is my middle name), but a promise to your grandson is a hard one to back out of. But as the day got closer, I was feeling a little apprehensive. So, as a last-minute thought, I created a Just Giving Page in the hope of raising maybe £50. The family thought this was a great idea.

The day before the walk I quickly created my page over lunch. That evening - to my surprise and joy - I'd already reached the total of £50, so I topped it to £100. The day arrived and we headed off for a late breakfast-prior to our adventure. The enormity of what I'd signed up for didn't hit me until the first obstacle of a tightrope walk, whilst looking down at my husband below in the woods. But here I was, perfectly safe and attached to a cable with Jacob in front bravely striding out.

I won't bore you with a blow by blow account, but there was a lot of throwing myself off of things and tree hugging each time I got to the end of the next obstacle. Half way round Jacob must have realised that I was struggling as I was grabbing hold of a tree trunk and looking off to the horizon to try and steady my wobbly head. He shouted out "Slow and steady doesn't win the race, but will get you there in the end". At that moment I've never been more proud of him. So, with gritted teeth we continued. On the final zip wire, I whooped with joy and clapped my hands as we descended over a lake to the final crash net. It took more than a few days for me to recover from aching limbs and fatigue. But finally, after a month I closed the Just Giving page with a total raised of **£210** plus gift aid!

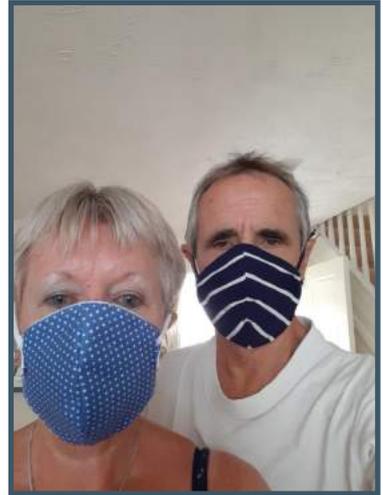
I can't believe that I managed to raise so much money on something I would have just done! All it took was creating a charity page and popping it on Facebook. Thanks to everyone who donated, I couldn't have done it without you.

# Masks to help BANA

*By Sue Sykes*

At the beginning of lockdown, being over 70 years old, my husband and I were mostly indoors looking for thing to do. I have always had a sewing machine and enjoyed sewing, so I started experimenting making masks, following YouTube videos.

I made them for family initially and discovered which styles were more comfortable. I tried to use recycled clothing for the masks and eventually I set up a Just Giving page for donations to BANA as I knew that in the pandemic, small charities would struggle to survive financially. BANA has been very helpful to me during my AN journey.



I made loads of masks and sent them to friends and colleagues asking for a donation if they liked them. To date I think I have raised more than **£400**.

Masks are so readily available now so I think my job is done! The photos are of my husband Robin and I modelling the masks and a selection of the masks I have made.

# Membership/Donation Form

Title ..... First Name .....Surname.....

Home Address .....

.....Postcode .....

Tel .....Email.....

I enclose:

Membership (£23 per year) £.....

Joint Membership (£30 per year) £.....

Donation £.....

Total £.....

I give permission for BANA to acknowledge my donation in Headline News magazine **Yes/No**

## 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.....

Dated.....

**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)

### Thank you for your help

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# Data Protection

## BANA Data Processing Statement for General Membership

As a charity that has a membership and provides services to people, BANA requires certain information to fulfil that provision. All of that information, or data, is governed by the laws of the Data Protection Act 1998 in how we may use and keep it, and it is our responsibility to explain this to you. By taking up a membership, you agree to our processes:

- When you join BANA, we will ask for information to be able to contact you and to provide the main services that are open to everyone. You may refuse to provide certain information at any time, but this may affect the provision of some services.
- If you would like to participate in other services that require more information, we will ask you for it as part of that service provision. This may include medical specific information, and we must ask for your permission to hold and use it, for that specific purpose.
- Your information will only be used and shared on a 'need to know' basis, with governance in place for how it must be used and disposed of by those using it.
- Your details will only be held on the BANA network of computers, and in hard copy at the main office.
- We will apply security to our electronic systems, and use locked cabinets where applicable. The office is in a locked, secure building.
- If you leave the membership, we will retain your contact details on a record of ex-members, to assist with accountability enquiries. If you have email, we will add this to an ex-members mailing list to inform of our continuing work. All medical specific information will be deleted. All financial data involving your membership or service provision will be stored for six years plus the current financial year, as required by HM Revenue & Customs, and will then be securely deleted or destroyed. We reserve the right to hold onto any correspondence or document where there may be a future issue, legal or otherwise, in the protection of BANA or a person.

With all of the information we hold about you, we will only ask for what we need to fulfil a service, and will not use any information for any other purpose, or without your permission, or pass it on to a third party. It is your responsibility to advise us if your contact details, name or status change.

BANA has and abides by a Confidentiality and Information Management Policy, which is reviewed annually if not updated during the year. There is provision under this policy for members to make Subject Access requests with regards the data we hold about them.

**If you do not wish to be contacted by a certain means, or wish to remove yourself from any services, please let us know. You may unsubscribe from an email list at any time.**

*We will try very hard to always ensure we are managing our services and your information appropriately. However, we are only human and would be grateful if you have any issues or concerns to contact the BANA office as soon as able to notify us. We will take all actions necessary to rectify problems.*

## **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.



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*Registered Charity No: 1165065*

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