

A portrait of Allysa Dittmar, a young woman with long blonde hair and blue eyes, smiling slightly. She is wearing a dark blue short-sleeved top with thin white vertical stripes and a thin necklace with a small circular pendant. She is standing in front of a red brick wall, with green foliage visible in the background to the left.

RN I:D

Company president Allysa Dittmar

Breaking Barriers

ACTION

information, campaigns,
services

PEOPLE

interview, opinion, diary,
experience

EXPERTS

biomedical, information,
technology



On their last day at Blanche Nevile secondary school, deaf students Kimberly (left) and Roumy, friends since they were eight, look forward to going to college. They were photographed by Stephen Iliffe as part of his portrait series at www.deaf-mosaic.com

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As the days get shorter and the nights draw in, we are all likely to find ourselves stuck inside more as summer fades. So I’m delighted to bring you your latest magazine issue full of insight, interest and, we hope, inspiration for the months ahead. **Dawn Dimond, Editor**

5 facts about RACHEL COX

1 I have worked for RNID for nearly 15 years, mostly for the Information Line. I can honestly say I love my job. We are often the first place someone will go to share their concerns, worries and fears about hearing loss. Information can be life-changing and I genuinely get great satisfaction from helping others.

2 We're a small team of only five and, on average, the Information Line deals with around 25,000 enquiries each year! During the pandemic we had extra support from five Regional Information Managers, which was vital in helping us expand our reach to those who needed it.

3 Recently, the top enquiries have been around equipment, audiology provision, tubing and batteries, equal access to information, benefits and masks/face coverings. We also support people who are experiencing feelings of loneliness and depression via our Tinnitus Helpline.

4 I live in Peterborough with my husband and two young children. In 2017, we bought a new house and started a massive renovation project - we're well on the way to having our dream family home.

See our new Information Line Q&A feature on p32

5 I used to be a competitive swimmer in my teens - swimming for the County, Midlands and at National level. This taught me many life skills like the value of hard work, high levels of commitment and dedication to my training of 2-3 hours before and after school, 6 days a week, from a very young age.



Action

CAMPAIGNS | INFORMATION | SERVICES



LIFE-SAVING SUCCESS

A new 999 video relay service which could potentially save at least two lives a year will be introduced for British Sign Language (BSL) users by next June, Ofcom confirms. RNID has welcomed the news, having campaigned with SignHealth and the UK Council on Deafness for the 999 emergency phone line to be accessible to BSL users since 2019.

The video relay service enables a deaf person to make a video call to a BSL interpreter, who will then relay the call via the phone to the 999 call handler.

Some of the details will be finalised over the coming months but here's what we know so far:

- › The service must be available by 17 June 2022
- › It will be available through a mobile app and website and users will not need to register in advance
- › It will be available 24/7 and completely free to use
- › All BSL interpreters will be registered and have appropriate experience
- › Emergency text relay and emergency SMS will continue to be available.

"We are thrilled with Ofcom's decision to make 999 accessible in British Sign Language. We are proud we have achieved something which will ultimately save lives." Roger Wicks, our Associate Director of Insight and Policy, is grateful to everyone involved

FIGHTING YOUR CORNER

How we're campaigning to bring down the barriers our communities face in society

Until now, SMS and text relay services were often the best option for Deaf people contacting 999. English has a completely different structure to BSL, so reading and writing in English can be difficult for BSL users – and especially in a stressful or dangerous situation. This can lead to delays in getting the appropriate support, which can have life-threatening consequences. In response to our petition of 874 signatures, Ofcom ran public consultations setting out the case for a 999 video

Photograph: Shutterstock

relay service and asking for feedback from telecommunications providers and also the Deaf community. We set up a Facebook group where BSL users could share their experiences and feedback and over 4,000 people joined. There was overwhelming support for providing BSL access to 999, and ensuring equal access for all to emergency services.

We're so grateful to all of you who provided feedback and helped us to achieve this life-saving change. We've encouraged Ofcom to keep working with the Deaf community until the service is up and running to ensure that it's fully accessible. We will continue to share opportunities for you to have your say along the way.



FIRST STEP IN BSL BILL

The House of Commons will debate the need for BSL legislation in January after a backbench MP introduced a BSL Bill.

Rosie Cooper, MP for West Lancashire, was one of 20 MPs drawn in the Private Members' Bill Ballot, which allows backbench MPs to bring forward a piece of legislation for consideration. She used the opportunity to propose that BSL is recognised in law as a language and that the government publish guidance and plans to ensure that Deaf signers can access services and receive information in their first language.

The Bill will receive its Second Reading 28 January, at which stage MPs will have to decide whether to agree

the principle of the Bill and allow it to proceed for further scrutiny.

RNID has been working as part of a cross sector campaign group led by the British Deaf Association (BDA) to campaign for the introduction of a BSL Bill. Between now and January, we will engage with MPs and Ministers to reinforce the importance of the legislation, and the difference it could make to the Deaf community. We will also support the Deaf community to lobby their MPs and have their say on the Bill.

Although it's unlikely that Rosie's Bill will make enough progress to become law (her place in the ballot means there is little chance the Bill will be passed in this session of Parliament), this is still a great opportunity to highlight the needs of the Deaf community. RNID will use this to work with the BDA and other charities to build support for the Bill in Parliament and to influence policy changes that make real and lasting improvements to services for BSL users.

Rosie Cooper, MP for West Lancs (below) in the House of Commons



Stay up-to-date with all our campaigns and find out how to join our Campaigns Network at: rnid.org.uk/campaign-with-us/

A gift that keeps on GIVING



David Leader from our gifts in Wills team explains why including RNID in your Will can help change the future

I joined the team at RNID in April 2021 because I have a close personal connection to hearing loss. In my short time at RNID, I've already seen the incredible difference that gifts in Wills make to people who are deaf, have hearing loss or tinnitus and, of course, it's a really touching and inspiring way of giving. As we plan for research projects that run long into the future, we need to know that we're going to have the income we need to support these. We also rely on gifts in Wills during times of financial uncertainty, which I think we can all appreciate is more relevant now than ever before.

That said, my primary aim is to make sure that everyone can easily make their Will, safeguarding their own wishes, and their family's future. RNID has recently partnered with Farewill – the largest online and telephone Will-writing service in the UK* to help you with this. You can make, or update, your Will for free with Farewill but we know that family comes first and you are under no obligation whatsoever to leave us a gift in your Will.

NOW AND IN THE FUTURE

Stephen (right), a long-standing RNID supporter, explains why he's kindly included a gift in his Will to

us and shares his personal story of hearing loss and how RNID has improved his life. We're all extremely grateful to Stephen and others who have left us a gift in their Will and helped to improve lives, both now and in the future.

If you would like to know more about Farewill, leaving a gift in your Will, or any aspect of RNID's work, please email giftsinwills@rnid.org.uk or call 0203 227 6034.

How a gift in your Will can make a difference:

- Fund research into life-changing technologies, like Stephen's cochlear implant.
- Provide information and support to people who are deaf or have tinnitus or hearing loss, to help them to overcome challenges and live a full and happy life.
- Campaign to change attitudes and make society more inclusive of people who are deaf or have hearing loss.

* Farewill's telephone service is available in England, Wales, Scotland and Northern Ireland. Farewill's online Will-writing service is available in England and Wales only.

I have always been a very sociable, people-loving person. As a music teacher, being able to organise and motivate people was an extremely important aspect of my life and the kind of activity that made me thrive.

From around 1975 I had increasingly intrusive tinnitus, followed by the loss of high frequencies in 1990. Just over a decade later, I became profoundly deaf. For years I struggled with hearing aids and it was only when I received a cochlear implant in 2006 that I became truly aware of the importance of the research projects funded by RNID. That's when I decided to leave the charity a gift in my Will.

I am very thankful for my cochlear implant and for the positive impact it has had on my life.

I've been especially grateful for it during the pandemic. When everyone is wearing a mask, lipreading becomes impossible so, apart from exercising more often and enjoying green space, my wife and I have stayed home. Life online has become even more vital, so we can all keep in touch through Zoom and all the other amazing ways that the internet provides.

With live cultural events suspended, I've been spending a lot of time on YouTube enjoying performances of familiar music. I've found lots of free downloadable music scores online and they act like subtitles for the music, so I can read what's going on in a performance.

My cochlear implant makes all this possible and everything in my life so much easier. When things return to normal, I just hope that many more people can experience the life-changing benefits of an implant.

That's exactly why I have left a gift in my Will to RNID – so that research into future technologies can continue, eventually allowing others to regain the soundtracks to their lives."

Stephen



HOW THE HEARING CHECK CAN HELP

Our new hearing check is an interactive tool on the RNID website. You listen to a series of recordings of someone saying three random numbers and key in what you hear.

Based on your answers, the check suggests whether your hearing is within a normal range or whether you may have hearing loss.

It's not the same as a full hearing test with an audiologist but it's a reliable way to find out if you actually need one.

HOW IT WORKS

The test measures how well you can hear the numbers over background noise. The level of background noise stays the same, but the voice gets quieter and quieter.

It's an effective way to check your hearing because many people with hearing loss find it hard to hear speech clearly when there's background noise going on.

If it suggests you have hearing loss, you'll need to

Check your hearing

see an audiologist for a full hearing test. You can download a certificate of your hearing check result to share with your GP. You can also subscribe to information by email about getting your hearing tested.

If it suggests that you do *not* have hearing loss, it recommends ways to protect your hearing in the future (such as using earplugs for loud music events).

HOW WE MADE IT

Our User Experience Team developed the hearing check with HörTech, a company that makes technology for hearing aid users. They also worked closely with our audiology, brand and technology teams.

The team developed a prototype and tested it with

We've launched a free online tool which lets you check if your hearing is within a normal range in just three minutes



people with hearing loss. They then used the resulting feedback to launch an improved version of the check on 17 May.

WHAT NEXT

To date, more than 24,000 people have taken our hearing check and around 57% of these either have (or may have) hearing loss. This means we're helping people with early diagnosis and intervention that may potentially mean less social isolation and greater inclusion.

The hearing check is part of a wider service called 'Get support online' with information to help people get, or make the most of, hearing aids. We'll continue to add new topics to meet the needs of everyone who might benefit.

and encourage your friends and loved ones to check theirs, like Gerry (right)



Gerry's story

When I was in my 20s, I went to lots of rock concerts and discos. I often had ringing in my ears afterwards but, at that time, we believed that the louder the music, the more you enjoy it! In my work as a lecturer, I often struggled to hear students asking questions but I had no idea I had a serious hearing loss.

Later, I was employed by the International Labour Organization (ILO), a United Nations agency for social and economic justice. I spent more than 20 years journeying around the world with the ILO.

In 1993 I had a meeting with the Vice President of Guyana. When he asked me for a comment, I was unable to hear him over the noise of the air-conditioner whirring away in the background. I was mortified; it was so embarrassing.

When I was on a home visit back to Belfast, I was invited to give a talk at a large conference hall with a high ceiling and terrible acoustics. The talk went well but, in the Q&A session after, a member of the audience asked me a question and I just I couldn't hear him. The audience began to murmur and giggle with embarrassment for me – I could feel myself becoming anxious and that led to my tinnitus

“Such a quick and easy way to check for hearing loss – everyone should give it a go, even if you think your hearing is fine. It recommended I get mine checked by a professional, so I will.”

Karen, Wiltshire



Gerry believes
an online
hearing check
could help so
many others



24,000

people have
taken our
hearing check

kicking in. I asked the Chair if he could repeat the question for me. This was another occasion when I wished the floor would swallow me up.

At the age of 52, I got my first hearing aids. If I'd dealt with my hearing loss earlier, I believe it would've saved me from many embarrassing moments. But because my work involved travelling from country to country, I never had the chance to address it. I'm convinced that an online hearing check, that can be used wherever you are, is a great tool to have.

After I retired in 2010, it was discovered that I had

a genetic disorder, known as MYH9 – and that early hearing loss is a feature of it. My younger daughter may have this condition as well. She helps with my hearing issues and together we're learning the fingerspelling alphabet and basic sign language.

On top of all of that, I'm getting older (now 73!) and my hearing continues to get worse.

This online hearing check is a fabulous development for my daughter, and many others. It will encourage them to get their hearing checked earlier – and not wait as long as I did! ►

To check your hearing, go to: rnid.org.uk/HearingCheck or to get further support, visit: rnid.org.uk/check

People

INTERVIEW | OPINION | DIARY | EXPERIENCE



Farrier Mark Rudge tells Margaret Rooke why the outdoor life is the only one for him

Horse power



Left: Mark living the outdoor life at his forge in Aylesbury in the Chiltern Hills

AN OFFICE JOB WAS NEVER GOING TO BE FOR ME. I saw the stress my dad lived under; on a train before my brother and I were up for breakfast, often home after we'd gone to bed, always with deadlines to meet. It wasn't the life I wanted.

Dad always instilled in us that you have to earn what you want; nothing comes for free. So, when I was 14, I looked through our local newspaper to find a weekend job and saw an advert asking for help in a stable yard. I started working there part-time and enjoyed teaching young children to ride horses and ponies and being around the animals.

I'd thought about a career in the army but, when I applied at 16, my medical flagged up a slight hearing loss. They could see from my records that there was a history of hearing loss on my dad's side of the family. The college predicted firearm use would increase how quickly my hearing deteriorated and they turned me down.

I don't wear hearing aids at work. It's a dirty job; hot and sweaty

My next idea was to become a vet but, in the summer holidays after my GCSEs, I worked full-time at the stables, out in the sunshine. I realised I didn't want to go back to school. As I started my A levels, I found myself staring out of the window all the time. I didn't want to be cooped up – I wanted to be outside.

I dropped out and got a full-time job at the stable yard. I got to know the farrier who came to care for and shoe the feet of the horses and ponies. I liked the idea of this physical work and I found a farrier to take me on for a four-year apprenticeship.

Dad wore his first hearing aids in his 30s. I remember everyone talking loudly around him when I was growing up. For me, the cue to getting my hearing checked was having to turn the TV volume up higher and higher, to the point where it was becoming uncomfortable for anyone else in the room. If there was a group of us sitting round a table, I'd struggle to keep up with the flow of conversation.

Whatever goes
against you in life,
you work through
it and keep on
doing your best

money for my current hearing aids, and I won't risk damaging them. But it's not just the money, it's the inconvenience of being without one if it's broken or if the battery goes. If I only have one hearing aid, I feel unbalanced. At least now I have my NHS aids as a back-up.

One problem with not wearing hearing aids at work is that if I don't have eye contact with the horses' owners, I have no idea they're talking to me. If they're on the other side of the horse and we have 500kgs of animal between us, or if I'm working around my forge or anvil, then I have no chance of hearing them. Before I had my hearing aids, some people thought I was stuck-up and arrogant because they'd ask me a question and, if I hadn't heard them, it would seem like I'd ignored them. Now, with any new clients, I pre-warn them that I'm partially deaf and ask them to either speak up or shout, and make sure we have eye contact so I can lipread. This saves embarrassment and miscommunication.

I think my other senses are more highly-tuned to make up for my lack of hearing at work. A horse can hear something coming a long time before we can. I've learnt to read their body language, so when I'm working on them and I feel them tense up or twitch, it makes me aware that something's changed or wrong. It's so important to make sure you have that awareness and understanding of animals before coming into this line of work – whether you're a farrier, vet, dog trainer or working in a zoo. You have to be switched on around animals because any of them can be unpredictable – from a domestic moggy to a tiger.

I was bullied at school but I inherited a mental fortitude from my dad: whatever goes against you in life, you work through it. All I need to do is keep on doing my best and being the best version of myself.

www.facebook.com/MarkRudgeFarrier



IN PERSPECTIVE

This summer has been a package of wonderful, unexpected holidays, with me managing preparations with the usual questions of how will I hear/not hear, along with, what about Covid? While managing the latter was mostly a matter of paperwork, getting tests and taking care, I prepared my hearing for travel by making sure my hearing aids and earpieces were wax-free, the charger was charged, its domes new and not torn. Naturally I couldn't prepare for all life's eventualities – but I discovered those depended on how I perceived my lot.

For example, as I approached the check-in gates on my way to Los Angeles for my nephew's wedding, I froze with fear looking at groups of travellers speaking animatedly with personnel. How would I hear over them to get myself checked in? Until a uniformed gentleman approached me

and, when I told him I was hard of hearing, his eyes smiling, he ushered me to the business class check-in, and whispered something to the woman behind the desk. From a distance she lowered her mask, spoke slowly and made sure I understood everything I needed to know. You see, I told myself, people want to be of help.

During the flight I wanted to hear the dialogue in the movies on offer as well as read the captions. However, I struggled, despite putting the earphones over my hearing aids. But lo and behold, there's hope out there because I discovered the entertainment system can be paired with mobile phones. And so I'll be writing Virgin Atlantic, suggesting they could go one step further and stream the sound to hearing aids which are themselves paired with phones. They might even increase their customer base!

During the wedding ceremony, the rabbi agreed to wear my ReSound mini mic. But I panicked when the wedding couple said their vows, far away from my personal amplifier. I shouldn't have! My nephew gave me my own copy of his speech and,

good as it was, the expressions on both his and his bride's face, and their body language, gave me all I needed to feel warm and gushy.

The festivities themselves were often accompanied by loud pounding music. As I stood with other guests trying to converse, I had moments of resentment – until I noticed they couldn't hear me either.

I realised I was lucky because I, at least, had an excuse for why I was no longer even attempting to talk.

Sometimes with a disability it can feel as if what is being affected by it is the most noticeable or memorable thing about an event. Maybe it's after the last 18 months of being at home, missing family, and bouts of isolation but this trip reminded me that sometimes it's everything outside of my disability that makes for a beautiful occasion – the smiles, helpful gestures, clinking glasses, wide eyes waiting for the vows to be spoken, and goodbye hugs. An overdue refresh, then, of my perspective and all the ways ability manifests itself.

Jean Straus

Dedicated to the memory of Nissim Marshall, who provided me with the subject matter for so many columns over the past nine years.

A fun day out?

Vicki, who is severely deaf, is a working mum with two young daughters

Going out with the children as a deaf parent is certainly an experience. As well as all the normal planning and packing for any child-related eventuality (can you ever have too many snacks?), we have a whole other level of stress in order to achieve a successful day out. The extent to which my deafness has the ability to affect – or sometimes even ruin – a day out depends a lot on where we are going, but also the attitude and awareness of the staff.

Outside trips like a zoo or gardens are unlikely to be a major issue, largely because there's not a lot to listen to, other than keeping the children safe and occupied. Anything museum or history based, though, is much more likely to cause me problems. It can really spoil a day out if we get somewhere and I can't

hear video or audio material, which can prevent me from joining in properly with the children. More worryingly, in some places, not having proper deaf alerting in place could end up as a safety issue. A while ago, I got stuck on a broken ride, in the dark, at a theme park and had no idea what was going on as I couldn't hear the voiceovers, or lipread anyone in the room. Luckily, the children were on another ride with family, but it was pretty scary to feel that vulnerable, even when I just had myself to look after.

I've found that the deaf awareness and basic kindness of staff has a huge impact on how included and welcome I feel. Several years ago, I had a horrible experience the first time I ever asked for help in a museum. When I requested a transcript for their audio tour,

the staff member told me I spoke "too well to be deaf". It really shook me up to be doubted, and feeling like I had to justify what was, at the time, a very personal element of myself.

However, that one person's response has been far outweighed since then by incredible staff willing to go the extra mile to help, or even just to treat my access needs as perfectly standard and easy to meet. Something I've not tried yet, but which several deaf friends recommended when going to get their vaccines surrounded by mask wearers, is to get a sunflower lanyard from 'Hidden Disabilities' to flag up that you have additional needs. These are now widespread enough to be recognised in shops and other venues, so staff can discreetly check what extra help you may need.

A gamechanger for me recently has been my discovery that, as a deaf person, I can often take advantage of discounted tickets for attractions. I'd

always assumed that such discounts were more for physical disabilities, in the same way as blue badge parking. However, a couple of years ago, with considerable nervousness, I booked my first disabled ticket for a day out. I went prepared with my PIP letter of approval (Personal Independence Payment, which replaced Disabled Living Allowance), convinced that someone would (again) not believe me. I needn't have worried – I wasn't questioned at all (my hearing aids seemed to be proof enough) and off we went into the attraction, a few pounds richer!

For most places, such tickets are full price, or slightly discounted, and the 'carer' ticket is free. Whilst I don't really love the implication that disabled people are dependent on a carer, in reality I've found that I'm normally with another adult when I take the children out anyway, so it's less of an issue. I've also found that the saving is especially welcome in places which have a big audio component, as I feel less annoyed about missing out if

I haven't paid full price.

Subtitling for audio and video material seems to be more widespread now, too. At a planetarium recently with my girls, they offered at least one subtitled showing every day, together with the discounted ticket, which was brilliant. Even if something isn't advertised, it's always worth asking ahead of time.

I've learned that, somewhat counter-intuitively, my deafness can have an impact on my enjoyment of a day out if there's too much noise. On a family outing to an open plan science museum, I was overwhelmed

within a couple of hours, with the background noise of hundreds of children playing with loud experiments all amplified by my hearing aids!

My final frustration is lack of choice. I hardly ever go to the cinema or theatre, largely due to lack of accessibility – and when I do, it's really hard to find subtitled showings, and almost impossible for children's films. I have, however, found that some of the smaller independent cinemas more than rival the multiplexes for subtitled screenings – and they tend to be far cheaper, so it's not all bad!

Here's my tips for enjoying a less stressful day out as a deaf parent:

Plan ahead – is there likely to be an audio element? If so, have a look on their website or email to find what provision there is in terms of subtitling or transcripts

If you're likely to be overwhelmed by background noise, have a plan – maybe an hour or two inside an attraction, with a break outside if you can
Look into discounted tickets if you qualify. Some places say the attractions require specific proof, such as a PIP letter; others don't

Consider getting a sunflower lanyard

Do some research and consider less likely options for subtitled film screenings – you may find some local hidden gems!

Want to know more?

For more information on what benefits (such as PIP) you may be entitled to, go to our website at: rnid.org.uk/benefits

Entrepreneur **Allysa Dittmar**, profoundly deaf since birth, tells Margaret Rooke how a distressing surgical experience led to her co-founding ClearMask, now employing 250 people, and earning her a place on the Forbes under-30 list of top innovators to watch

CLEARLY GOING PLACES

As I was being wheeled into surgery for an operation a nurse told me quite suddenly that, due to an administrative error, the sign language interpreter I'd requested to assist me wouldn't be present. I have been profoundly deaf since birth and this was shocking news, presented to me at a shocking time. Inside the operating room, I was unable to read the lips of my surgery team or see the expressions on their faces. Their masks hid all of this. I presume they gave me instructions, asked me some questions, maybe said a few words to reassure me – but I couldn't see any of it, not even a smile.

The whole experience felt dehumanising and unsafe. I was 23 at that time and, ever since I could

remember, I'd depended on visual cues, sign language, and lipreading every day of my life to connect and converse with others. Even for people who can hear, so much of communication is in the face. For me and others who have hearing loss, access to facial expressions is everything.

What happened to me in that operating theatre six years ago never left me. In fact, it launched my career in public health and advocacy. I knew I didn't want to go through another dehumanising experience, or have it happen to anyone else. There had to be an alternative to traditional masks that hide so much of our faces away, remove human connection, and leave us questioning what's being communicated and expressed.

I was born in New Jersey, USA, into a hearing

family; my deafness is the result of a rare gene. My father, who worked in our family's insurance agency for nearly his entire career, and my mother, who left her career to raise my older brother and I, did all they could to support me.

ACCESS TO THE WORLD

But I felt different, growing up. It wasn't easy being deaf in a hearing family and in a hearing-dominated world. I felt like the only outsider in many situations – socially, academically; even at home. Whether it was at the dinner table or on the school bus, I knew I was not like everyone else.

Looking back, the best way my parents supported me was turning to the deaf and hard of hearing community for guidance and support and choosing sign language as my primary language. They aimed to do all they could to help me thrive in both the hearing and deaf worlds.

They decided to send me to a state school for the deaf until I was five and then into mainstream education with sign language interpreters. There, my interpreter and I taught my teachers, classmates, and friends some signs. It wasn't perfect, but it made a difference. I was determined to do well in school and so many people worked hard to support me.

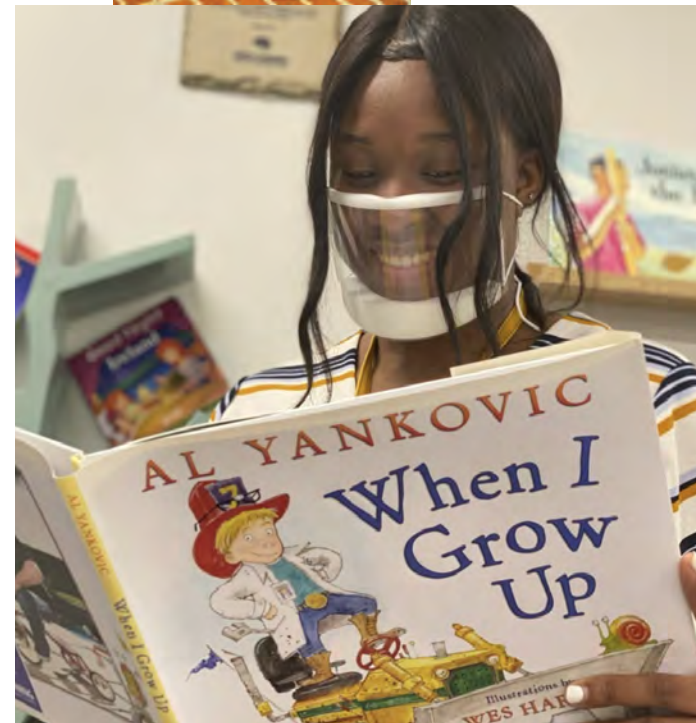
But ever since I was young, I knew my education experience was different. I had to put in more hours to catch up on what I may have missed or not understood during my classes, all the way through from elementary to graduate school. I never wanted to miss out on anything. I view that as everyone's fundamental right – access to the world.

Everyone who helped me during my education built my sense of confidence as a young deaf woman, capable of doing anything I set my heart and mind to do.

After high school, I attended the Johns Hopkins University to study for an undergraduate degree in public health. I was the first student there to use interpreters. It had never occurred to me to take a safer option and choose a school more experienced >



Left: Allysa, aged 5, was born into a hearing family. Below: ClearMask in use in the classroom



with deaf students. I always wanted to go to the best college, no matter how challenging it might be.

Many of my professors and classmates had never met a deaf student before, so it was a daunting and isolating experience at times. I spent many hours and significant effort educating those around me, but I realise this was teaching me to become a well-seasoned and practiced advocate for others. By showing professors and other students what I needed, I was explaining what others needed, too.

While at college I faced the deepest tragedy in my personal life when I lost my mother to suicide. We'd been extremely close, and my world turned upside down. I learnt in the worst possible way about the importance of mental health and equal access to healthcare, not only for deaf and hard of hearing people, but for everyone.

This immense loss could have derailed me, but I've always tried to turn my challenges into something for the good, as difficult as this can sometimes be.

I continued with a Master's degree and made the decision to study health disparities within the deaf and hard of hearing communities at the Johns Hopkins School of Public Health. I'd experienced barriers in accessing healthcare long before my surgery experience. Statistically, deaf individuals experience worse health outcomes than their hearing counterparts for many reasons, including a lack of access to quality communication in medical care. Nothing could be clearer: we need qualified interpreters and culturally competent medical staff who've had appropriate training; elements that I've rarely experienced in my life.

The other thing we need are transparent masks that show the full faces of caregivers, providers, and family. At Johns Hopkins, I organised a team of fellow students and alumni to design and create one. Our team spent three years on fundraising, research, customer validation and product development. We made hundreds of prototypes to test our design for comfort, fit, anti-fogging,

and mass-production. We finally submitted our product, ClearMask™ to the US Food and Drug Administration and received clearance in April 2020 as the world's first and only fully transparent mask approved by the FDA. We started shipping them out a month later.

KNOCKING DOWN BARRIERS

It turns out that our biggest customers have not been the deaf and hard of hearing communities but international, national, and state governments; hospitals who purchase them for paediatrics, older individuals and patients with dementia; schools who use them for early childhood education or specific student populations such as children with autism; and businesses who support a positive and safe customer experience and workplace. It's been incredible to see a growing, widespread recognition of how regular, traditional masks impede natural communication.

Of course, as we worked to develop our device, the team could never have predicted mask-wearing becoming universal because of the pandemic.

As soon as we saw the pandemic was becoming a full-blown public health crisis, our team met to come up with a rapid roll-out plan. We made decisions in just days instead of weeks or months.

I remember taking a flight a day before the crisis was formally declared a public health emergency in the US. I looked around and saw some people on the flight wearing masks. It seemed so odd. I had the realisation that masks were going to become the norm for some period of time and that this would be a significant communication barrier for all of us, but especially for deaf people. More than 55% of communication is visual for someone with typical hearing. This percentage is even larger for deaf people. For people who communicate through sign language, access to the full face is vital.

Altogether, we've sold over 17m masks worldwide with our message 'see the person, not the mask'. We've expanded from a team of just the four co-founders to more than 250 staff.

We've also established a charitable side to the business. We provide our transparent masks for free to organisations that need them most, including

schools, clinics, and social support groups. For so many different groups of children and adults, it's incredibly helpful to see the facial expressions to build rapport and understanding.

I don't think I've ever been as busy in my life as I am now, frequently working 80-hour weeks. My education has trained me well for working harder and adapting constantly to the environment around me. Just like I did at school, I educate others on how best to communicate and work with me on a daily basis, through interpreters, Zoom, and the written word.

Yet, even now, I have moments where I wish I hadn't gone through my experience in the operating room. It actually makes wearing a mask difficult for me, often reminding me of what happened six years ago. But I'm so aware that millions have been helped by ClearMask and I know that this experience has only increased my focus and resolve.

All my life, I've needed to knock down the barriers and challenges in front of me; to stand up for myself and others. As a result, I've been able to forge my own path as a deaf person and make my own impact in the world. www.theclearmask.com

Left: Allysa, President of ClearMask, with one of her co-founders and company CEO, Aaron Hsu
Below: a physical therapist wearing ClearMask



When Vera Brearey's progressive hearing loss started more than 40 years ago, one of the first things she did was book a short but intensive sign language training course. Although she loved it, she didn't pursue it – she explains why

It's 1977, I'm 24, and I'm standing in the kitchen of a London flat share. My friends are settling round the kitchen table for supper. They ask me how I got on at the hospital that day. "Not good," I said. "They told me I might go deaf."

I was in shock. I had developed tinnitus, gone to the doctor, and eventually been referred to the Royal Ear Hospital. As far as I was aware, my ears were otherwise functioning normally but the hospital discovered that I'd lost a slice of high-pitched hearing.

"It's quite possible this will get gradually worse" the doctor had said "and, given your age, you may end up severely deaf. You might not, but you might."

A friend from those days remembers us discussing if I would need to learn sign language. It seemed ludicrous; I could hear perfectly well. But the thought must have stuck in my mind because, a few years later, when I first noticed there were things I couldn't hear (bird song was the first

to go), I booked some leave and joined a sign language class for a very intensive week. I loved it. I loved how expressive it was. I was fascinated to discover how differently it was structured – a fully different language, not an imitation of English. Some of the teachers were Deaf and some weren't, but we immersed ourselves in sign as much as we possibly could for the whole five days.

And then? Well, I went back to work and life went on. I didn't forget about signing but I didn't follow it up either. I had other stuff to do; a life to get on with. And that's what happened for 40 years.

Of course, in one way, I was very foolish. If a crystal ball had appeared on that supper table, I would've seen that 40 years later I would be profoundly deaf – no hearing at all in my right ear and a bit of very low-pitched hearing in my left. The doctor's gloomiest predictions had come true.

FIRMLY ROOTED

Luckily (very luckily!), my hearing's slow decline was matched by many technological advances. When analogue hearing aids were not enough for me anymore, digital ones became available, succeeded by ever more clever models and, eventually, in 2017, a cochlear implant.

As well as these devices, there were lots of other technological advances, too, such as hearing loops, email, smartphones, texts, personal listeners, Relay UK and Bluetooth streaming.

They all meant that I was able to stay in the only place I've ever wanted to be – the hearing world. The experience of someone who loses their hearing in adulthood is very different from those who are deaf from birth or early childhood. By the time my hearing loss started to have any meaningful effect, I had a fully hearing life. I had friends, a husband, hobbies, passions, a career – all firmly located in the hearing world. I can't even conceive of what it might've been like to try to change that. I've read very moving accounts of people losing their hearing in adulthood, meeting

Deaf people, learning to sign, moving into the Deaf community and being immensely happy with their choice, but it was not for me.

I love hearing. I love sound. I love it that I can hear birds singing, my boots scrunching through frost on wintry days, my washing machine telling me that it's finished the spin cycle (all lost to me for years until I got my cochlear implant – I cried when I heard them again).

I love being able to chat easily to almost anyone. Being fluent in a language shared by almost everyone you meet means that you can connect with almost everyone you meet.

This Spring I had one of those moments when you reflect on all that is right with your world. I was queuing in my car at the entrance to a nearby country park. The driver of the car ahead of me was having a long conversation with the woman in the kiosk.

I was in no hurry, so I just sat back and watched. After a while, the woman in the kiosk started dancing about, waving her hands in the air, then bent over double with laughter. Intrigued, when it was finally my turn, I asked her what had been going on. It turned out she and the woman in front of me had kept their spirits up on previous wintry, Covid days by singing a different Christmas song every time they met. Today's song had been Slade's Merry Christmas Everybody.

Soon, I was bent double laughing too. We chatted for a while, I waved my barcode at her machine and she wished me a great visit. The moral? For me, the ability to share a joke with a random stranger is one of the things that makes life worth living. I'm glad I made the choice I did.

Read more about Vera's cochlear implant journey at: www.morethanabitdeaf.com
To find out more about cochlear implants, go to: rnid.org.uk/cochlear

A life in the hearing world



Illustration: Christopher Nielsen

tinnitus and me

Hilde Beate Berg from Oslo in Norway
tells Dawn Dimond how she deals
with the condition

For uplifting stories on mental health, follow
Hilde on Instagram @hildebeateberg

“ It started about five years ago when I was in my early 50s. The sound came as a marked, even, high-frequency hissing sound in the head. It came suddenly and remained as a constant sound. It has not changed over time. But in a way it has, since I mostly manage to focus away from it; then I do not hear it.

It happened in connection with a big transition in my life. I'd made a career change and was in the process of a new education and re-establishing myself professionally. It was a big change; an exciting but also demanding phase. I was studying coaching and sports psychology and I work now as a trainer in mental health. But I think my tinnitus came as a result of many years of stress – I used to be magazine editor. As a person, I am also quite enthusiastic and energetic. That's a good thing, but I may not always have been good at setting boundaries.

When the sound suddenly came overnight, I became desperate. I have always greatly appreciated silence. I love to sit on a pier looking at the horizon or stroll in the garden, listening to the birds. This is where I get my energy. But when the sound came, it was like being invaded, with no way to escape. I've always slept well, but now I would wake up in the middle of the night or early in the morning, when everything was quiet. Then it was difficult to fall asleep again. I got tired faster during the day, became more sensitive to sound and also had concentration problems. With my studies and establishing myself professionally all over again, this was a

very interesting, but intense, phase. However, I've always been solution-oriented, so this was something I just had to manage.

As a former journalist and now NLP (neuro-linguistic programming) coach, I'm interested in the power of words – how they define our reality and can limit us. In the beginning, then, I was a bit careful calling it 'tinnitus': it would be more defining and maybe stay longer, I thought. But it continued to stay – and tinnitus was what I had.

I decided early on that the sound should neither define nor limit me. In fact, I made an active choice: I chose to focus on the things I normally focus on in my life. I didn't make a big deal out of it. I understood that it would be a very limiting life if I had to constantly focus on this sound – it was something I had, not something I was. In parallel, my studies gave me greater insights into myself. I began to accept more

aspects of myself, even what I defined as weaknesses. That approach helped me to go more acceptingly into the sound. I chose to face it rather than meet it with resistance. I worked on becoming friends with it and not see it as an enemy. At the same time, I focused on other aspects of myself that were more fruitful to focus on. I also became more aware of how I handled stress, and adjusted. I tried to go a little slower where before I'd be jogging between chores.

I mentioned it to my close family but, mainly, this was something I worked on for myself. It wasn't that I meant to keep this hidden from the outside world but, because not paying attention to the sound was my coping strategy, it wasn't important to talk about it either. The more focus I gave it, the louder the sound.

As a mental coach, I think it's important to see opportunities in adversity. It's also something

I try to do in my private life. I've become better at dealing with stress and listening to myself, taking more breaks in everyday life. I have also become better at accepting that I am a human being; that it's okay to have bad days. I'm more than good enough. Before, I was more concerned with striving for perfection. The fact that I accept myself to a greater extent has made me stronger in dealing with other challenges. I have become better at taking care of my physical health, too.

But this is not just a happy story about everything being fine all the time. I'm just a person with good and bad days, like everyone else. I have a soundtrack in my life. It's there but it's not what I choose to focus on. That's my way of redefining silence.

I understand and empathize with everyone who experiences this condition. The most important thing is not to lose hope. There are several strategies for getting relief from it and everyone must find their own way of coping.

It helps to think that tinnitus is not something you are, but something you have, because we are so much more than this sound. This 'more' is what we can choose to give more space.

I think good quality of life is, among other things, about finding meaning in the little things we have around us, trying to be present in these, taking care of our physical and mental health, having a social network and not cultivating the ailments.

Today, tinnitus is not a big part of my life. The sound is probably as strong as before but, most of the time, I do not hear it.

Want to know more?

For confidential information and support contact our Tinnitus Helpline: 0808 808 6666; tinnitushelpline@rnid.org.uk

Photograph: Marika Mørkestøl



READ my lips

During this last difficult year, when face coverings became the norm, many of us discovered just how much we rely on lipreading, writes Molly Berry.

Face coverings have caused no end of communication difficulty for many people – with or without hearing loss – and it’s driven home just how much we all rely on lipreading in certain situations. If lipreading is essential to your needs, have you ever considered improving your skills, meeting new people and generally sharing your experience of hearing loss?

If so, now is the time to enrol for a new teaching year of Lipreading and Managing Hearing Loss classes run by Atla (Association of Teachers of Lipreading to Adults). There are in-person classes nationwide, as well as online, so you can be sure to find one that suits you best. If necessary, you can even ask your employer for time off

to attend a class if it clashes with work, as this is considered a ‘reasonable adjustment’ for employees with hearing loss.

Classes are great fun, and really do make a difference to how well you cope in a lot of different situations. You’ll meet others with similar experiences, share tips and stories, find out what you’re entitled to (such as the Access to Work government scheme to give you the equipment you need to do your job), and how to get equipment to keep you safe at home (did you know that the fire brigade will fit you a smoke alarm with a vibrating pad for under your pillow, to wake you if it should go off at night, free of charge?). You will also learn many communication tactics, and checking strategies that can help a lot in everyday life – such as wearing a sunflower lanyard to indicate you have a hidden disability; ways of wearing a face covering

without hooking them over your ears, or knowing that you’ve every right to ask people to lower their face covering to speak to you as long as social distance is maintained.

But perhaps most importantly, we laugh a lot in lipreading classes; it’s good to laugh together.

Many of us have reassessed our lives in the last year, of course, and if you’re considering a career change, for instance, then now is also the time to enrol on a training course as a lipreading tutor. It’s a great, fulfilling job, and one of the few where hearing loss is an advantage – but there is a desperate shortage of qualified lipreading tutors.

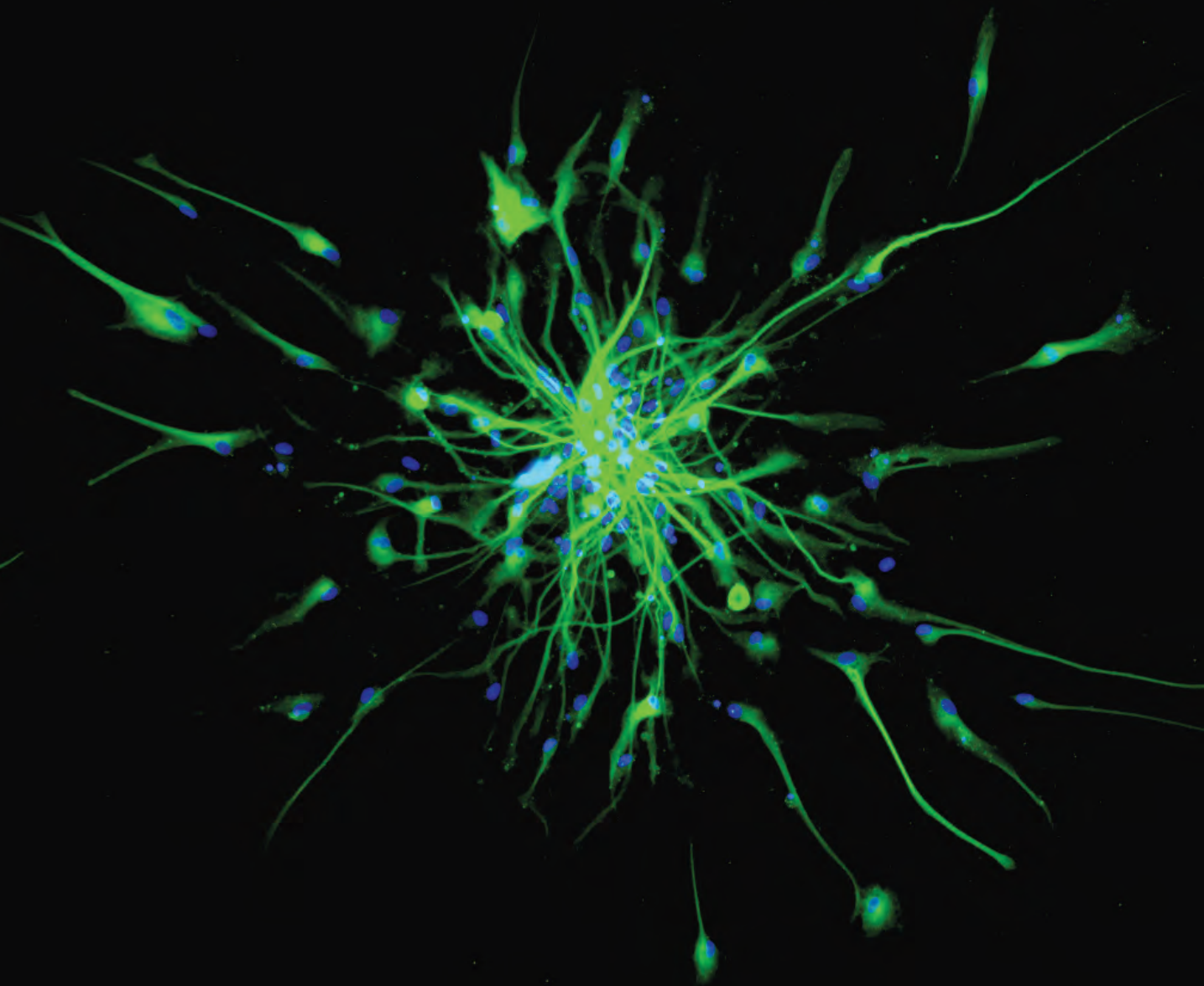
City Lit college in London has a training course starting in October and mostly home learning, with only a few visits to the college.

Contact lipreading@citylit.ac.uk for more information.

For classes nationwide and for information about online classes, go to www.atlalipreading.co.uk or Atla’s Facebook page

Experts

BIOMEDICAL | INFORMATION | TECHNOLOGY



Researchers around the world are making new discoveries about the biological causes of hearing loss and tinnitus. We're learning more every day about how the specialised cells needed for hearing within the cochlea are formed, and how they actually work. This research is providing vital insight into ways of potentially treating hearing loss and tinnitus.

But discovery research is just the first step. It can then take up to 12 years to turn these ideas into an approved medicine. First, scientists have to search libraries of tens of thousands of molecules to identify those that have the desired biological effect. Even then, a selected molecule's structure may need to be fine-tuned to optimise its performance.

Next, researchers will need to test the treatment in laboratory models to ensure that it's safe, that it protects or restores hearing in the way they expect, and to figure out the best way of getting the drug into the cochlea so that it reaches the right cells, at the right time, and in the right amounts. This 'pre-clinical' stage can take around five years and only after this can the treatment move along the drug development pipeline into Phase 1 of clinical testing.

Over the next 12 months or so, the treatment is tested on 100 healthy volunteers to check that it is

safe. In the next, Phase 2, trial it's tested on a larger number of people to check it's effectiveness and assess the dosage needed. This can take up to two years. In the third and final stage of clinical research, the treatment is then tested on an even larger number of people, generating the data needed to gain permission from regulators to market the treatment. This stage can take up to four years.

Hearing treatments There are 79 treatments currently in the pipeline for hearing loss and tinnitus – and five of these are at the most advanced stage of clinical testing (Phase 3). They include treatments for tinnitus, Ménière's Disease, sudden onset hearing loss and reducing hearing loss caused by cisplatin, a common cancer treatment.

There are 11 treatments at Phase 2, including those that aim to trigger the regeneration of damaged hair cells in the cochlea. Hair cells are the 'microphones' of the cochlea; damage to these cells is a common cause of hearing loss, so being able to re-grow them would be a real game-changer in restoring hearing.

The remaining treatments include seven at Phase 1 stage and 56 at the start of the pipeline in pre-clinical development.

Dr Ralph Holme, our Director of Research and Insight, looks at the development of new treatments for hearing loss and tinnitus

How we're fuelling the pipeline

- We're funding research that will advance our understanding of the causes of hearing loss and tinnitus – knowledge that will fuel the pipeline with new treatments.
- We're funding PhD studentships and early-stage career fellowships so that there will be more research scientists able to work on advancing treatments.
- We're working across the research ecosystem to identify what may be blocking progress and find solutions to speed things up.

Gene therapies There is growing interest in developing treatments for genetic forms of hearing loss, with 13 gene therapies in pre-clinical development. The aim would be to introduce a working version of the faulty gene causing hearing loss and would be particularly effective if someone is treated before their hearing significantly deteriorates.

Several genes are being targeted including OTOF which codes for a protein involved in transmitting signals from the sensory hair cells in the cochlea to the auditory nerve. There's also potential to introduce a working copy of the gene that encodes a protein called connexin 26 (as defects in this protein is one of the most common causes of inherited deafness).

Challenges ahead The good news is one in four new treatments for hearing loss and tinnitus have entered the pipeline in the last three years. However, there are challenges to how fast things progress, including how difficult it is in a lab setting to mimic

the wide range of types of hearing loss seen in the human population. This means that researchers may develop a treatment that appears very effective in their laboratory models but then fails to live up to its promise in clinical testing.

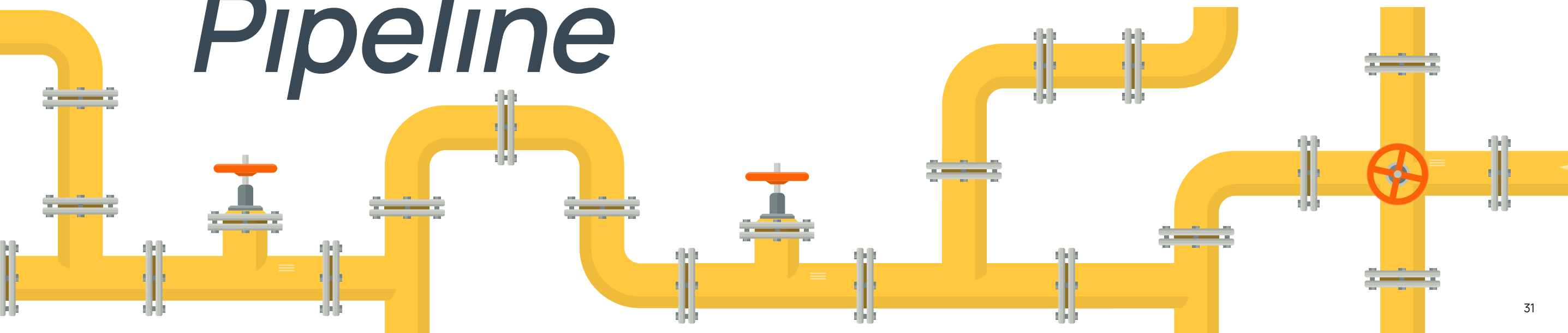
Tests are also needed that can indicate whether a treatment is having a biological effect (such as a change in the level of a protein in the blood). Without such tests, researchers are left in the dark when a treatment fails to work as expected.

Perhaps the biggest challenge of all is identifying people who have the type of hearing loss the treatment has been designed for – there's no point giving someone a treatment that regenerates sensory hair cells if the reason for their particular hearing loss is a damaged auditory nerve. Better tests are needed to determine the cause of an individual's hearing loss so that the right treatment can be given. This is a likely reason why many trials of tinnitus treatments, for instance, have been unsuccessful to date.

These challenges aside, there's every reason to believe that, with a diverse range of innovative treatments in clinical development and an increasing number entering the pipeline, new treatments to prevent some types of hearing loss, restore hearing and silence tinnitus will become available in the next five to ten years.

For more information about our biomedical research and the difference it makes go to: rnid.org.uk/research

In the Pipeline



A problem shared

Whatever your question or problem relating to hearing loss or tinnitus, our Information Line team is here to help

I've found the lockdowns of the past 18 months particularly stressful and have noticed that my tinnitus has increased. What can I do?



Rachel

There is a big link between stress and tinnitus and many people

notice a change in their tinnitus if they're going through a particularly difficult time or have raised anxiety levels. Cognitive behavioural therapy (CBT) can help people to manage this.

When we're low or upset, we often fall into patterns of thinking and responding which can make us feel worse. CBT helps us notice and change problematic thinking styles or behaviour patterns so that we feel we can cope better.

A therapist will encourage and support you to challenge your ways

of thinking and feeling about tinnitus, and find the best way for you to deal with it. Research has shown that it can have a positive effect on tinnitus management and CBT is recommended in the National Institute for Health and Care Excellence (NICE) guidelines for tinnitus. Your GP can refer you or you can refer yourself directly to an NHS psychological therapies service without a referral. If you can afford it, you can choose to pay for your therapy privately.

A regular relaxation routine can also help to reduce stress levels. As you become calmer and more relaxed, you may find you're less aware of your tinnitus or find it easier to manage.

The smaller hearing aids become, the more difficult it is for the wearer with manual dexterity problems. I know arthritis sufferers who, living

alone, have given up using their tiny hearing aids. Where is the research (and the advertising) for sensibly-sized hearing aids for the less than nimble-fingered?



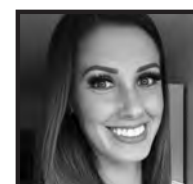
Franki

More could be done to educate hearing aid wearers (and even some professionals) about existing solutions for those who struggle with manual dexterity. As you rightly say, we don't want people to give up wearing them over something like this. One aspect that could prove to be revolutionary in the future is rechargeable hearing aids (as changing batteries is a particular problem). Unfortunately, this technology is only available privately at the moment but, as we see improvements to it and a

reduction in cost, we could see this moving to the NHS at some point in the future.

We're currently reviewing some of the information we have on our website and we'll be sure to review what information we provide for people with manual dexterity problems or sight loss.

My husband has stopped wearing his hearing aids because he's flipped them off with his mask so many times – what's the solution?



Vicky

We've had a lot of enquiries during the pandemic from

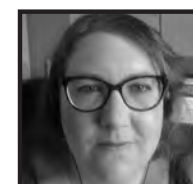
people having difficulty wearing a mask and hearing aids, so we've developed some extra resources on our website that may help, including these useful tips:

- Face coverings that tie around your head and do not touch your ears will help keep your hearing aids or cochlear implant processor secure.
- If you have a face covering that has elastic straps, try a mask extender, which you use to link the straps at the back of your head. You can buy these, make your own, or try something similar by adding an extra piece of material to tie the straps together at the back of your head.
- Try to only remove your face

covering when you're in a place where your hearing aid or cochlear implant processor could be easily found if it falls out.

- If you're concerned about losing your hearing aid or cochlear implant processor, consider using safety line or retention cords (available from RNID Connevans).

My dad wears hearing aids but still needs to have the TV volume very loud and now his neighbours are complaining. Is there anything we can do to help him?



Rachel

Sometimes people can find that hearing aids alone are not

enough and they may also need assistive equipment to work alongside to help with things like TV volume. TV listeners allow you to listen at a volume you're comfortable with, separate to the TV speaker. This means your father can listen at a volume he prefers without disturbing anyone else watching (or next door!).

Some listeners also have features to help him hear the sound more clearly, including tone control and speech enhancement. We've

partnered with Connevans, a leading supplier of assistive hearing technology and products are available at: www.RNIDConnevans.co.uk

I have a build-up of wax which needs removing professionally. My GP says I need to pay privately for this; is this true?



Jess

Primary care and community ear care services should offer to

remove earwax for adults if the wax is contributing to hearing loss or other symptoms, or if it needs to be removed in order to examine the ear or take an impression of the ear canal, as outlined in NICE guidelines. We've had many similar enquiries to yours so we have now updated our website with information on what to do if NHS ear wax removal services aren't available in your area: www.rnid.org.uk/take-action-if-nhs-ear-wax-removal-services-arent-available-in-your-area/

This page includes our template of a letter you can use to write to your MP and a short form to let us know about the problems you're experiencing in your particular area.

For details of how to contact our Information Line, see back cover. Read more about Info Line manager, Rachel Cox, on p4

TECH TIME MACHINE

To celebrate 110 years of RNID history, **Kevin Taylor** looks back at over 30 years of assistive technology.

A smartphone would have seemed very futuristic when I joined RNID in the spring of 1988. Back then, mobile phones were just starting to make an appearance. The size of a brick, unaffordable and cumbersome, you had to pull out a long telescopic aerial to get decent reception. Accidentally poking someone in the eye while on a call was a distinct possibility!

Apart from voice calls, they didn't do much else. They generated so much radio frequency interference that hearing aids would buzz loudly when anywhere near them.

Today almost everyone has a smartphone and most work well with hearing aids. They are the cornerstone of everyday life and play an increasingly pivotal role in accessibility, from speech-to-text apps to video calls, signing and captioning.

THE DIGITAL UTOPIA

The pace of technological change that led to smartphones and much of the tech we use today is astounding. The key breakthrough was the shift from analogue to digital technology; the binary language of ones and zeros that computers understand. If this hadn't happened, there would be no internet, no smartphones, no mass media, no artificial intelligence (AI), no social media, no apps, no digital hearing aids. The world would be a different place.

From left: screenphone,
Bellman alarm clock,
portable telephone amplifier



When I joined the RNID technology department, digital technology was limited to a few things; mostly wristwatches, alarm clocks and electronic calculators. Everything else was stubbornly tied to analogue.

Before digital, the radio spectrum in the UK could only squeeze in five (analogue) terrestrial TV channels. There were tantalising hints, however, of many new TV channels to come once the digital TV satellite and terrestrial platforms were up and running. With digital you can send and store so much more information than would ever be possible with analogue.

Digital TV was just the start; a multimedia 'utopia', driven by the internet, emerged a bit further on. It would deliver unlimited choice and the freedom to watch when and wherever you wanted on handheld devices – and with it came greater opportunities for accessible content, such as automated captioning.

It's a far cry from the 80s and 90s. Back then, subtitles were available, but only on some programmes through Teletext, an electronic information system that piggybacked on analogue TV transmissions. It was limited to pages of blocky text and graphics that took an age to appear on the screen.

For subtitles you had to press 8-8-8 on the TV remote. The TV would take a bit of time to think about it before they'd appear. Later TVs had Teletext built-in but, to start with, most didn't so if you wanted subtitles you had to buy or rent an expensive Teletext decoder and hook it up to the TV. Digital technology drove miniaturization

which, in turn, led to many possibilities including, in 1996, the first digital hearing aids. RNID campaigned for their availability on the NHS and in 2000, as a first step, they were made available as part of a pilot scheme before national roll-out.

All hearing aids are now digital. Many have advanced features with the ability to receive audio from remote microphones, TVs, and phones.

EVERYTHING IS CONNECTED

Digital technology also led to a revolution in how devices link to each other. Almost any device you can think of, whether it's headphones, speakers, doorbells, smoke alarms or hearing aids, many can 'talk' to other devices, and the outside world, wirelessly.

Up until the late 90s, this was the stuff of science fiction. Devices were bound by a physical cable which is much more limiting. I remember a visual signalling system (The Mountcastle), designed in the 70s for people with hearing loss and deafness which would flash the house lights whenever the doorbell rang. It was ingenious for its time but an electrician had to wire it in to the house electrics.

At RNID, the technology department thought there was a better way of doing it using wireless technology. A programme of work was set up to develop a prototype alerting system that would be easier and cheaper to install. The result was a wireless doorbell transmitter, wearable vibrating pager, and flashing light table-top receiver. This proof of concept came about long before Bluetooth and Wi-Fi were conceived of.

For more on RNIDs role in Technology see page 37

What would you like to see in our Technology section in future issues? Email dawn.dimond@rnid.org.uk with your ideas



From left: CL1 telephone ringer, T2 Sonido, AmpliComms baby alarm studio, Teleflash

SPEECH-TO-TEXT

At RNID public events, our technology zone always drew large crowds eager to know what could help them and what was in development. 'What I need is a small device that I can carry around that instantly translates everything you say on to a screen, a bit like the universal translator in Star Trek...' This sort of request often came up well before smartphones and speech-to-text apps. But whether then or now, brilliant minds in the tech industry have an uncanny track record of solving the 'unsolvable'.

BACK TO THE FUTURE

Now such future tech is here and now, what's next? By 2025, IP voice and data will have replaced one of the last bastions of analogue technology; landline telephony (PSTN). This is a certainty. But hang on to your amplified landline phones; they should still work by plugging them in to the analogue telephone adapter (ATA) socket on the router.

Next up, the ability for Bluetooth LE Audio (and no doubt future versions of Bluetooth) to simultaneously stream audio to multiple devices (including hearing aids). This technology may eventually replace hearing loops in public places altogether.

Beyond that it gets interesting. The next major development is the ability to control devices through our thoughts. This may seem far-

fetched, I know – but researchers have already developed a brain-computer interface (BCI) that enables people with paralysis to 'write' text on a computer screen, using AI to interpret neural activity from someone's imagined attempts at handwriting. However, the idea of 'machines reading our thoughts' might be a step too far for some and, depending on the application, raise ethical and privacy issues.

Then there's the combination of AI and robotics and what that may lead to; probably a bewildering array of robotic helpers. Perhaps one day your smart doorbell will message your walking, talking, captioning, signing, smart home bot who'll then answer the door for you!

Check out Boston Dynamics at bostondynamics.com or visit their YouTube channel to see some agile robots at work.

And finally... As this is my final article for the magazine, I'd like to say it has been a huge honour to have worked with some great people over the years in the RNID technology department. Many were pioneers who laid the foundations for much of the assistive tech we use without a second thought today. I raise a glass to them! 🍷

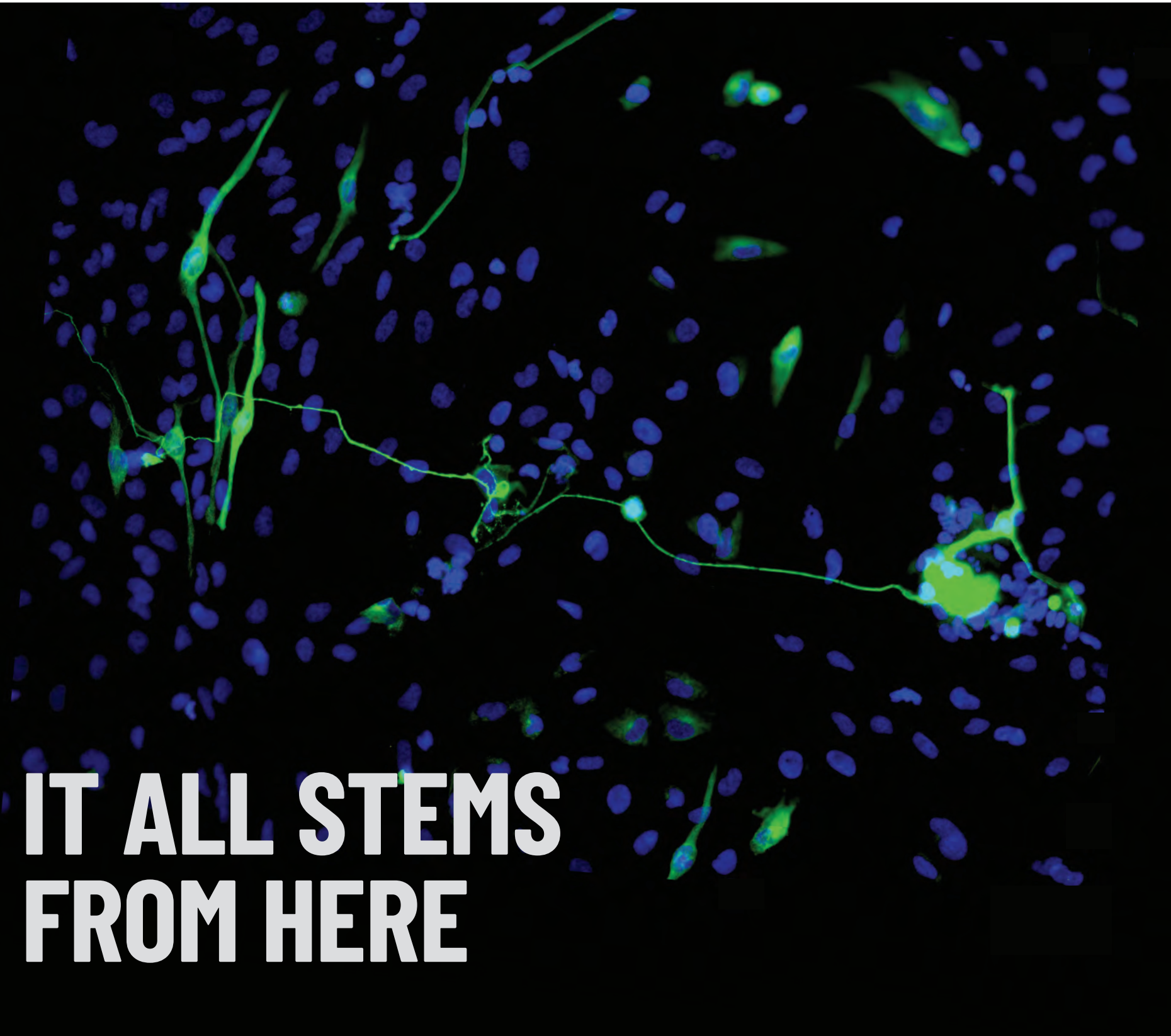
RNID's tech track record

RNID established a department solely dedicated to technology in 1947. Over the decades since, it's been responsible for many ground-breaking technological developments that have had a real impact on the lives of people with hearing loss, deafness and tinnitus. Staffed by multi-skilled engineers, researchers, and innovators, they all had one thing in common – an eye on the future. Here's a look back at some of their key achievements:

- 1971 Development of an experimental videophone service for calls between deaf and hearing staff. It allowed technical staff to gain insight into how videophone systems might benefit people with hearing loss and deafness in the future
- 1978 Technical development and operation of a Text Relay Service compatible with textphones
- 1996 Computer software to simulate how settings on a hearing aid picks out speech more clearly
- 1996-98 Software application to enable a desk-top computer to operate as a textphone
- 2011 Development of over-the-phone hearing check.

Technology staff also supported the development of national and international accessibility standards in broadcasting, communication, and assistive equipment such as smoke alarms for deaf people.

- 1955 Baby alarm for deaf parents
- 1967 Vibrating pad (sensory device placed under a mattress or pillow that vibrates when alarm goes off)
- 1969 Hearing aid battery tester
- 1979 Sentinel alarm – a battery-operated device that could detect sounds such as a doorbell
- 1985-2005 Various kinds of assistive listening systems such as the RNID Crystal Listener and Sonido personal listener, developed with Bellman and Symfon
- 2005 RNID Smoke Alarm System
- 2006 Screenphone, an amplified phone combined with a textphone developed with Geemarc Telecoms
- 2008 Tinnitus CD with bespoke compositions and masking sounds.



IT ALL STEMS FROM HERE

Dr Faizah Mushtaq, one of our former PhD students, is now clinical manager at Rinri Therapeutics, a biotechnology company based in Sheffield that’s developing a new stem cell therapy to restore hearing.

I am an audiologist by background. It was during the final year of my BSc degree in audiology when I was first introduced to the effects of deafness on the brain. I found this topic fascinating and was inspired to explore it further, encouraging me to start my Master’s degree in Cognitive Neuroscience. I then encountered the world of research for the first time and thoroughly enjoyed the research project I was required to complete as part of my studies.

This then led me to apply for my PhD to explore brain function in children with and without cochlear implants, which was funded by RNID. It’s simply not possible for researchers to continue working on hearing loss research without such appropriate resources and support. The experience was thoroughly enjoyable and taught me an enormous amount about how to successfully run high-quality research studies, paving the way for my career in hearing research.

The funding that RNID offered not only enabled me to conduct my research, but also allowed me to network with other researchers across the globe and attend international conferences to showcase my work. I then went on

to accept a position as a Research Fellow and, more recently, was successful in my application to UKRI’s Innovation Scholars Secondment award, which has brought me to my current role as Rinri Therapeutics’ clinical manager.

I have always been drawn towards working with people who have hearing loss; first as a clinician and then as a researcher, due to the highly personal nature of hearing loss and the way in which it affects people in their day-to-day lives. Sometimes it’s forgotten how very isolating deafness can be. Over time, it can often reduce people to a shadow of their former selves as it makes communication, which is so integral to daily life and which we often take for granted, very difficult.

Ultimately, it’s my interactions with individuals, be that patients in the clinic or participants taking part in my research, that motivate me. Their stories are a constant reminder of the way in which hearing loss can cut people off from the world, considerably impacting their confidence and mental health.

Most forms of hearing loss come from damage to special cells >

in the cochlea in the inner ear. Rinri Therapeutics is working on a cell-based treatment that replaces these damaged ear cells to restore normal hearing. My research involves finding a suitable way to determine how safe and effective this treatment is in patients. Specifically, we're investigating ways to objectively measure the health of our hearing organ, the cochlea, using cochlear monitoring technology. We're half-way through this exciting project and hopefully the results of the study will validate the use of this technique in Rinri's upcoming clinical trial. If successful, this work will have enormous implications for people with hearing loss which is very exciting. The long-term goal is for hearing to be improved without the need for hearing devices.

My favourite thing about a career in research is how fast-paced and dynamic it is, with no two days being the same. Running a research project involves so many different steps – from working with patients to testing cell samples in a lab – which means that the skillset you develop is fantastic. Although my research has varied over the last few years, my goal remains the same: to improve people's lives.

Follow the scientists

To find out more about the work of other scientists we're supporting, go to: rnid.org.uk/hearing-research

It's vital to continue working on finding better solutions for people, especially given the ever-increasing prevalence of hearing loss which is now slowly being recognised globally. This has definitely pushed the hearing research field in the



"Having suffered profound hearing loss at high frequency later in life and learning to appreciate the impact deafness has on an individual's life, I was happy to participate in the study if this could, in any way, improve the lives of deaf people."

John

right direction, encouraging the exploration of novel approaches. I'm confident that the field will make great progress over the coming years and that we're on the brink of some exciting new discoveries and treatments. ▀



"I was delighted to contribute to this important research project looking at ways to assess the health of the cochlea for future clinical trials of these incredible new therapies. Science needs data and, as a beneficiary of scientific advancements in cochlear implants, I was really happy to pay it forward."

Alison



In September, Rich Campbell took part in our month-long Challenge RNID event to run/walk 100km in aid of RNID.

Rise to the Challenge

There's no doubt that living with tinnitus can be tough at times. Mine started eight years ago, when I was 24. As I was driving back home from work, I heard a strange whistling sound. I thought there was something wrong with the car – until I got home and could still hear it. My GP later told me it was probably tinnitus and there was nothing that could be done.

I remember ironing my shirt for work a few days afterwards and being in floods of tears. Thinking back, the idea of having to manage and control it to a point where I didn't have to worry was overwhelming. Instead of understanding how to control my stress and anxiety around it, the tinnitus was taking control of me. Even when it wasn't 'spiking', the anticipation of when it would reappear was enough to lose sleep over!

I found that exercise helped a lot; just getting up and doing something. Lots of people I spoke to about tinnitus would tell me that they'd experimented with tweaking parts of their lifestyle to see what worked, and what didn't. Some found a change in diet helped, others found techniques that helped them sleep better. I've always been physically active but had never

really linked it with managing my tinnitus. Exercising became an important part of my routine. Whether it was a brisk walk, a longer distance run, or gym workouts, I noticed that I was able to manage the way I felt about tinnitus and turn the tables in feeling I had control back. It gave me confidence in myself and allowed me to take ownership in the way I wanted to live my life. Physically, mentally, and socially, exercise helped me to focus on more important aspects of my life and, as a result, move tinnitus down my list of priorities and, ultimately, pay less attention to it. Taking part in Challenge RNID was a fantastic opportunity to continue this journey – one I hope others can experience in terms of managing their tinnitus and taking back ownership of their lives. I also think that raising money through such a Challenge is a vital step in paving the way for our future relationship with tinnitus."

If you would like to find out more about fundraising events in aid of RNID, go to rnid.org.uk/events

Each issue we hand-pick a selection of things that

...we love



Photograph: BBC

WE'RE DAAANNNCIING!

Strictly is back on our screens this autumn and EastEnders actress Rose Ayling-Ellis is set to become the BBC show's first deaf BSL-user dancer. Rose, who's played Frankie Lewis in the BBC soap since 2020, said: "To be the first Deaf contestant on Strictly Come Dancing is so exciting and a little bit scary. I hope I will do the Deaf community proud and break down more barriers."

More than 4,000 people have now created and downloaded one of our digital cards – a quick and easy way to show that you have hearing loss and your communication preferences when you're out and about. We love this feedback from one of our supporters, Briege: "Having to explain to people that I have hearing loss and communication needs every time I'm in a loud shop is exhausting and depressing. But I'll feel less anxious when out shopping with RNID's new communication card!"

Create your personalized communication card at:
rnid.org.uk/mycard



"The help I got from RNID was outstanding. Now I'm running to help others."

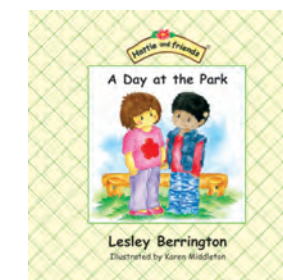
James Coleman loves a physical challenge, as you can see from his skydiving adventure (above). The support he received from RNID following sudden hearing loss has now inspired him to run for us in this year's London Marathon! James says: "I love to run. It can be solitary but deafness can be too, without the right help – and that's where RNID came in. I'll be pushing myself to the finish line to raise what I can for RNID – so that they can raise awareness and help others – just as they helped me."

If you've been inspired by James's story and would like to take on the London Marathon in October 2022 in aid of RNID, please register your interest by emailing community.fundraising@rnid.org.uk

Time for you



In June, we transferred our care and support services in England and Wales to Achieve together – a leading provider of specialist support for people with learning disabilities, autism and associated complex needs. We celebrate our amazing colleagues that work in these services (including Mulberry House, pictured), who will continue their inspiring work with Achieve together. Our Chief Executive, Mark Atkinson, says: "We believe Achieve together is well placed to invest in our services, support them to grow and continue to run them in the future."



'A DAY AT THE PARK' IS THE FOURTH TITLE IN THE 'HATTIE AND FRIENDS' BOOK SERIES FOR YOUNG CHILDREN featuring positive images of disability throughout. In this latest book, Hattie's friend Toby is deaf and has a cochlear implant. Author Lesley Berrington says: "Disability is part of life and we need to see that reflected in children's books." Visit: www.hattieandfriends.co.uk

Over to you

Letter, email, social media - we want to hear from you



From our social media channels:

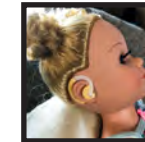


This weekend, I attended a wedding in London. Little did I know that the bride and groom had got me a 'speech to captions' screen so that I could hear a wedding speech, for the first time.

Laura



Going into a shop is just horrendous at the minute. At a supermarket, the lady on the till started shouting at me and I couldn't hear what she was saying. I stepped forward and said 'pardon?' and she almost had a fit. Apparently, she'd been telling me to wait on the white line. I said 'I'm sorry, I'm deaf' but she just looked at me in



My daughter saw the earphone buds in my husband's ears, then touched her own hearing aids. We realised she knew that she had them and others didn't. It was a beautiful moment when she saw her new doll with hearing aids, just like her!

Monica

disgust. But I have had some positive experiences. In a coffee shop recently, I couldn't hear above the noise of the coffee machine, so the staff member popped round the corner of the screen and spoke to me. Little things like that make it easier. It's a difficult time for everyone but staff need to realise that people might genuinely not be able to hear you. **Margaret**

WHO KNEW?

I've just finished your magazine with great enjoyment. It's informative, interesting and very readable, and I will be passing it on to my sister who seems a little reluctant to wear her recently acquired hearing aids!

Who knew my phone had an accessibility menu? Not me, but I'm now ready to explore HAC (hearing aid compatibility). My local audiology department is excellent but as pressed for time as any NHS unit, so I really appreciate how the magazine offers a range of information in a very attractive format that I can peruse at leisure.

Christine Wills

FACE TIME PLEASE

There must be thousands nodding in agreement with Pam Robinson's letter last issue about the lack of subtitles; I miss so many good films and TV programmes. However, unlike Pam, I have no problem with the main free-streaming options. Pam mentions ITV Hub – there is a 'cc' indicator to click on, either in the bottom right or upper right corner and, if the original programme had subtitles, they should be there

HOSPITAL FRUSTRATION

I read Davina Robins' letter last issue with great interest. I have just been in hospital for three weeks and how frustrating it was – I am very deaf and everyone was wearing masks. Nobody seemed to know how to cope with the situation!

Visors for speakers and masks for the listeners is surely the answer. Deaf awareness training is also desperately needed in hospitals and the pandemic situation has exacerbated the need. With an ageing population, can this not be incorporated into doctor/nurse training as part of the course?

Irene Oakley

when streaming. I also subscribe to Britbox and the subtitles are all there.

Madeleine Thomas

A QUIET ROOM

I read your campaign article on subtitling and have the same problems. Background noise is now a major problem for me, including background music on television. Not only is subtitling useful (especially when some actors' diction leaves something to be

desired), but the stupid background music, which is now on everything, is really annoying. Can it be put onto a different channel so that it can be switched off – like subtitles can be switched on?

Going out to restaurants is now a real challenge and, mostly, unenjoyable. I have a 'Connectclip' which I place in the middle of the table, which Bluetooth streams to my hearing aids and definitely helps in those situations. But perhaps restaurants could have a quiet room for those who cannot cope with background chatter/coffee machines or music?

Bryan Cath

HAVE NO SHAME

I have no qualms in saying I am deaf and, if someone is speaking too fast or not clearly, I say so.

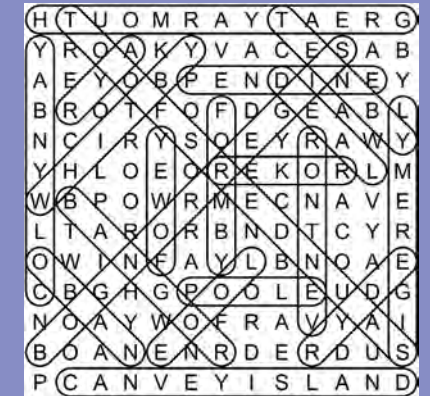
I lost my hearing completely due to a medical condition at 16. I am now 90 with excellent digital hearing aids. I was sorry to read in the previous issue that there seem to be so many people who hate to admit they are deaf. People who wear glasses don't feel ashamed so why should it matter that we wear hearing aids?

Sue Handoll

Answers to previous issue

Wordsearch and Crossword

How did you do? For this issue's puzzles, see page 46



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Get in touch

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Email: dawn.dimond@rnid.org.uk. Social media: see back cover

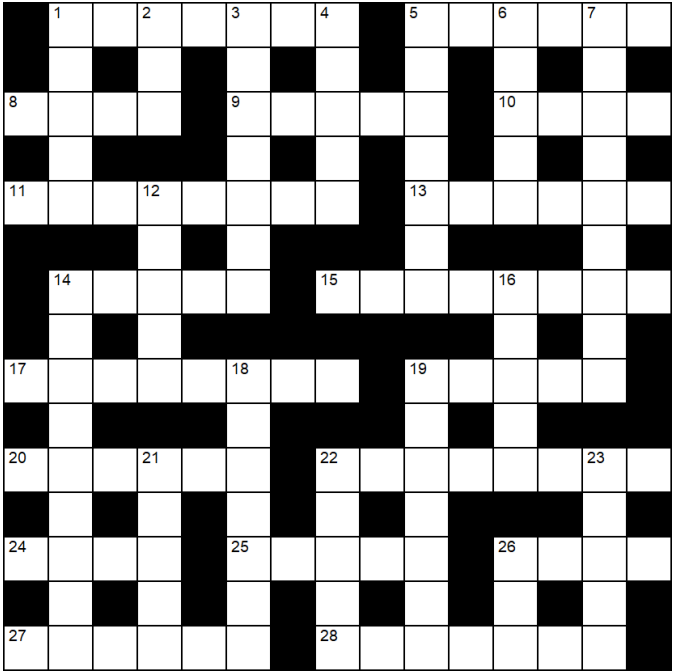
RNID

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Look out for anagrams in clues marked*



Across

- 1 *Coiled tube of inner ear housing hair cells – a cloche, surprisingly! (7)
- 5 Trader ... in blockade alert (6)
- 8 Evelyn Glennie, percussionist and RNID ambassador, is entitled to be called this (4)
- 9 They connect e.g. BTE aids to earmoulds (top of ear put in baths!) (5)
- 10 Dreadful ... bit of misdirection (4)
- 11 *Real-time speech to text app. for phones – the extra changes (8)
- 13 Handsome Greek youth's ... rare blue butterfly (6)
- 14 Run-down, shabby – Pip at end of day (5)
- 15 Customer's response? "Unwelcome noise from hearing aids!" (8)
- 17 *Hand movements that can help communication – gets user confused! (8)
- 19 They provide physical

- support in finger-spelling! (5)
- 20 See 19dn.
- 22 Listening devices like stethosets (8)
- 24 Risqué colour indicating a left ear aid? (4)
- 25 Audiogram I am interpreting reveals a Florida resort (5)
- 26 Confess what choir members do? (4)
- 27 *Musical dramas: small operation affected ears! (6)
- 28 Describes a non-analogue hearing aid (7)

Down

- 1 Yearn for (5)
- 2 Signal to start speaking? Snooker player has it in hand (3)
- 3 e.g. RNID's Weekly Superdraw – starts with an auction item (7)
- 4 Yellow-brown fossil resin in Morecambe reservoir (5)
- 5 *Otitis for example, sees aid affected (7)

- 6 Initially, amplifying units don't improve ordinary sound recording (5)
- 7 Loop listeners may come in this form (9)
- 12 Social networking message ... in faint, wee text (5)
- 14* Type of lightweight headset for audio listening – optics let loose (9)
- 16 e.g. malleus, incus and stapes, of the middle ear (5)
- 18 Starts again after a pause ... summaries (if accented)? (7)
- 19/20 *RNID Scotland's support service for veterans 65yrs+ with hearing issues – er foreign cash, involved (7,6)
- 21 Evident such diction helps those with hearing problems (5)
- 22 Perceived sound ... right inside head (5)
- 23 Relating to differences in pitch (5)
- 26 In short, audio transcription service of e.g. Live Transcribe and 11ac. (3)

For the chance to win a £20 M&S voucher send your Wordsearch and/or Crossword entries to: Magazine puzzles, RNID, Brightfield Business Hub, Bakewell Road, Orton Southgate, Peterborough PE2 6XU

D I C T R I H S T A E W S
L R I Y R S C R F R S B P
P U E A S N A E J S I O L
S A S S H K A M E G T K U
U I R K S A Y R H J E A S
R L D N R I D A F N K L F
P B I C K T N W A R C K O
L A O Y H J E G N I A S U
I K R G K E A E G M J C R
C T I K L R N L H O I K S
E N L S A S F S H A W L I
J A E I J E A M N G I N R
N D I C K Y B O W P S U T

20 items of clothing

DICKY BOW DIRNDL DRESSING GOWN
JACKET JEANS JERSEY KILT
LEG WARMERS NIGHTDRESS PARKA PLUS
FOURS SARI SCARF SHAWL SKIRT SLIP
SUIT SURPLICE SWEATSHIRT YASHMAK

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Plus, when you play the RNID Weekly Lottery, you'll be automatically entered into our Superdraw for a chance to win a whopping £5,000

The money raised will go towards making life fully inclusive for deaf people and those with hearing loss and tinnitus.


Photograph: Bruce Mars


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We are RNID, the charity working to make life fully inclusive for deaf people and those with hearing loss or tinnitus.


We campaign for an inclusive society, connect people to practical advice, and pioneer new treatments for hearing loss and tinnitus. We rely on donations to continue our vital work.

Contact our free, confidential Information Line:

 0808 808 0123

 0808 808 9000

18001 then 0808 808 0123 (Relay UK)

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