Welcome to your autumn issue of In the Loop

I always look forward to updating you on how your donations are transforming the lives of people confronting deafness, tinnitus and hearing loss.

This time: ambitious projects to find new treatments; improving healthcare through campaigning; and how Viv, who is deaf, has reconnected with his loved ones since moving to an Action on Hearing Loss residential home.

None of this would be possible without your incredible support! You’re such an important part of what we do and I’m excited for what we’ll achieve together in the coming months.

Thank you so much,

Paul Breckell
Chief Executive

“This photo was taken at the end of my sponsored bike ride – so from one supporter to another, let’s keep up the good work!” Paul Breckell

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This month on the cover

Akinola watering the garden at the Huguenot Place care home in Wandsworth, which supports deaf and/or deafblind men and women with a range of diverse and sometimes complex needs.
Living life to the full!

Meet Viv, an upbeat and sociable 70-year-old who was born deaf and has cerebral palsy. He used to live in residential care far away from his family and friends. Without the right support, Viv couldn’t see them or stay in touch. He missed their company and it was a difficult time for him.

But seven years ago, Viv got the chance to live closer to his loved ones by moving to a dedicated Action on Hearing Loss residential home. Since then, Viv has reconnected with family and friends. He’s had the help he needs to visit his sister and see friends for the first time in years.

Viv also meets new people at a local ‘young at heart’ Deaf club. The communication support he gets means he can stay in touch through phone calls, texts and emails too.

Viv is much happier now – he’s an avid fan of his local rugby and football teams and he enjoys bingo nights. He’s even been on holiday to Dublin with his support workers Paul and Richard.

Viv is now more confident and sociable than ever – and he’s in control of how he lives his life.

Last year* we helped people who are deaf with additional needs to live as independently as possible across our 47 dedicated care and support services


Read Viv’s holiday diary at actiononhearingloss.org.uk/intheloop
Incredible research means incredible discoveries

A huge step forward

Hearing loss can occur when inner-ear hair cells are damaged or lost. If scientists could regrow hair cells, hearing loss could be reversed – but researching this area is difficult as the inner ear is so inaccessible. Your support has helped fund a study into how to grow human hair cells from stem cells in the lab – and it’s worked! This breakthrough is a huge development for hearing research. The hair cell ‘model’ replicates what happens in the body, so it is an important resource to help scientists discover new treatments to protect and regenerate hair cells with the aim of restoring hearing.

Why ion channels are key

A Washington University of Medicine study has led to an improved understanding of ion channels within the auditory (hearing) nerve, and how these send sound information to the brain. This could help develop treatments to improve hearing or the effectiveness of a cochlear implant when the auditory nerve is damaged.

Magnificent magnesium!

Around one in 10 people are affected by tinnitus, where ringing, hissing or roaring sounds are heard in your ears or head. But although there are ways to manage the condition, there is no cure. It often occurs after exposure to loud noise. But new research suggests that magnesium could help prevent tinnitus developing after noise exposure. This important finding brings us closer to developing a treatment for thousands of people.

Thank you – all our research is funded by donations.
Talented young scientists determined to stop hearing loss

Thanks to your incredible support, five new PhD projects are starting this autumn. You’re helping talented young scientists focus their careers on hearing research, enabling more scientists to be dedicated to this field, which means more brains on ears for the long-term.

Helping children with hidden hearing and listening problems

Auditory processing disorder (APD) is a hearing or listening problem where the brain struggles to understand sound – for children this may mean difficulties with learning and poor school performance. More children are being referred for APD assessments, but few NHS clinics can diagnose it. PhD student Katharina Zenke will measure spatial listening abilities in children – as a key problem is understanding speech in noisy classrooms. Katharina hopes a better understanding will improve diagnosis and therapies for children with APD – so their learning doesn’t suffer.

Improving hearing aids for millions

It’s difficult to predict which hearing aids will provide the best outcome for their user. But innovative research could create scientific measures to predict the sound quality and speech intelligibility each user will experience. The NHS could then select the best equipment for patients – and help millions hear better! These measures could also help test new technology to improve the quality of hearing aids.

Transforming more lives through cochlear implants

Action on Hearing Loss helped develop the UK’s first cochlear implants, which allow profoundly deaf people to hear. But only 5% of those eligible choose to have one, as there’s a risk of losing any remaining hearing when they’re fitted. A new study could help reduce damage caused when implants are fitted – preserving the remaining hearing and leading to more lives being transformed through cochlear implants.

£60 could help fund half a day of groundbreaking research by a PhD student.

actiononhearingloss.org.uk
Marc’s tinnitus journey

“I’ve had tinnitus for 10 years. It can flare up and be unbearable, causing weeks of stress and anxiety.

I love music and played drums at school – now I’m a DJ. When I was 25, and started hearing a ringing in my ear that wouldn’t go away, I blamed myself. I was told nothing could be done and I’d be stuck with tinnitus for life. I struggled with depression and severe anxiety.

But then I found Action on Hearing Loss’s Tinnitus Information Line and the advisor was really understanding. They gave me useful advice, helping me to manage and accept my condition. I was told scientists haven’t found a treatment yet, but they’re looking for one right now – which gave me hope for the first time.

And it’s all down to generous donations from people like you that I know vital research will continue.

Exercise and good-quality earplugs help me every day. I volunteer regularly with campaigns like Tinnitus Awareness Week, and give talks to share my experiences. It’s hugely rewarding to know I’m helping in some way.” Marc Nicholson

Free Tinnitus Information Line
Telephone 0808 808 6666
Textphone 0808 808 9000
Email tinnitushelpline@hearingloss.org.uk

Each call from someone like Marc costs £5.80 to answer, so your support really matters!
Zehra’s Hear to Help

“I’ve been running free Hear to Help services for over two years. They’re informal sessions that people can attend to get help with their hearing aids. I hold them at community venues that are easy to get to, like libraries, community centres and day centres. They’re very well received; one gentleman told me he was astonished that it’s free! It means he doesn’t have to wait for hours at his audiology service.

If someone struggles with mobility, I visit them in their home so they don’t miss out on the support needed. And building relationships locally is vital too. I talk at community groups, I meet health professionals and audiologists, and give leaflets to hospitals and other health services so local people are aware of how the service can help them. Often someone has been struggling with their hearing aids for months. I’ll change the tubing and they’ll see an instant improvement in their hearing.

That always puts a huge smile on my face too. I find it hugely rewarding. I’m pleased I’m able to help people so they can enjoy all that our ears give us.”

Zehra Hassan runs Hear to Help services in South London.

Find your closest Hear to Help or Hear to Meet befriending service for yourself or a loved one by contacting our Information Line for free:

Telephone 0808 808 0123
Textphone 0808 808 9000
Email informationline@hearingloss.org.uk
Tackling the issues you care about

Transforming access to healthcare

It’s unacceptable that people with hearing loss still regularly face needless and costly barriers when visiting their GP and other NHS services. Our research found that 28% of people didn’t fully understand their diagnosis and 68% of people who asked for an interpreter at a health service didn’t get one*. So, last year we launched our On the Record campaign to improve access to health services.

You’ve helped us influence healthcare providers to make this happen – with great success. Henry said, “My deaf father is a BSL user and needed to go to A&E. They found an interpreter for him as staff now know who to ask for communication support – so together we really can improve access to healthcare!”

The campaign also means stricter standards are now used for healthcare service inspections. These help ensure people with hearing loss can more easily contact services and communicate during appointments, helping them understand their condition and the help available.

*Access all areas, Action on Hearing Loss research 2012
Margaret discovers her best therapy

**Online Today** is a free nationwide initiative helping people who are deaf or have hearing loss to develop digital skills. Margaret has had hearing loss and tinnitus for many years and it means she struggles to sleep at night. Through Online Today she’s had training from Briege, our Digital Skills Officer, about ways her computer can help her manage life with tinnitus and hearing loss.

Margaret is overjoyed to be reconnected with her sister in Canada, as she can now keep in touch through email. She’s also learned how to use the internet and download eBooks. Margaret told us, “Learning new things is therapy and has taken my mind off my tinnitus.”

Your incredible gifts mean that more people can be supported locally. Last year*, tens of thousands of people across the UK benefited from one-to-one dedicated support. This includes hearing aid support, befriending services, information, and care and support services.

*Financial year April 2016 to March 2017

You could be a winner!

“I play the Weekly Lottery because it’s so important to help people, like my late son, who suffered from hearing loss. I am thrilled and proud to have won. Hopefully a cure for hearing loss and tinnitus will be discovered soon.” **Margaret Helen Blow**

For just £1 a week, you’ll have the chance to win cash prizes of up to £500 every week. And you’ll be entered into a £5,000 Superdraw every three months – the next draw opens soon!

**Join today: 01524 752 548 or visit actiononhearingloss.org.uk/lottery**
Appeals update

Hundreds of kind supporters donated to last year’s appeal from PhD researcher Camille Tardieu, raising a huge £47,855! Camille’s project is now complete. She’s successfully created a model in fruit flies that assesses how the ear changes in response to noise.

The Summer Superdraw raised a fantastic £47,689 to help people with hearing loss. Watch out for the Christmas Superdraw with a £5,000 jackpot; it opens soon!

Thanks to everyone who responded to our recent sudden sensorineural hearing loss appeal.

You’ve helped to raise an amazing £77,500 so far. It focused on Dr Benjamin Shapiro’s research into how to deliver drugs to the inner ear – and he’s seen tremendous success! In animal models, he’s shown that his new method works better than the current injection method with a syringe. This is an important step forward for hearing research.

The June appeal also featured Carly Sygrove, who suddenly lost the hearing in her left ear when she was 33.

Thank you to everyone who has donated to help people with hearing loss!

Brilliant news just out: a treatment for sudden sensorineural hearing loss is being tested in clinical trials. If it succeeds, then this could be life-changing for thousands.

Read Carly’s story at actiononhearingloss.org.uk/treatments
Make a difference for generations to come

“My daughter Mary was born with hereditary deafness. Her hearing declined very quickly so she used to avoid the playground and parties. I’ve learned to accept my deafness - but Mary shouldn’t have to. Gifts in Wills fund research towards a cure for my daughter and others like her. Thank you if you’re considering leaving a gift.” Hugh Strickland

For a FREE Gifts in Wills pack, email legacies@hearingloss.org.uk

Win with our ‘Autumn’ wordsearch

Find the 20 words related to autumn in this wordsearch and you could win a £20 M&S voucher. Simply return your completed wordsearch in the freepost envelope provided and you’ll be entered into the draw.

Please send us your completed wordsearch by 4 October 2017. If you’ve won, we’ll let you know by post by 18 October.

Name............................................................... Postcode......................................................................

We’d like to keep you updated about how you can help, including fundraising, campaigning and volunteering – and the help we can offer, including our products and services. If you are happy to hear from us by email, SMS and phone, please provide your phone and email details:

Tel/textphone ..................................................
Email ........................................................................
“It took a while to get used to the fact that my hearing wasn’t going to come back. I kind of hoped for a miracle. Since my cochlear implant, I don’t feel I’m missing out on anything anymore. It’s fantastic being able to hear people again and being part of the conversation.”

Laura, 30, had her hearing restored by a cochlear implant.

Supporter promise

We value you, our supporters, so much. Without you, the world would be a very different place for those confronting deafness, tinnitus and hearing loss. We promise we’ll keep your personal information safe and won’t allow other organisations to contact you without your permission. We’ll communicate with you in the way you choose. If you’d like to change how you hear from us, please get in touch. We’ll listen and act upon your wishes.

Action on Hearing Loss

@ActionOnHearing

actiononhearingloss.org.uk

Email supportercare@hearingloss.org.uk

Telephone 0333 320 6995

Textphone 020 3227 6185

Each copy of In the Loop costs just 5p to print and it’s our chance to thank you for your support. If you would prefer not to receive our newsletter, please contact our Supporter Care team.

Action on Hearing Loss is the trading name of The Royal National Institute for Deaf People. A registered charity in England and Wales (207720) and Scotland (SC038926) A1377/0817