Biomedical Research Strategy 2015–2018

Making sure there are effective treatments for deafness, hearing loss and tinnitus

ACTION ON HEARING LOSS
A national charity since 1911

Formerly RNID

1. Introduction

We help people confronting deafness, tinnitus and hearing loss to live the life they choose. We enable them to take control of their lives and remove the barriers in their way. We do this by providing care and support, campaigning for equality, and supporting research into technology and treatments.

This Biomedical Research Strategy outlines the key challenges (section 2) that we face in developing effective medical devices and new treatments for hearing loss and tinnitus, and the approach we are taking (section 3).

2. Hearing loss affects millions

Currently, one in six people in the UK has a hearing loss – that's 11 million people. It's associated with age – and, with a population that's getting older, it's a growing problem. It's been estimated that, by 2035, more than 15.6 million will be affected – that's one in five of us. As we're experiencing now with dementia, hearing loss is a potential public health crisis.

Personal Impact

If left untreated or ignored, hearing loss can lead to very real social isolation, cutting people off from friends and family, as well as affecting their ability to take part in everyday life. It's associated with an increased risk of depression and other mental health problems, not to mention dementia, where the risk is nearly double for people with untreated mild hearing loss, and this risk increases for those with moderate and severe hearing loss. The World Health Organization (WHO) predicts that, by 2030, adult-onset hearing loss will be in the top 10 disease burdens[1] in the UK and other high- and middle-income countries, above cataracts and diabetes[2].

Children are also affected by deafness. In the UK, about 840 children are born every year with a hearing loss. Communication difficulties can adversely affect education and future employment. People who are severely or profoundly deaf are four times more likely to be unemployed than the general population.

Economic cost

Hearing loss has a significant impact on quality of life and is a significant economic burden on society.

A recent report by the Ear Foundation estimates that hearing loss costs the UK £30bn per year due to lost earnings, reduced quality of life, additional GP visits and increased social-care costs[3]. This figure doesn't include private and NHS costs associated with treating hearing loss.

Hearing loss costs the UK £30bn per year – not including private and NHS treatment.

Clinical need

Hearing loss can be caused by problems affecting both the conduction of sound across the middle ear to the cochlea (conductive hearing loss) or by problems within the cochlea itself (sensorineural hearing loss). Conductive hearing loss can often be treated surgically or by treating middle ear infections, which are common in children.

Sensorineural hearing loss is the most common type of deafness, accounting for 60–90% of all deafness. For people with some residual hearing, amplification of sound via hearing aids can be of benefit. But these devices often perform poorly in noisy environments – and their uptake is disappointingly low.

There are estimated to be 6.7 million people in the UK who need hearing aids.

Cochlear implants bypass the damaged cells within the cochlea to stimulate the auditory nerve directly and provide a sensation of hearing. In the UK alone, there are around 12,000 people using an implant. Although cochlear implants provide enormous benefit, their ability to represent the full range of sound frequencies that we hear – and to convey pitch is very limited.

Our 2010 Annual Survey revealed that 97% of our members still experience difficulty hearing when using their hearing aids or cochlear implants, showing that there is still considerable unmet need.

Currently, there is no way to halt the progressive loss of hearing associated with age, nor treatments to lessen the damaging effects of noise and other external insults. Nor is there any way of restoring natural hearing or silencing tinnitus.

Under-investment in hearing research

In 2014, less than 1% of the collective spend on research by the UK's main public and charitable funders of medical research was directed at hearing research. That is equivalent to only £1.11 spent on hearing research for every person affected[4]. This figure compares with £11.35 spent on vision research for every person with sight loss[5].

In 2014 £11.35 was spent on vision research for every person with sight loss. Only £1.11 was spent on hearing research for every person affected by hearing loss.

Most hearing research is funded through 'response mode' grant schemes and is focused on supporting basic research into the biology of the auditory system and causes of hearing loss. Competition for this type of funding is high and, with a relatively small number of hearing researchers competing against larger numbers of scientists working in high-profile areas such as cancer, cardiovascular disease and neurological conditions, hearing research attracts a disproportionately low amount of funding relative to the scale of the problem. We need to build future research capacity and work with national funders to increase public spending on hearing research.

Turning discoveries into treatments

We're making rapid progress towards understanding the causes of hearing loss and in developing strategies to both protect and restore hearing, and silence tinnitus.

But progress in moving promising new approaches into clinical trials has been slow. This type of research – to refine a promising new treatment to a point where it can be safely tested in patients – is called translational research.

The challenge is two-fold. First, many academics lack the experience and know-how needed to translate their research into treatments. Second, as there are no drugs on the market, the route through clinical trials, gaining regulatory approval, and getting hearing therapeutics adopted by healthcare providers is unknown and largely untested. This means that the pharmaceutical industry, whilst recognising the huge commercial opportunities, is reluctant to invest in an area where the perceived risks are high.

We need to encourage those companies willing to invest in developing new treatments for hearing loss and tinnitus, and support academics to translate the outcomes of their research into patient benefit.

Lack of public awareness

The public's response to news about potential treatments for hearing loss and tinnitus is always very positive – ours is a cause that resonates with many. There are many other worthy causes competing for limited funding. To make sure hearing research can compete, we must increase public awareness of the potential benefits that medical research could bring to people confronting deafness, tinnitus and hearing loss.

1 Disease burden is the impact of a health problem in an area according to set indicators. The disability-adjusted life year (DALY) is a measure of disease burden expressed as the number of years lost due to ill-health, disability or early death.

2 Mathers and Loncar. PLoS Med. 2006 Nov; 3(11): e442.

3 The Real Cost of Adult Hearing Loss: Reducing its impact by increasing access to the latest hearing technologies. 2014. The Ear Foundation.

4 Calculated from data from UK Health Research Analysis Report 2014, (UKCRC, 2015) and Action on Hearing Loss figures on the number of people in the UK with hearing loss.

5 Calculated from data from UK Health Research Analysis Report 2014, (UKCRC 2015), and the number of people living with sight loss according to RNIB.

3. Our approach

Overview

Since 1999, we have funded world-class research and training and, in 2013, merged with Deafness Research UK to create the world's largest charitable funding programme dedicated to advancing treatments for hearing loss and tinnitus.

Collectively, to date we have invested over £25 million into hearing research – research from which people are already benefiting through the technology used to screen the hearing of newborn babies, cochlear implants and advances in the fitting of hearing aids.

We have launched the careers of several research leaders, and our funding has resulted in key scientific advances and opened up new areas of research that may lead to new ways of treating hearing loss and tinnitus.

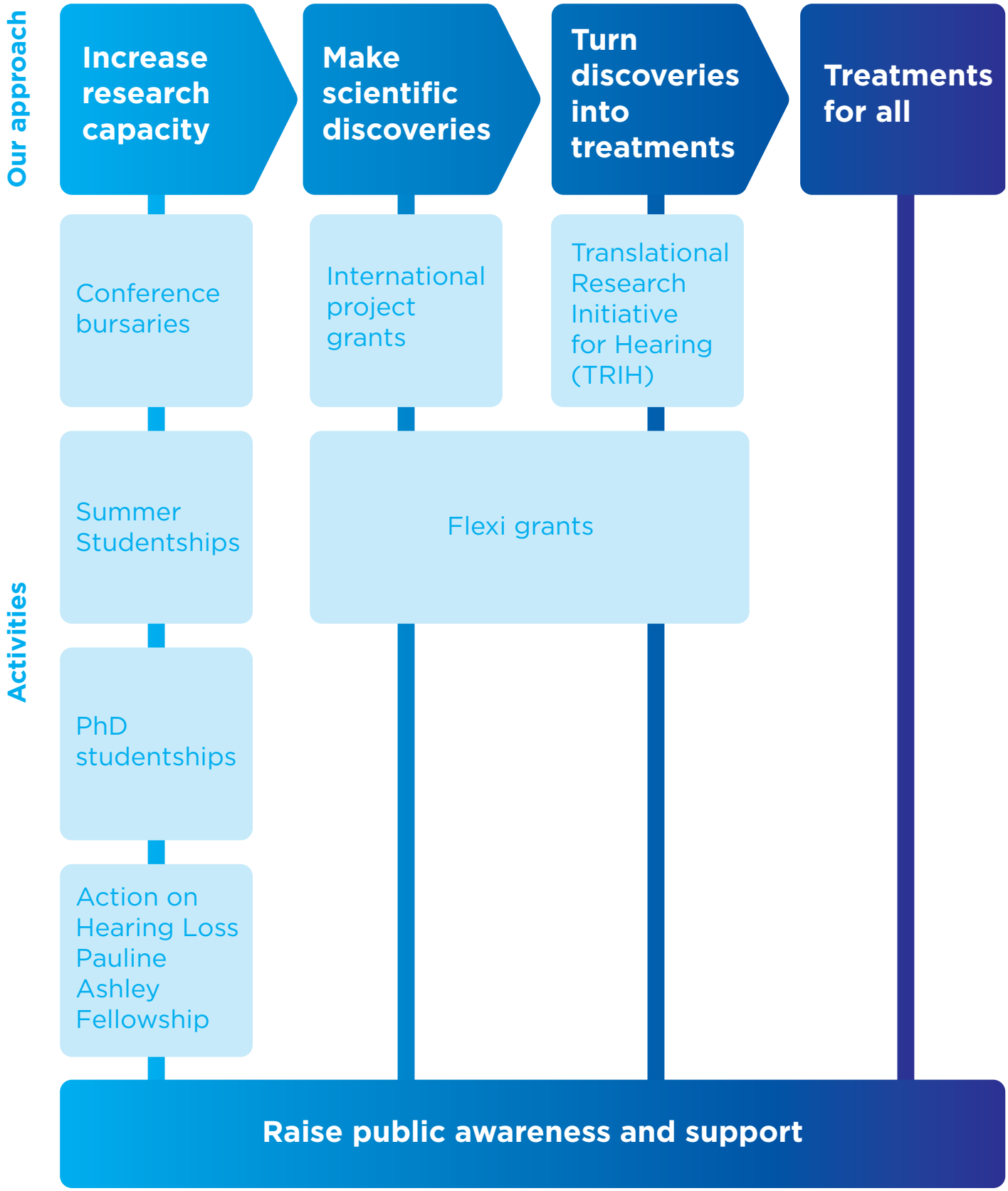
We have been able to increase the biotechnology and pharmaceutical industries' involvement in developing treatments: the first drugs for hearing loss and tinnitus are in clinical development. Our Translational Research Initiative for Hearing, a sector-leading initiative, is providing vital support to companies and academics to accelerate the development of promising treatments.

Finally, we have worked in partnership with Age UK, cochlear implant companies and the Biotechnology and Biological Sciences Research Council (BBSRC) to increase investment in hearing research. On average, for every £1 we invest, projects we support attract a further £10 in follow-on funding.

We are continuing to work with universities, companies and investors to build on these successes, ensuring new treatments for hearing loss and tinnitus are developed as quickly as possible.

We are doing this by:

- increasing hearing research capacity within the UK
- targeting funding towards research projects that will generate discoveries that could lead to new treatments
- supporting the translation of promising discoveries into treatments ready to be tested in the clinic, and working with the pharmaceutical sector to ensure new treatments are clinically tested and quickly brought to market
- raising public awareness of hearing research to aid recruitment into clinical trials and support our fundraising efforts.


Our approach
Increase research capacity
Make scientific discoveries
Turn discoveries into treatments
Treatments for all
Activities
Conference bursaries
International project grants
Translational Research Initiative for Hearing (TRIH)
Summer Studentships
Flexi grants
PhD studentships
Action on Hearing Loss Pauline Ashley Fellowship
Raise public awareness and support

3.1. Our research priorities

Hearing research has been one of the most exciting areas of biomedical research over the past 10 years. Rapid progress has significantly improved our understanding of the biological causes of hearing loss. This progress has already created new ideas for the prevention and treatment of hearing loss, but there is still much we don't know.

We will support research to:

- improve the diagnosis of hearing loss
- increase the benefit gained from medical devices (such as hearing aids and cochlear implant technology)
- increase the understanding of the biological causes of hearing loss and support the development of treatments to prevent hearing loss
- advance cell, gene and drug-based therapies to restore hearing
- understand the biological causes of tinnitus and support the development of effective treatments to silence tinnitus.

Improving the diagnosis of hearing loss

It is important to be able to diagnose hearing loss rapidly and accurately, so that people can quickly be offered the support and medical interventions that will benefit them the most. This is particularly important for young children. Knowledge of the amount of hearing loss and the cause of hearing loss allows the most appropriate intervention to be offered, and, in the case of hearing aids and cochlear implants, for them to be set up to provide maximum benefit. As new treatments emerge in the future to restore hearing, we'll need tests that can identify precisely what part of the auditory system is damaged, so that the correct treatment can be given.

We will fund research to develop diagnostic tests able to:

- identify which parts of the auditory system are not working correctly and/or the cause of the hearing loss
- predict outcomes, following intervention, to help select the most appropriate treatment
- help set up devices to better meet an individual's needs.

Better medical devices to help people hear

We've made significant progress towards improving hearing aid and cochlear implant technology – and this is benefiting millions of people worldwide. But there's still a huge need for further improvements, in particular, around speech intelligibility in the presence of background noise.

We will fund research to:

- improve approaches to fitting devices
- develop new signal processing strategies
- improve rehabilitation strategies
- improve the interface between the implant and auditory nerve
- catalyse the development of novel medical devices to aid hearing.

Preventing hearing loss

We already know many of the main causes of hearing loss, such as ageing, exposure to noise and ototoxic medication, and genetic factors, but there are many more still to be identified. Progress is also being made towards understanding the biology underlying many of these different types of hearing loss, bringing with it the hope that treatments can be developed to prevent hearing loss.

We will fund research to:

- identify the causes of hearing loss
- improve the understanding of the molecular and cellular changes associated with different types of hearing loss
- develop and evaluate new strategies to prevent hearing loss.

Restoring hearing

Sixty to 90 per cent of hearing loss is caused by damage to cells within the cochlea or auditory nerve. Once damaged, these cells often degenerate and die. In mammals, the cochlea is unable to regenerate these cells, so hearing loss is permanent. Our research in this area is focused on understanding how we might be able to repair damage to the cochlea to restore natural hearing.

We will fund research to:

- develop cell-based therapies to repair damage to the auditory system
- identify biological pathways that could be targeted to trigger the regeneration of damaged cell types
- advance drug or gene-based approaches to activating biological pathways to restore function or trigger cell regeneration.

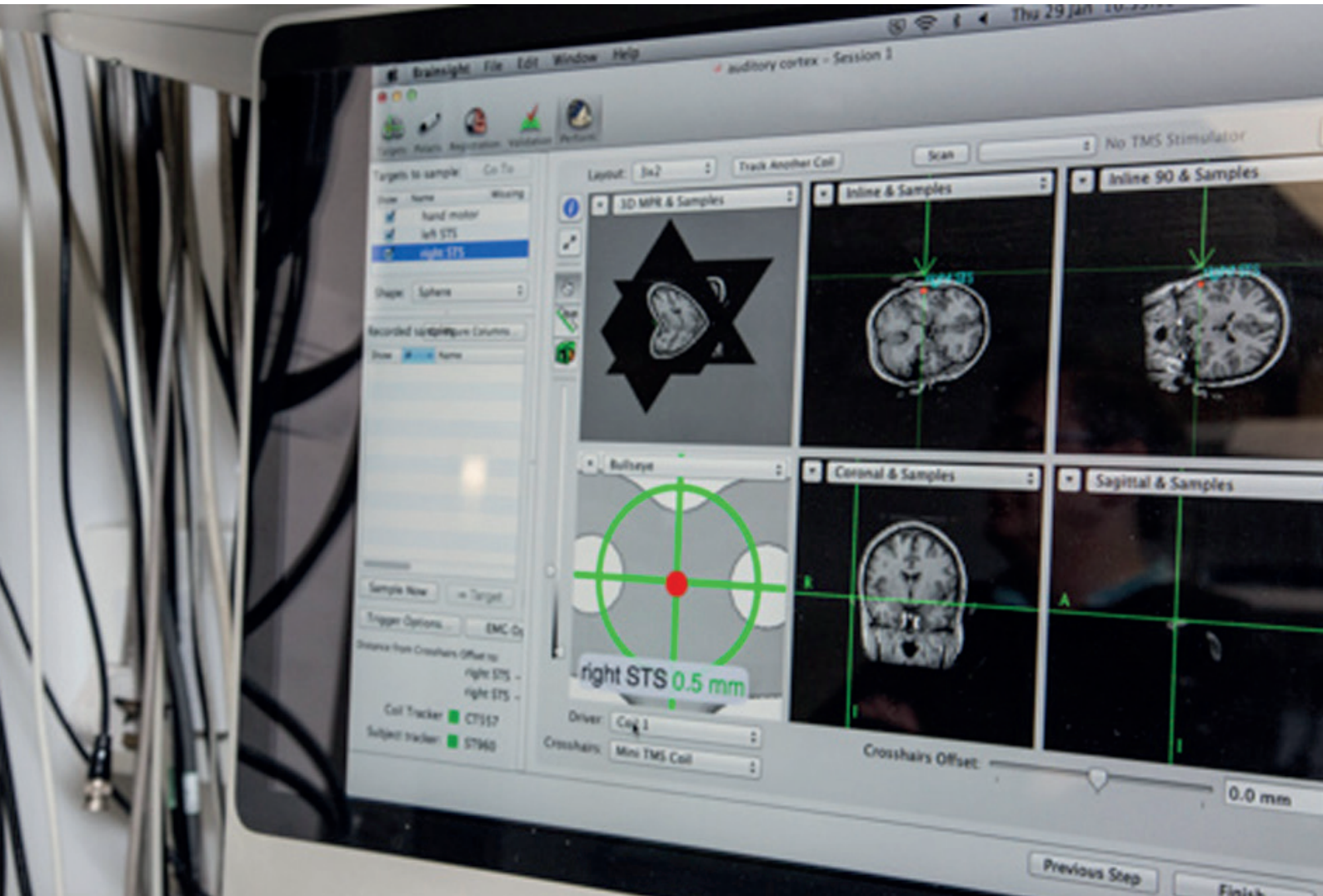
Silencing tinnitus

Six million people in the UK have experienced tinnitus and, for around 600,000, it can seriously affect their quality of life. There are practical steps people can take to manage their tinnitus, but there are no safe and effective treatments to silence tinnitus.

Our research in this area is focused on better understanding the biological basis of tinnitus – and using this knowledge to develop treatments.

We will support research to:

- identify the causes of tinnitus
- improve our understanding of the biological basis of tinnitus
- develop and evaluate strategies to alleviate tinnitus.



3.2. Our funding schemes

We will support research and training that address our research priorities through a range of targeted funding schemes.

Capacity building

Summer studentships

Awards of up to £1,600 will be made available to researchers based at UK universities and non-profit research institutes. These grants will fund an undergraduate student to carry out a small research project (lasting up to eight weeks) during their summer break.

Through this scheme, we aim to give science undergraduates practical experience of hearing research and inspire them to follow a career in hearing research.

Conference bursaries

Awards of up to £750 will be made available to PhD students and early-stage postdoctoral fellows based at UK universities and non-profit research institutes to enable them to participate at international research conferences.

Through this scheme, we aim to support the careers of the most promising UK hearing researchers by allowing them to develop their professional network, gain experience of presenting their research and develop new ideas to strengthen their research.

Awards will be limited to specified conferences only.

PhD studentships

Our studentships provide a stipend and contribution to university fees, conference attendance and project costs over three years.

Potential supervisors must be based at either a UK university or non-profit research institute. Grants will be awarded yearly following an open call for project proposals that address our research priorities and a rigorous peer-review process.

Through this scheme, we aim to attract the very best students into hearing research – and grow future capacity.

Action on Hearing Loss Pauline Ashley Fellowship

Awards of up to £60,000 will be made available to researchers at the start of their careers. The fellowship is designed to support salary and project costs for usually 12 months. Recipients of this award must be based at either a UK university or non-profit research institute. Grants will be awarded yearly following an open call for project proposals and a rigorous peer-review process.

Through this scheme, we aim to support the progression of talented researchers towards an independent research career.

Discovery research

International Project Grant

Awards of up to £160,000, over three years, will be available to researchers based at universities or non-profit research institutes from any country. Grants will be awarded yearly following an open call for project proposals that address our research priorities and a rigorous peer-review process.

Through this scheme, we aim to support world-class research projects, that will generate scientific discoveries that will underpin the development of diagnostics, treatments and medical devices.

Flexi grant

Awards of up to £5,000 will be made available to support small-scale activities that will strengthen hearing research. Grants will be awarded twice a year to recipients at universities, non-profit research institutes or small commercial enterprises in any country.

Through this scheme, we aim to support any innovative idea or activity, such as pilot experiments to support larger grant applications, workshops to explore new areas of research, laboratory visits to exchange and share technical skills, and initiatives to provide access to scientific resources or data.

Translational research

Translational Research Initiative for Hearing (TRIH)

Our Translational Research Initiative for Hearing (TRIH) is advancing medicines to protect and restore hearing, and silence tinnitus. Through this initiative we will work globally with academic researchers, pharmaceutical and biotech companies, and investors to:

- fund translational research
- provide a consultancy service to support companies in developing new treatments
- create partnerships between companies, academic researchers and investors
- involve people with hearing loss and tinnitus in clinical research.

Funding

Awards of up to £300,000, over three years, will be made available to researchers and small commercial enterprises from any country to strengthen the translation of fundamental research towards patient benefit.

The scheme will support:

- applied research with a strong, commercial potential that is likely to attract follow-on funding when the grant ends
- small molecule-, gene-, or cell-based approaches for the treatment of hearing loss or tinnitus
- studies that will facilitate and enable the progression of promising, basic research towards testing in clinical trials.

The scheme will not support the development of medical devices.

Grants will be awarded yearly, following an open call for project proposals that address our research priorities and a rigorous peer-review process.

Consultancy

After 15 years of funding hearing research, we have an unparalleled understanding of the hearing and tinnitus markets, and an extensive network of academic researchers, clinicians, investors and companies working on hearing loss and tinnitus. With this knowledge and insight, we will support and encourage companies to become involved in developing treatments for hearing loss and tinnitus.

We will provide:

- advice on the hearing loss market, current status of research, and targets and pathways of therapeutic interest
- links to contract research services and key opinion leaders
- access to people with hearing loss and tinnitus.

Partners

TRIH partners are a consortium of organisations that, along with us, work to support the development of treatments for hearing loss and tinnitus.

We will identify:

- Research Partners with a strong interest in identifying research, collaboration, and/or licensing opportunities in the areas of hearing loss and tinnitus. We will share TRIH grant proposals with these partners, who will have the option to collaborate on or fund any project that may be of interest to them.
- Enabling Partners able to offer preclinical and clinical services, and expertise in the development of treatments for hearing loss and tinnitus. We will promote their services to companies looking for support to develop new treatments.

Patients

We will provide people with hearing loss or tinnitus access to information about how to find and take part in clinical trials of new treatments for hearing loss and tinnitus.

This information will not only be of interest to people with hearing loss and tinnitus, but will also speed up recruitment into clinical trials.

More information about our funding schemes and TRIH can be found at:

- actiononhearingloss.org.uk/biomedicalresearch
- actiononhearingloss.org.uk/trih

3.3. Raising public awareness and support

Many people are simply unaware of the promising research being carried out to understand the causes of hearing loss and tinnitus, and find effective treatments, or aren't confident that effective treatments can really be found. But people with deafness, tinnitus and hearing loss tell us that it's having better treatments that would make the biggest difference to them, and that this is the area that they would most like to see their donations put towards.

To strengthen our fundraising activities – and capitalise on people's propensity to give to research – we will work to increase people's awareness of, and interest in, hearing research.

We will also continue to raise the profile, and highlight the importance of hearing research across government, the Research Councils and medical research charities, to increase public spending on hearing research.

We will:

- make sure that our biomedical research work is clearly articulated – and integrated into the Action on Hearing Loss brand
- develop our website and use our social media channels to promote our researchers and projects to the general public in an accessible and engaging way
- produce a monthly e-newsletter to promote the latest research to the public
- secure national media coverage of hearing research
- publish an annual report to highlight our research achievements to our members and supporters
- make sure our staff and volunteers can learn about biomedical research and use their knowledge to champion our work
- work in partnership with the Research Councils and other research charities to increase the funding available for hearing research
- highlight the social and economic value of hearing research to the government to increase public-sector investment
- work with other medical research charities to strengthen the medical research environment within the UK.

4. Our expected outcomes

By 2018:

- we'll have a high profile as a charity that funds vital research
- people will be excited about – and demanding – new treatments
- the amount of funding going into hearing research will have increased significantly
- there will be more scientists working on hearing loss and tinnitus
- scientific advances will have improved the quality of speech and music experienced by people using hearing aids and cochlear implants
- through scientific discoveries we will have improved our understanding of how to prevent hearing loss, restore hearing and silence tinnitus
- there will be new treatments for hearing loss and tinnitus in clinical development.

ACTION ON HEARING LOSS

A national charity since 1911

Our purpose is to help people confronting deafness, tinnitus and hearing loss to live the life they choose. We enable them to take control of their lives and remove the barriers in their way.

To find out more about our biomedical research funding, go to:
actiononhearingloss.org.uk/researchfunding

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Join us

Action on Hearing Loss

@ActionOnHearing

On the cover: Professor Van Camp, a past Action on Hearing Loss grant holder, who has advanced our understanding of the genetics of hearing loss.

Action on Hearing Loss is the trading name of The Royal National Institute for Deaf People.
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