

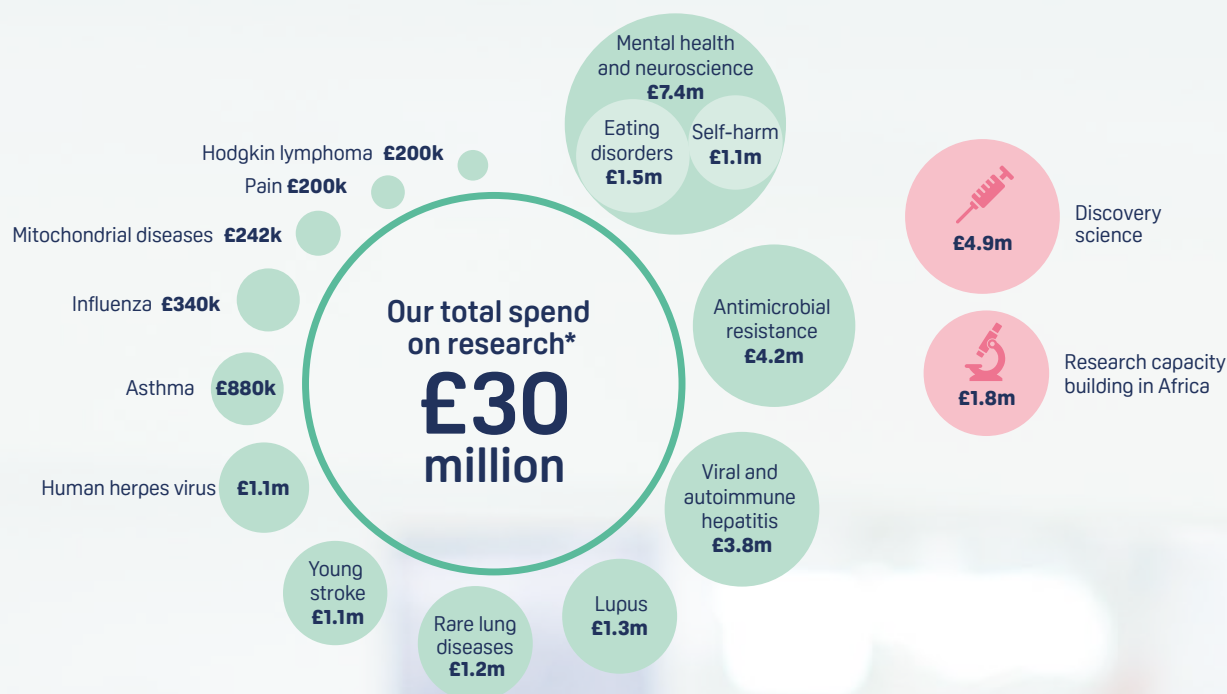


**Medical  
Research  
Foundation**

**Celebrating 100 years  
of life-changing  
medical research**



# Funding the research our society needs



## 280 research awards to more than 250 researchers



## 450 research publications

Our funded researchers have shared their findings in more than 450 research publications, helping to advance knowledge and understanding of key health challenges.



## 180 unique research collaborations

Our support has sparked over 180 unique research collaborations, and our researchers have gone on to secure more than £45,000,000 in additional research funding – ensuring their life-changing work can make a difference for many years to come.



## 100 academic prizes

Over 100 academic prizes have been awarded to our researchers, including prestigious fellowships and honorary degrees, demonstrating the broad impact of their work and potential to change lives.



## 3.5x applications

However, despite all of our efforts in finding and funding exciting new research, we receive 3.5x more research applications than we can currently fund.

## Africa



## Scotland

University of Dundee  
Glasgow Caledonian University  
University of the West of Scotland  
University of Edinburgh

## North East

Newcastle University

## Yorkshire and Humber

University of Leeds  
University of Hull  
University of Sheffield

## East Midlands

University of Nottingham

## East of England

University of Cambridge  
MRC Laboratory of  
Molecular Biology

## South East

University of Oxford  
University of Southampton

## London

- 1 University College London
- 2 The Francis Crick Institute
- 3 Birkbeck University
- 4 London School of Hygiene  
& Tropical Medicine
- 5 King's College London
- 6 Queen Mary University of London
- 7 Imperial College London
- 8 Royal Holloway University of London
- 9 St George's University of London

£5.6m

£400,000

£1.4m

£1.3m

£850,000

£1.4m

£3m

£290,000

£2m

£1.4m

£10.6m

£370,000

**Northern Ireland**  
Queen's University Belfast

## North West

University of Manchester  
Liverpool School of Tropical Medicine

## West Midlands

University of Birmingham  
University of Warwick

## Wales

Cardiff University

## South West

University of Bristol  
University of Exeter



# Welcome

**This report tells the story of the ground-breaking medical research we've funded over the years, and the life-changing difference it has made for people with a wide range of diseases and conditions.**



Dr Angela Hind

Our researchers have uncovered crucial information about life-saving treatments for adults with hepatitis C, they have provided greater certainty for children and families living with intellectual disability, and they have helped to tackle the mental health problems that can have such a devastating impact on people throughout their lives.

All the vital research featured in this report stems from areas of health with a great unmet need for new research, but historically low investment.

We are a purely research-led organisation, meaning our efforts are entirely centred around funding scientists and research. This has allowed us to focus solely on finding and funding research that has the potential to change lives now, or that may become important in the future.

While we have access to the best scientific advice through our connection with the Medical Research Council (MRC), support from the public allows us to independently fund research into whatever we feel are the most important medical research questions of the time. Because we are not allied to any specific disease, condition or research institution, we are able to remain flexible and react to emerging health needs.



Professor Nick Lemoine

## Tackling the research our society needs

We are completely dependent on the generosity of our supporters. They are critical to ensuring that we can continue to fund the most exciting, most promising research that our society needs. Every five years, we identify key areas of research that are particularly important to global human health. These are often areas that are underfunded, or where there is a lack of understanding and great potential for discovery.

As you will discover in this report, we have supported scientists who are leading the way in areas such as antimicrobial resistance, mental health, lupus and pain research. Not only are we funding brilliant new research now, but we're also ensuring these scientists can continue to make discoveries for years to come.

## Funding the scientists of tomorrow

Research funding early in a scientist's career can help to shape their area of focus long into the future. They may have a keen interest in infectious diseases or investigating a condition that receives little attention elsewhere. But without funding at the early stages, they can be forced to abandon their passion and leave science altogether, with an immeasurable loss to future human health.

We award funding to scientists during this critical period, helping them become leaders in their field so they can go on to continue pushing forward important research long into the future.

We're immensely proud of what we've accomplished together over the years, on behalf of our donors, and we hope you enjoy reading about some of these achievements.

**Dr Angela Hind, Chief Executive**

**Professor Nick Lemoine, Chair of the Board of Trustees**



# Changing medicine today.

## Our vision

### **Our vision is to advance medical research, improve human health and change people's lives.**

Many of the diseases and conditions that affect human health have been cured or overcome as a result of medical research. But there will always be more to do. Although significant resources are being spent around the world on developing exciting new treatments and therapies, there are areas of medical need that receive little or no support – and people's lives that see no improvement. That's where we step in.

As an independent charitable foundation, formed by the Medical Research Council (MRC), we are inspired by the responsibility and independence that our donated income gives us. We fund and support the most promising new medical research, wherever we discover great opportunities that are not being pursued.

### **Cutting-edge research, where it is needed most.**

Guided by the expertise available to us through our relationship with the MRC, we identify the health issues with the most pressing need for new research.

Some of the research areas we fund are specified by individual supporters, who restrict their gifts to fund research on particular diseases. In these cases, we rely on independent scientific experts to advise us on the most urgent questions that need to be addressed and the most effective way to do so.

### **We take a targeted approach – only funding research that aligns with one or more of our key strategic research themes.**



**High need,  
low research  
investment**

Supporting research on the conditions and diseases that devastate lives, where there is an unmet need for new research but a low research investment.



**Emerging  
research  
leaders**

Providing opportunities for the emerging research leaders who will address the biomedical research questions of the future and support for their cutting-edge research today.



**Increasing  
understanding**

Supporting the discovery science that increases understanding of the processes underpinning all human health and disease.



**Changing  
policy and  
practice**

Supporting the dissemination of research results beyond the scientific press to people who are able to influence healthcare policy and practice as well as personal life-choices.



# Changing lives tomorrow.

## Continuing a legacy

Ever since the first known donation in 1919, many generous individuals and organisations have made gifts or left part of their estate to the Medical Research Council (MRC) in recognition of its important work.



In 2006, Dr Angela Hind was tasked with modernising these charitable funds to create a new charity. This meant appointing an independent board of trustees, creating our own research award mechanisms, and legally separating from the MRC, to form the organisation we know today as the Medical Research Foundation, in 2011.

Angela – now our Chief Executive – leads a dedicated team which is committed to ensuring we use our donations responsibly and make the biggest possible impact on human health.

We are different from other medical research charities in two important ways. Firstly, research is our only purpose. We don't provide support or information to patients or do the kind of campaigning or advocacy work which other charities do.

Secondly, we aim to support the very best research and researchers in areas of health

with the greatest clinical need, including the threat of drug-resistant infections, adolescent mental health, pain research and more.

"We provide funding at a really critical point in a scientist's career, when they could very easily follow a different path and leave medical research altogether. This support secures their future in research and helps them become research leaders in their given field, which can only benefit the people who live with the conditions that they work on," says Angela.

"The people we support are our greatest legacy for the future of people's health.

"While we are still relatively small compared to other medical research funders, we punch above our weight in terms of the impact we make. This is thanks to the trust placed in us by our donors, who allow us to fund the very best scientists, the most needed research, and the research that could have the biggest impact in years to come."



Lady Wadia  
Philip Alexius de László  
(1869–1937)

## 1920s – 1950s

The MRC receives a small number of significant donations from high-profile public figures, scientists and the general public, including **Florence Temple-Cross** and **Lady Julia Wadia**, in memory of her husband Sir Cusrow Wadia, Bombay millowner and philanthropist.

## 1969

**The Fleming Memorial Fund for Medical Research charity** is established, to commemorate Sir Alexander Fleming's work on penicillin. This fund now supports our Changing Policy and Practice Awards, which have helped leading scientists communicate their ground-breaking work to patients, healthcare practitioners, policymakers, and the general public.

**Read more on page 31–33.**

# 100 years of support

From monetary gifts in Wills to estates, properties, portraits, and even a gentleman's outfitters – we've benefited from a wide range of generous donations over the years.

1919

1920

1930

1940

1950

1960

1970

1980

1990

## 1919

**The League of Red Cross Societies** supports a study in Vienna on the causes of rickets and scurvy, by making a donation towards hospital maintenance.

## 1926

**Major General Sir Leonard Rogers**, a great pioneer of tropical medicine, makes a donation of shares to fund medical research in Africa. The Sir Leonard Rogers Fund is still active today and still supporting promising young African researchers to tackle health problems in Africa.



Wellcome Images



## 1983 and 1992

**Effie Millar Munro** and **Alfred Tartellin** leave separate gifts in Wills to help fund liver disease research. These donations have since supported vital research into the hepatitis C virus (HCV), including one of the largest HCV research cohorts in the world.

**You can read more on pages 10–11.**

## 1960s – 1990s

Interest in medical research gathers pace, matching the rate of scientific discovery and increasing as science reporting reaches more homes. The number of gifts in Wills and donations we received increased from 30 throughout the 1960s to 250 in the 1990s.





## 2012

**Kathleen Frances Goff** left a significant part of her estate to the Foundation. This generous gift has helped to fund our National PhD Training Programme in Antimicrobial Resistance Research led by Professor Matthew Avison (pictured above). **Read about the programme on pages 24–25.**

## 2015

**Catherine Mary Evans** leaves a gift in her Will, which continues to support much-needed research into eating disorders and self-harm. **Find out more on pages 18–19**

## 2017

**Professor Victor Louis Ménage** and **Johanna Alicia Ménage** leave gifts in their Wills, which have helped to fund our Emerging Leaders Prizes in adolescent mental health, antimicrobial resistance and pain research. **Read more on pages 20–23.**

## 2018

A donation from **GlaxoSmithKline (GSK)** allows us to make a major investment in research infrastructure at the Francis Crick Institute. **Find out more about the cutting-edge In Vivo Imaging (IVI) facility on pages 28–29.**

2000

2010

2012

2015

2016

2017

2018

2019

## 2016

**Dr Erina Herrick** leaves a gift in her Will to create a prize for lupus researchers. The following year, we launched the Emerging Leaders Prize in lupus to honour Erina's wishes. **Read more about our lupus Emerging Leaders Prize on pages 20–21.**

## 2010

**Esme Irene Griffiths** leaves a gift in her Will, in memory of her parents, to help fund vital research into motor neurone disease. Thanks to Esme, we've funded some of the UK's brightest researchers in the field, including Dr Bradley Smith from King's College London. **Read about Bradley's research on page 30.**



## 2019

- **Robert Colville** raises over £120,000 to fund new research into autoimmune hepatitis, following the tragic death of his wife Andrea at the age of 40. Thanks to Robert and his supporters, we're now funding vital new research which could lead to better treatments for autoimmune hepatitis.
- The pharmaceutical company **Shionogi B.V.** donate towards our 2019 Emerging Leaders Prize in antimicrobial resistance (AMR). **Find out more about our 2019 prize-winners and the work they're doing to tackle AMR on pages 22.**

# Finding the right treatments for hepatitis C



High need,  
low research  
investment

**For over a decade we have supported life-saving research into the hepatitis C virus (HCV), which still affects 71 million people worldwide.**

Hepatitis C is a blood-borne virus that causes scarring and inflammation of the liver. The longer patients are infected, the more likely they are to suffer potentially life-threatening damage to the liver.

Despite extraordinary progress in how HCV is treated - including anti-viral drugs capable of destroying the virus - vast numbers of people still develop serious liver disease, causing 400,000 deaths globally every year.

HCV Research UK was established to address critical gaps in our understanding of HCV. Now one of the largest HCV research cohorts in the world, it has provided vital information about the longer-term impact of the virus to researchers, patients, the NHS, and the pharmaceutical industry.

Thanks to gifts in Wills from Effie Millar Munro and Alfred Tartellin, we were able to provide £2 million of funding for the pioneering initiative, set up by a group of clinicians and scientists from across the UK, led by Professor John McLauchlan at the Medical Research Council (MRC) University of Glasgow Centre for Virus Research and Professor Will Irving of the University of Nottingham.

## Data from 12,000 patients

Having obtained clinical data from 12,000 patients and assembled a repository of 150,000 samples, the clinical research database and biobank has underpinned more than 65 research studies in the UK, Europe and Australia.

John describes HCV Research UK as “a bigger success than we could ever have imagined.” “Looking back, we envisioned a national resource which would allow researchers to ask a whole range of unanswered questions about HCV. To look at patterns of transmission in the UK, or examine genetic differences between groups of people, you can’t just rely on isolated laboratory studies. Clinical information from

vast numbers of people is required, and that’s what HCV Research UK has offered the research community. It has been a unique opportunity to ask the most pertinent and challenging questions, powered by integrated biological, epidemiological and clinical data, at a national level,” says John.

## Life-saving treatments

By a stroke of good fortune, HCV Research UK began its patient recruitment just ahead of new treatments being tested in the clinic. These drugs are called direct-acting antivirals and transformed the landscape for treating HCV infection. They offered potentially very high success rates for curing infection, shorter length of treatment and few side effects. Each of these issues were problematic for previous treatments, that used weekly injections of a drug called interferon.

Following a decision by NHS England to make these new treatments available through an early access programme to very ill HCV patients – on the condition that their data and samples were provided to HCV Research UK – clinicians could now access invaluable insights into the performance of these new therapies in the real world and outside the confines of a clinical trial.

**“We discovered that these treatments were capable of curing HCV in these very sick patients, and without this early access programme, they wouldn’t have received the therapies that they desperately needed.”**

Professor John McLauchlan

Data from the resource has underpinned many active research studies, including the MRC’s £5.2 million STOP-HCV programme, which has helped researchers and clinicians better understand disease progression, and improve treatments for patients.





HCV Research UK has also contributed data to 22 research publications, including a *Journal of Hepatology* study which presented some of the first evidence that antiviral treatment was of value to patients with advanced liver disease.

Through their own analyses of the cohort, John and his colleagues have revealed important trends, including higher than average levels of alcohol use, drug use and mental health issues. “Epidemiological studies to disentangle the impact on health of chronic infection itself, versus these co-existing conditions is of real value, as is the development of interventions to tackle these issues,” says John.

### **Amplifying patient voices**

The Foundation’s support has also laid the groundwork for greater involvement of public and patient groups in hepatitis research, including collaborations with the Hepatitis C Trust, Hepatitis Scotland and the Terrence

Higgins Trust. These contributions have helped to explain why taking part in research is so important, in order to answer questions which will have a real impact on the daily lives of patients.

### **Making a difference**

“We are immensely proud of what the HCV consortium has achieved, in memory of Effie Millar Munro and Alfred Tartellin. Thanks to their donations and the Foundation’s transformative investment in our work, we’ve been able to make a real difference to people living with HCV. It is extremely satisfying to think our work could have such a tangible and far-reaching impact on people’s lives.

“Although we’ve stopped recruiting patients, the data collected over the years will always be available to researchers and clinicians. This will ensure that the impact of HCV Research UK is felt for many years to come.”



# Improving the nation's mental health



High need,  
low research  
investment



Emerging  
research  
leaders

**Mental health problems are common, affecting one in four people each year in England, and the number of people reporting these problems continues to rise. Addressing this growing burden of mental ill health is one of our longest-standing research priorities.**

The UK needs a pool of talented 'academic psychiatrists' who can both strengthen our understanding of mental illness and push the boundaries of exciting scientific progress in prevention, diagnosis and treatment. Academic psychiatrists are doctors who carry out research into the causes and treatments of mental illness, alongside their clinical work.

Following the Medical Research Council's (MRC) 2010 review of mental health in the UK, we – along with the MRC – invested £2 million in the PsySTAR (Psychiatry: Scottish Training in Academic Research) PhD training programme to bridge the gap between cutting-edge discovery science taking place in laboratories and clinicians who care for people with mental health problems.

## Translational neuroscientists

"PsySTAR was a response to the need for more 'translational neuroscientists'," says Professor Stephen Lawrie from the University of Edinburgh, who leads the programme. "It's vital that lab-based scientists are exposed to clinical issues and that clinician scientists spend time in cutting-edge discovery research laboratories, so they become familiar with the strengths and limitations of different experimental techniques."

PsySTAR's nine trainees are tackling a range of mental health problems across the lifespan, from predicting how childhood adversity affects later mental health and improving treatments for depression, to exploring the relationship between mental health and ageing.

"A really important part of PsySTAR is interaction with patients, as we feel very strongly that trainees need to do research that has a direct benefit to patients," explains Stephen. "It's too easy for researchers to lose touch of the realities, experiences and everyday needs of patients, so our trainees have regular contact with people affected by the devastating disorders they are trying to diagnose, prevent and treat."

Between them, the PsySTAR trainees have already published their discoveries in more than 50 research papers, including publications in high impact journals such as the *British Medical Journal* and the *Proceedings of the National Academy of Sciences*. Collectively, they have secured more than £400,000 in additional research funding and won three academic prizes for their work.

The PsySTAR programme provides opportunities for talented doctors to work with leading basic and clinical scientists in the fields of psychiatric genetics, behavioural neuroscience, brain imaging, epidemiology, biomedicine, social and public health sciences, and clinical trial methodology.

Interaction with patients is encouraged and aided by the presence of at least two lead supervisors – one from a discovery science background, and the other a clinical specialist.

## Reducing stigma

PsySTAR also strives to reduce the stigma of mental health disorders, by providing the trainees with guidance on communicating with the general public. The trainees have all been very active in various forms of public engagement, including presentations to schoolchildren and at the Edinburgh Festival Fringe. "I think this is critical for early career psychiatrists and scientists – that they can talk passionately about the research they're doing and its potential, as well as correcting myths and giving more realistic messages about psychiatric disorders," says Stephen.

As Director of PsySTAR, Stephen has gone on to become a Director of a £5 million Wellcome Trust Translational Neuroscience PhD scheme. "The PsySTAR funding provided by the Foundation and the MRC has changed the landscape of academic psychiatry in the UK, and leading organisations have taken note of our work," says Stephen.



Professor Stephen Lawrie from the University of Edinburgh

**“My passion in clinical work is for older people, who bring along their own life histories and often have a complex mix of health problems. As people increasingly live for longer, often taking numerous medications over many years, we need to look at the whole picture of their physical and mental health”**

Dr Lucy Stirland, Clinical Lecturer in Old Age Psychiatry at the University of Edinburgh



“Although it will still be some time before the full impact of PsySTAR is felt, we’ve given our trainees the tools they need to become future leaders of mental health research in the UK. They are already offering new insights into major mental illnesses, which will put us in a much better position to diagnose and treat the conditions that all too often blight people’s lives.”

**Dr Lucy Stirland completed her PhD on mental health and ageing in 2020, and credits PsySTAR with helping her secure a clinical lectureship at the University of Edinburgh.**

Lucy’s PhD explored the mental health of people with two or more co-existing physical health conditions, who used multiple medications to treat these conditions.

“My passion in clinical work is for older people, who bring along their own life histories and often have a complex mix of health problems. As people increasingly live for longer, often taking numerous medications over many years, we need to look at the whole picture of their physical and mental health,” says Lucy.

“PsySTAR was an unmissable opportunity and I wouldn’t be leading my own research today without it. I thoroughly enjoyed my PhD, mostly for the chance to work independently on something that gave me such a sense of achievement.

“I’m most proud of my research paper published in the *British Medical Journal*, which reviewed different ways of measuring multiple conditions, to help guide clinical decision-making.”

Lucy was awarded the Royal College of Psychiatrists’ Scottish Division Research Prize in 2019, and in the same year she presented her findings at the world’s largest Alzheimer’s research conference – the Alzheimer’s Association International Conference in Los Angeles, USA.

To stay grounded in what her work could mean to real people, Lucy has been in regular contact with Mary Nisbet, a member of the general public, who has contributed to Lucy’s research. “Discussing my research ideas with Mary has been really valuable, as it reconnects me with the people at the heart of what I do,” Lucy explains.

Now a Clinical Lecturer in Old Age Psychiatry at the University of Edinburgh, Lucy is investigating multi-drug treatment use in a large Scottish research cohort, looking for potential links with dementia and depression over time.

“My PhD was about so much more than just writing a thesis. Thanks to PsySTAR, I’ve learned immensely valuable skills in critically analysing research, speaking confidently about my work at conferences, and collaborating on large and complex research projects.”



Mary Nisbet

# Understanding mental illness in children with intellectual disabilities



High need,  
low research  
investment

**Children with intellectual disabilities are known to be at increased risk of a range of mental illnesses. However, it is hard to predict with any certainty what problems a child might face in the future, which makes it difficult to anticipate what support they will need.**



Professor David Skuse and  
Dr Jeanne Wolstencroft from  
University College London.

Professor David Skuse is a child psychiatrist and researcher based at University College London. He believes that children with intellectual disabilities haven't received the support they need from mental health services.

Improving mental health support for these children needs sustained investment in research. However, child psychiatry and intellectual disabilities have been chronically under-funded fields of research, compared to other areas such as cancer, heart disease, or dementia.

## The IMAGINE-ID project

To redress this lack of funding, we partnered with the Medical Research Council (MRC) to provide a total of £2.6 million to better understand the link between intellectual disability and mental health. This money funded the IMAGINE-ID project led by Professor David Skuse, in collaboration with researchers at Universities of Cambridge and Cardiff.

**“Let’s make sure that these kids who are at risk are actually getting tests, and then make sure that that optimal support is available countrywide – not just in a few pockets.”**

Professor David Skuse

Although intellectual disabilities can be caused by a range of factors, it's known that 85 per cent of cases have a genetic origin. This means that variations or faults in a child's genes (mutations that are either inherited or newly occurring) have contributed to their disability. David and his colleagues wanted to investigate whether some rare mutations might be associated with a greater risk of specific emotional and behavioural problems later in life. If we had this information, it would make

it possible to provide families, whose children have these very rare genetic conditions, with the information they need about their child's future and care. At the moment, very little information is available about most of these rare events, which are increasingly being diagnosed by the NHS's genetic screening programme.

The IMAGINE-ID project has brought together more than 3,500 children with an intellectual disability and a known genetic mutation, making it the largest study of its kind in the world.

The team found that children with intellectual disabilities with a known genetic cause were over 30-times more likely to develop an emotional or behavioural problem, compared to typically-developing children. Nearly half of the children in the study have at least one mental health disorder, and 80 per cent have multiple disorders. More than one in three has an autism spectrum disorder, about one in eight have attention deficit hyperactivity disorder (ADHD), and one in 10 has severe anxiety.

David and his colleagues expected to find that specific genetic mutations would be associated with a greater risk of emotional or behavioural disorders. What they found overall was that the problems the children were experiencing were very similar across the board, regardless of their genetic condition. The research team are now following these children for another five years, to see if the risks to their mental health change as the children become teenagers and young adults.





## Providing better information and support

The most immediate impact of the IMAGINE-ID study is the information that can now be provided to the families of children with rare genetic disorders that are associated with learning difficulties. With data from the study, doctors looking after these children will have greater awareness that many rare genetic conditions are usually associated with a much-increased risk of behavioural and emotional disorders. They can also advise parents on the type of problems they might face and make recommendations for managing those problems that might be helpful to them.

David's also acutely aware of the policy implications of the IMAGINE-ID programme. He will be using the IMAGINE-ID data to study how genetic testing and mental health support for these children varies across the country, such as whether there are differences between affluent areas and poorer areas. In the longer term, David hopes that the IMAGINE-ID project will help to make access to both genetic testing and mental health services much more equitable for children with intellectual disabilities.

**Nicole, 10, has a genetic disorder called '16p11.2 deletion', meaning a small piece of genetic material is missing from her DNA. Present from birth, the condition can cause language impairment and a delay in reaching certain developmental milestones, such as walking or talking, learning new skills or interacting with others.**



# How has the IMAGINE-ID project helped families?

**Brandon, 17, lives in London with his mother, Claudia. He is a keen kayaker and likes to go hiking and trekking in the countryside.**

Brandon has a genetic disorder called '22q11 deletion', which can cause heart defects and learning difficulties. "Brandon was very lucky, as he only showed some of the problems associated with his disorder, including social difficulties, delayed speech when he was little, and curvature of the spine (scoliosis)", says his mother, Claudia.

"The information provided by the IMAGINE-ID researchers has been very useful. It highlighted the main difficulties he has, particularly with social interactions. Before we got involved in the study, we didn't know whether some of his behaviour was part of his condition or part of his personality. I could now see that there was a genetic explanation for some of these traits, and that was very helpful.

"The IQ test was also really valuable, particularly for discussions around Brandon's schooling, as it just proved what we already knew: Brandon is a very intelligent boy, the way he learns and interacts is just different. For example, we realised he was a visual learner, so we allowed him to watch more videos related to his learning, rather than just reading books. Without the IQ test, we might not have pushed him academically as much as we did. Brandon is now doing BTEC science at college, and he got a merit in his first year."







**Nicole, 10, lives in London with her mother Nichola and three older sisters. She loves swimming and wherever Nicole goes, her dollies go too (except the pool).**

Nicole has a genetic disorder called '16p11.2 deletion', which can cause language impairment and a delay in reaching certain developmental milestones, such as walking or talking, learning new skills or interacting with others.

"Nicole was born a few weeks early and showed some signs of the condition straight away, including having very flexible joints (hypermobility), drooped eyelids and developmental delay" says her mother, Nichola.

"We got involved in the study through Great Ormond Street Hospital several years ago. We were already part of the 1000 Genomes Study and were happy to get involved in more research to help other families in the future.

"Being part of the study has been really interesting. And if it wasn't for this research, I never would have known that I had the same condition as my daughter. As I didn't find out until adulthood, it makes you wonder how many more people live with these conditions, without knowing about it."



# Preventing eating disorders and self-harm



High need,  
low research  
investment

**Adolescence through to early adulthood is a time of rapid physical, emotional and social change – all of which can make young people more vulnerable to mental health problems.**



Dr Amy Harrison (pictured right) and colleagues from UCL are exploring whether sensitivity to reward and punishment could play a role in the development of eating disorders.

Three quarters of mental health problems emerge before the age of 24, and these issues continue to rise in young people.

other eating disorders such as bulimia can lead to severe medical complications.

**£3.9 million**

invested in 13 ground-breaking projects  
projects, in partnership with the MRC

**£1.1 million**

invested in four solely Foundation-funded  
studies

Despite advances in technology and new insights drawn from large sets of biological, social and environmental data, the burden of mental ill health has not gone away - nor has it been matched by investment in new research, which remains low compared to many physical conditions.

That's why child, adolescent and early adulthood mental health remains one of our longest-standing research priorities.

In 2017 we identified eating disorders and self-harm as an area where we could make a real difference. These are devastating conditions which blight the lives of increasing numbers of young people and their families.

Around 1.2 million people in the UK have an eating disorder. Anorexia has the highest mortality rate of any psychiatric disorder, and

The UK's rates of self-harm are among the highest in Europe and have increased steadily over the past decade. Repeated self-harm results in around 150,000 attendances at accident and emergency departments each year and is one of the top five causes of acute medical admission.

## Life-threatening disorders

Despite the devastating impact of these life-threatening disorders, our understanding of what drives them to develop is still limited.

In partnership with the Medical Research Council (MRC) we have invested £3.9 million into 13 ground-breaking projects, as well as a further investment of £1.1 million into four solely Foundation-funded studies. These projects are improving understanding of what causes eating disorders and self-harm, and ultimately, these insights are helping to inform larger-scale prevention and treatment studies – all of which are aimed at improving the lives of affected young people.

## Exploring why eating disorders develop

We awarded a research grant to Dr Nadia Micali, from University College London, for a project exploring how changes in our genetic and physical make-up – particularly related to metabolism, appetite and growth - could lead to the onset of eating disorders. “We still have very few treatment options for eating disorders,” Nadia explains. “Certain treatments work well in some people, but it’s often difficult to predict those who will not respond to treatment. We need to get better at detecting young people at risk, in order to improve prevention and develop new approaches to treatment.”

**“We need to get better at detecting young people at risk, in order to improve prevention and develop new approaches to treatment.”**

Until recently, researchers have focused mainly on the psychology of eating disorders, and how they might be driven by the cultural and societal pressures faced by young people.

But Nadia and her colleagues are starting to explore the biological roots of eating disorders, including factors related to genetics, metabolism, appetite and growth. Nadia’s Foundation-funded research has shown that certain patterns of eating behaviours during the first ten years of life are associated with higher risk of eating disorders. More specifically, children who tend to consistently overeat are more likely to develop a binge eating disorder, whereas persistent fussy eating or undereating is linked to increased risk of anorexia nervosa. Nadia also found evidence that persistent high body mass index (BMI) in children may be a risk factor for the development of binge eating, eating-disorder related thoughts, and that genes associated with BMI may also predict how eating behaviour develops throughout childhood.

“By untangling all of these factors, we can build a much better picture of how genetic and environmental influences shape eating behaviour. These insights could help with predicting which children will go on to develop eating disorders, so that we can intervene as early as possible,” says Nadia.



Dr Nadia Micali, University College London

## Examining links between childhood trauma and self-harm

To tackle the growing problem of self-harm among young people, we funded Dr Becky Mars from the University of Bristol to investigate whether negative experiences in early life – such as abuse, witnessing domestic violence or having separated parents – are associated with specific biological processes linked with self-harm in adolescents.

We know the social environment can have an impact on the body’s internal working, including inflammation, alterations to DNA, and puberty. And previous research has shown a link between adverse childhood experiences and teenage self-harm, however it was unclear whether biological inflammation, sparked by the ‘fight or flight’ response to stress, could help to explain this association.

One of Becky’s studies was the first ever to look at childhood trauma, inflammation and self-harm, to help identify potential markers of future self-harm risk, as well as possible

targets for treatment for young people who self-harm. Becky analysed data from 4,300 young people in Bristol’s ‘Children of the 90s’ study to see if adverse childhood experiences such as experiencing abuse, witnessing domestic violence or having separated parents are linked to self-harm at the age of 16. She found that for each extra type of adverse experience, a young person is 11 per cent more likely to self-harm at the age of 16, and 22 per cent more likely to have self-harmed with suicidal intent. There was no evidence that levels of inflammation or age of puberty linked childhood trauma and self-harm, so more research is needed to investigate other biological and psychological pathways linking adversity and self-harm.

“The evidence we’ve gathered so far shows the importance of addressing childhood adversity as early as possible, identifying potential markers of self-harm risk, and developing new ways of treating young people who self-harm,” says Becky.



Dr Becky Mars, University of Bristol

# Research stars of the future



Emerging  
research  
leaders

**Since our first Emerging Leaders Prize in 2017, we've awarded £800,000 to 17 outstanding scientists working in the fields of lupus, adolescent mental health, antimicrobial resistance (AMR) and pain research.**

The prize fund is flexible, allowing the winners to decide how best to use it. That could mean spending time in a lab overseas, buying cutting-edge technology to support their research, or investing in their personal career development.

Our Trustee and Chair of the Emerging Leaders Prize panel, Professor Danny Altmann, explains: "Through the Prize, we've looked for scientists on a trajectory to do something unique and special in their field, and that's undoubtedly the case with our winners. Each year I'm blown away by the pool of talent we've been able to unearth.

"We know this prize has already been a real game-changer for many of our winners, providing a vital springboard for the next stage of their careers."

Between them, our prize-winners have secured additional funding totalling nearly £2.5 million and published more than 40 research papers in leading medical journals. This reflects both their advancement of understanding and knowledge surrounding key health challenges, and potential to become research leaders of the future.

**Our first ever Emerging Leaders Prize-winner, Dr David Hunt from the University of Edinburgh, scooped our top prize in 2017. David recently received £1.5 million from the Wellcome Trust for a Senior Clinical Fellowship, and he attributes this success in part to the Emerging Leaders Prize.**



Dr David Hunt, University of Edinburgh

"The Emerging Leaders Prize has been transformative for my lab's research into lupus brain disease. The research funds have enabled me to purchase state-of-the-art equipment and develop bold new collaborations. Winning this award has also increased my group's visibility and allowed me to connect more closely with the lupus community."

Brain disease is a serious and common problem in lupus, yet its molecular basis is largely unknown. Thanks to our Emerging Leaders Prize, David is decoding the molecular basis of lupus to develop better personalised treatments.

His laboratory is exploring how to combine results of an extremely sensitive blood test

with images from brain scans, to follow how lupus-related brain disease develops. This information could be used to design clinical trials aimed at preventing brain damage.

David adds: "My very first job in medicine involved looking after people with lupus, and this contact has inspired my research and clinical practice.

"Our ability to develop treatments to prevent or treat brain disease in lupus is hampered by two problems. Firstly, we understand very little of the molecular pathways which drive brain disease. Secondly, we don't have good ways of measuring brain dysfunction in clinical trials. My group addresses both of these roadblocks, trying to decode the molecular pathways and develop practical biomarkers of brain disease."



# Emerging Leaders Prize – the story so far

## Lupus – 2017

Sometimes our donors specify areas of research important to them, and that was the case for **Dr Erina Herrick**, who left a gift in her Will to support emerging research leaders in the field of lupus. Our first ever Emerging Leaders Prize in 2017 was a tribute to Dr Herrick, a scientist who lived with lupus for most of her adult life.

Lupus is a long-term autoimmune disease that affects around 15,000 people in England and Wales. It is very difficult to diagnose and is currently incurable, although the disease can be managed if detected early.

Our 2017 prize-winners are tackling vital research questions around the genetic drivers of lupus and the molecular basis of brain disease in lupus.

## 1st place, £100,000 prize

**Dr David Hunt**, *University of Edinburgh*

## 2nd place, £80,000 prize

**Dr Tracy Briggs**, *University of Manchester*

## 3rd place, £20,000 prize

**Dr Edward Vital**, *University of Leeds*



Left to right: Dr Tracy Briggs, Dr David Hunt and Dr Edward Vital

Dr David Hunt is studying how lupus-related brain disease develops.

Credit: Mark Bastin, Joanna Wardlaw, and Stewart Wiseman, University of Edinburgh.



# Emerging Leaders Prize – the story so far



Emerging  
research  
leaders

## Adolescent mental health - 2018\*

Our 2018 prize-winners are probing various aspects of adolescent mental health, including the genetic factors that put young people most at risk of developing mental health problems, and brain imaging techniques which could establish whether changes in neural pathways are connected with mental ill health.

### 1st place, £100,000 prize

**Dr Jean-Baptiste Pingault**, *University College London*

### 2nd place, £80,000 prize

**Dr Tobias Hauser**, *University College London*

### Runners-up, each awarded £5,000

**Dr Catherine Sebastian**, *Royal Holloway, University of London*

**Dr Valeria Mondelli**, *King's College London*

**Dr Helen Fisher**, *King's College London*

**Dr Anne-Laura van Harmelen**, *University of Cambridge*



Our 2018 winners with Foundation Trustees Professor Nick Lemoine (left) and Professor Danny Altmann (right).

## Antimicrobial resistance – 2019\*\*



Left to right: Dr David Eyre; Dr Myrsini Kaforou; Dr Tihana Bicanic; Dr Alison Mather.

Antimicrobial resistance (AMR), and specifically antibiotic resistance, poses a global threat to human life, requiring urgent action to halt drug-resistance and to accelerate new treatments for bacterial infection. Already, drug-resistant infections are estimated to cause 700,000 deaths each year globally, and that figure is predicted to rise to 10 million by 2050.

In 2019 we recognised outstanding scientists working on a range of research problems related to AMR, including finding the best gene combination to determine whether someone has a bacterial infection, rather than a viral infection, in turn guiding whether they genuinely need antibiotic treatment.

### 1st place, £100,000 prize

**Dr Myrsini Kaforou**, *Imperial College London*

### 2nd place, £90,000 prize

**Dr Tihana Bicanic**, *St George's University of London*

### Runners-up, £5,000 prize

**Dr David Eyre**, *University of Oxford*

**Dr Alison Mather**, *Quadram Institute Bioscience*



## Pain – 2020\*

Pain affects around 28 million people in the UK. It is not simply a symptom of disease but has a biology that is important to understand due to its wide-ranging effects on people's quality of life. Chronic pain also carries a large societal and economic burden by putting extra strain on healthcare systems, as well as contributing to unemployment and work absence due to sickness. Chronic pain costs the UK economy billions of pounds every year.



2nd place prize winner Dr Annina Schmid, University of Oxford

Despite these personal, societal and economic burdens, there is still a significant gap in our understanding of pain. Our 2020 Emerging Leaders Prize funded four exceptional scientists, who are grappling with issues such as alleviating pain in babies and preventing pain after whiplash injury in adults.

1st place prize winner Dr Lorenzo Fabrizi, University College London (UCL)

## 1st place, £100,000 prize

**Dr Lorenzo Fabrizi**, *University College London*

## 2nd place, £80,000 prize

**Dr Annina Schmid**, *University of Oxford*

## Highly commended, £10,000 prize

**Dr Philip Holland**, *King's College London*

**Dr Franziska Denk**, *King's College London*

*\*These prizes were funded by a gift in Will from Professor Victor Louis Ménage and Johanna Alicia Ménage.*

*\*\*This prize was made possible by Professor Victor Louis Ménage and Johanna Alicia Ménage's gift in Will, as well as an additional grant from Shionogi B.V.*



# Training future leaders to solve antimicrobial resistance



Emerging  
research  
leaders

**Modern medicine relies heavily on antibiotics and other antimicrobial drugs. We use them to treat everything from minor illnesses to life-threatening bacterial infections, and to make all kinds of surgery and cancer treatments safer.**

However, antimicrobials are becoming less effective. The overuse and misuse of these precious drugs has led to the rise of resistant strains of bacteria which pose a great threat to global health. Drug-resistant infections kill hundreds of thousands of people every year across the world. Without urgent action, some routine medical procedures and operations will become dangerous, many common infections will become untreatable, and millions of lives will be lost.

## 700,000 people

**die each year due to drug-resistant infections and without action, this could reach 10 million deaths by 2050**

issue had been de-prioritised for research investment, while non-infectious illnesses like cancer and heart disease received more interest.

### Multiple problems, multiple solutions

Antimicrobial resistance has traditionally been seen as something to be solved by microbiologists, scientists who study bacteria and other microbes. The reality is that antimicrobial resistance does not have one simple solution. Instead, the problem needs to be looked at from multiple angles, involving researchers from fields including ecology, engineering, anthropology, physics, and behavioural sciences.

Professor Matthew Avison leads a research group at the University of Bristol studying antimicrobial resistance. He feels that in high-income countries like the UK, where people place a lot of trust in vaccination and existing antimicrobial drugs, antimicrobial resistance had been largely overlooked by the government and the media for many years. This, according to Matthew, meant the

We are part of a consortium of research funders which has recognised that a new approach to antimicrobial resistance is needed. We invited applications to create a unique PhD training programme in antimicrobial resistance research. And in 2018, the first cohort of 16 students began their studies, followed by a further 14 students in a second cohort in 2019.



Our 2018 and 2019 AMR PhD students.



**“I’ve been able to widen my perspective on the different aspects and approaches to understanding antimicrobial resistance, in a way that I wouldn’t have otherwise.”**

Nidhee Jadeja , PhD student.

The PhD programme, led by Professor Avison, has interdisciplinary research at its core. The aim is to break down the barriers between different areas of science, to help the students understand and ‘speak the language’ of each other’s research.

To achieve this, the students have two supervisors drawn from different research disciplines, rather than just one. They also undergo placements and cohort building events to see first-hand the factors which influence antimicrobial resistance. Matthew and his team also established a residential training programme, where over 150 PhD students from around the UK learn about multi-disciplinary research and the problems of antimicrobial resistance.

## **“We’re building this for the future”**

**One of the Foundation-funded PhD students, Nidhee Jadeja from Imperial College London**, is studying how to improve public policies in low-resource hospital settings, in order to tackle antimicrobial resistance. Her project will provide insights on the health and cost impacts of policy strategies for decision-makers.

“Being part of the PhD cohort has been fantastic,” says Nidhee. “It is a really supportive community of inspiring people, answering all types of interesting questions about antimicrobial resistance. I’ve been able to widen my perspective on the different aspects and approaches to understanding antimicrobial resistance, in a way that I wouldn’t have otherwise.”

Although there have been lots of exciting developments from individual projects, Matthew believes that the biggest impact of the programme will be seen in the future. His hope is that it will create a group of leaders in research, policy, and other areas of public life, who understand antimicrobial resistance and can bring a collaborative ethos to wherever their career leads them. As he puts it: “We’re building this for the future.”



Professor Matthew Avison,  
University of Bristol



# Building a community of inspired African scholars



Emerging  
research  
leaders

**Through our West African Scholars programme, we've enabled 21 promising West African students to complete either a bachelor's degree or a master's degree – or both – in subjects ranging from biochemistry and radiography, to biomedical sciences and global health management. Not only has the programme helped to nurture the careers of African scientists, but it has also empowered them to tackle some of Africa's most pressing health challenges.**

Over a period of nearly 15 years we've invested almost £2 million into the programme, with our alumni going on to secure PhDs and research fellowships, and even set up their own charities.

Now an investigator in the Human Genetics team at GlaxoSmithKline (GSK), Dr Neneh Sallah is well on the way to achieving her main ambition of leading a research group back home, in The Gambia. But it all started with her Foundation-funded BSc in Microbiology, which she completed at the University of Manchester, before going on to do a genomics PhD at the University of Cambridge.

Like all of our West African scholars, Neneh had the opportunity to work at the Medical Research Council (MRC) Unit The Gambia, and she has since contributed to a UN Inter-Agency taskforce for non-communicable diseases at the World Health Organization, and carried out genetic research at the London School of Hygiene and Tropical Medicine (LSHTM) and UCL's Institute for Health Informatics.

"As a lab technician at the MRC Unit The Gambia, I was fascinated by the progress being made in genomics research overseas. We were generating vast amounts of valuable data, but we didn't have the expertise to handle or make sense of it", says Neneh. Recognising this skills gap is what motivated Neneh to pursue a genomics PhD in Cambridge.

In her postdoctoral role at the LSHTM, Neneh combined genome sequencing, clinical information and bioinformatic approaches to investigate whether genetic differences explain why people respond so differently to infection.

She remains fascinated by the genomic diversity of African populations, and the implications this has for public health.

"African populations are known to have some of the highest levels of genetic variation in the world, yet only three per cent of genomic studies have been conducted in African populations. As a result, in Africa, the contribution of various genetic risk factors to a range of different diseases, is largely unknown."

More recently, as a Senior Research Fellow at UCL, Neneh's research focused on understanding the influence of our genetics and the environment on complex diseases in under-represented populations by leveraging large scale population, health care and genomics data.

In her new role at GSK, Neneh is using similar techniques to guide clinical decisions around drug development and treatment for infectious and immune-related diseases.

Neneh has also found the time to co-found an independent, non-profit organisation – Health and Science for The Gambia – which focuses on strengthening the academic, scientific research and health sector and instead of by organising lectures on a range of public health issues. Neneh is also a Director of OXCAMP Africa, a programme that mentors talented and disadvantaged African students, especially girls, to address gaps in education and gender inequality.

"The BSc degree not only deepened my understanding of infectious diseases, but it also opened my eyes to what I could achieve



**“The Foundation’s scholars programme undoubtedly laid the groundwork for my development as a researcher”**

Dr Neneh Sallah

as a scientist, and provided the networks I needed to get where I am today. I’ve had the opportunity to work at some of the most prestigious and respected research institutions in the world, while carving out my own unique skills in data science.”

Neneh sees her future in The Gambia, where she wants to harness the power of data science to solve health problems in her own country, and across Africa. “I’m really excited about what the future holds. In Africa, we need to catch up with the global movement towards personalised medicine, and our work could contribute to a new era of precision medicine across the continent.”



# Revealing the biology underlying human disease



Increasing  
understanding

**Underneath all disease is biology – cells replicating out of control, organs failing, immune systems being overwhelmed, and lives being cut short. Uncovering the basic biology behind human health is essential to finding new ways to diagnose, prevent, and treat diseases better.**

This has been the philosophy from day one of the Francis Crick Institute, a huge research lab just around the corner from London's St Pancras Station. To understand how diseases develop, the Crick performs 'in vivo' research to effectively 'see inside' living organisms to observe how well organs are functioning, and to look at the structure of cells within the body. They have a specialised In Vivo Imaging (IVI) facility, which allows researchers to non-invasively track natural processes and diseases in live animals and monitor them over time, including ultrasound, fluorescence and Magnetic Resonance Imaging (MRI).

Dr Bernard Siow is the head of MRI in the IVI facility. Bernard says that, in the same way that a lab scientist would use a microscope, in vivo imaging is like a microscope that reveals the details of how diseases develop inside living beings.

## Cutting-edge equipment

Set up with our help, through a £1.8 million donation, the IVI facility houses the Crick's cutting-edge imaging equipment and a team of experts to help scientists use it. As well as scientific imaging equipment, there are miniature versions of hospital scanners including CT, MRI, and PET, as well as ultrasound machines.

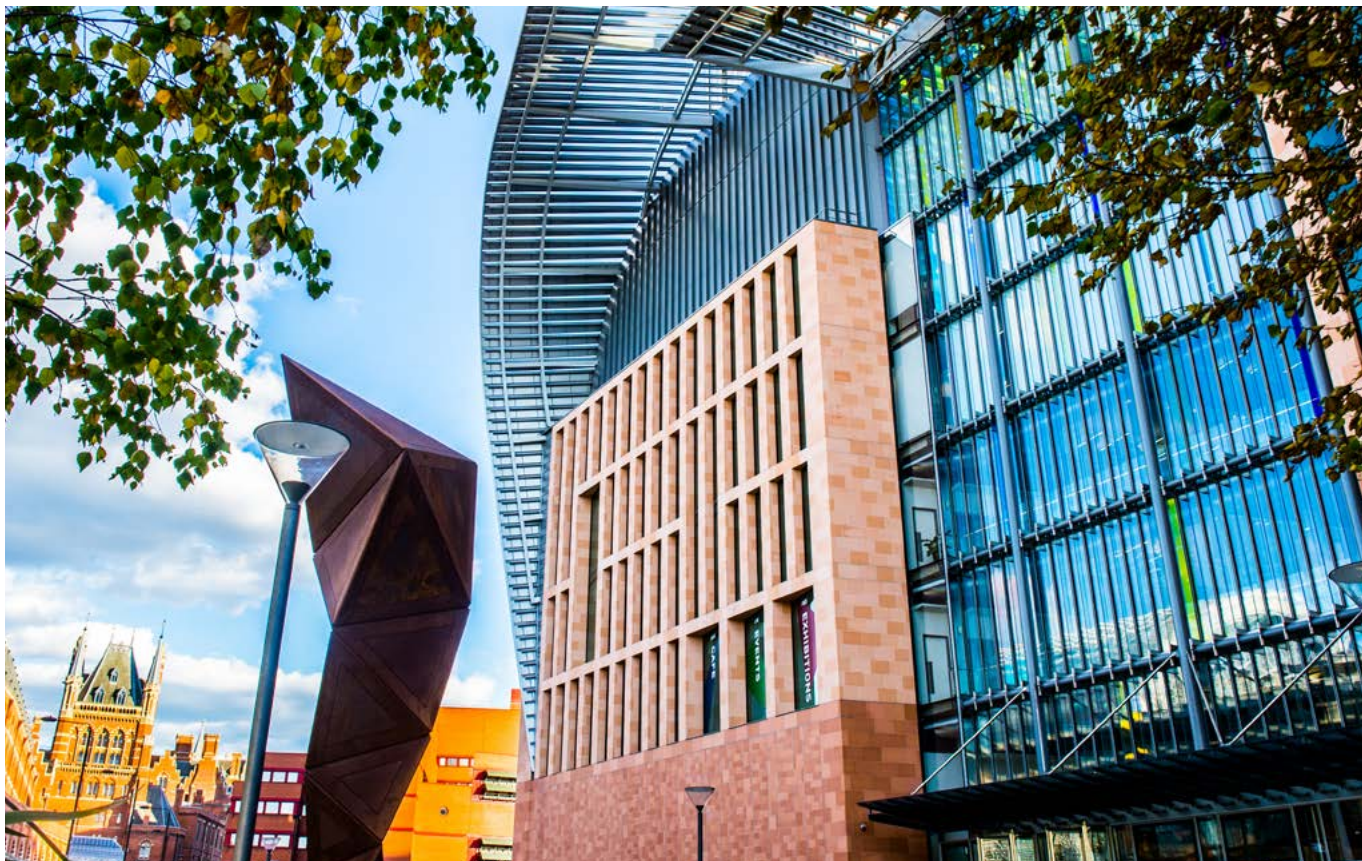
## £1.8 million

donation invested in a new IVI facility

Crick scientists are using the IVI facility in lots of different ways. Sometimes the equipment is used for relatively basic but important functions, such as accurately measuring the size of tumours to track how cancer grows.



Visiting Dr Bernard Siow at the Francis Crick Institute in 2018.



The Francis Crick Institute, London.

**“Without that contribution [from the Foundation], the IVI facility would be much smaller, would have far fewer machines, and would be far less rounded. Now I would say we are one of the top imaging facilities in the UK”**

Dr Bernard Siow,  
Francis Crick Institute

Other projects involve Bernard and the IVI team developing bespoke imaging techniques for researchers. And the benefit of having hospital-style research scanners is that these new imaging techniques could potentially be used for human patients in the future.

The IVI facility has significantly improved how animal research is carried out at the Crick. For example, in vivo imaging allows scientists to study diseases inside mice without needing to sacrifice and dissect them, which reduces the numbers of mice used in experiments and the harm they might experience. And studying a disease in one mouse over time, rather than in different mice at different stages, can give a better picture of how the disease really develops.

Part of our donation paid for a single-photon emission computed tomography (SPECT) scanner. This provides scientists with 3D images of blood flow to show how certain molecules are being used and how they travel through the animals' bodies. One research team is using the SPECT scanner to monitor the growth and spread of tumours from cancer cells in mice.

## A central hub of expertise

But the equipment is not the IVI facility's only asset. Having everything in one place with the support of experts like Bernard is a key strength. This allows the scientists to get the most out of the facility and the best from their research. “Bringing everything together really just helps to centralise things, so that people feel comfortable to come to us, exchange ideas with other experts from different fields, and use the equipment,” says Bernard.

The IVI facility is making a big contribution to the research at the Crick, and Bernard believes our support has been crucial to its success. “I don't think we would have been able to create such a facility without the Foundation's donation,” he says.

“Without that contribution, the IVI facility would be much smaller, would have far fewer machines, and would be far less rounded. Now I would say we are one of the top imaging facilities in the UK.”

*Thank you to GlaxoSmithKline, who made the donation to the Crick's IVI facility possible.*



# Using zebrafish to increase our understanding of motor neurone disease



Increasing understanding

**Motor neurone disease (MND) can be devastating, both for people affected by the condition and their families.**



Dr Bradley Smith, King's College London.

In people with MND, the motor neurones which normally control voluntary muscle movements like speaking, walking and swallowing begin to weaken and gradually waste away.

Although rare, affecting two in 100,000 people in the UK at any one time, around one in 300 people will develop MND at some point in their lives. MND has a significant impact on people's lives and there is no cure. Life expectancy for around half of those with the condition is just three years from the start of symptoms – making new research vital.

Thanks to a gift in Will from Irene Griffiths, who wanted to help UK scientists tackle this devastating disease, we have been able to support some of the brightest and best MND researchers in the country – including Dr Bradley Smith from King's College London.

Bradley uses zebrafish models of MND to pinpoint biological mechanisms of potentially harmful genetic mutations in new MND genes. His research has found that the most common genetic mutation in a new gene called Annexin A11, when modelled in zebrafish embryos, slowed down the movement of neurones in the brain. He also discovered that 'switching off' the zebrafish equivalent of this gene resulted

in abnormal motor neurone formation, such as reduced branching of neurones. Bradley's research highlighted that this gene is important for normal neuronal function, and next he will assess these results in mouse models.

"The fellowship has been immensely valuable to my research," says Bradley. "It has provided two key opportunities, firstly to address a fundamental issue in MND genetics, which is the evaluation of new gene candidates to assess if mutations are detrimental to motor neurone function.

"Secondly, it adds highly specialised new skills to my professional toolkit and will provide a stepping-stone to being an independent researcher in the MND field.

"Through our research to date, we have identified a potential disease mechanism, and we can now link this gene into several well-known MND pathways, helping to build a better understanding of common denominators for the disease."

Bradley added: "The fellowship has also contributed to my own development by enabling me to communicate my research, present at MND patient forums, and train emerging scientists. I have also been awarded Lectureship at King's College London, off the back of my fellowship."

**"We have identified a potential disease mechanism, and we can now link this gene into several well-known MND pathways, helping to build a better understanding of common denominators for the disease"**

Dr Bradley Smith, King's College London





# Offering hope to families affected by genetic disorders



Changing  
policy and  
practice

**Dr Emma Baple and her team of researchers at the University of Exeter have received six Changing Policy and Practice Awards from our Fleming Memorial Fund, totalling £176,000, for their landmark translational research project - ‘Windows of Hope’.**

The ‘Windows of Hope’ team has defined over 150 different genetic disorders in North American Anabaptist (Amish/Mennonite) communities, more than 25 of which are new to medical science. The team’s findings have revolutionised the approach to molecular diagnostic testing and genetic counselling.

Our awards have allowed their team to disseminate their research findings and deliver wide-ranging benefits to families affected by genetic disorders and their healthcare and education providers.

The team has created a searchable database of all known inherited disorders affecting the communities, which is widely used by clinicians, genetic counsellors, healthcare professionals, teachers and academics worldwide. Educating professionals on the benefits of a community approach to genomic medicine and research has been crucial to Emma’s research, helping to reduce health inequalities faced by communities affected by inherited disease, and ultimately improving long term health and developmental outcomes.

Emma’s team have directly enabled early intervention, improved patient management and therapeutic development for these communities, as well as other families with these conditions worldwide. The team has since used the Windows of Hope project as a model for parallel studies in Pakistan, Palestine and Oman.

“Before the Windows of Hope project began in 2000, less than five per cent of people in Anabaptist communities with a genetic disorder had received a diagnosis,” says Emma. “Now, that figure is around 70-80 per cent. For many of the families we have worked with, the specific genetic cause of the disorder affecting them was not known to medical science prior to our studies.

“Lack of knowledge and awareness of these newly described conditions among the Amish community and their healthcare providers meant that children with genetic disorders have often been subjected to needless, expensive and sometimes painful investigations, and so obtaining a diagnosis has been incredibly important for these families.”



Dr Emma Baple and Professor Andrew Crosby from the University of Exeter.

# Spreading the word about harmful ‘skunk’



**In the UK, cannabis is widely used, and a particularly harmful type of cannabis - called ‘skunk’ - makes up 80 per cent of all cannabis available.**



**80%**

of all UK cannabis is  
‘skunk’

Cannabis use places a significant burden on both the NHS and our broader society as a result of mental health issues associated with use of the drug, as well as having a detrimental impact on young people’s education and prospects.

By increasing public awareness of just how harmful skunk can be and changing cannabis smoking behaviour, it may be possible to reduce negative health consequences for a significant number of people.

Dr Valerie Curran, a researcher at University College London (UCL), was awarded over £27,000 to disseminate the findings of her research into different types of cannabis and the harm they cause. Her research found that the harm caused by cannabis is determined by the level of cannabinoids in the plant.

She discovered that smoking cannabis is associated with an increased risk of schizophrenic-like symptoms, and a composition of high THC levels and low cannabinoids causes greater memory impairment. It is also more addictive. This is all because cannabinoids normally protect against the harmful effects of THC, and so skunk,

which has high THC and no cannabinoids, is even more harmful.

With research suggesting that 14 per cent of people with schizophrenia might never have developed the condition had they not smoked cannabis, Valerie’s research carries an important public health message. Valerie presented her work at New Scientist Live in 2019, and featured on Channel 4’s ‘Drugs Live – the cannabis trial’.

We also funded a public health campaign video – ‘Cannabis Effects’ – which brought together the latest research findings, and young people’s lived experiences of cannabis use, culminating in an award-winning drugs education tool.

“The Medical Research Foundation’s funding has proved invaluable,” says Valerie. “The video we produced has been used for eight years in training and peer mentoring by two London charities; Mac-UK and Art against Knives, which work with vulnerable young people who have complex mental health needs. The video was featured in the Guardian as an example of excellent practice working with young people and won an award for science communication.”

# Optimising HIV treatment in low income countries



**Despite the availability of life-saving treatment for HIV, called antiretroviral therapy (ART), there are large gaps in coverage in many countries in sub-Saharan Africa.**



In high income settings, doctors use regular laboratory tests to monitor the effectiveness of the medicines, but these are expensive and inaccessible to people living in low income or rural settings.

approach that had the potential to save many more lives.”

To help Diana communicate her findings, we awarded almost £60,000 of research funding as part of our Changing Policy and Practice Award.

The discoveries from DART were transformed into a short film, which was featured multiple times on BBC World during World AIDS Day in 2009 and during the 2010 British Science Festival. Diana and her team also hosted a formal event to launch the project’s briefing document in Westminster, which was attended by more than 120 people from a wide range of organisations.

**“The Foundation’s support enabled us to share the results of our trials with policymakers and clinicians globally”**

Professor Diana Gibb,  
University College  
London

Professor Diana Gibb, from the MRC Clinical Trials Unit at University College London, wanted to find out how best to use ART medicines in Africa to treat people as safely, effectively and easily as possible where laboratory testing is not available. In 2005, when Diana was conducting her research, just 17 per cent of people who needed treatment were receiving ART in sub-Saharan Africa.

Diana led two trials, known as the Development of Antiretroviral Therapy in Africa (DART) and Anti-Retroviral Research for Watoto (ARROW), in 2003 and 2007 respectively. Funded by the Medical Research Council (MRC), they investigated the best treatment approaches for HIV in Uganda and Zimbabwe, with DART focusing on adults, and ARROW focusing on children.

These studies, involving over 3,000 adults and 1,200 children, drew very similar conclusions. “Our research showed that ART medicines can be delivered safely and effectively by healthcare workers, in communities where routine laboratory services are not available”, says Diana. “We also recommended that HIV programmes focus their resources on getting more people on to life-saving treatment – an

ARROW was communicated to national policymakers in the Ministry of Health in Uganda and Zimbabwe, and paediatric HIV treatment-implementing organisations, to inform their decisions on how to treat children with HIV in Africa. Evidence from the trial also helped to inform the World Health Organization’s guidance on cotrimoxazole treatment.

Diana also produced a series of 20 case study training videos to help health workers across Africa treat children with HIV more effectively, which have been distributed to around 200 teachers at medical schools in 20 African countries.

“The Foundation’s support enabled us to share the results of our trials with policymakers and clinicians globally,” says Diana. “Without this funding, we would not have been able to produce or distribute these tools, making it harder for clinicians to learn and apply the results from our trials.”



# Help us fund more life-changing research

**There has never been a more important time to support medical research.**

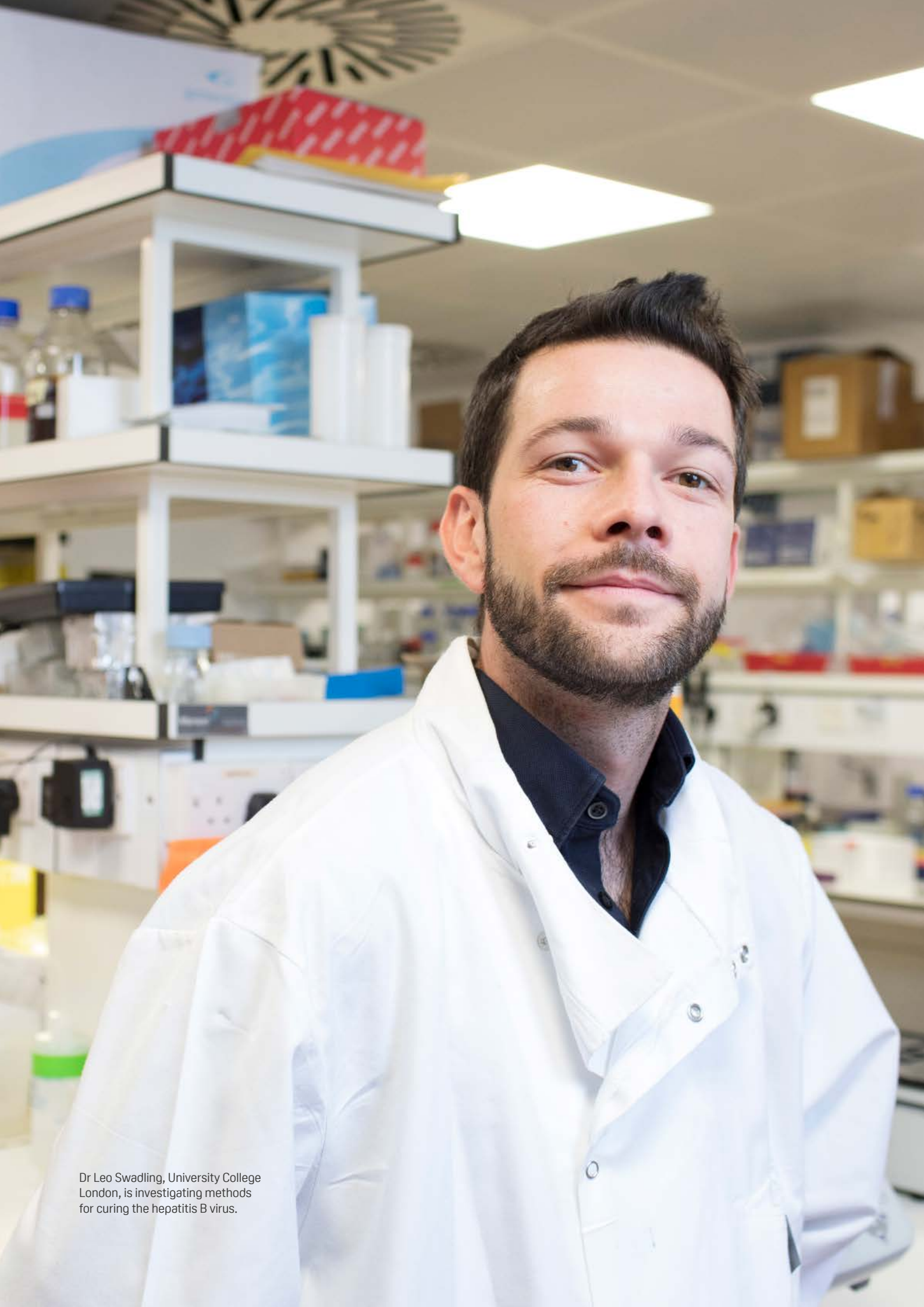
With COVID-19 and other global health crises, we have seen how quickly they can emerge, and how much we depend on science to offer a way out. While we cannot predict the next global health emergency, we can be certain that it is only through considered, quality medical research that we will meet whatever new challenges come our way. And without you, we could not continue to support the UK's next generation of research leaders, who will make a difference to human health for decades to come.

In 2021, our Emerging Leaders Prize celebrated and supported outstanding scientists whose research made a tangible difference in the fight against COVID-19, ensuring they can continue to understand and tackle the virus and its impact, long into the future.

We will also continue to tackle the diseases and conditions which possess the greatest need for new research, many of which have only deepened in severity and scale during the course of the COVID-19 pandemic – from eating disorders and self-harm in young people, to the pain conditions that affect many millions of people in the UK, and the urgent global threat of antimicrobial resistance.

You can help us tackle these health issues, and together with our fantastic research community, we can continue to provide the science that will protect the health of future generations.

**Visit our website to find out how you can support us:**  
**[www.medicalresearchfoundation.org.uk](http://www.medicalresearchfoundation.org.uk)**



Dr Leo Swadling, University College London, is investigating methods for curing the hepatitis B virus.





**Medical  
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