

# BE INSPIRED!

Supporter Newsletter



**It's time to talk about  
Atrial Fibrillation  
Our 2019 Research Grants  
Year in Figures**

**Chest  
Heart &  
Stroke**

Cover image: TV presenter Pamela Ballantine takes our 30 second Atrial Fibrillation/AF (irregular heartbeat) test at our stand at the Balmoral Show, May 2019.

# Welcome

**from all the team at NICHS to this edition of Be Inspired!**

We are the leading local health charity dedicated to the fight against chest, heart and stroke illnesses in Northern Ireland.

We're delighted to have the opportunity to update you on the work we do every day to bring our vision and values to life, on behalf of you, our amazing supporters. Without your support, we couldn't be here making a difference.

Thank You!

## The NICHS Team

For Supporter Care queries and feedback, or to update your personal information please contact us on **028 9026 6709** or **supportercare@nichs.org.uk**

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# Over 80%

of our work relies on donations from the public.  
Without your support we couldn't be here making a difference.

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# Year in Figures

We need £3.5million to fund our care, prevention, research and campaigning work each year. A huge thank you to everyone who supports us by donating, fundraising and volunteering, enabling us to continue leading the fight against chest, heart and stroke conditions. Without you, we couldn't be here making such a difference. Here's how you have helped during the last year.

## Care Services

**3,372** people supported in 2018/19



**555** people attended our stroke groups

**201** people attended our Taking Control Self-Management programme

**80** carers attended our carers groups

**760** people attended our PREP programme (13% increase)

**513** people attended our Breathing Better/Respiratory programmes (28% increase)

## Health Promotion

**4,036** Well Checks delivered across Northern Ireland



**1,407** additional free blood pressure checks delivered at community and exhibition events

Well Talks delivered to **3,000** PEOPLE

**1,540** PUPILS were reached by our Chester's Challenge schools programme

**OVER 1,000** people who are homeless benefitted from our Health and Homeless Programme

## Research

**17** Ongoing projects



**7** Respiratory projects



**6** Cardiac projects



**4** Stroke projects





# Jim & Roisin's Story

**Jim Lilley, from East Belfast, has survived three strokes - two in 2015, and another in 2017. Both he and his wife Roisin have found support through our services in learning to live life after stroke...**



**“The tiredness is a big thing. It’s one of the biggest impacts on my life, as well as the loss of independence,”**

Jim says. His speech and balance were also affected.

After Jim’s third stroke, one of our Stroke Family Support Co-ordinators got in touch. He embarked on our Post Rehabilitation Exercise Programme (PREP) and Taking Control Programme, and now attends a Stroke Activity Group, while his wife Roisin joined our Carer’s Group. They also take part in the NICHs Inspire Choir together.

“I felt a fraud when I heard how badly affected some of the other carers’ partners were,” Roisin says. “At that stage, Jim was doing really well.

“But in summer 2018, Jim temporarily lost power in his left leg. It totally floored us. Jim couldn’t walk or drive and had severe fatigue, so I retired to care for him full time.”

Both Jim and Roisin have found the social support at the groups invaluable. Jim says, “My family try to do everything for me and mollycoddle me. Talking to others at the group, you find out it’s the same for them.”

Roisin agrees, “I overreacted after the third stroke and when Jim’s leg went; it was the fear of not knowing what’s going to happen next. The other carers say they’ve been overprotective of their loved ones too, so you realise it’s a natural reaction.”

“It helps to be able to vent. Without that support, I think there would be much more friction between us,” Roisin says.

To find out more about our care services, visit [www.nichs.org.uk/oursupport](http://www.nichs.org.uk/oursupport)



L-R: Chris Henry, Gareth McGleenon and Tommy Bowe at the summit.



# Chris Henry's Testimonial Trek

**Earlier this summer, a team of 14 trekkers including Chris Henry, a host of sports legends, and our Deputy CEO Gareth McGleenon, bravely climbed Mount Toubkal in Morocco to raise funds for our life changing services, which help us to support people like Jim and Roisin. The trek was part of Chris Henry's testimonial year 2018/19, awarded for his service to Ulster and Irish rugby.**

**Take a peek inside Gareth's diary of their amazing challenge...**

## **Sunday 9th June, 3:00pm**

We've arrived at airport buzzing with excitement! It feels more like we're heading on a lads trip than to trek 4,000 metres up the highest mountain in North Africa. We'll land in Marrakesh tonight and then head off tomorrow morning – let's go!

## **Monday 10th June, 9:25pm**

After a lunchtime picnic, we trekked to camp where we located our tiny tents. Luckily I have one to myself, unlike Tommy Bowe and Mike McCarthy who have to share, and with both being over six foot three inches tall, fitting into one tent is no easy feat...one of them ended up with their feet hanging out the end! The day ended gathered around the campfire playing games.

## **Tuesday 11th June, 8:40pm**

We've made it to base camp at the foot of Toubkal. Some of the climb

today has been at altitude, where the air is thin. But shouting Lord of the Rings quotes along the way got us through!

## **Wednesday 12th June, 9:30am**

We reached the summit! After setting off at 5am, and thinking I wouldn't make it, we did it. Some of the guys celebrated with a Rugby Scrum, probably the first at 13,000 feet! Now the long trip back down...

## **Wednesday 12th June, 10:30pm**

Back at the hotel, I've never been as glad to have a hot shower! Everyone is exhausted...today was like a military operation. Chris thanked everyone for taking part, and then we hit the hay. It's been a huge challenge, but nothing compared to the challenges that people with chest, heart and stroke illnesses face every day, the people we're supporting!

# Rolling out our Breathing Better Service

**Over the past two years, we've been piloting our new Breathing Better Programme, which helps people with respiratory conditions to breathe better and lead more active, full lives. Now, we're delighted to be able to roll it out to new venues across Northern Ireland!**

Right now, there are almost 40,000 local people living with Chronic Obstructive Pulmonary Disease (COPD) in Northern Ireland. It is the most common reason for a GP visit and the third most common long-term disease. There is no cure for COPD, and that is why we are committed to supporting people living with these chronic conditions.

COPD and other respiratory illnesses can be devastating for the people living with them and their families. They can leave people struggling to breathe easily and often unable to work, enjoy their hobbies or do everyday household tasks. They may also be reluctant or unable to exercise or even leave the house, leading to weight gain, isolation and mental health issues such as depression and anxiety.

In our Breathing Better service, we work together with local Health and Social Care Trusts and local leisure facilities, combining lots of different rehab and support classes and groups into one programme.

The programme gives survivors the opportunity to meet with people like them who are living with respiratory conditions, and to chat, connect and support each other. This can be a lifeline for people who have lost the confidence to make or keep up friendships as a result of their condition.

Many people with respiratory illnesses often want to learn to exercise safely with their condition, and keeping active has been shown to improve overall quality of life. Breathing Better gives them a place to do this without feeling self-conscious, as they are surrounded by others who understand. Our 'Taking Control' Self-Management Programme combined with the support groups also provides the skills, techniques and support to cope with these conditions long term.

By rolling out this life changing service across Northern Ireland, we hope to be able to:

- Increase the number of people attending the Breathing Better programme, so more people benefit
- Work together more closely with local Health Trusts to provide better support to people in need
- Reduce GP and A&E visits and hospital admissions across NI.



“I thoroughly enjoyed it. It helped me get out of my shell. Pauline brought it out of me. She spoke at my level and was very helpful. After 6 months I aimed to take part in a sponsored walk at Stormont Estate. Pauline and the rest of the respiratory group joined me.”

**Ivan Black,**  
Breathing Better Service User



We believe that people living with long term chest conditions both need, and deserve the best support possible to manage their illness on an ongoing basis, to enhance their quality of life. It is through your generosity that we

are able to offer this lifeline to so many more people across NI who are facing the day-to-day challenges that come with living with a respiratory condition.

- Current Breathing Better services being delivered
- New Breathing Better services being rolled out



To find out more about our care services, visit [www.nichs.org.uk/oursupport](http://www.nichs.org.uk/oursupport)

Northern Ireland Chest Heart & Stroke



**Atrial Fibrillation (AF)  
increases your risk of  
stroke by five times**

It's time to talk about AF

Find out more at  
[www.nichs.org.uk/AF](http://www.nichs.org.uk/AF)



Financing by NIH, Ireland



**MACE**

**In our survey  
of 1000 local  
people only  
300 had  
heard of AF**

Supported by

**MACE**

# Atrial Fibrillation

**It's time to talk about AF!**

**There are almost 40,000 local people who are diagnosed with atrial fibrillation, or AF as it is more commonly known. It causes an irregular and often abnormally fast heart rate, and can increase your chance of having a stroke by up to FIVE times.**

Some people with AF have no symptoms at all, and their condition only comes to light during an unrelated medical examination. Others might feel tired, faint or breathless or have heart palpitations or fluttering in their chest.

With the right treatment, people with AF can live a long, healthy life. That's why it's important to be aware, get tested by your GP or NICHs if you have symptoms, and get the right treatment if you're diagnosed to reduce your risk of stroke.



The test for AF only takes 30 seconds and involves simply placing your fingers on a small pad.



## What are we doing about AF?

### AF Awareness

We've been getting the message out about AF through billboards and bus shelter ads, radio ads, and on posters in GP surgeries, pharmacies and libraries. MACE, our long term corporate partner, also displayed AF posters in their stores, AF information on their leaflets and offered AF testing for customers in selected stores.

### AF Testing

AF sometimes has no symptoms, so can only be detected during a medical exam or by having a health check with us. We're currently the only charity in NI that tests for AF, and we've been out and about doing tests all across the country so as many people as possible can get tested!

In May, we tested over 1000 people at the Balmoral Show including TV personality Pamela Ballantine. We also provided tests in MACE stores in June as part of MACE's Big Brunch.

This 30 second detection test is offered as part of all of our 30 minute Well Checks. In total, we've tested

3010 people for irregular heartbeat so far, and made 99 GP referrals!

### AF Inquiry

We commissioned Ulster University, supported by a steering group, to conduct an inquiry into AF in Northern Ireland which will report in Autumn 2019. The results of this inquiry will hopefully feed into future policy in NI and help reduce avoidable strokes and improve the quality of life for people living with AF.

To find out more about AF, visit [www.nichs.org.uk/AF](http://www.nichs.org.uk/AF)





# “Atrial Fibrillation caused my stroke”

Paul McClean, Stroke Survivor

**Paul McClean, who lives in Co. Down, was diagnosed with atrial fibrillation (AF) which can increase your risk of stroke by up to 5 times. In 2017, Paul had a stroke, and now urges others to get checked.**

Paul’s stroke was severe, which AF related strokes frequently are. Paul’s wife Suzanne was told to call his family in case he didn’t make it, and that if he survived, he could be left paralysed on both sides and unable to talk.

However, the fast actions of Suzanne and the paramedics meant he was rushed straight to the Royal Victoria Hospital in Belfast, where by chance, the consultant who carries out the procedure thrombectomy had popped into the hospital briefly when Paul’s scans came through. He decided to operate and removed the clot from Paul’s brain, saving him from total paralysis.

Paul still had to learn to talk and walk again, and suffers extreme fatigue. He can only speak for a few hours a day as it exhausts his brain. He used to work as an English teacher, but can no longer read a book as he forgets what happened after one page.

“There is life after stroke,” Paul says. “Suzanne and I are now expecting our first baby. I am really excited about becoming a dad. It is just amazing.”

**While unfortunately it wasn’t the case for Paul, it can be possible to reduce the risk of stroke caused by AF through medication. The first step is to detect it. We are the only charity in NI currently offering a test for AF – get checked and protect your health!**

For more information or to book a health check check, go to [www.nichs.org.uk/AF](http://www.nichs.org.uk/AF)



## What does your health mean to you?

**Most of us would agree that it's one of the most important things we have. Without good health, many other things wouldn't matter at all. This is why making healthy lifestyle choices is so important. Lifestyle factors such as exercise, weight, sleep, stress levels, alcohol and smoking can all affect our risk of developing long term ill health problems, including chest, heart and stroke conditions, or of dying younger.**

Our aim is to prevent chest, heart and stroke conditions by helping people of all ages and all walks of life across Northern Ireland to make healthier choices and protect their health for the future.

Our **Well NI programme** offers a range of different packages for local business, community groups and individuals, which support people to make manageable changes to their lifestyle to improve their health. These include:

### **Well Checks**

– health checks which assess the risk factors for cardiovascular illness, such as Atrial Fibrillation, high blood pressure, cholesterol and body composition (BMI).

### **Well Talks**

– interactive talks on a range of topics.

### **Well Mind**

– a training course for workplaces which covers the impact of stress and teaches practical tools to manage personal stress levels.

### **Well Team**

– a health programme for workplaces which supports organisations to develop an action plan to improve health and wellbeing of their staff.

### **Well You**

– a 12 week programme which aims to support and encourage people to make healthy lifestyle changes.

For more information or to book one of our Well NI packages, call **028 9032 0184**



# Our 2019 Research Grants

Every year, we award grants to a selection of some of the best local research projects that are working to advance how we treat, care for and prevent chest, heart and stroke conditions. This year we have funded seven new exciting projects at Queen's University Belfast and one at Ulster University. Find out more about them below!

## Chest

**Who?** Dr Karim Dib

**Where?** Queen's University Belfast

**How much?** £58,442

Neutrophils are a type of white blood cell that help heal damaged tissues and fight infections. In people with severe asthma, neutrophils attack the tissue in the airways. We don't know why this happens. This study is the first to investigate if it is due to histamine – usually released during an allergic reaction - produced by bacteria in the airways, and will test whether blocking the histamine could help treat severe asthma.

**“Since 1994, we have invested over £7.2 million pounds into local research, funding 96 research projects in total, with 78 projects completed”**

## Heart

**Who?** Professor Tara McMullen

**Where?** Ulster University & University of Dundee

**How much?** £250,000

Over the last few years, with our funding, Professor McMullen has developed “early warning” technology that can help predict your chance of developing cardiovascular diseases by looking at the blood vessels in your eye. This technology works well using a mobile phone's camera, so this year we've funded the team to develop and test a mobile “app” version.

**Who?** Dr Qiaozhu Su

**Where?** Queen's University Belfast

**How much?** £98,306

Fenugreek is a herb used in cooking, and has been used in medicine in India and China throughout history. Dr Qiaozhu Su and her team are testing whether Fenugreek seed could be used to treat Hyperlipidemia (high levels of lipids or fat, like cholesterol, in the blood) and Cardiovascular

Disease (CVD) in place of current drugs, such as statins, which sometimes cause side effects.

**Who? Chris Watson**  
**Where? Queen's University Belfast, University College Dublin, & Cleveland Clinic, Ohio, USA**  
**How much? £76,795**

This research team previously discovered for the first time that a protein found in the heart, called CLEC3B, is lower in people with Coronary Heart Disease (CHD), and linked to changes in heart stiffness, how well the heart pumps, and blood levels. This has led them to believe that CLEC3B plays a role in CHD developing. This study aims to find out exactly what that role is, and to see if testing for CLEC3B would be useful for CHD patients.

## Stroke

**Who? Noleen McCorry**  
**Where? Queen's University Belfast**  
**How much? £59,898.00**

"Cognitive" problems with language, memory and thinking are common after a stroke. These can affect the person's relationships, quality of life and mental wellbeing. Many psychological therapies are not always suitable for stroke survivors with cognitive problems. This research team has adapted a type of therapy, Acceptance and Commitment Therapy (ACT), to better suit those with cognitive issues. In this study, stroke survivors will test this new therapy and give feedback on what they think of it.

**Who? Professor Michael Donnelly**  
**Where? Queen's University Belfast**  
**How much? £65,000.00**

The team previously tested out a home-based rehab programme for people who have had a TIA, also sometimes called a 'mini-stroke'. They found out that patients wanted an electronic version of the programme, so they are now developing an app version, called "Brain Fit", and will test how well it works in a pilot study with a group of local people who have had a TIA.

**Who? Professor Michael Donnelly**  
**Where? Queen's University Belfast and Ulster University**  
**How much? £32,933.00**

Professor Donnelly and his team previously did research testing the "SHARE-D" programme, a tool used by health professionals and patients to help them make lifestyle changes to prevent heart disease and stroke. The team is now working to create a simplified version of SHARE-D that's easy to use every day. The team will hold focus groups at our NICHs support groups, to test the tool and get feedback to improve it.





# Well Schools Charity of the Year

**Fundraise for us in your school to help us lead the fight against chest, heart and stroke conditions, and we will visit your school and deliver a tailored, fun and interactive health and well-being programme for staff and students!**

We believe prevention is better than cure. It's important for everyone to be made aware of how they can keep healthy and reduce their risk of becoming ill. And what better place to start than in our schools, teaching the next generation about how to make healthy lifestyle choices when it comes to things like food, exercise, smoking and alcohol.

Whether you hold your own fundraising event at school, take part in one of our ready-to-go schools events, or select us as your Charity of

the Year partner, we have lots of ideas and resources to help you. Depending on your chosen fundraising activity, we can also visit your school and give a health presentation for pupils and teachers!

Our friendly community fundraising team are on-hand to give advice and assistance, and can provide you with lots of fun, branded materials to help you promote your activities, including balloons, posters, sponsor forms and collection buckets. We can also come to your school to take part in a cheque presentation or a Thank-You assembly, to say thanks for your amazing effort.

To find out more, and to get your school signed up, email [schoolsfundraising@nichs.org.uk](mailto:schoolsfundraising@nichs.org.uk), call **02890 320 184** or visit [www.nichs.org.uk/schoolsfundraising](http://www.nichs.org.uk/schoolsfundraising)

# What lasting difference will a gift in your Will make?

**A gift in your Will to us could not only help your loved ones, but also leave a legacy of hope for generations to come. Currently, in Northern Ireland, 37% of all adult deaths are caused by chest, heart and stroke illnesses with one in six local people here living with these conditions every day.**

The care services we deliver transform the lives of those people affected by chest, heart and stroke illnesses. Our life-enhancing self-management programmes, family support home visits, health prevention programmes and research projects have a massively positive impact on the lives of thousands of local people and their families.

Thanks to advances in medical care, more people now survive following a stroke, heart attack or severe respiratory condition. Although this is good news, it means that the

demand for our support services is ever increasing. A gift in your Will, no matter its size, could help us provide the care and support needed by a chest, heart or stroke survivor to rebuild their lives and overcome the impact of these devastating conditions.

If you are interested in receiving information about leaving a gift in your Will to Northern Ireland Chest Heart & Stroke, please contact Alison Vidamour on 028 9032 0184 or visit our website – [www.nichs.org.uk/GiftsinWills](http://www.nichs.org.uk/GiftsinWills)



# over 80%

of our work relies on donations from the public.

Whether you have given the gift of your time and care through volunteering, gotten involved in a fundraiser or event, or made a donation towards our work, we would like to **Thank You** for your generosity.

Without your support we couldn't be here making a difference.

**Help us lead the fight against chest, heart and stroke illnesses.**

For more information about how you can support us, please get in touch.

Visit [www.nichs.org.uk](http://www.nichs.org.uk), email [mail@nichs.org.uk](mailto:mail@nichs.org.uk) or call **028 9032 0184**.

