

BE INSPIRED!

Supporter Newsletter



**SPECIAL
STROKE EDITION!**

**Meet Zoe from our
Care Services Team**

Judith's Journey

Expanding our stroke services

Chest
Heart &
Stroke

Inside your BE INSPIRED!

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

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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Cover image:
Stroke survivors,
volunteers and staff at
our Armagh Post Rehab
Exercise Programme

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Welcome

to the first 2019 special stroke edition of our supporter newsletter, which focuses on the work we are currently doing and the work we plan to do in the future, to support stroke survivors and their families.

There are over 37,000 stroke survivors in Northern Ireland. We currently support around 2,000 of them, so there are so many more people we want to help and support. In October, we announced that we will **DOUBLE** the number of people we support by 2023. You can read more about how we plan to do this on pages 8-9.

I'd like to take this opportunity to express my gratitude for the work carried out by our 31-strong Care Services team and 270 volunteers. We have already begun recruiting new members of staff into our Care Services team to support the expansion of our services. On pages 4-5 you can meet Zoe Campbell, who has been part of our Stroke team for the past five years. Zoe and her colleagues play a crucial role in supporting people along our care pathway from referral, through rehabilitation and towards recovery.

One of the people they have supported in the past year is Judith and you can read her story on pages 6-7. Judith's story exemplifies the Care



Fiona Greene,
NICHS Director of Care

Pathway that we have shaped and developed in partnership with Health and Social Care and its Clinicians, Allied Health Professionals, Nursing Staff, Trust Managers and Health and Social Care leaders, to significantly improve the quality of life of stroke survivors.

We would not be able to deliver our services, or plan to expand them, without your commitment and support. Over 80% of our work is funded by donations from the public. We can only showcase a very small number of supporters in our newsletter, but we are deeply grateful to the hundreds of people who donate, fundraise on our behalf, who give their time to volunteer, and help raise awareness of our work.

I hope that you enjoy finding out about our ambitious plans. If you would like any more information about our work, please contact us. Thank you again for your support.

A handwritten signature in black ink that reads "Fiona Greene".

Fiona Greene
NICHS Director of Care

In the frame...

Zoe Campbell

from our Care Team

The people who make up the Northern Ireland Chest Heart & Stroke team come from all sorts of backgrounds and from many different parts of our community. Yet we all share a burning passion – to support as many stroke survivors, their families and carers as possible.

In this edition of our supporter newsletter we take the opportunity to speak to one of our members of staff, Zoe Campbell, to get an understanding of what makes her tick and to share her experiences of working with the charity.

So, Zoe, explain to us what your job title is and what your role involves.

There are two parts to my answer. I'm currently engaged as a Care Service Co-ordinator. This is a very active, hands-on role where I work one-to-one with our clients, providing assistance and guidance to them and their families in coping with life after stroke. However, in January 2019 I'll be taking on the role of Senior Care Services Co-ordinator, which means that I'll be also be providing help and support to my other colleagues in Care Services.

How long have you been with NICHS?

I have been working for NICHS for just over 5 years, and I can honestly say that I've enjoyed every minute of it. While the work can be physically and emotionally challenging, it is also deeply satisfying. I knew from day

one that this was the job for me.

Explain what you do each day.

Well, I'll outline what I do in my current job, as my new one hasn't started yet. Each day I'm usually out and about delivering services to stroke survivors and their families. I talk to them about their stroke and how they are coping with it. I explain to them how NICHS can help them through our support groups and, where required, signpost them to other information or support. I am trained in the delivery of Exercise After Stroke, which is a specialist area, so I also coordinate and deliver three Post Rehab Exercise Programmes (PREP) and our 'Taking Control' Self Management Programme. As you can imagine, I'm kept busy!

What is the best part of your job?

There's only one answer to that – it's seeing the progress that people make because of using our services. I can even give you some specific examples that really touched me and make my job very special. Recently a grandmother told me she can hold her baby granddaughter for the first time because she attended

PREP. Then there was the person who was able to start farming again - their favourite hobby and work - all because they regained their strength and confidence by attending PREP.

What is the most difficult part of your job?

Stroke can have devastating effects on families' lives so the most difficult part of my job is hearing and seeing some of the challenging situations that people are dealing with.

Finally Zoe, what are your hopes for the future of stroke services in NICHS?

I am excited we are developing new services for stroke survivors so they can continue improving physically, socially and emotionally. My hope would be for us to have a maintenance class that would allow stroke survivors to continue exercising together in safety and comfort with other people who have been through the same traumatic experience. I think this will make a huge difference to the overall long-term health and wellbeing of people living post-stroke.



Judith's Journey

Judith's life changed forever one Monday afternoon in March 2017. Quite unexpectedly, and with no warning, the 37 year old landscape gardener suddenly felt "weird". She quickly became so unwell that she was told she could go home from work. However, when her employer's wife saw Judith, she was so concerned that she rushed her to hospital. Judith was to remain there for the next eight months.

It transpired that Judith had an aneurysm which affected not only her mobility on her right side but also her speech. At the outset her parents were told that she had only a 50:50 chance of survival, but as she pulled through those early days, they were then told the awful news that their

daughter would spend her life in a wheelchair and would never be able to speak again.

Now more than 18 months after that dreadful day, Judith has far surpassed those initial prognoses. Although her right hand side has been badly affected by the aneurysm, she is able to walk with a stick. And while her speech has been affected, she is now very talkative indeed!

Once she was discharged from hospital, Judith's mum got in touch with us to see if our support would be suitable for her daughter. Aneurysm and stroke have similar long term effects as both can result in damage to the brain. So the good news is that with our support Judith's needs have been successfully met.

Judith's journey started when she met with one of our Stroke Family Support Co-ordinators, who

Judith
beforehand



Judith
horse-riding



Judith in
hospital



suggested a number of our support services. Here's what Judith has to say about them:

- NICHHS's Post Rehab Exercise Programme (PREP) - "I loved this. It has helped me to realise that I can still do exercise despite my disabilities. It helped me get back to living independently, which is very important to me as I live by myself."
- Taking Control Self-Management Programme - "The people I met at Taking Control have all become friends. At first, some people were embarrassed by their conditions and did not want to talk. But Taking Control provides an environment where you can talk about your condition without feeling stupid and everyone understands, because everyone there is facing some health issue."
- Belfast Young Stroke Group - "This is just great craic. Meeting

other people in the same boat as me has been very important. It's great to have fun with them."

- Horse-riding - "When the NICHHS Stroke Family Coordinator phoned me to ask if I wanted to go horse-riding, I honestly asked her if she had phoned the right person! But horse-riding has really helped my balance which has also increased my confidence when I'm out and about. I absolutely love it"

We'll let Judith have the last word.



"I'd like to thank everyone at NICHHS. Their support has made a huge difference."

Judith today
in her home



Judith
at PREP



We're expanding our Stroke Services



Stroke is a dreadful disease and it strikes like a thunderbolt. One minute you are well and life is normal, yet a moment later you can have lost your mobility, speech, memory or sight. Nor is the damage restricted to your physical well-being. Stroke can rob you of your independence and autonomy and can have a traumatic impact on your self-confidence and happiness.

The figures are stark. Today, as you read this, eleven people across Northern Ireland will have a stroke - that's about one every two hours. And right now over 37,000 people are living with the life-changing effects of stroke. Our Stroke Support Co-ordinators provide excellent help to stroke survivors and their families right across Northern Ireland. But now we have ambitious goals to expand our services into the future.

Our pledge for the future

Last year, we supported around 2,000 stroke survivors and their families and carers. But we believe that we must and can do even more, so we are boldly pledging to double the number of stroke survivors and carers we support across Northern Ireland by 2023. As well as expanding our existing stroke services, we will develop new services that are tailored to the long-term needs of stroke survivors and their carers.

We have listened to stroke survivors who use our services. The overwhelming message coming from them is that they want the best outcomes for themselves and for others who will have a stroke in the future. Our pledge to them is to offer our exceptional and life-changing support services to more people who need us.

What this means

At present our Care Pathway supports the stroke survivor on their journey from hospital to home and

right through to long-term support programmes. The services which we will enhance and further develop over the next five years include:

- Stroke Family Support Service, which provides an opportunity for the stroke survivor, their family and carers to talk about and reflect on the impact of the stroke, get information and signposting and receive emotional support
- Post Rehab Exercise Programme, which is a unique exercise and education programme for stroke survivors who have been discharged from Trust services
- Taking Control Self-Management Programme, which is a worldwide evidenced based programme that NICHS is licensed to deliver
- Stroke Activity Groups, which offer long term support via therapeutic and informative programmes focussed on keeping stroke survivors active and well

And there's more

Our plans include the introduction of Stroke for Life Classes, which will support stroke survivors after the completion of our Post Rehab Exercise Programme through ongoing exercises classes. We will also be addressing the needs of carers through a Carers Wellbeing Programme and Carers Self-Management Programme.

Achieving our goals

In order to achieve this ambition we have set our priorities as follows:

- We aim to at least double the total number of people supported per year
- Our team will grow to meet this new

target, with more new volunteer roles as we grow and expand

- Service User Panels will also be developed, to involve service users in our planning
- We will continue to work in partnership with other relevant agencies and organisations
- We will continue to pursue Research & Development opportunities relating to stroke with local universities

We believe no one who experiences a stroke should have to cope on their own. Any help you can give us to achieve our ambitions means everything to us, and even more to the 37,000 people in Northern Ireland who are living with the harsh reality of stroke.



“Every day in Northern Ireland **11 people** have a stroke”

Chris Henry's Testimonial Gala Dinner



Sports legends, celebrities and top business people joined forces to enjoy a fabulous night, rich in entertainment, at Chris Henry's Testimonial Gala Dinner in Belfast City Hall in November. Chris, the Ulster and Ireland rugby icon, welcomed stars including Johnny Sexton and Rory Best to this spectacular event which raised a fantastic £90,000 for NICHs.

: Chris had a mini stroke in 2014 on
: the morning he was due to play a
: test match against South Africa. He
: returned to play just four months
: later and was selected for the 2015
: Rugby World Cup. "Northern Ireland
: Chest Heart and Stroke is a charity
: very close to my heart ever since I
: suffered a mini stroke. I am delighted
: that money raised by the event will
: support the expansion of NICHs's
: stroke services over the next five
: years."

: For more information on the up
: and coming events or to support
: the testimonial year please contact
: Sinead Lynch on 028 9032 0184.



L to R, Gareth McGleenon (Deputy Chief Executive, NICHs), Jackie Trainor (Director of Income Generation), Johnny Sexton (Leinster, Ireland and World Rugby Player of the Year 2018), Sinead Lynch (Corporate Partnerships Manager), Charlie Vernon (Armagh GAA), Chris Henry (NICHs Ambassador, Ulster Rugby and Ireland)

Wake Up! Pyjama Walk

Our second annual Wake Up! Pyjama Walk, sponsored by MACE, took place at Stormont in September. Donning our finest PJs in public, we walked, strolled and dandered our way for 5km around the grounds of Stormont, raising awareness and funds for our Family Support Services.

This year's event also featured the 'Inspirational Mile'. This shorter option meant that many of our volunteers and the beneficiaries of our care services could take part in the event and show their support.

A delicious healthy brunch was served up and morning entertainment came courtesy of U105.

We would like to send a massive "thank you" to everyone who took part and raised funds through sponsorship and other activities. Your efforts made the day a massive success and helped us all "Wake Up!" to the seriousness of chest, heart and stroke conditions.



Kristian's Story



Kristian Robinson

Mark and Charmaine Robinson have fundraised tirelessly throughout this year in memory of their son, Kristian. He passed away in September 2017 following a seizure and cardiac arrest. Kristian was only 24.



Despite their grief and heartache, the family have honoured his memory by raising an astounding £3,420 for NICHS. Some of this has come from a crowdfunding campaign via their JustGiving page www.justgiving.com/crowdfunding/kristianrobinson but others have helped too. Kristian's brother-in-law, Jonathan, ran the Belfast Marathon, adding his sponsorship money to the fund. And Kristian's friend and carer of seven years, Katherine, organised a Disney Fun Day in Killard School, adding £405 to the Robinsons' total!

Katherine's sister, Emma, also joined in. She set herself the sponsored goal of walking 5km every day in February 2018 – which she completed despite rain, hail, sleet and snow!

These funds were raised through the ceaseless hard work and determination of the Robinson family. The money raised will allow us to continue the fight against chest, heart and stroke disease and help to prevent more young people from dying of these illnesses in the future.

"We long to fill our empty lives with the goodness of Kristian. To this end, we dedicate our undying love for as long as we live and vow to keep his memory and beautiful face in as many hearts for as long as we are able."

Charmaine and Mark Robinson.



“If I hadn’t been running for NICHS I think I might have dropped out half way through.”

Elaine McGready’s Challenge

Some of our supporters hold morning teas. Others take part in sponsored walks. Some even enter a team for their local 10km run. Elaine McGready went a step further when she ran the Toronto Half Marathon for NICHS!

It all sparked off after Elaine’s doctor told her that she needed to lose weight and lower her blood pressure. She embarked on a strict training regime and decided to complete a long-distance run - the Toronto Marathon. Choosing a charity to benefit from all her efforts was easy. With a family history of strokes, heart attacks and her own high blood pressure, NICHS was “the perfect charity”.

Despite a rocky start that included delayed flights, an emergency detour, an injury, a midnight evacuation from the Toronto hotel, plus some less-than-ideal snowy conditions – Elaine completed her run in 3 hours and 23mins!

We can’t thank Elaine enough for her determination, spirit, enthusiasm, and of course her wonderful donation.

How do I leave a gift to NICHS in my Will?

We know that when considering your Will, loved ones come first. But including a gift to NICHS, no matter the size, is straightforward and could dramatically change the lives of people affected by chest, heart and stroke conditions. It might even be the most important gift you ever give.

Below are some informative Q&As about how you can include a legacy gift to NICHS in your Will. We hope you will find it useful but if you need any more information or advice, please get in touch.

I want to leave a legacy gift to NICHS – how do I do this?

Including a gift to NICHS in a Will is an easy and cost-effective way to support our work. However, the only way you can leave a legacy gift to NICHS, or any charity, is to make a Will or change an existing one.

Who writes the Will and can NICHS do it for me?

It is essential that your Will is legally valid and complies with any requirements to make it so. Ideally, it should be drawn up by a Solicitor, and signed in the presence of two witnesses. NICHS cannot be involved in preparing your Will or witnessing it, if it contains a legacy in our favour, otherwise the Will could be challenged in the future.

I have already made a Will – can I change it to include NICHS?

It is quite straightforward to do this. You can make what is called a Codicil, which is a simple legal document that changes an existing Will. You can ask for a Codicil form from NICHS directly using the contact details below. Alternatively, your Solicitor can advise you on how to make changes to your Will. In either case please make sure that a copy of your Codicil is stored with your Will.

Do I need to include any particular information about NICHS in my Will?

Yes, please include:

Our full name: Northern Ireland Chest Heart & Stroke

Our registered address:
21 Dublin Road, Belfast BT2 7HB

Charity Registration Number:
NIC103593

Can I leave a legacy to a specific NICHS project, activity or to fund research?

We would encourage our supporters to leave a gift in their Will for general use, as it can then be used where it is most needed. But if you would like to support a specific area of our work, the best way to do this is to make your gift subject to an 'expression of wishes'. Doing this means NICHS will be obliged to carry out your wish. However, it also builds in flexibility in case our activities have changed by the time your gift is received.

If you would like more information about making a legacy gift to NICHS, please contact Alison Vidamour on 028 9032 0184 or avidamour@nichs.org.uk or visit www.nichs.org.uk/gifts-in-wills

Your Legacy Of Hope And Care

- a gift in your Will to Northern Ireland Chest Heart & Stroke

A gift in your Will to NICHS could not only help your loved ones, but leave a legacy of hope for generations to come.

In Northern Ireland almost half of all adult deaths are caused by chest, heart and stroke illnesses. NICHS are working to change this through funding research and caring for those who are affected by devastating health conditions every day.

A gift to us in your Will could be invested in critical local research that will change the future for families at risk from our biggest killers.

The smallest investment can lead to the biggest breakthrough.

Please visit our website to see how our Medical Research Programme has already supported groundbreaking projects and is committed to many more over the coming years. www.nichs.org.uk

For a leaflet or further information on leaving a legacy to NICHS, please call us on: 028 9032 0184, or write to NICHS Gifts in Wills, 21 Dublin Road, Belfast, BT2 7HB



Chest
Heart &
Stroke

Run, walk or relay to support local people

**Belfast City Marathon
Sunday 5th May 2019**

Sign up now!

**www.nichs.org.uk
[/belfastmarathon19](http://belfastmarathon19)**

**Chest
Heart &
Stroke**

