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If you would like to update your name, address or other details please contact our Donor Care Team on **028 9032 0184**.

Cover image: Baby Joe Degan from Larne with mum Kerri, who are supporting NICHS' Baby Hearts Appeal. Read about Joe's story on page 5.

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# Meet Fidelma Carter

# NICHS' Director of Public Health

I joined NICHS just over a year ago as Director of Public Health. The purpose of my role is to help prevent people getting ill in the first place through the promotion of healthy living and calling for healthier public policies.

My health promotion team promotes healthy choices such as staying active, not smoking, healthy diet and safe alcohol limits. We deliver talks and programmes in schools, youth clubs, businesses, community groups and amongst the homeless. We also have a team of nurses that carry out health checks and offer advice and support to reduce health risks.

As you know NICHS is committed to funding research into chest, heart and stroke illnesses and it is my responsibility, along with my team, to develop our research strategy and manage NICHS' research portfolio to ensure it is as effective as possible.

My team also campaigns at the Northern Ireland Assembly on behalf of people and families impacted by chest, heart and stroke conditions. We helped establish the All Party Group on Heart Disease and Stroke and are currently campaigning for new smoking related legislation.

I very much enjoy my job. All of my career and studies to date have been dedicated to preventing premature deaths from lifestyle related diseases as well as promoting health and tackling health inequalities that exist within our society. I spent most of my years working within the health service in inner-city London and was so excited to get this job with NICHS. Keeping people healthy, out of hospital and living life to the full within their own community is what keeps me motivated.

Thank you so much for your support of NICHS. Without the generosity of you and others like you our work simply would not be possible.

Here's to an even healthier and happier 2014 for more families across Northern Ireland. Page 4 Issue 2: Winter/Spring 2014 Issue 2: Winter/Spring 2014 Page 5

# Unlocking the mystery of Congenital Heart Disease

## Our Babies' Hearts Study

Before Christmas you may have been following coverage of NICHS' Baby Hearts Appeal in the Belfast Telegraph. The paper featured many moving personal stories of families affected by this condition and highlighted just how devastating congenital heart disease can be.

The aim of the study is to increase our knowledge of why some babies are born with congenital heart disease, whilst others are not and it is hoped that this increased knowledge could lead to the development of preventive measures.

Our Baby Hearts Appeal aims to raise the £172,000 required to fund this major 3 year research project being carried out at the University of Ulster which could help prevent babies around the world being born with congenital heart disease. To date our incredibly generous supporters have given over £65,000. This will support 454 babies to take part in the Baby Hearts Research Study.

The groundbreaking study is being led by Prof Helen Dolk and her colleagues at the University of Ulster in conjunction with Paediatric Cardiologists at the Royal Belfast Hospital for Sick Children. It will gather vital information by targeting families who are affected by congenital heart disease and those who are not. They plan to compare data on the backgrounds, lifestyles and environments of families to isolate key differences. Once causes of congenital heart disease have successfully been identified, doctors may be able to recommend strategies to prevent it.

You can also support our Baby Hearts Appeal by watching and sharing our Baby Hearts Appeal Video on You Tube.

www.facebook.com/Belfast.NICHS

#### Three stars of our campaign...



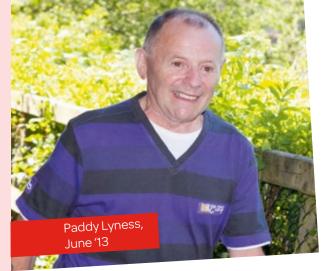
This is Joe from Larne. Baby Joe was born with congenital heart disease in August of this year. His condition is known as double inlet left ventricle. He was not even a week old, when he underwent life saving surgery on his heart. Joe survived but his problems weren't over. After his operation, he had difficulty breathing due to fluid building up and pressurising his heart and lungs. This caused his whole body to swell to such an extent that his eyes were swollen shut. He remained in a critical condition for two weeks and had to undergo a second surgical procedure to close his chest, which had been left open because his tiny body would not have accommodated his swollen heart after the original operation. He remained in a critical condition and was placed on a ventilator, but happily survived and is now at home. His parents Kerri and William have every hope that their little boy will be able to lead a happy, healthy life.



Meet 3 year old Grace from **Groomsport**. Grace has already had 13 hospital admissions in her short life. She has had surgery to close the hole in her heart, widen an artery and remove a build up of fatty tissue there. In fact, Grace celebrated her first birthday in hospital. After that operation, she was stabilised on a heart bypass machine, but when she was taken off it, her heart went into shock and her organs began to shut down. She was literally wrapped in cotton wool to keep her warm and given a 24 hour recovery period, after which there would be nothing more the medics could do. Thankfully though her heart restarted and she began to recover. Today Grace is a happy child but she will need more surgery in later life because, as she grows bigger, the patches on her heart will need to be replaced.



This is 14 year old Chloe from Kilkeel, who was born with Fallot's Tetralogy. Her congenital heart disease wasn't detected before she was born. As a baby she slept a lot and didn't feed very well and a midwife suspected that something was wrong as she didn't like the tone of Chloe's skin. Chloe was taken to the Royal Belfast Hospital for Sick Children where she was diagnosed and had surgery. All that surgery seems a long time ago now. Today Chloe is a bright, lively teenage girl. Chloe will need more surgery, but is determined to live life to the full.



# "This charity saved my life!"

Not long ago Belfast father-of-two Paddy Lynas thought his life was over. Following a diagnosis of lung disease, the resulting loss of his job and the death of several close family members Paddy began to struggle with depression. Now, just a couple of years later, he walks 12 miles a day and is off all medication. He no longer takes drugs to control his chest condition, bronchiectasis. And he puts it all down to the help he received from Northern Ireland Chest Heart & Stroke.

Paddy joined NICHS' selfmanagement group for people with similar respiratory conditions to his own. On joining group members make a promise about what they hope to achieve. Paddy pledged to walk three miles, then another six and after that managed nine which he extended to 11. Before long, Paddy had lost more than two stones in weight and stopped all his tablets. He says, "If it hadn't been for NICHS, I simply wouldn't be here today. The charity saved my life." To give something back, Paddy decided to undertake the Belfast City Marathon to raise funds. Some friends and family were not sure he would manage the full 26 miles, but he told them he would run it, walk it or skip it. And he did. Paddy said, "I felt as if I could do it all over again. When I thought of how I used to be, I felt as if all my Christmases had come at once. That's why I've decided that from now on, I'm going to live my life for others. Northern Ireland Chest Heart & Stroke gave me my life back, so I'm going to do everything I can to help anyone else who might find themselves in a similar position."

If you are inspired by Paddy's story and want to register for the Belfast City Marathon in support of NICHS please contact Cheryl on **028 9032 0184** or, email **ccunningham@nichs.org.uk** for more information.

# New Year New You!



Most people go to extremes over Christmas and New Year. First we overeat and laze in front of the TV. Then we make New Year's resolutions and go on a diet or take up exercise. However by February many of us have given up.

NICHS' New Year Campaign, which has only been possible as a result of your generous gifts, is about breaking that cycle and encouraging people to get the balance right in their lives for a happy, healthy new year – all 12 months of it! We are encouraging people to make small, manageable changes which can become part of their lives and reduce their chances of ill health.

STON

The campaign looks at 4 areas which are important to get in balance for good cardiovascular health:

- a healthy weight the balance of calories you eat and calories you burn
- a balanced diet getting all the nutrients your body needs
- a balance of activity the different types of exercise the body needs
- the overall balance of your life - coping with stress

To help people achieve this we have produced an information pack containing leaflets about cardiovascular health, how to cope with stress, healthy recipes, tips from personal trainers and how to make successful lifestyle changes. It also contains a NICHS tape measure, as waist measurements are an important indicator of a healthy weight, and a pedometer to encourage people to get more exercise.

This campaign is a key part of NICHS' commitment to care and prevention in Northern Ireland and it would not be possible without your support. We all know that prevention is better than cure, and we believe that this campaign has the potential to change the choices that people make on a daily basis and so reduce their risk of becoming ill.

"Life is full of choices. Don't leave yours up to chance."

If you would also like an information pack please contact us on **028 9032 0184** or, email **healthpromotion@nichs.org.uk**, or visit our website **www.nichs.org.uk/choices** for more information.



Without the support of our fantastic volunteers we simply wouldn't be able to provide the range of services we do across Northern Ireland. We currently have five key fundraising volunteer roles that we hope might inspire you to think about supporting us in this special way and help make a real difference to people's lives. These are:

Community Fundraising Leader

 someone who will take the lead in an area, recruiting more supporters

and initiating events and collections.

- Ambassador someone who will represent NICHS at cheque presentations and at local events.
- Community Volunteer someone we can call on to help with collections and to distribute promotional materials in their local area.

- Static Box Collector someone who will take responsibility for placing and changing static boxes in their local area and banking monies received.
- Events Marshall hardy individuals to help marshall our exciting new programme of events.

Whatever time you can spare is incredibly valuable to us.

If you are interested in joining NICHS as a Fundraising Volunteer, please contact Orla Clarke on **028 9032 0184** or, email **oclarke@nichs.org.uk** to register your interest for these new roles.

We would be delighted to hear from you.

# Gifts in Celebration – make your special day even better

Many of our generous supporters are now choosing not to receive personal gifts on their birthday, anniversary or other special occasions but instead are asking their friends and family to make a donation to Northern Ireland Chest Heart & Stroke – the charity that is

By choosing to support NICHS in celebration of your special day, you could help us to change the lives of thousands of people right across Northern Ireland.

It's your day – and you want to make it as special as possible.

Let NICHS help you!

close to their heart.

#### **Wedding favours**

We have an affordable range of wedding favours and personalised table cards to let your guests know ve made a donation to NICHS

you have made a donation to NICHS in lieu of favours.

## Birthdays, anniversaries or other special occasions

If you're holding a party, we can send you our special 'party pack' full of balloons, gift collection envelopes and announcement cards to send out with invitations. We will thank everyone who donates individually and let you know exactly how much has been raised in celebration of your day.

If you would like to receive a party pack or wedding favours samples, please get in touch with Orla Clarke on **028 9032 0184** or, email gifts@nichs.org.uk.

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# **Community Round Up** thank you!

#### **Galbally Vintage Club**



September '13 Galbally Vintage Club from

County Tyrone have been organising tractor runs for the last nine years and raised over £12,000 - well done!

#### The McMullan family



June 13

The amazing McMullan family of Jonesborough, recently presented NICHS with a cheque for a staggering £28,127.55, raised in memory of their beloved family member, Tatty McMullan. A huge thank you!

#### Loughshore Sponsored Walk

Glengormley Fundraising Support Group has had a very successful year of fundraising commencing with an annual Sponsored Spring Walk in April along the scenic Loughshore path at Newtownabbey. The group were bowled over with the success of their recent annual ten pin bowling competition which raised a fabulous £1,762.00. Glengormley Fundraising Support Group has surpassed a significant milestone by raising a staggering £266,081 over the past 27 years. Keep up the amazing fundraising!

## Corporate **Round Up**

#### **Ulster Bank Raises** over £17,000 for **NICHS**

During June of last year, Ulster Bank raised £430,000 through The bank's 'One Week in June' charity campaign. The Ulster Bank matched pound-forpound the money raised by customer and staff fundraising events and NICHS were fortunate enough to be one of the charities who benefitted.

This amazing initiative saw thousands of staff members and customers taking part in activities that ranged from bake-offs and 10km runs to a staff 'Battle of the Bands' gig as well as a Dublin-Belfast Cycle. Ulster Bank's own Henri Hippo also got in on the act with a cash-dash around a number of local branches. Ulster Bank customers can still donate between £1 and £150 to support Northern Ireland Chest Heart & Stroke at the 281 Ulster Bank



Ulster Bank employees and cyclists Alister Gibson and Mike Gogan join Ellvena Graham, head of Ulster Bank Northern Ireland, to launch the bank's fundraising initiative, 'One Week In June'. June '13.

ATM's across Northern Ireland. All you have to do is select the 'Donate to a Charity' option clearly displayed on the same screen as other options like 'Cash Withdrawal' and 'Pay Bill'. We are delighted to let you know that we will be working with Ulster Bank in 2014. NICHS is looking forward to another succesful corporate partnership.

If your business would also like to support NICHS, contact Vanessa Elder, Fundraising Manager on 028 9032 0184 or, email velder@nichs.org.uk.

# **Events Round Up**



#### Run to Remember, Benone

NICHS' first bespoke Run to Remember took place on September 14th at the beautiful Benone Stand near Limavady. And what a Run to Remember it turned out to be, with over 160 dedicated runners taking part to remember lost loved ones, as well as family and friends who are currently living with chest, heart and stroke illnesses. For many of those running, the date and location of the event held special importance, so it was an emotional day, with tears and joy at the finish line. Well done and huge thanks to all.



#### NICHS & Strandtown Primary School Stormont Fun Run

On November 3rd, NICHS joined forces with Strandtown Primary School, East Belfast, to organise a joint Run to Remember at Stormont Estate. Over 200 people came out to participate on what turned out to be a gloriously sunny autumn day. And with a 10km, 5km and kids' fun run option there was an event suitable for all the family! We plan to run this as an annual event as part of our calendar so look out for us next year.

Please contact Cheryl on 028 9032 0184 or, email ccunningham@nichs.org.uk for more information.



Run to Remember is about taking on a personal challenge to remember a loved one lost to a chest, heart or stroke condition and in support of the one in three people living in Northern Ireland today with these conditions.

You can Run to Remember for NICHS at any event across UK or Ireland or even further afield. We're here to support you every step of the way with motivation when the training gets tough and tips on how best to raise sponsorship.

Simply sign up for the event of your choice and we'll send you our Run to Remember technical running vest and sponsorship pack. We'll also send you regular Run to Remember e-updates featuring fundraising and training advice, along with lots of Run to Remember event news.

To find out more about NICHS running events go to - www.nichs.org.uk/runtoremember

#### **Calendar of Events**

Causeway Trek	May 2014
Belfast Marathon	Monday 5 May 2014
NICHS Cycle Challenge	Sunday 1 June 2014
Great North Run	Sunday 7 September 2014
Titanic Marathon Walk	Sunday 7 September 2014
Causeway Coast	
Marathon Walk	Saturday 27 September 2014
Dublin Marathon	Monday 27 October 2014

To find out more about, or sign up for any of these challenges or another event of your choice, simply contact our Events Team on **028 9032 0184** or, email **events@nichs.org.uk**. We would be delighted to help you in any way we can.

# Celebrate one life. Change thousands.

A donation in lieu of flowers is a special way to honour the memory of your loved one by helping to fund the Care and Prevention of chest, heart and stroke conditions.

Contact our Donor Care Team on 028 90 320184 or visit www.nichs.org.uk

> Chest Heart& Stroke

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