

Crumlin Heroes

YOU ARE A HERO IN THE EYES OF SICK CHILDREN

CMRF
CRUMLIN



Every sick child deserves every chance

Spring 2017

**You are helping
care for tiny
hearts like Poppy's
- THANK YOU!**

Poppy is getting stronger every day, thanks to you



- **You are giving babies born with heart defects every fighting chance**
- **Thank you for mending tiny hearts like Poppy's and Albie's!**

Thanks to you, children like Poppy and Albie will continue to get the world-class care they need to keep their tiny hearts beating strong!

Because of your generosity, doctors in Crumlin can get a perfect picture of what is happening inside a child's heart.

Just days after Poppy and Albie were born, Echo scans revealed they each had multiple serious heart defects.

Both babies had to undergo emergency, life-saving heart surgery.

But thankfully they both pulled through and are doing well now.

Poppy's mum said her daughter is enjoying the longest break she's had from hospital since she was born. She even got to spend Christmas at home.

"We were in our house for Santy. She was so grateful for her presents, she was kissing them!"

Poppy's mum was thankful too, to supporters like you who sent back cards at Christmas.

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You are improving the lives of Crumlin's tiniest heroes!



Lisa-Nicole Dunne, Chief Executive

My name is Lisa-Nicole Dunne. I'm the new Chief Executive at CMRF Crumlin.

I'm honored to be part of an organisation that is committed to saving and transforming the lives of sick children in Ireland.

And I'm excited to have the support of amazing people like you, who are helping tiny heroes in Crumlin achieve little victories everyday. Thanks to you sick children are living better lives, they're getting home to their families sooner, and they're surviving against all the odds.

Thank you for believing that every sick child deserves every chance. Now and into the future.

Despite a new Children's Hospital on the horizon, sick children cannot and should not wait for the best of everything - equipment, environment, treatments and care. They need our help now.

I hope you enjoy reading your newsletter about some of the little heroes whose lives you have helped improve or save.

Thank you for helping Crumlin's tiniest heroes achieve little victories everyday.



Lisa-Nicole Dunne,
Chief Executive

Poppy's mum Ellen told us:
"I was so grateful for the cards I received from people who support the hospital. People are so good, and for them to understand if they're not on the same journey."

Albie also got to spend Christmas at home with his family, as his mum told us.

"We had a fabulous Christmas at home. And because Albie likes to bang and bash stuff, we said 'let's ask Santa for a drum kit'. He loves it!"



Albie's doing well, and preparing for his third heart surgery

Because of the complexity of their heart conditions, both Poppy and Albie have a long journey ahead of them. But through your support, you have already helped improve their lives.

Thanks to the generosity of supporters like you, we've raised the money we need to buy two new Echo Machines, which will make all the difference to the care and treatment tiny hearts like Poppy and Albie's receive.

Albie will have his third open heart surgery later this year. And Poppy is preparing for her second heart operation in the coming months.

The new Echo Machines will produce sharper pictures of their hearts. They will enable doctors to better monitor their progress, and how they're responding to treatment.

But providing new equipment is only part of the solution. We need to keep funding more cardiac research, to save more lives in the future.

Research like Dr. Terri Prendiville's, whose team in the National Children's Research Centre, is turning skin cells into exact replicas of the heart tissue. Using this replica, his team will be able to safely test how the heart responds to different treatments.

Albie's mum knows the key to her son's healthy future, and the future of children like him and Poppy, rests on research, and people like you.

"You depend on ever changing medicine and ever changing technologies to help your kids, and bring them forward. You never know when it's going to be you, and we're just glad that people were so generous."

Will you help us fund more life-saving cardiac research for children like Poppy and Albie?

**You are giving tiny babies
like Zoe every chance**

You are helping improve the odds for Crumlin's tiniest and sickest babies

Zoe, born at just 24 weeks



Zoe weighed just over a pound at birth. Born 24 weeks into pregnancy, this tiny fighter battled to get better in Crumlin's Nazareth Ward. Now thanks to the money you helped us raise in last year's Annual Raffle, we're ready to start Phase 1 of Nazareth Ward's rebuild.

When the new Nazareth Ward is complete it will have 20 individual and spacious rooms. This means that new mums will be able to spend every minute they want with their tiny baby, while ensuring medical staff have instant, unobstructed access when needed to their tiny patients.

All of these changes will improve the quality of life and care for Crumlin's tiniest patients. But to make this new ward a reality, we need to continue raising funds, to keep the rebuild moving forward.

Thanks to all of you who took part in our Annual Raffle, tiny and sick babies like Zoe will get a medical facility that matches the exceptional care they receive.

**Congratulations to
Pauline Gilligan from
Co. Galway on driving
away in a brand new
Ford Focus in last
year's Raffle!**

Look out for and support this year's Annual Raffle – help more tiny babies like Zoe have more small victories!

Cancer research you fund
is giving hope to families

Thank you for helping bring cutting edge cancer treatments to children like April

April bravely fighting her neuroblastoma



- More tailored treatments mean less risk and fewer side effects for children
- New research looks at tackling weakness in tumour's 'defence system'
- Doctors will be able to predict how tumour cells will respond to a treatment

Dr. Piskareva's cutting edge neuroblastoma research is just another example of your support in action!

Looking at microRNAs, small parts of genetic material that are present in all cells, Dr. Piskareva's team are investigating new and innovative ways to defeat neuroblastoma, and improve the odds for children

The biggest progress for Dr. Piskareva's team, which builds on research led by Professor Raymond Stallings, has been identifying that there are differences in the genetic make up of all tumour cells. These differences can be spotted

**Did you
know just 4%
of medical research
that takes place in
Ireland is dedicated
to childhood
illnesses?**

in blood and used to predict what kind of response children with neuroblastoma will have to a particular treatment.

Being able to determine if tumour cells are responsive or resistant to a

drug is crucial, given that children with highest risk neuroblastoma experience relapse rates as high as 70%. And the rate of success of treatment is very low.

"If a patient doesn't respond to treatment because the 'messages' from the tumour cell are saying 'we don't like this treatment' then we could transfer the patient to another drug and prevent poisoning their body with a drug which has no effect.

In future, this would make disease management more personal. And it would mean less harm and better quality of life for the patient."

Your gift today could pave the way for the next big breakthrough in cancer research.

You are helping
April fight back

**“Research is massive
in terms of creating
a safer medicine for
kids and a long-term
remission.”**

April's Mum



We recently spoke to April's mum, who told us that despite all the cancer treatment April has received, she remains the same positive and brave child she's always been.

“If she has to get an injection, she says ‘it is okay, this is going to make me better’. Everything is positive with her. She knows she has to get things like needles, and she’s totally fine with it.”

Researchers like ‘Dr. Piskareva, whose work you’re funding, are looking at new ways to better understand and treat neuroblastoma in children. This research offers vital hope, to

**Your gift today
will help our
researchers find
new and better ways
to fight childhood
cancer**

all children who have to face neuroblastoma.

April's mum believes with all her heart that research – that you make possible – is key to making children

like April healthy again.

“Supporting research is vital. It’s the only way we are going to find better and safer ways to treat children. The way a child like April is treated today would have been completely different three years ago. That’s how fast the medicine can change. And that’s down to research.”

It's crucial that research into childhood illness keeps moving forward if doctors are to be able to continuously improve, refine and create better treatments.

“I see research as a huge beacon of hope to families. They feel as if they’re being involved in something that’s positive. Something that’s moving forward all the time.”

Professor McNally, Principal Investigator,
National Children’s Research Centre



Professor McNally talks about how the SHIELD CF study is improving the lives of children living with Cystic Fibrosis.

“SHIELD CF is an enormously powerful vehicle for Cystic Fibrosis research that will grow and become one of the key international studies in this area. It will help to improve both life expectancy, and quality-of-life outcomes for children with CF.”

For the past seven years, doctors and researchers like Professor McNally, have been compiling all Cystic Fibrosis patient samples into one centrally controlled database – the Discovery Bank.

Thanks to ever-changing and continuously improving treatments, more children with Cystic Fibrosis are living to adulthood. This has created a huge shift that Professor McNally believes is down to small steps, as well as big leaps forward, in research.

“Now there are more adult patients with Cystic Fibrosis than paediatric patients. That’s happened recently, and that’s never happened before. It’s a real example of how you can make progress through research.”

Please will you give a gift today to help bring the latest Cystic Fibrosis treatments to children like Alfie?

Research you are making possible.

LONGER, BETTER LIVES

Researchers have developed a combination therapy that’s currently being trialled in young patients. Through clinical trials of new drugs, researchers are continuously working to improve the life expectancy for children with Cystic Fibrosis.

MAKING LITTLE LUNGS HEALTHIER

Through our AIM study researchers are looking at how lung bacteria differ in patients with Cystic Fibrosis versus children that don’t have the disease, and how the bacteria change over time. Doctors are feeding this data into the SHIELD Discovery Bank, and will use the information to guide them on the best ways of treating lung infection in children with Cystic Fibrosis.

NEW, PAIN-FREE TESTING - EASIER ON CHILDREN

Researchers are developing a no needle test that will detect CF biomarkers, ‘flags’, in a child’s urine. Doctors will be able to run regular tests to get up-to-date information on any change in a child’s lungs. This could transform the quality of life for Cystic Fibrosis patients.

Will you help us make the next big leap forward?



Children like Alfie need you

“Our hopes and dreams for Alfie remain the same. I still want him to do all the things I hoped for him.”

Alfie's mum

Alfie was diagnosed with Cystic Fibrosis at just one-month old

- Alfie was diagnosed with Cystic Fibrosis when he was one month old
- You can help us find newer and better ways to help children like Alfie

Less than six hours after Alfie was born he had to be rushed into emergency surgery to fix a blocked intestine.

After a month recovering in Crumlin, Alfie's parents brought him home, not realising they'd be back in hospital one week later to receive news that would forever change their lives.

Professor Paul McNally met with Alfie's parents and told them that their little boy had Cystic Fibrosis. The next few months were rough, as Alfie's mum recalls.

“We were in to see Professor McNally everyday for the first week for tests to learn about medication, physio treatments and everything his care would

Will you give children like Alfie every chance for a better future?

now involve. For the next month we spent a lot of time in Crumlin with Professor McNally's team learning a new way of life for our little baby.”

Alfie receives regular check-ups from Professor McNally and his team. This information is fed into the SHIELD CF long-term study,

which will help doctors better understand the disease and develop more novel Cystic Fibrosis treatments.

Alfie's mum is happy for her son to be included in this groundbreaking study, as she knows that the research it fuels will help improve the odds for Alfie.

“It's a life-limiting condition and without any groundbreaking treatments, we are very aware of what the future holds.

As a parent, you put all of your hope in research. In the hope that one day something will come along that will offer children like Alfie a longer, healthier and happier life.”

Will you help sick children ... now and in the future?

Leaving a gift
in your Will



- **More supporters are remembering CMRF Crumlin with a gift in their Will, helping protect future generations of children.**
- **After you've provided for your loved ones, your lasting gift will provide life-saving treatment to children in the future.**

Every day you help sick children. These little heroes come into the world with the odds stacked against them. But thanks to big heroes like you, they beat the odds.

Through your support, you are

ensuring sick children receive the best care, and access to the latest innovative treatments and potential cures. The research you are funding now will save and improve the lives of children for generations to come.

When writing your Will, your family and loved ones come first. But perhaps you would also consider leaving a lasting legacy that will have a major impact on the future of childhood illness.

If you'd like to have a confidential conversation about leaving a gift to CMRF Crumlin in your Will, we're happy to talk to you. Please call **Siobhan Broughan** on **01 709 1743**. Or email her at **sbroughan@cmrf.org**.