Twin sisters,
Juliette & Elayna Marley

Impact Report

APRIL 2019 - MARCH 2020

CHILDREN'S HEARTBEAT TRUST
Northern Ireland's
Children's Heart Charity

Charity no: NIC 102410

Mission & Vision

Mission: To support children, young people and their families affected by heart disease in Northern Ireland.

Vision: Our Vision is of a society that provides high quality and inclusive clinical, practical and emotional support for heart families at each stage of their journey.

Chairperson's Welcome

I am very proud to introduce our Annual Report from April 2019 – March 2020.

A major achievement of this year was the launch of the Children's Heart Centre at Royal Belfast Hospital for Sick Children. This flagship facility represents the culmination of over five years of campaigning and significant financial support from the charity working in close collaboration with the Belfast Trust and the Department of Health. It was a delight to see the success of this partnership realised in such a bright, child and family-friendly centre that will provide a dedicated clinical outpatients space for children with heart disease for many years to come.

This project and the achievements detailed in this report are testimony to the dynamic and dedicated efforts of the small Children's Heartbeat Trust team who work hard to put the needs of heart families at the centre of all the services we provide and advocate for. I thank them all for their passion and dedication to the work of the charity. I also am very appreciative to our voluntary Board of Directors who guide and oversee the direction of the charity for their integrity, commitment and expertise.

The global pandemic COVID-19 struck just at the end of the period this report covers and changed the way we work, live and support each other. The impact of COVID-19 continues to be a major challenge for the charity and the whole third sector, but I am confident that we will weather this storm and continue to offer sustainable and tailored services for each heart family, young person or child we support in Northern Ireland.

Professor Nichola Rooney
Chair

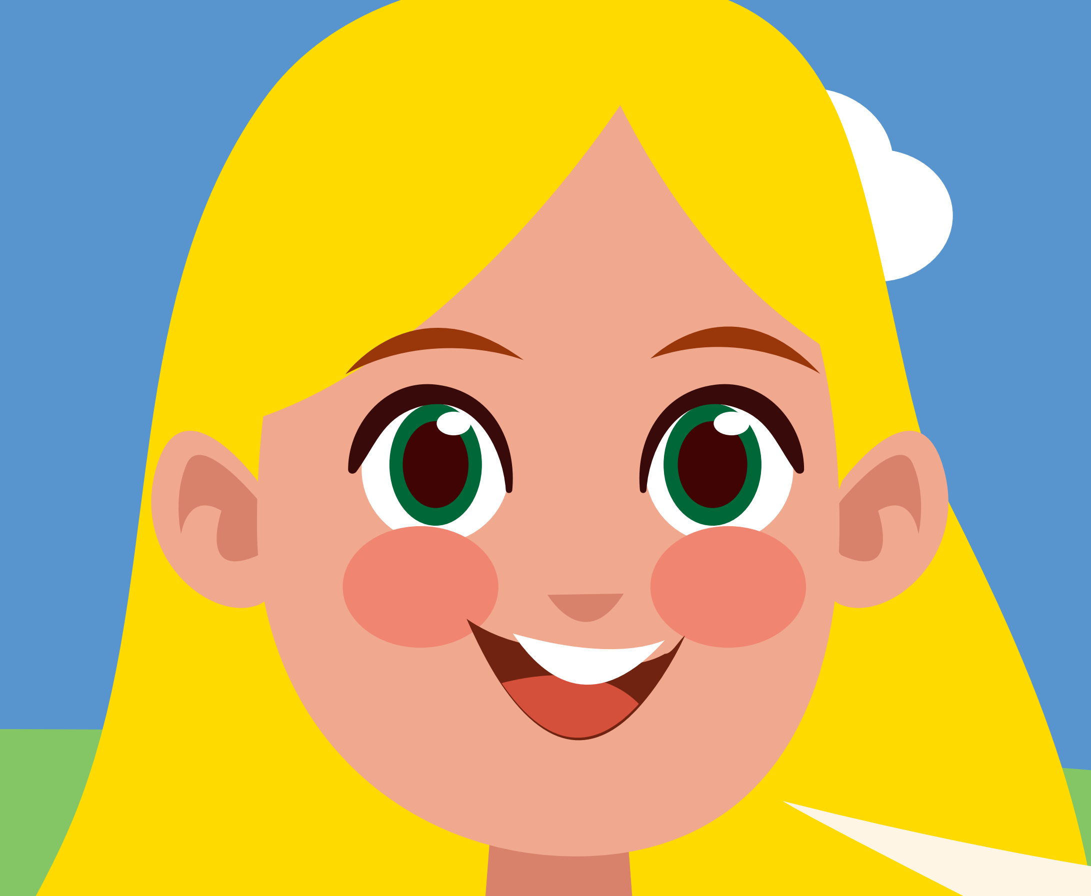
> **We are privileged to work with over 500 heart families each year.**

CEO Message

Helping Heart Families is at the core of all that the charity does. We are privileged to work with over 500 heart families each year and our focus is on providing support for any heart family in Northern Ireland, at any point of their journey, when they need us. This year we received an email from a heart mum, Julie Marley, which stopped us in our tracks as she set out how different elements of our services had helped her and her family. Julie's words capture the impact of our work much better than we ever could, so a large part of this year's Annual Report is dedicated to her family's journey as sent to us in her email, word for word.

Sarah Quinlan
Chief Executive

Julie's Journey ➔



Julie's Journey

Hi, I'm Julie. I'm mum to the wonderful Zac (8) and our adorable 1 year old twins Juliette & Elayna, and married to the lovely Alan. Our 20 week foetal scan had picked up that Elayna had a complex heart defect called Tetralogy of Fallot and when the girls were born on the 14th January 2019 she had to go straight to NICU and then Crumlin Children's Hospital in Dublin for monitoring. Elayna spent 7 months of her first year in hospital and had open heart surgery in September 2019.

It's been a crazy year for us and our family but the support of Children's Heartbeat Trust has made it so much more bearable. Here are some of the ways you have helped us personally...

Children's Heartbeat Trust's support throughout
JULIE'S JOURNEY...

1. Telling us that we weren't alone, no matter what happened in our journey you would be there to help. With so much to worry about, that reassurance meant the world to us!
2. Visiting us in the NICU when the girls were born and we were totally lost and afraid.
3. Getting me in touch with another twin mum who's babies battle CHD.
4. Touching base with us every week when we were in Clark clinic.

This year we supported

46

families ante-natally when they found out about their foetal cardiac diagnosis.

123

parents stayed in our parent accommodation at the Children's Hospital, Belfast.

Children's Heartbeat Trust's support throughout
JULIE'S JOURNEY...

5. Phoning me every few days when we were in Dublin to check in on Elayna.
6. Being a constant and reassuring friendly voice throughout our journey.
7. Paying for vital machines and equipment used for reading vitals in children with heart disease. For us it was a hand held sats monitor. This allowed us to take Elayna home before her surgery. We used this several times a day, every single day of her life and it helped us decide when to take her to hospital and informed her cardiologist of changes needed in her medication. Ultimately helping us and her doctors determine when her heart was failing and it was time for surgery.

This year

37

families benefitted from the medical equipment we purchased in partnership with Clark Clinic:

- **6** pulse oximetry sats monitors
- **30** blood monitoring coaguchek machines for the Cardiac Specialist Nurse's home monitoring programme
- **1** Portable Infusion Pump

Children's Heartbeat Trust provided financial support to

129

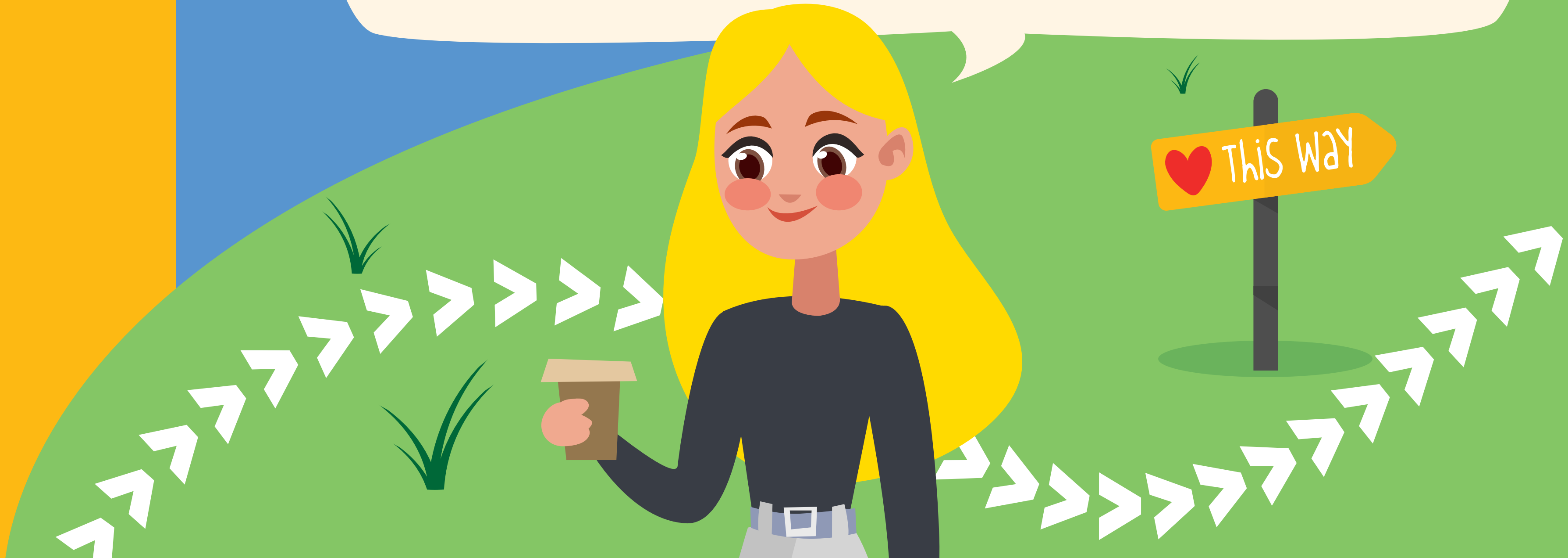
families staying in Clark Clinic and

136

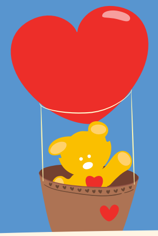
families who had to travel outside of NI for their child's treatment or surgery over the course of this year.

Children's Heartbeat Trust's support throughout
JULIE'S JOURNEY...

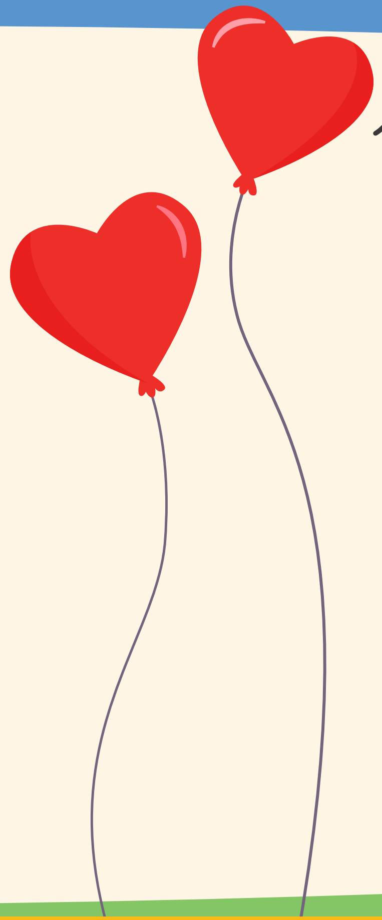
8. Financial support when we were inpatients in Belfast and Dublin. The Financial strain when your family is separated by hospitals is crazy. There's a lot of eating on the go, taxis, carparks, train rides, long drives to Dublin and lots of petrol, hotels, hospital accommodation, ferrying your other kids off here and there because you can't be in two places at once ... emergency trips to shops because you've ran out of clean baby grows / blankets / all sorts of baby food since u can't cook in hospital and are desperate for your child to start eating again. Living away from home cost us a fortune.



Children's Heartbeat Trust's support throughout
JULIE'S JOURNEY...



9. Counselling... As amazing and caring as the hospital staff were, living in a hospital environment with your child is rough. It felt like a war zone to me. You are on a constant state of high alert. You are worried someone you love dearly might die. You miss your family you are separated from so badly it hurts. You say 'I love you' a lot, behind tears on FaceTime. There's beeping and alarms going off constantly. You eat badly, you sleep badly. And you see a lot of pain and suffering. You need to talk through that kind of stuff!

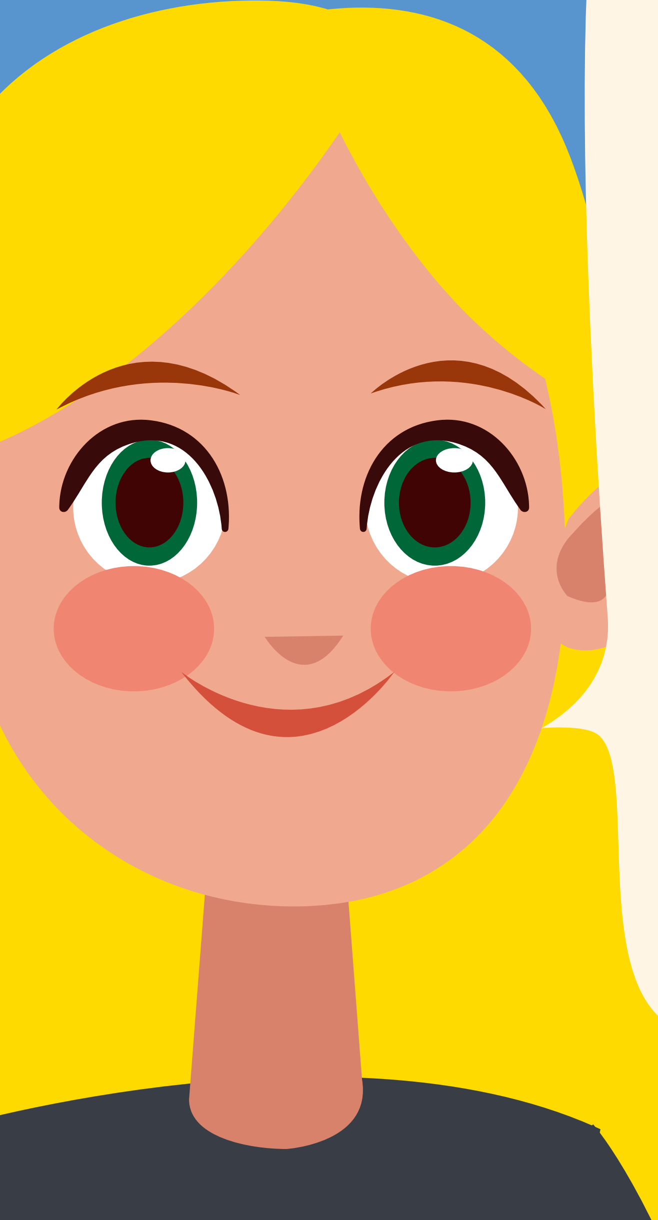


10. Helping to make the children's heart centre more bearable for the kids who have long and frequent outpatient appointments. Needing two tired and restless 1 year old twins to sit still for an ecg and an echo is not easy. Especially when one of them is frightened and freaks out as soon as anyone in a hospital touches her. The iPads the charity have attached over the beds for these scans are an absolute lifesaver! As are the sensory toys in the rooms, making it all a bit less scary for them. Thank you, thank you, thank you!

23 families accessed **67** sessions through our free, 24 hour counselling service.

Read more about the launch of the new Children's Heart Center on p.17

Children's Heartbeat Trust's support throughout JULIE'S JOURNEY...



This is just some of the ways you have helped us, since you support families with different needs and lots of older children there will be lots I haven't mentioned above.

But most importantly we know Children's Heartbeat Trust are here for the long haul - when you have a child with heart disease your journey never really ends, you know there's a big chance you could be back there in the future. The amazing thing about this charity is that your support develops with the changing needs of the child and family.

It's all a little easier knowing you will always be there with us....

Julie's right, this year we also had...

130

families enjoying a respite stay in one of our three caravans

99

families attended one of 12 local family support groups

An incredible

54

teenagers and young adults engaging with our youth services programme

We also introduced a student bursary programme which was awarded to

4

young people with CHD

A trusted voice for heart families

We advocate and campaign on key issues to ensure that the welfare of children and young people with CHD are at the centre of any decisions made about the services upon which they rely.

CHILDREN'S HEART CENTRE LAUNCH

On the 13th June 2019 Ireland and Ulster Rugby Star Rory Best and 10 year old Aimee Brady officially opened the new Children's Heart Centre at RBHSC. Following many years of campaigning and collaboration from the charity it was a great achievement to see this dedicated facility open to provide flagship services for children in Northern Ireland as part of the All Island CHD Network.

The charity also donated £50,000 to create a child and family-centred environment including sensory equipment in the waiting areas and investigation room, IPADs and interactive panels to engage children of all ages and wonderful artwork throughout the centre.

Tragically, Aimee passed away on 9th October 2019 after waiting nine months in hospital for a heart transplant. Aimee was a wonderful friend to the charity and is greatly missed by all who knew and loved her. Our deepest condolences to her mum and dad, Valerie & Stephen and her big brother Taylor.

A trusted voice for heart families (CONTINUED)

ORGAN DONATION WEEK 2019

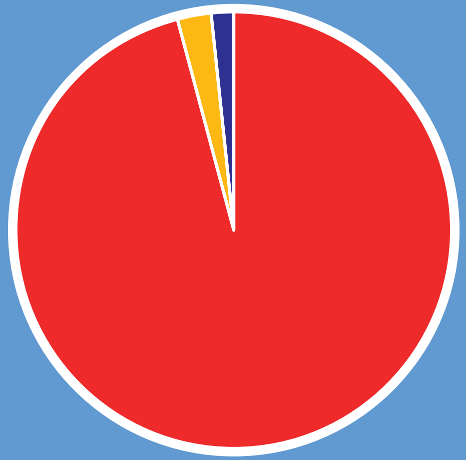
Organ Donation is a significant issue in Northern Ireland with less than half the population on the Organ Donation Register. Children on the urgent list for heart transplants will face on average a two and a half times longer wait for a suitable match for an adult. As part of Organ Donation week in September 2019 we ran an awareness campaign sharing five short films highlighting the stories of families who were either waiting on or had received a heart transplant for their child, to encourage families to talk about joining the Organ Donation Register.

Photo: Ryan O'Callaghan received a heart transplant in 2018 when he was 10 years old. He and his family are so thankful to the donor and the donor's family for giving him the gift of life.

Financial

INCOME:

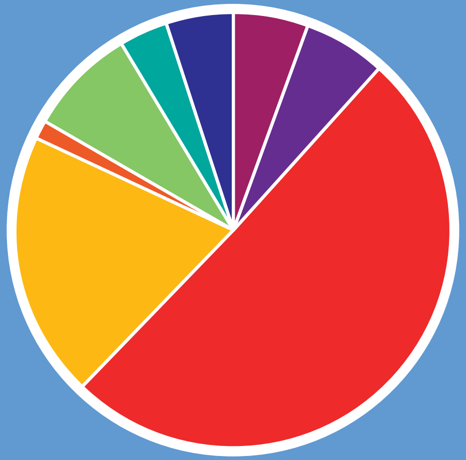
In 2019/20 we received a total of **£478,824**



- ● Donations & Fundraising: **96%**
- ● Restricted Funding: **2.5%**
- ● Other Income: **1.5%**

COSTS

Expenditure and contracted expenditure for this period came to **£457,486**



- ● Family Support Services: **50.4%**
- ● Support Costs: **19.8%**
- ● Information Resources: **1.5%**
- ● Awareness & Advocacy: **7.9%**
- ● Research: **3.6%**
- ● Merchandise & Fundraising: **4.9%**
- ● Clark Clinic support: **5.6%**
- ● Administration: **6.3%**

Our Supporters

Children's Heartbeat Trust is nearly 100% funded by donations from our wonderful supporters whose fundraising enables us to provide our wide range of crucial support services for heart families here in Northern Ireland.

* * *

We really couldn't do it without you.

This year we were honoured with the support of…

10 charity of the year corporate partnerships

30 schools

228 fundraising events in the community

128 fundraisers taking part in CHT events

4 grants from Openworks Foundation, Hospital Saturday Funds, Cash for Kids and Black Santa Appeal

141 incredible volunteers donated **583** hours to support the work of the charity

Digital Engagement

Twitter:
@Childns_Hrtbeat
1.6k followers
up 6%

Facebook:
@childrens.h.trust
14k followers
up 17%

Instagram:
@childrensheartbeattrust
1.9k followers
up 41%

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