



**Children's Health**  
**FOUNDATION**

Crumlin • Temple Street • Tallaght • Connolly

SUPPORTING CHILDREN'S HEALTH IRELAND

Impact Report 2019



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# Welcome and Overview



## 1.1

### About Us

Children's Health Foundation raises vital funds to support sick children and their families in CHI hospitals and urgent care centres in Crumlin, Temple Street, Connolly and Tallaght – funding vital life-saving equipment, providing essential patient and parental supports and making ground-breaking, paediatric research possible. Children's Health Foundation is the new name for CMRF Crumlin and Temple Street Foundation, which came together in January 2019 to become one foundation supporting all CHI sites to ensure every sick child has the very best chance.

This is simply our first step in ensuring we are stronger together, and geared up for supporting the new way that healthcare and research will be delivered in Ireland to improve outcomes for sick children.

However sick children cannot wait – they need great care right now – and we need all our supporters, fundraisers and partners by our side.

With the continued kindness and generosity of our supporters across Ireland and beyond, we will work as one organisation to continue our vital work in supporting the patients, families and staff in CHI – today, tomorrow, and in the future.

## Our Vision and Mission

**Vision:**

To give every sick child the very best chance

**Mission:**

To work together to provide world-class facilities, research and compassionate, loving care for every sick child in Ireland

## Our Values

**Child-centred:**

The child is at the heart of everything we do. We are here to ensure every sick child has the very best chance and everything we do is to improve outcomes for sick children.

**Compassion:**

We care for those we work with, and all our interactions are characterised by respect, courtesy, warmth and professional dignity.

**Integrity:**

We are true to our mission - always striving to do the right thing, by being open, honest and transparent.

**Ambitious:**

We are ambitious for the health and well-being of the children we serve and we will do everything we can to ensure that each and every child has the very best chance of a full, healthy and happy life.

**Respect:**

We value ourselves, each other and all members of our community showing understanding and appreciation for all our similarities and differences.

**Collaborative:**

We believe in the power of working together to improve outcomes for sick children.

**Innovative:**

We constantly strive to redefine the standard of excellence in everything we do. We are open to ideas that challenge the conventional views and drive innovation and support better outcomes for children.



"Children are at the heart of everything we do. We are here to ensure every sick child has the very best chance."

1.2

## Chief Executive and Chair Welcome



**Denise Fitzgerald**  
Chief Executive



**Helen Conlan**  
Chair

We are delighted to welcome you to the 2019 Impact Report for Children’s Health Foundation – formerly CMRF Crumlin and Temple Street Foundation – to share with you an overview and celebration of the incredible impact that your generosity has had on sick children attending CHI at Crumlin and Temple Street in 2019. We will also give you an insight into the vital and ground-breaking paediatric research that your support has made possible in CHI hospitals and urgent care centres and the National Children’s Research Centre (NCRC) in 2019.

2019 signified the birth of a new Foundation whose purpose is to ensure that every sick child in Ireland gets the very best chance. Temple Street Foundation and CMRF Crumlin officially came together in January 2019 to become one united entity, working together to raise vital funds for all of Ireland’s sick children. This was just the start of this ambitious new phase of our work, as we continue to prepare and strengthen our organisation to support the new way that healthcare and research will be delivered to improve outcomes for sick children.

For many years, paediatric healthcare in Ireland has been delivered through a combination of primary, secondary and tertiary services at three paediatric hospitals (Crumlin, Tallaght and Temple Street). The Children’s Health Bill 2018 saw the formation of Children’s Health Ireland, and this new company took over responsibility for the three existing hospitals from 1st January 2019.

Aligned with this change in paediatric healthcare, the three Foundations associated with each of the hospitals: The Children’s Medical and Research Foundation (CMRF Crumlin), National Children’s Hospital Foundation Tallaght (NCHF) and Temple Street Foundation (TSF) agreed that they would come together to form a new Foundation in 2019 with Tallaght to join us when Ministerial approval is secured.

At Children’s Health Foundation our ambition is huge – for children’s and young adolescents’ care and health - and for building a Foundation to support that. Together we are part of a new paediatric healthcare framework that puts children at the very centre and ensures the best outcomes for them.

Working toward the opening of the new National Children’s Hospital in the next few years, we work together with Children’s Health Ireland (CHI) to foster a new environment for children’s healthcare in Ireland, to provide the patient and parent supports, new service developments, research and innovation, infrastructure and vital life-saving equipment for Ireland’s sickest children.

We are committed to supporting CHI Hospitals in Temple Street and Crumlin who provide the highest standard of medical care to sick children in Ireland by ensuring they and their families have immediate access to the best facilities, the finest research and the most compassionate and loving support.

In this milestone year, the Foundation remained firmly focused on meeting the growing needs of CHI at Temple Street and Crumlin, as well as providing on-going essential funding of paediatric research in CHI and NCRC. With your help and support, we raised over €18million in 2019; an achievement made possible through a wide range of high-profile fundraising activities, national public engagement and key partnerships.

In the pages that follow you’ll learn more about the equipment that your support has made possible, including a new laparoscopy tower and portable ultrasound machine for CHI at Crumlin, and a much-needed new paediatric bone density service in Temple Street. Your donations have allowed us to invest in a wide range of patient and family supports, such as fun, seasonal events for children

in hospital and weekly much-anticipated therapy dog visits in Temple Street. Patients in Crumlin have also benefitted from supports such as music and play therapy, which have received essential funding from Children’s Health Foundation.

2019 saw major investment to redevelop facilities in both hospitals including Nazareth Ward in CHI at Crumlin and St. Philomena’s ward in Temple Street. These investments have a direct and positive impact on children, young people and their families who need these facilities, which have been optimised and refreshed to meet their specific needs. A total of €6.2million was invested in potentially life-changing research and funded studies into a wide range of childhood illnesses and conditions including obesity and its impact on the immune system, neuroblastoma and childhood cancer, to name just a few.

The teams in CHI at Crumlin and Temple Street work around the clock to deliver world-class care to sick children from all over Ireland. In fact, more than 300,000 children are treated across both hospitals every single year. With the generosity and kindness of our supporters across Ireland and beyond, we are committed to raising the vital funds needed to ensure that sick children continue to have access to the very best facilities, equipment and supports when they need it most.

The work of the Foundation is only made possible with the ongoing trust of our supporters and we remain fully committed to being transparent and open in all of our activities. That is why we ensure that you are kept fully updated on how and where your donations are being invested. In partnership with CHI in 2019, the Foundation continued to place priority on investments that would have the greatest impact and fulfil the most urgent and immediate needs.

**Denise Fitzgerald**  
Chief Executive, Children’s Health Foundation

**Helen Conlan**  
Chair, Children’s Health Foundation



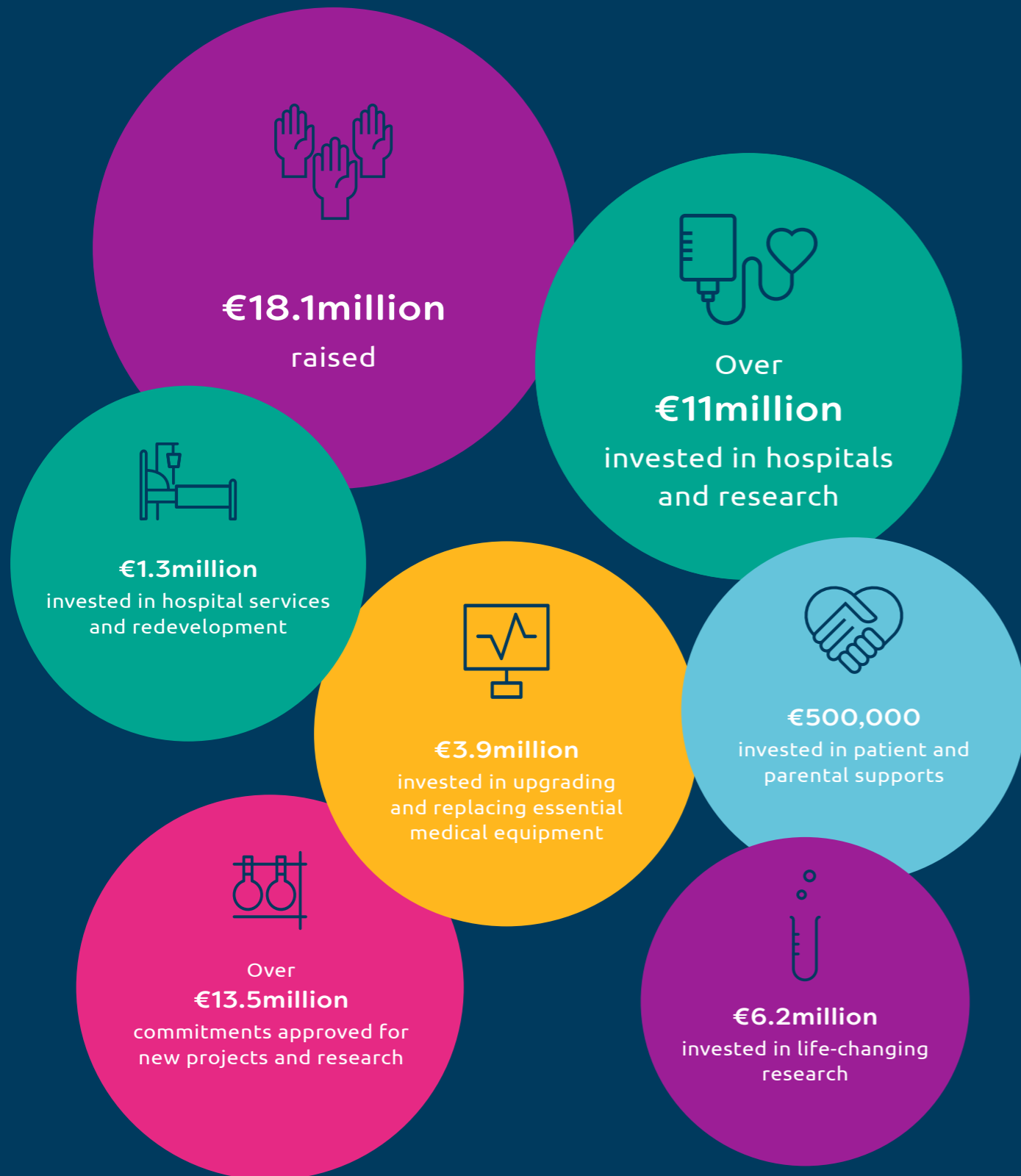
### 1.3 About Children's Health Ireland (CHI)

The three children's hospitals at Crumlin, Temple Street and Tallaght and the Children's Hospital Group transitioned from four separate, independently governed entities into one new single organisation effective on 1st January 2019 to govern and operate local paediatric services in Dublin and all national paediatric services, some of which are on an all-island basis.

CHI operates as a single service across the existing locations of Crumlin, Temple Street and Tallaght. The first of two paediatric outpatient and urgent care centres opened on 31st July 2019, at CHI at Connolly Hospital in Blanchardstown, which will be followed by the second facility at Tallaght Hospital which is planned to open soon and the new children's hospital on the campus shared with St James's Hospital is now under construction.

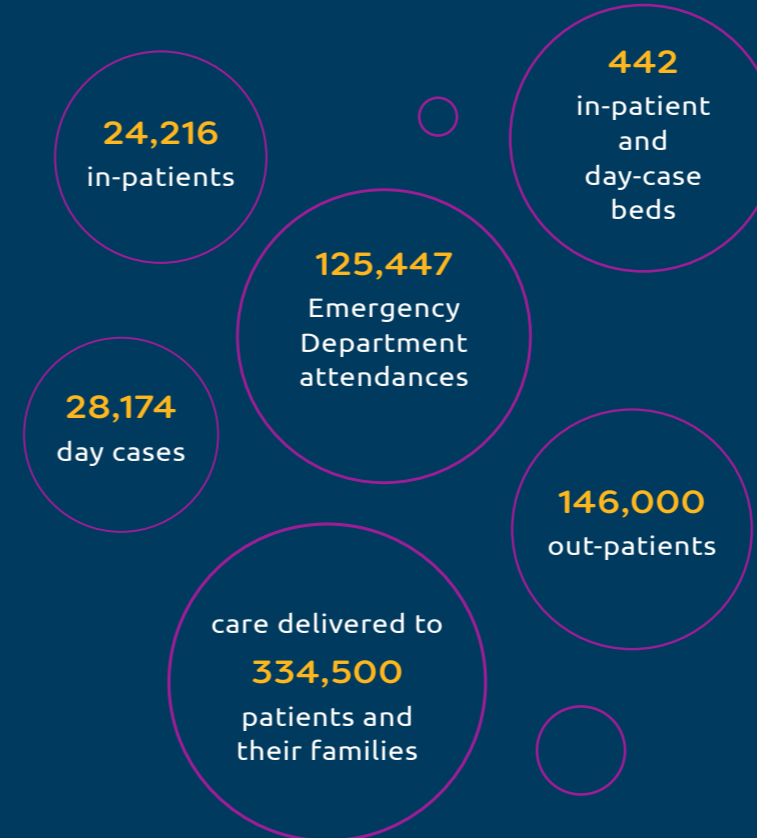
1.4

## Key Facts and Figures at a Glance



### CHI Key Facts & Figures 2019

Connolly, Crumlin, Temple Street, Tallaght



### Clinical specialities include:



# Achievements in 2019

## 2.1

## Our Objectives and Outcomes

Objectives and Priorities	Performance and Outcomes
<b>Funding</b>	
Raise funds that enable CHI at Temple Street and Crumlin to continue to provide world-class medical care and supports for sick children and their families when they need it most	<ul style="list-style-type: none"> <li>Successfully raised over €18 million in fundraising income in 2019 thanks to the ongoing support and generosity of our supporters, fundraisers, volunteers and partners across Ireland and beyond</li> </ul>
Make funds available to CHI at Temple Street and Crumlin and the NCRC to invest in projects, equipment, supports and service developments over the course of the year	<ul style="list-style-type: none"> <li>Over €11m drawn down by the Hospitals and NCRC in the year and over €13.5m of commitments approved in the year for new projects and research</li> </ul>
Develop strong relationships with supporters across Ireland and overseas and grow our network of supporters across both Temple Street Foundation and CMRF Crumlin sites	<ul style="list-style-type: none"> <li>Succeeded in developing relationships nationwide and abroad through a range of campaigns, fundraising events, philanthropy and supporter engagement</li> </ul>
<b>Strategic Grant-Making</b>	
Continue to support CHI at Temple Street and Crumlin's life-saving work by continuing to invest in the Hospitals	<ul style="list-style-type: none"> <li>Invested almost €6m in CHI at Temple Street and Crumlin along with commitments of €7.1m made during the year for new projects</li> </ul>
Ensure that CHI patients have access to the latest advances in medical treatment and critical care equipment	<ul style="list-style-type: none"> <li>Invested a total of €5.2m across the hospitals and purchased a range of state-of-the-art equipment for wards and departments including:               <ul style="list-style-type: none"> <li>Incubators for CHI at Temple Street's ICU and neo-natal ward</li> <li>Cardiac Workstation and Audio Visual Lab system for CHI at Crumlin</li> </ul> </li> </ul>



Objectives and Priorities	Performance and Outcomes
<b>Strategic Grant-Making (cont'd)</b>	
Invest in the redevelopment of hospital facilities and its infrastructure	<ul style="list-style-type: none"> <li>Investment of over €500k in redevelopment of Out Patients Department and Nazareth's Ward in CHI at Crumlin</li> </ul>
Continue to support ground-breaking research studies within CHI at Temple Street and the NCRC	<ul style="list-style-type: none"> <li>Provided funding of over €2m for peer-reviewed research studies that could lead to significant clinical improvements in the care of sick children and granted €1m in research fellowship awards; invested €0.8m in clinical trial unit in NCRC</li> </ul>
<b>Good Governance</b>	
Continue to maintain the highest standards of governance and financial reporting	<ul style="list-style-type: none"> <li>We are committed to upholding the triple lock principles of transparent reporting, good fundraising and good governance</li> </ul>
Risk Assessment	<ul style="list-style-type: none"> <li>Full review of risk framework for Children's Health Foundation during the year and formulated a governance action plan for 2020</li> <li>Children's Health Foundation is fully compliant with Charities Regulator Governance Code and continue to aim for the highest standards of governance across all our activities</li> </ul>
<b>Future Strategy of the Foundation</b>	
To continue discussions with the National Children's Hospital Foundation Tallaght in respect of merging	<ul style="list-style-type: none"> <li>We continue to work closely with our colleagues to finalise the merger with Tallaght Foundation which is dependent upon Ministerial Consent</li> </ul>



## 2.2 Our Work for Sick Children

We work closely with CHI to identify and place priority on investments that have the greatest impact and fulfil the most urgent and immediate needs. Children's Health Foundation invested almost €12million in CHI at Temple Street and Crumlin and the NCRC under our four pillars - equipment, new & emerging services and development initiatives, patient and parental supports and paediatric research.

Children's Health Foundation depends entirely on the kindness, generosity and support of individuals, communities and corporate partners nationwide and beyond to continue its work investing in life-saving equipment, essential family supports, enhanced facilities, new services and essential paediatric research in the hospitals and the National Children's Research Centre (NCRC).

### 2.3 Funds Raised in 2019 with your Support

2019 was a landmark year for Children's Health Foundation as we embarked on our first year as one united Foundation. Over the course of the twelve months, over €18million was raised in support of both CHI at Temple Street and Crumlin and NCRC; a figure made possible only with the phenomenal help and trust of our supporters across Ireland and beyond.

None of the work that we do would be possible without the continued support of every individual, community group, school, creche, company or family who takes the time and effort to raise funds for Children's Health Foundation. We are truly honoured to have the help of our supporters, ambassadors and volunteers, who work with us to make a truly transformative difference for sick children each and every year.

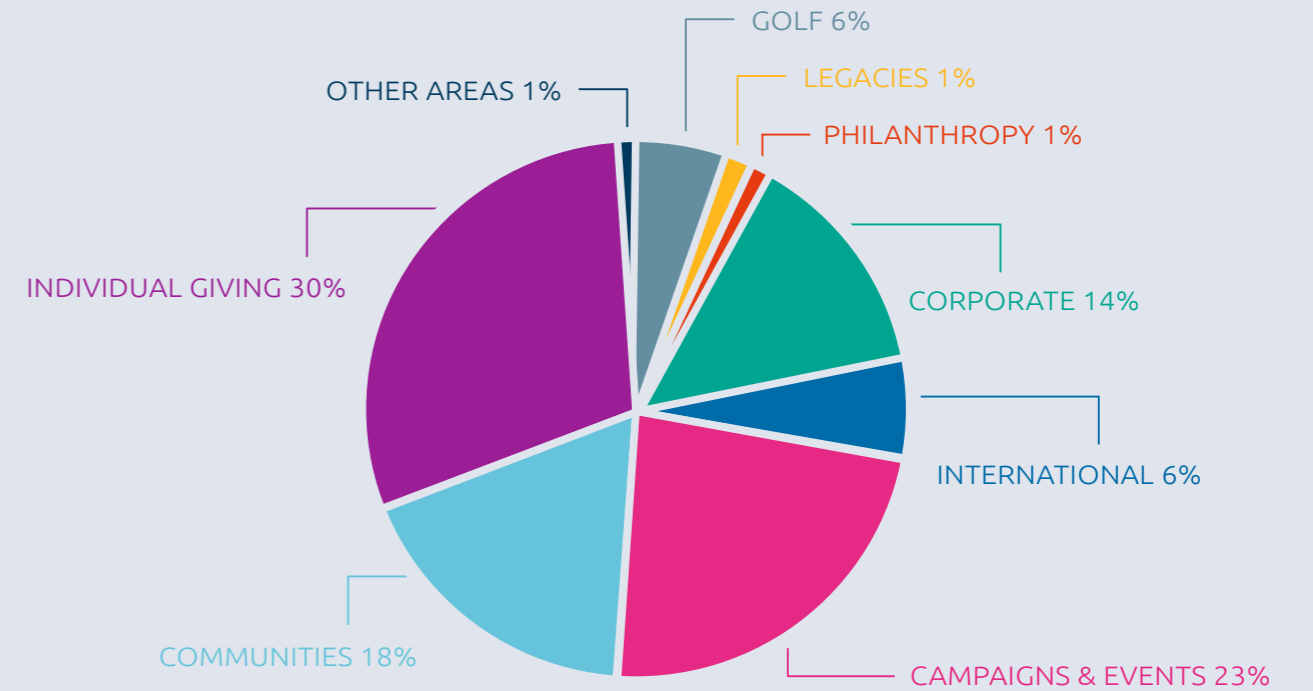
We were proud and honoured to work with over 3,400 community fundraisers from every county in Ireland, who held their own fundraising challenges, events and activities. Children's Health Foundation would like to thank every single individual who contributed to making those fundraisers the success they were for sick children in 2019. We are immensely grateful to our regular supporters who are an integral part of our community of care who enable us to support the ongoing work in the hospitals.

We are fully committed to building on the already-strong relationships with our supporters to demonstrate the impact of their support and to keep them updated on the real, lasting and positive difference that they are making to the lives of CHI patients, their families and their wider communities.

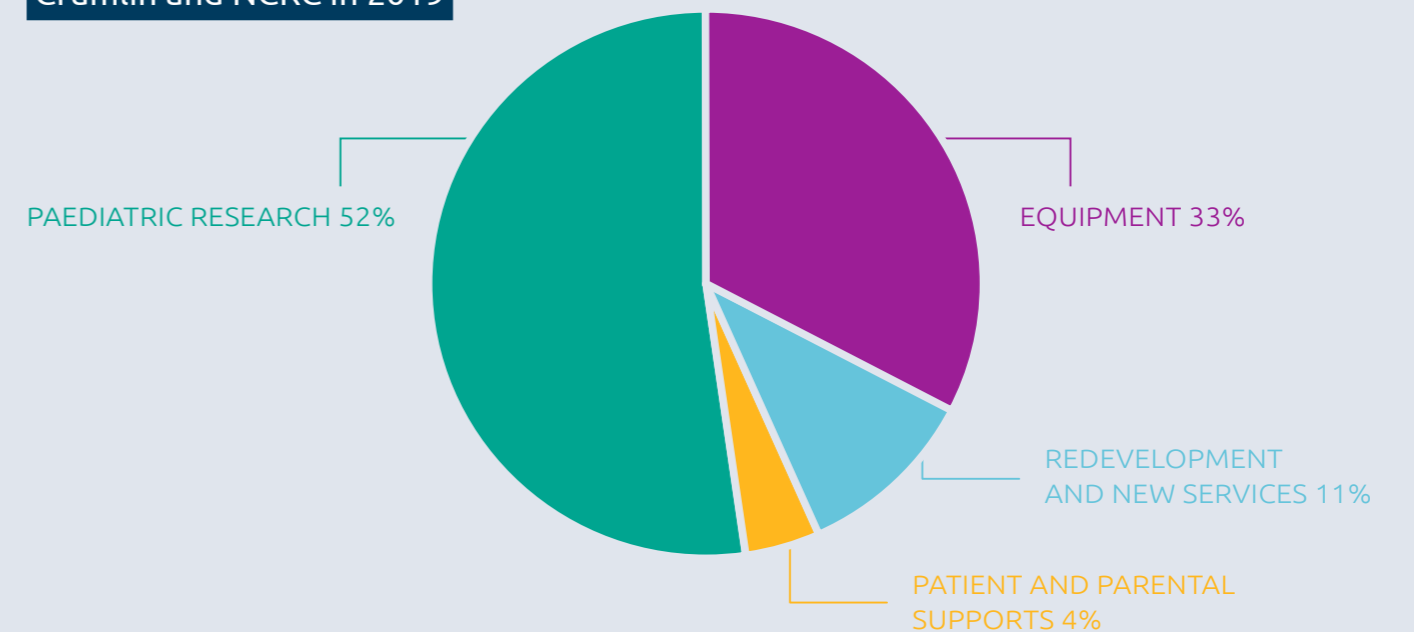
We were proud to work with a large number of corporate supporters across both Crumlin and Temple Street sites in 2019, who go above and beyond every year to raise vital funds. We continued to work closely with Tesco Ireland, who raised more than €1million in the fifth year of their partnership with Children's Health Foundation Temple Street.

Woodies DIY were also a key partner - raising almost €100,000 in support of CHI at Temple Street as part of their innovative Woodies Heroes Campaign. Long-term partners such as Dalata, One4All and Zeus continued their wonderful support of sick children in CHI at Crumlin with generous contributions from their fundraising campaigns. We also worked together on a number of joint fundraising ventures with key corporate partners supporting both hospitals - including Penneys and Smyths Toys Superstore.

€18.1million raised by Children's Health Foundation in 2019



€11.9million invested in CHI at Temple Street, Crumlin and NCRC in 2019



# Impact Report

3.1

## New and Emerging Services and Development Initiatives

**Irish Childhood Cancer Survivorship Project**  
CHI at Crumlin

€64,779



Today there is great hope of a positive outcome for children who receive a cancer diagnosis. Survival rates of childhood cancers are improving with eight out ten children surviving cancer. Decades of research has greatly improved the amount of time it takes to diagnose cancer in children, revolutionised the type of treatment available, and decreased recovery times. We are now seeing more survivors of childhood cancer than ever before, and with current trends this number should continue to increase in the coming years.

While this is fantastic news, more progress needs to be made in terms

of lengthening the lives of survivors. Survivors of childhood cancer are at an increased risk of premature death. Nearly two-thirds of survivors have at least one or more chronic health condition(s) and over a quarter have a severe life-threatening condition. There is a great need for life-long follow-up to identify survivors most at risk who could benefit with early intervention. This would be complimented with a secondary initiative of helping survivors to live their lives to the fullest by addressing physical and psychological needs that they may have.

For the first time ever, with the help of Children's Health Foundation supporters, the Irish Childhood Cancer Survivorship Project is tracking the numbers of childhood cancer survivors in Ireland. The project works in tandem with the National Cancer Control Programme (NCCP) and the Department of Health's National Cancer Strategy. Data is also being collected on treatment-related effects. The vision is to develop a comprehensive Irish Childhood Cancer Survivor Study database, and service that could offer vital supports, including possible genetic testing to those at risk of developing other cancers.

Cancer treatment saves lives but there also challenges associated with it that can affect children more than adults relative to their stage of development. Speech and language

development and cognitive function are just two examples of such. There are also challenges with survivors of childhood cancer transitioning from paediatric oncology follow up teams to adult care providers who may have

limited expertise and experience with adult survivors of childhood cancer. Also unfortunately, some adult survivors of childhood cancer may be more susceptible to developing other cancers later in life.

**St. Philomena's Ward Redevelopment**  
CHI at Temple Street

€1,066,005



Eight isolation rooms were developed and fully equipped to allow for improved patient facilities. These isolation rooms are tailor made to the needs of our most vulnerable patients, including controlled air conditioning which assists with infection control. To achieve greater privacy for patients all bedrooms now have en-suite bathrooms. Treatment room facilities were also upgraded, they were designed to create a better environment and ease of access for all.

Due to stairs access only, the ward has never been fully accessible, in the past children would have to walk or be carried to the ward. This redevelopment and reconfiguration project has not only improved access but also created additional bed capacity within the hospital.

With the help of our supporters we have funded the refurbishment of St. Philomena's Ward. A key part of the refurbishment was to allow for better comfort and privacy for patients and their families, and to provide the best facilities for our staff. A designated parent's room was also developed in this project. Overnight chairs were provided for each room, ensuring parents who wish to stay overnight can do so in a comfortable environment.

As part of the refurbishment a new link corridor was created to allow for lift access with the inclusion of a lift platform, this has meant greater access for all regardless of mobility. The floor was levelled across the entire ward giving uninterrupted access.

This refurbishment of St. Philomena's ward has meant that there are better facilities available for the treatment of vulnerable patients who require isolation.



With the help of our supporters, Children's Health Foundation was able to fund a wide range of fun, diverting and therapeutic events and activities in both hospitals, to help create a home-from-home environment.

3.2

**Patient and Parental Supports**

**Music Therapy**

€31,107

In 2019, the support from our Circle of Care across Ireland and beyond made it possible for Music Therapists to work with patients in both CHI at Temple Street and Crumlin. Music Therapists are clinically trained to use music to encourage development, change and healing in our patients. The beauty of music therapy is that it is very natural because everyone is born with the ability to respond to musical sounds, which is not affected by injury, illness or disability. It also lends itself to being wholly or partly non-verbal so it can be a great medium for children regardless of their language abilities.

Music is a great complimentary therapy because it is a positive intervention for both our patients

and their families. This type of therapy boosts moods after a tough day, relaxes and eases anxiety particularly before a medical procedure, helps to reduce the perception of pain and can assist with helping people to regain their speech.

In CHI at Crumlin, the Music Therapy Clinical Treatment Room has been up and running for several years and has benefitted some of the hospital's sickest patients. The recent acquisition of a grand piano for the room has enhanced patients' experience of feeling and touching music and sound, which has been positively received by patients, especially those with hearing loss and sensory considerations.

Patient Support Activities allow for positive memories, alleviate the negative perception of being in hospital, and can bring a sense of normality and comfort to patients and their families.



### Patient Support Activities CHI at Temple Street and Crumlin

€148,154

CHI at Temple Street and Crumlin are committed to creating a home-from-home environment in the hospitals for children who spend time on the wards and, with the help of our supporters, Children's Health Foundation was able to fund a wide range of fun, diverting and therapeutic events and activities in both hospitals.

The Saturday Club has been running successfully in Temple Street for the past 12 years, and was looking for funding to support activity for the next two years. The club is primarily run by two play staff members and consists of many different activities such as arts and crafts, face painting or art tattoos, and various sensory toys. The wide range of activities available suit children and young people of all ages and abilities. There are also two children's entertainers who visit each of the wards, providing entertainment for all children and their families. These include magic shows, clown doctors and musicians. The Saturday Club gives patients something to look forward to, alleviates boredom, and allows for positive memories from a child's stay at Temple Street.

Seasonal Events are hosted by the play team in CHI at Temple Street annually to celebrate popular dates and events such as Halloween, Christmas, summer, Valentine's Day, Mother's Day/Father's Day, and St. Patrick's Day. Each event has a specific theme, such as the

Easter bunny and eggs relating to Easter. The playroom and wards are decorated with theme specific decorations, arts and crafts events take place, and patients from each ward including the outpatient and the A&E Department will receive small gifts depending on the event. These events allow for positive memories, alleviate the negative perception of being in hospital, and can bring a sense of normality and comfort to patients and their families.

The Giggle Fund in CHI at Crumlin is supported through the generosity of our donors across Ireland and beyond and helps bring smiles and joy to sick children who must spend time in hospital. This is achieved through a wide range of activities across the year – from summer ice-creams and birthday parties to movie nights and pizza parties in the hospital.

The Annual Assisted Therapy Programme provides children in CHI at Temple Street with pet therapy once a week, and has taken place in the hospital since 2011. Buster and Schui alongside their owner Jeanette have become a regular feature at the hospital. Pet therapy has become the highlight of the week for many patients, especially those who are long term. Pet therapy can bring affection, companionship and aid social interaction, can promote a positive experience in the hospital, and may help with withdrawal and loneliness.

## 3.3

## Vital and Life-Saving Equipment

### The Zeiss Vario 700

€115,200

In 2017, 88 children had cleft palate surgery in CHI at Crumlin. One in 700 babies born in Ireland are born with a cleft. A cleft lip is a separation in the upper lip, and a cleft palate is an opening in the roof of the mouth. Cleft lip and palate are congenital defects and are the fourth most common birth defect in Ireland.

The Zeiss Vario 700 is an operating microscope with cutting edge technology for cleft surgery. It assists the surgeon to repair tiny nerves and blood vessels that would be difficult to see with the naked eye. This microscope incorporates face-to-face capability for microsurgery, a live video feed and has photographic

and video recording options. State of the art eyepieces magnify and light up the area being operated on for maximum control during the procedure.

Having access to this vital piece of equipment has decreased the amount of time that surgery normally takes, and it has improved the outcome of cleft surgeries resulting in fewer referrals to speech therapy. There is also a reduced amount of trauma done to the nose and mouth, which dramatically reduces the need for follow on surgeries or removes the need all together.

### Laparoscopy Tower

€164,540

Laparoscopy - also known as keyhole surgery - is a minimally invasive surgery essential in a paediatric department. It allows for shorter surgical procedures, reduces post-operative pain, use of pain relief, chance of infection and offers a shorter stay in hospital and quicker recovery.

Demand for these kinds of minimally invasive procedures amongst paediatric patients is growing each year and this type of modern technology offers a high quality standard of care expected in Ireland today.

This year, a new laparoscopic tower was purchased for CHI at Crumlin, allowing surgeons to increase the number of keyhole

surgeries performed - including pyloromyotomy, inguinal hernia repair and appendectomy amongst others. Having access to this vital equipment will allow surgeons in CHI at Crumlin to carry out some procedures that would not previously have been possible.

The benefits of this equipment include being able to offer minimally invasive surgery to children; allowing them to be discharged home earlier and with a smaller surgical scar. Laparoscopies allow patients to resume normal routine activity within just one week and physical activity just a fortnight after their operation.



This year, a new laparoscopic tower was purchased for CHI at Crumlin, allowing surgeons to increase the number of keyhole surgeries performed.



By enabling scans to occur in a child friendly environment, it helps to reduce stress associated with scan attendance.

### Paediatric DEXA Scanner

€165,000

In 2019, with the help of our supporters, we have funded the establishment of a paediatric bone densitometry service - the first of its kind in Ireland. This service is designed to meet the unique needs of able and disabled children in age appropriate service, combining a sensory environment with up to date technology. By enabling scans to occur in a child friendly environment, it helps to reduce stress associated with scan attendance.

Thanks to donations to Children's Health Foundation, children under the age of six will be able to access bone density scans in a paediatric environment for the first time, instead of referrals to adult centres. Other benefits include reductions in additional visits for children, due to

the same day scheduling of scans. Vertebral scanning, made possible by the bone density system reduces the need for x-rays reducing the radiation dose to the child.

Bone health is fundamentally linked to long term health outcomes in many childhood conditions. Bone densitometry identifies children with extremes of bone density at risk of fracture, to enable appropriate intervention and reduce the morbidity and mortality associated with fractures and immobilisation. This service will support research initiatives that will further the knowledge of bone health in Irish children and adolescents.

## 3.4

### Research

#### Research in CHI at Temple Street

**3D tissue engineering-based model of non-syndromic craniosynostosis for identifying potential therapeutic targets that control premature ossification.**

Researcher: Dr Dylan Murray  
Clinician: Dr Dylan Murray  
Research Institute: RCSI

Craniosynostosis (CS) is a bone developmental condition where the bone plates of the skull – called sutures - fuse too early – with different types of craniosynostosis depending on what suture is affected. Craniosynostosis affects approximately 1 in 2000 children. It is a congenital condition where premature fusion of the skull sutures occur and cause an abnormal head shape. If left untreated the final skull shape will be abnormal and can restrict brain growth. At the moment, the only treatment available is a surgery called 'cranial vault remodelling'.

Tissue engineering is an emerging speciality where medicine, engineering and biology merge together to investigate and treat diseased or damaged tissue by regeneration, rather than replacement. A previous research study where researchers at Tissue Engineering Research Group (TERG) at Royal college of Surgeons in Ireland (RCSI) examined and analysed small samples of skull bone taken by Mr. Murray at the time of surgery, thanks to families and children who consented to that research study.

Researchers discovered some very interesting findings on how the bone cells in the sutures behave and in particular what makes them change their behaviour to fuse rather than stay open and allow the skull to grow normally.

The team are now hoping to expand on this research by producing a laboratory model of craniosynostosis. In order to achieve this, biologic implants, referred to as scaffolds, are designed and seeded with the bone cells grown from a child's skull. The scaffold will provide structural support but also provide signals to bone cells that encourage them to grow and develop into desired tissue types. Researchers will be able to study what makes these cells change their behaviour.



### Development of a Gold Standard multi-disciplinary Research Framework for the National Center for Inherited Metabolic Disorders

**Researcher/Clinician:**  
 Prof Ina Knerr  
**Clinician:**  
 Prof Ina Knerr;  
 Prof Ahmad Monavari;  
 Prof Ellen Crushell;  
 Dr Joanne Hughes  
**Research Institute:**  
 NCIMD Temple Street and UCD

The National Centre for Inherited Metabolic Disorders (NCIMD) cares for all pediatric metabolic patients in the Republic of Ireland. It is internationally renowned and generates research that tangibly changes the lives of patients and contributes to international high-level standards of care.

In order to maximize research and collaboration within the unit and with European and international collaborators funding for a research position was provided by Children's Health Foundation. This support will build upon research foundations in place and enable a research framework that will generate high level research into metabolic disorders.

### Seed Funding:

#### The MAPPAED Study: Is the mid-arm point technique a reliable guide for safe chest drain insertion in injured children?

**Researcher:** Nuala Quinn  
**Clinician:** Nuala Quinn  
**Research Institution:** CHI at Temple Street

The aim of this research project is to find a way to help doctors looking after a severely injured child to perform a life-saving action quickly and accurately.

At the moment, when a child is brought to the Emergency Department with severe injuries, life-saving actions may be required. This can include inserting a tube (chest drain) into the child's chest to let blood and air out.

If a doctor is unsure about where on the child's chest to insert the drain, this life-saving act may be delayed.

If the doctor puts the chest drain in the wrong spot, it might not do its life-saving job and can cause damage. In this project, researchers aim to establish a quick and accurate technique for doctors to find the right spot on a child's chest to insert the chest drain - no matter the stress of the moment or the size of child.

There is an easy three-step technique used to quickly find the right spot to put a chest drain adults, and this has been validated and published by one of the centres in this study (The Alfred Trauma Centre). However, it is not known if this technique works on children.

Researchers will recruit children who are already having a chest x-ray done as part of their treatment. First, the child's arm is rested by their side, and the doctor measures the halfway along the injured person's arm, which is the mid-arm point. For this reason, the technique is called the 'mid-arm point technique'. Next, the doctor uses a non-permanent surgical pen to put a mark on the injured person's chest where the mid-arm point and chest touch. A child-friendly sticker with a radio-opaque ball in placed on the child's chest. The child goes to the radiology department, has their x-ray done as normal and our radiologists report the level of the radio-opaque ball (intercostal space).

This is a novel technique which has never been done in children. Researchers hope it will change paediatric trauma practice and improve the care of severely injured children.





(NCRC) Figures at a glance 2019-20 (April 2019 - March 2020)

Investment prioritised in areas of:



Cancer



Cardiology and Vascular Biology



Immunity and Infection

194  
research  
professionals  
supported

NCRC over **95%** funded  
by Children's Health  
Foundation Crumlin  
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countries

2  
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awards

5  
Paediatric  
Research  
Project  
Grants



Paediatric Research Project Grant:

**Investigating the impact of childhood obesity on the immune system**

Researcher: Andrew Hogan  
Clinician: Declan Cody  
Research Institution - National University of Ireland, Maynooth

Andrew Hogan and his team at National University of Ireland, Maynooth are investigating the impact of childhood obesity on the immune system. Their aim is to identify how early in the life course of obesity the risk of chronic diseases such as type II diabetes, cardiovascular disease and cancer begins.

Currently in Ireland, 1 in 4 children are either overweight or obese. Globally over 140 million children are obese, and it is well established that childhood obesity tracks strongly into adulthood, with up to 8 in 10 obese children becoming obese adults. This is a significant concern, as obesity is strongly linked to the development of many serious diseases including heart disease and cancer.

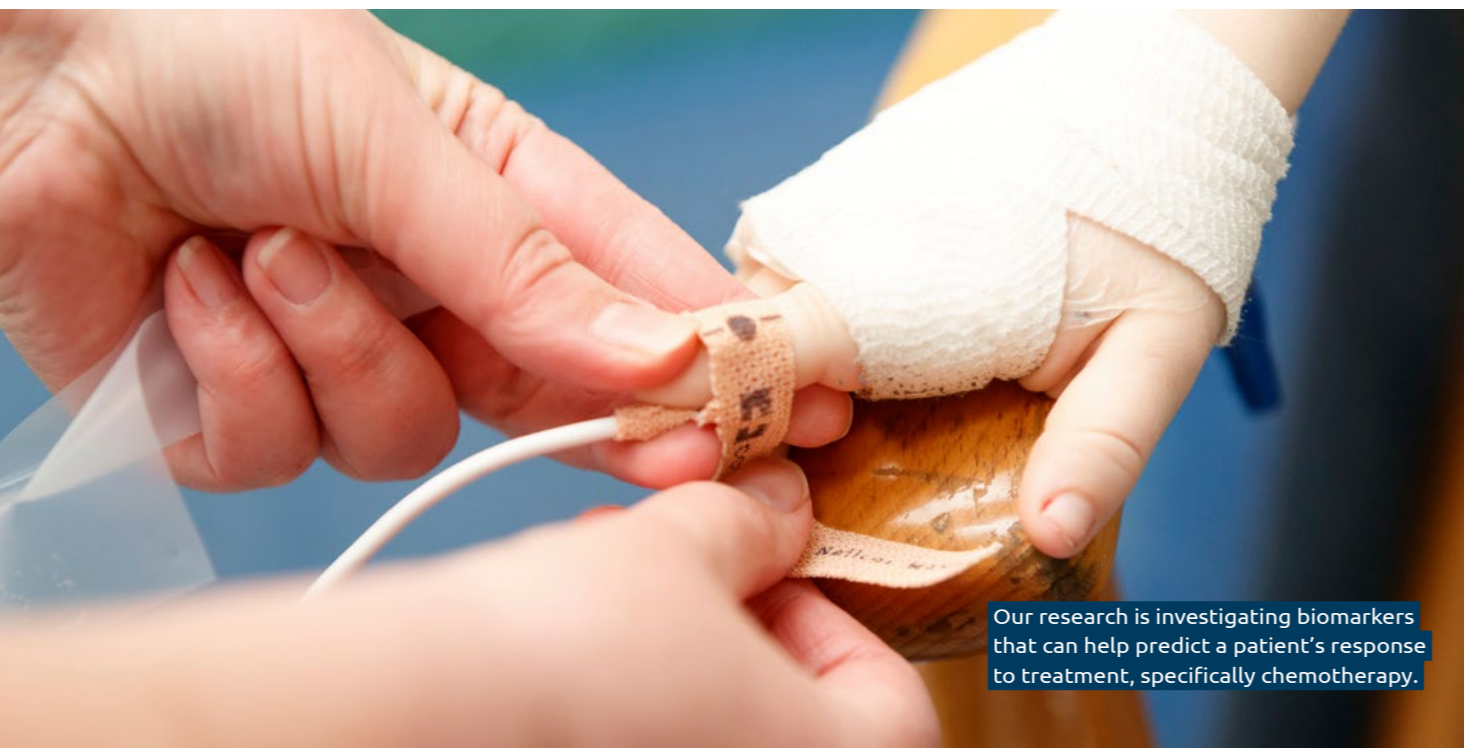
Research from this group, and many others, has highlighted inflammation and immune system dysregulation as a major driver in the development of chronic diseases such as type II diabetes, cardiovascular disease and cancer. They are now working to identify the point at which the risk of these illnesses begins, and better understand their development.

The overall aim of the research is to investigate what elements of the immune system are affected by obesity, and why. To do this, they have recruited groups of children living with obesity and matched them with children of the same age who have a healthy bodyweight. Using cutting edge multi-colour cell analysis, they have been measuring immune cells in groups of children with obesity and comparing them to children with a healthy bodyweight. This has allowed them to see which type of immune cell is altered and see why some cells such as Natural Killer cells, are no longer working in children with obesity.

To date, Andrew's team have looked at Mucosal associated invariant T cells (MAIT cells), a subset of T cells in the immune system. MAIT cells are found in the blood, liver, lungs, and mucosal tissues, defending against microbial activity and infection.

This research has found that MAIT cells use glycolysis (a metabolic pathway involved in consuming and breaking down glucose) for their function. With obesity there are defects in glycolysis, which explains the changes seen in patients MAIT cells.

This research has detailed for the first time the impact of obesity on the metabolism of immune cells. These findings explain why certain immune cells are defective in people with obesity, which can lead to increased risk of cancer and type 2 diabetes.



Our research is investigating biomarkers that can help predict a patient's response to treatment, specifically chemotherapy.

### Paediatric Research Project Grant:

#### Biomarkers of chemotherapy response in patient with aggressive neuroblastoma

Researcher: Dr Olga Piskareva  
Clinician: Dr Cormac Owens  
Research Institution – Royal College of Surgeons in Ireland

Neuroblastoma is a rare cancer normally diagnosed in young children between birth and five years of age. It affects around 5-7 children in Ireland every year. The outcomes of this cancer vary considerably; half of the children diagnosed with neuroblastoma will respond very well to treatment, but unfortunately in the other half the cancer grows aggressively and becomes resistant to treatment.

Research being conducted by Paediatric Research group at the Royal College of Surgeons in Ireland, headed up by Dr. Olga Piskareva, focuses on understanding why some children respond very well to treatment and why others do not. They are interested in understanding this process so as to identify new ways of treating the disease. Looking at better ways to predict patient response to drugs will allow the design of better treatments based on the drugs already available.

This research is investigating biomarkers that can help predict a patient's response to treatment, specifically chemotherapy. Potentially, these biomarkers could be used to design more specific, personalised therapy, and improve patient outcome. The potential biomarkers in this case are molecules called miRNA that are being

pumped out from the cancer cells in small membrane bound packages called extracellular vehicles (EVs). Along with miRNAs, EVs can carry proteins and other genetic material. This group are also interested in understanding how the contents of EVs contribute to cancer progression. Knowledge of how this process works will provide the information needed to potentially target this route of cancer progression.

There are many different types of neuroblastoma cells, each with different characteristics such as the ability to spread or to resist certain treatment. Olga's team are now expanding their study to include different cells in order to validate the results observed with this panel of EV miRNAs. By doing this, patient diversity is more accurately represented, allowing the strongest and most representative EV miRNA candidates for further validation in blood samples of patients with neuroblastoma.

They have also shown that the contents of these EVs play a role in promoting the formation of blood vessels. This is significant because the formation of new blood vessels is a key step in cancer progression, allowing tumours to grow and eventually spread to other parts of the body.

Further work is required in order to understand the contribution of individual elements of the EV contents, but this information will allow identification of new drug targets, which is a vital step in advancing treatment for children with neuroblastoma.



### Clinical Research Fellowship:

#### Exploring childhood cancer in the Irish population

**Clinical Research Fellow:**  
Noelle Cullinan  
**Supervisory team:** Professor Owen Smith and Dr Cormac Owens  
**Research Institute:**  
University College Dublin

Many survivors of childhood cancer develop long-term complications of their cancer therapy, such as chronic health problems and the development of subsequent cancers. We currently know little about the incidence or risk of developing a second cancer in the childhood cancer survivor population in Ireland. Noelle Cullinan and her supervisors aim to explore how often second cancers occur in survivors of childhood cancer. The research also aims to examine cancer predisposition syndromes in this population. The ultimate goal is to streamline referrals for formal genetic evaluation.

Between 150 and 200 children (aged 0-16 years) are diagnosed with cancer each year in Ireland. Significant improvements in paediatric oncology care over recent decades have led to increasing survival rates. Despite this, many survivors of childhood cancer develop long-term complications and can develop second cancers. There is limited data available on the incidence of and risk factors for the development of second cancers in the childhood cancer survivor population in Ireland. The recent publication of the National Cancer Strategy highlighted the need to prioritize the development and provision of dedicated survivorship programmes in Ireland and interrogation of national data is therefore important

in order to inform future needs of the service. Additionally, it is now recognized that approximately 10% of children with cancer have an underlying cancer predisposition syndrome. Identification of a cancer predisposition syndrome has implications not just for the affected child, but also extended family members, and deserves streamlined access to formal genetic evaluation and dedicated surveillance programmes. This research project aims to quantify the occurrence of second cancers in childhood cancer survivors and will explore cancer predisposition syndromes in the Irish paediatric oncology population.

Noelle plans to explore the possibility of incorporating risk factors for the development of second cancers within existing structures. A study assessing the possibility of using clinical risk prediction tools in children with cancer will be performed through Children's Health Ireland (CHI) at Crumlin. The aim is that this research will allow 1. measurement of the number of potential referrals for genetic evaluation, and 2. assessment of the practicality of using risk prediction tools to streamline referrals in this population.

This project has just begun, and during the early stages of the work Noelle has been working with her supervisors and the NCRI to analyse national cancer statistics in order to determine how often second cancers occur in survivors of childhood cancer in Ireland. She has also initiated her assessment of implementing clinical risk prediction tools.

# Patient and Family Stories

## Thomas' Story

Temple Street



**Thomas O' Connor was born in Ballinasloe last year, and to his Mam Michelle everything had seemed like the perfect birth experience. It was a couple days later that Michelle had noticed that Thomas was holding his left leg up often, and something about it didn't sit right with her.**

The next morning the nurses in his local hospital mentioned that his breathing was a bit too fast, and as a precaution he was moved to the Special Care Baby Unit and monitored for the next 24 hours. The doctors decided it would be best for Thomas to move to CHI at Temple Street, suspecting a possible metabolic disorder as his ammonia level was incredibly high. Thomas was rushed to CHI at Temple Street that night, where the O'Connors were met by staff at the door, showing them the way to ICU.

It was at that moment while sitting in the waiting area that Michelle realised how serious their son's condition was. When Michelle and her husband were allowed in to the ICU to see their baby boy, they were told that Thomas was stable and his ammonia levels had already dropped down.

**“Not once did I panic because the ICU staff were so reassuring. Especially Dora. Every time I met her she was always smiling.”**

– Michelle, Thomas' Mam

Two days later Thomas was diagnosed with a metabolic disorder known as Citrullinemia. Michelle's family had never heard of the disorder before, but were given plenty of reading materials by their doctor.



Thomas now attends CHI at Temple Street regularly for all of his vaccines and blood checks, and due to his condition, needs to be monitored quite closely.

## Billy's Story

CHI at Crumlin



"It took some time to get my head around all the new information I was receiving every day but the staff were great at making sure not to overwhelm me. The metabolic team in Temple Street are amazing. They are so helpful with getting anything we needed. Whether it was information or just a chat."

Michelle recalls a moment that stood out to her the most during her visit when it was coming up to Easter.

"I came up one morning to find a Lindt Easter bunny sitting on the locker, and a little white rabbit teddy in Thomas' cot. It was a lovely gesture that came from donations to the hospital, and Thomas loves his little white bunny!"

– Michelle

Thomas now attends CHI at Temple Street regularly for all of his vaccines and blood checks, and due to his condition, needs to be monitored quite closely after all vaccines.

Michelle says that he is a happy little boy who loves his doctors and nurses up in Temple Street, as they always try and make his stays as pleasant as possible. He can chill out in his cot with a movie or go up and play in the playroom.

"We cannot fault Temple Street, they made our boy feel better and we are so thankful to them."

– Michelle

**Babies are born with tiny feet, hands and hearts but don't let their small bodies fool you, they are made of strong stuff. They have the amazing ability to do great battles and overcome the odds. That's what Billy Hannon – fondly referred to by his family as the Little Miracle Man – did when he was diagnosed with a serious heart condition.**

"Our little boy Billy was hours old on the 26th February 2019 when he made his trip to CHI at Crumlin."

says Sharon, Billy's proud Mammy. "He had been diagnosed with Coarctation of the Aorta [narrowing of the aorta stopping blood flow throughout the body] before he was born and everything was in place for his transfer and surgery in Crumlin.

What got me through the pregnancy was planning a fundraiser as I knew whatever was to going to happen would happen, we as a family would never be able to repay or thank the people that looked after him so we had that fundraiser on the 29th September and presented the cheque to the Heart Centre a few months later."

"We got a tour of the heart centre prior to Billy's birth, that helped me so much, I was happy that I knew where he would be going once he was taken from me. When I joined him in the heart centre it was amazing and overwhelming.

There were a lot unknown. It was so surreal and I was heartbroken leaving him again as I was only allowed three hours to visit with him before I had to return to the Coombe.

Thankfully my mum and aunt were with me in the Coombe, and whilst everything was ready for his surgery thankfully Billy had other plans. His coarctation wasn't as bad as initially feared and he avoided any surgical intervention.

"On day three I was discharged, it was on that day that Dr. Mark Walsh told my husband Declan that Billy may avoid surgery, and that the next few days of observation would be crucial. I couldn't have arrived to more amazing news, it was really unbelievable and we couldn't believe it.

"After five days of close monitoring, we left the heart centre to go home to Sligo before he was a week old. He has annual check-ups and is doing amazingly well. We cannot thank Dr. Orla Franklin enough for looking after us while I was pregnant, and Dr. Mark Walsh when he was born. They gave us unbelievable care and the heart centre staff were amazing for everything they did and every kind word they spoke to us.

"Even though it was so short lived the hardest part of it, other than having a child in hospital, was not seeing Billy's brother Mattie.

It was so tough not having him with us. Mattie did visit and absolutely loved the place especially the play room with the soccer pitch. It was no way a hospital setting for him and he even received stickers. The staff go above and beyond in all manners of their job.

"Everything was perfect in the hospital. We couldn't have met nicer staff. It's such a blur and I wish I could remember staff names. My husband does remember one individual called Hazel and she looked after them both while I was in the hospital.



He will never forget her because he felt completely out of his depth – the unknown, the fear, a new born and separated from myself. She relaxed him and calmed him down. She spoke to him and called into him numerous times. Another night we were both told to go to sleep and a nurse fed Billy overnight. Its things like that that are so lovely on a personal level. Another couple that were in there too came into Declan to say 'hi' the evening Billy arrived as they knew what he was going through. That's such a lovely thing to do, it's very homely in there.

**Our story is positive. We are so unbelievably grateful it is so positive and I hope it gives hope to other families beginning their journey."**

– Sharon, Billy's Mammy



**"Even though it was so short lived the hardest part of it, other than having a child in hospital, was not seeing Billy's brother Mattie."**

# Plans for the Future



"We are committed to working side-by-side with CHI to support this fantastic new era of paediatric care and treatment."

Children's Health Foundation has huge ambitions as part of the community supporting outcomes for sick children in CHI hospitals and urgent care centres. Hand-in-hand with our supporters across Ireland and beyond - we look to the future with hope and positivity as we embark on a new era in paediatric care in Ireland.

In 2019 Temple Street Foundation and CMRF Crumlin came together to fight for sick children, but this is simply our first step in ensuring that we are stronger together. We envisage that the National Children's Hospital Foundation in Tallaght will join us in the future to become a single, unified family; supporting children and their families who need it most in CHI.

When the new children's hospital on St. James' Campus opens, it will bring together the three existing children's hospitals in a world class,

modern, custom-designed building to deliver the best care and treatments for children. We are committed to working side-by-side with CHI to support this fantastic new era of paediatric care and treatment.

Sick children need great care right now – they cannot wait. And we will continue to give them that support. We will continue to raise the vital funds needed to support the work that takes place in the existing hospitals, with funds donated and raised today being put to work where they are needed right now to treat today's sick children. Children who cannot wait.

We cannot do this without your help and we need all our supporters, fundraisers and partners with us.

Thank you for staying by our side and for your generosity and kindness to every sick child in CHI at Crumlin and Temple Street.

# Governance and Transparency

## 6.1

## Our Commitment to our Supporters

Every day in CHI hospitals and urgent care centres, sick children depend on their world-renowned medical teams to provide them with the highest level of medical care. And every day those medical teams depend on Children's Health Foundation's wonderful supporters to provide the essential and practical supports that enable them to focus their care on the children.

Your generous donations can be seen in action across CHI, transforming children's lives for the better. And that's why we rely on our amazing family of supporters to keep the hospital going and make change happen. It's your loyalty that allows us to plan for the future with total confidence.

We are extremely proud of everything that has been achieved for the patients in CHI's care as a result of the kindness and compassion of our supporters, fundraisers, volunteers and ambassadors. We know that none of what we do would be possible without their trust and generosity.

It is because of the trust and generosity that our supporters place in us that we go to great lengths to ensure that we are open and transparent in everything that we do. We are fully compliant with all legal and regulatory requirements and our accounts are audited and available on our website for all to see.



Best Practice in Transparency and Accountability

Children's Health Foundation is a Triple Locked member of Charities Institute Ireland. This means that we are in full compliance with:

- Statement of Recommended Practice (SORP) for our annual accounts
- The Governance Code for the charity and voluntary sector
- Statement of Guiding Principles for Fundraising

We would like to take this opportunity to sincerely thank everyone who has supported us down through the years. Sick children receive the world class care they do today because of people like you and I hope you will continue to be part of our future.



6.2

## Children's Health Foundation Board of Directors

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### Registered Office:

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Registered number: 328920

### Charity Numbers:

Children's Health Foundation Temple Street: CHY 13534

Children's Health Foundation Crumlin: CHY 4483A

Charity Regulator Authority Number: 20042462



"It's your kindness and generosity  
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[www.childrenshealth.ie](http://www.childrenshealth.ie)

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