



**Heart Children Ireland**

**NEWS DIGEST 2021**

*Issue 2*

*Welcome to our new newsletter*

We have been busy behind the scenes during the COVID 19 Pandemic! We know this has been a very strange time for everyone and at long last, we can see light at the end of a very difficult year. We cannot wait to see you all in person, to visit the Children's Heart Centre for our wonderful coffee mornings and who knows, could we dare to dream of our Children's Christmas Party!!

We want to thank you for getting in touch with us over the past few months and for sharing your stories. We are forever grateful to you and are privileged to share your stories in our Newsletter.

The awful cyber-attack on our health system has had a huge impact on services right across the country and as you are all aware, has had a huge impact on services at CHI at Crumlin. This is a very worrying and anxious time for all. We are in touch on a very regular basis with Crumlin and almost daily updates are posted on their website. Please do check [www.olchc.ie](http://www.olchc.ie) on a regular basis. If you are concerned about anything do contact your clinical nurse specialist.



Laura created these beautiful stones for our adults at the Adult Congenital Unit at the Mater Hospital. Each one hand painted and delivered to our adults in hospital. Laura also painted a large stone for the unit, do watch out for it when you are attending the hospital.





**Our Coagu-Cheque** support to the Mater Hospital and our members at CHI at Crumlin continues at a pace.

We are delight to receive this lovely message from one of our adults, Fergus O'Farrell.

To all at Heart Children Ireland,

I would like to extend my extreme gratitude to the provision of a coagu-check machine through the Mater Hospital in January.

I received my first machine back in 2006 when I was 15 years old. It's been completely life changing for me and has been crucial to me minimising missed days throughout school, college and work allowing me to work towards becoming a qualified accountant.

My machine broke just before Christmas. I was worried about the time off work I'd miss attending blood tests over the coming months. I was delighted to hear that Heart Children Ireland were able to supply the Mater with a new machine for my use. I simply cannot thank you enough. Self-testing saves me hours each month.

Thank you very much for all your work during this particularly difficult time.

Fergus and his family spent many weekends in the past fundraising for Heart Children Ireland and Fergus is looking forward to becoming involved in future HCI events.



**Your stories, here is Miriam's story.**



Hi guys, I'm Miriam Bridgeman and I am an adult living with CHD. I won't bore you with the details. Through the years and through this crazy period of COVID, I have been in contact with about 10 other adults on our unofficial WhatsApp group and I have found it to be very helpful. Living with CHD and living as "normal" a life as possible, it is nice to have another mum with CHD to bounce a question off, or just to share different experiences to an understanding ear. What we are aiming for is to expand our group to all members so we can develop a community Big Hearts but not tied to any responsibility. There is nothing expected of you, unless you want to get more involved and that is also welcome. As everyday life can be challenging with sudden appearances from Fatigue, or kids, or relationship commitments, we offer just a social necessity and support.

It's Big Hearts goal to offer you a place to chat about things that your other mates may not get, or a place to just feel connected. I'm envisaging an annual meet up just to keep in touch. We have been trying to lift this off the ground and as my health is having a good period, I'm determined to get the ball rolling this year with the hope of including everyone. If it is not your cup of tea yet, then we will be here if you ever change your mind. If you are himming and hawing, I will happily chat with you either on a zoom call, or normal call, whatever suits you☺. If you would like to or love to reach out to get involved please email Linda at [linda@heartchildren.ie](mailto:linda@heartchildren.ie) Over and out, Miriam ☺

Miriam is a song writer and singer and you can listen to Miriam at Miriam's Songs on Facebook. <https://www.facebook.com/bridgewomanssongs/>



**A lovely story from Helga, here is Helga with her Son  
Cameron**

Hi there!

My name is Helga Mc Grath and I have been following your page on Facebook "Heart Children Ireland". I thought it might be nice and beneficial to parents out there who are in a deep state of worry about their child who has gotten a diagnosis or is waiting a probable diagnosis to tell my story. I was born 2 months premature in St Catherine's hospital in Tralee. After a very worrying time for my parents I was shipped up to Crumlin Hospital Dublin as I was very small and very weak. I was turning blue and an operation on my heart found that I had Tetralogy of Fallot. I underwent 3 open heart surgeries in Crumlin hospital under the care of Dr Neligan and Dr Duff. Throughout the years I thrived and at the age of 40 now all that shows of that time is a scar on my chest. I am healthy and happy and have 4 beautiful children.

I hope this story may help parents to see with technology then and how far we have come with technology now the prognosis is very good. I know my parents worried a lot especially when they see all the wires and machines, it can be a very distressing time.



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## Annual General Meeting

The Heart Children Ireland Annual General Meeting was held via zoom on March 2<sup>nd</sup> 2021. One of the main themes coming out of this meeting was a request to Heart Children Ireland to publish the profiles of its Board members and to seek the views of the entire members via a survey. We want to thank all those who attended the meeting. We will, over the coming weeks, send you all a survey seeking your views.

We are delighted to publish the profiles of our Board members further down the newsletter and have also updated our website to reflect this.

## Thank you for your support



We are forever grateful to you all for your incredible fundraising efforts during these very challenging time. So much effort, thought and a lot of physical work has gone into your fundraising events for Heart children Ireland. From a journey of wellness to a 30k challenge, to virtual mini marathons, to wax melt candles and so much more. Our heartfelt thanks.



A huge thanks to all our calendar sellers and to our charity Partner Chill Insurance for their wonderful support. Watch out for news of our 2022 calendar coming shortly....



***Our Charity Ambassador, the amazing Damien Duff is urging everyone to take part in Heart Children Ireland's 10k challenge***

We do need your support and this year has been particularly challenging for Heart Children Ireland. Our Charity Ambassador Damien Duff is urging everyone to take part in our Spring into Summer 10k Challenge. Just click on [https://www.idonate.ie/fundraiser/11401152\\_spring-into-summer-10k-challenge.html](https://www.idonate.ie/fundraiser/11401152_spring-into-summer-10k-challenge.html) for further information and to donate. Why not get together with family and friends to enjoy the outdoors, have fun and help us to continue with all of our services.



### ***The Amazing Milly***



€194k raised for Heart Children Ireland's Blue Ribbon Fund by little Milly Byrne her parents Gavin and Charleen, her siblings Dylan, Megan and Molly and the entire Magheraclone Community. Words cannot express our gratitude to the Byrne Family and this incredible community. The amazing Milly received her new heart last year at Freeman Hospital in Newcastle.

The Blue Ribbon Fund is restricted to families on the transplant journey and Heart Children Ireland are privileged to manage this fund on behalf of the Moran family. It is heartening to know that we

can support our families' way into the future. You can read Milly's full story in the next edition of our News Brief.



In our last newsletter we mentioned the Network of Childhood Illness Groups. Heart Children Ireland is a member with this group and attends regular meetings. We thought it would be good to share further details about this group with you.

The Network of Childhood Illness Organisations was established through funding received from the Department of Children and Youth Affairs under the What Works Network Support Fund in 2019

The Network is facilitated by Children in Hospital Ireland. <https://childreninhospital.ie/>

The aim of the network is to provide a unified voice for childhood illness so that we can be both stronger in our objectives together and that we can be an accessible and central contact point for policy makers.

We are delighted to attend these meetings on your behalf.



Patient Education Webinars –

1. Transition 2. Exercise

We are delighted to this link with you to the Irish Congenital Heart Centre's Patient Education Webinars. Do check in with our Facebook, Twitter and website for future webinars you may like to link in with.

<https://congenitalheartcentre.ie/patient-education-webinars/>

Some more news...

Margaret continues to attend meetings with our partner agencies and charities.

We continue to liaise with our cardiologists, Clinical Nurse Specialists and Social Workers to ensure our ongoing support.

Our services have continued throughout the pandemic.



Many of our members have been asking us about our Family Psychology Support Service. We are very happy to give you this update.



### Heart Children Ireland Family Psychology Support Service

### An update.

- *What does the Heart Children Ireland Psychology Service do?* The Heart Children Ireland Psychology Service provides psychological support for Heart Children Ireland members around cardiac-related issues. There is more information about the different supports provided by this well-established service on the Heart Children Ireland website. (Talk to your GP for information about psychology support for non-cardiac matters.)
- *Who provides the psychology service?* Dr. Deirdre O'Neill, Chartered Clinical Psychologist, of the Irish Psychology Service, provides the service. See our website for details about Dr. O'Neill's experience and qualifications.
- *How do I arrange to talk to the psychologist?* The service operates a self-referral system for members. If you wish to avail of the service, simply contact the psychologist by telephone or email in the first instance. Dr. O'Neill will offer you a brief call in order to establish if the service can offer you support in light of your particular queries or concerns.
- *Who can use this service?* Members of all ages around the country are welcome to link in with the service. The demand from members for this very popular Heart Children Ireland service has grown steadily since it was established in 2011. Have a look at our website to see examples of why members contact the psychologist and of the feedback members have given about the service.
- *How much does it cost to use the psychology service?* There is no cost to members to access this service. It is funded by Heart Children Ireland.
- *Has the service continued to operate during the pandemic?* Yes. During the pandemic, individual and family meetings have been prioritised. These meetings are taking place by telephone or via Zoom.
- *What are the plans for the service during Summer 2021?*
  - Individual and family meetings will continue to be prioritised during the summer months. It is anticipated that these meetings will continue to be held by telephone or via Zoom.
  - It is hoped that other supports, previously provided under the psychology service, will become available again in the future.
  - Please note that the service operates on a part-time basis. The psychology service is currently available on Mondays, Tuesdays and Wednesdays.

- We certainly do hope that the psychologist will take some much deserved holidays in the coming months. As usual, the psychologist will leave a message on her voicemail as well as an automated email message to indicate whenever she is away.
- *How do I contact the psychologist?* You can contact Deirdre by telephone on 085 2739772 or by email at [irishpsychologyservice@gmail.com](mailto:irishpsychologyservice@gmail.com).

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Dr. Deirdre O'Neill                      0852739772  
 The Irish Psychology Service, 13 Upper Baggot Street, 2nd Floor, Dublin 4

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Let me introduce you to the Board of Heart Children Ireland. All our board members are volunteers and throughout the pandemic have been meeting fortnightly to ensure our services continue. This is a huge commitment and I am very grateful for their support which has been invaluable during these very challenging times.



**Heart Children Ireland Board of Directors.**

**Eileen Carruthers Chairperson**



Eileen Carruthers is Director of Nursing for Specialist Palliative Care Louth, HSE Louth, Meath, Cavan, Monaghan. She has been a board member of Heart Children Ireland since 2016 and became Chairperson in 2020. Her interest in the Charity is a personal one having a nephew with Congenital Heart Disease.



**Eamonn McQuaid Secretary**

Eamonn has held several positions as a board member of HCI for the past 15 years, while his family have been members of HCI for 19 years. While originally from Tipperary, Eamonn has now been happily exiled in Dublin for many years. Working in the Information Technology sector, Eamonn's interests outside of family and work, cover sports (Munster rugby and Tipperary hurling), Travel and hill walking.



**Mike Foley Treasurer**

Mike is an Accountant and lives in Limerick with his wife Marie-Therese and son Stephen (TGA) and daughters Roisin and Aoife.

Mike has been involved with Heart Children Ireland for over 20 years, many of them on Committee and later the Board of Directors. He has served as Chairman and Treasurer previously and is currently Treasurer.

He has represented HCI on the New Crumlin Hospital Group which formed in 2002 to lobby for a New Children's Hospital such were the poor conditions in the Children's Hospitals at that time. He continues as Treasurer of that group who continue to monitor the New Children's Hospital progress until completion.

Mike has many years' experience in the voluntary sector and has served over 30 years in the Naval Service Reserve having retired as Officer Commanding the Limerick Unit of the NSR. He is currently Treasurer of his beloved Young Munster RFC and is a Trustee of Summerville Rovers AFC his local soccer club.

Mike is passionate that on completion of the New Children's Hospital that the campaign for better services and facilities for adult congenital patients will be the new frontier.



**Laura Heffernan**

I am the mother of a 12year old CHD Heart Warrior. I have extensive experience in the big Pharmaceutical industry, mainly in the areas of Quality Control and Quality Assurance, Training and Management. I love to volunteer and be creative whenever I can.

My volunteering experience spans over 30 years for various associations/organisations: Comhaltas Ceolteoirí Éireann, GAA, youth and Church music groups, school parents' committees and Heart Children Ireland.

My interests are music, art, wild swimming and hiking in the Wicklow mountains with Trooper the family dog in my free time. I am passionate about this amazing small charity Heart Children Ireland.



**John McGuckian**

John joined the Board of Heart Children Ireland in August 2020. He has a keen interest in children's cardiac care, having lost his younger sister, Clare, to congenital heart disease in 2004.

He is a chartered accountant and has spent over twelve years working for KPMG in London and Dublin, specialising in delivering audit and accounting advisory services to entities in the financial services sector.



**Lesley Osborne**

Lesley has worked in Accountancy Practices for 21 years. She joined Heart Children Ireland in 2003 as a member and became a Director in 2013 and Chairperson in 2016. She is a grown up

“Congenital Heart” and is involved in many activities to help families along their CHD journey.



**Bernard Raftery**

Bernard is the father of a Heart Child (now 24 years of age), and has been involved with HCI for many years as a long-serving director of the Board, ex-Chairman, and as an appreciative parent. He has held a number of senior positions in financial services, and currently works with Bank of Ireland in their lending growth division. Bernard also developed a number of start-up enterprises, including the launch of an Irish Pub Group in Canada.

He has a keen interest in all sports, and manages the Under 20's team at Old Wesley Rugby Club in Donnybrook. Bernard has been very active in the club's various committees, as well as coaching under-age rugby and GAA (with Kilmacud Crokes) for many years. As a parent, Bernard always kept an eye out for those kids with greater physical challenges.

As Chairman of the Stillorgan Residents Alliance, Bernard led a group of 30 resident's associations and community groups working for the sustainable development of this vibrant Dublin suburb.

With a strong mix of business, sports administration, and voluntary organisation skills, Bernard enjoys a deep understanding of the many challenges HCI have overcome during the last two decades.



**Michael Teehan**

‘Born with a Congenital Heart Defect back in 1985 I have been involved with and associated with Heart Children since its inception. My mum was a former chairperson and Heart Children Ireland has been a lifeline for mine and my family's life for as long as I can remember. In 2019 I was invited to be a member on the board. This is my proudest achievement yet. Having been through many surgeries I feel I can offer something as a former Heart Child and now an adult living with CHD. I have volunteered and worked with charities in many sectors since my early teens and have an insatiable thirst to make even the smallest of differences’

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***We hope to shortly return to our office at Carmichael Centre and will keep you posted. Hopefully soon we can arrange a coffee morning to get together with each other (in line with Government advice) Stay safe and well and do get in touch with Margaret or Linda***

[margaret@heartchildre.ie](mailto:margaret@heartchildre.ie)

[linda@heartchildren.ie](mailto:linda@heartchildren.ie)