CRY
Cardiac Risk in the Young
SO YOUNG. SO FIT. SO ACTIVE... **SO SUDDEN.**

CRY | ANNUAL REPORT 2018

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Chairmen's Reports

Michael Greene,
Chairman, 2002 – 2018

I am pleased to report that after 20 years of service I have decided to step down as Chairman of CRY Ireland and I am delighted to welcome Mr. Tommy Fegan who has agreed to step in for a period to enable me to step back a little.

I have, however, given an undertaking that I will stay on the Board of Trustees.

Having achieved so much in difficult circumstances over the past decades, during which time to keep the service in the Centre operational we had to fund certain staff to maintain the service.

I am pleased to say that there are major developments on the horizon which will lead to a very comprehensive service with the support of the HSE, Tallaght University Hospital (TUH) and the Minister for Health, Mr. Simon Harris and Minister of State at the Department of Finance, Mr. Patrick O'Donovan.

It was the Minister of State's initiative that led us to where we are and I greatly thank him for that. The initiatives that are now being undertaken will involve additional staff in the Centre in a new location and will broaden the service which will still remain, FREE TO PATIENT, a cornerstone of our policy.

It will enable CRY's service as a Charity to develop in this new Centre and enable the Centre under the direction of Dr. Deirdre Ward to recruit additional staff. This is likely to come to fruition over the next 6 to 9 months.

I would like to thank all of my fellow Trustees both present and deceased for the fantastic support they have given CRY during its years of existence. CRY and the CRYP Centre is now embarking on major change which will be designed to broaden the service with support for patients and family members.

Tommy Fegan,
Chairman, 2018 - onwards

I was surprised, honoured and somewhat humbled when Michael Greene invited me, on behalf of the Board of Trustees, to take on the Chairmanship role.

CRY Ireland staff and volunteers provided critical support to us when our son Kevin (24), passed away suddenly in 2010. So I welcome the opportunity to give something back, and I think Kevin would be so pleased and proud.

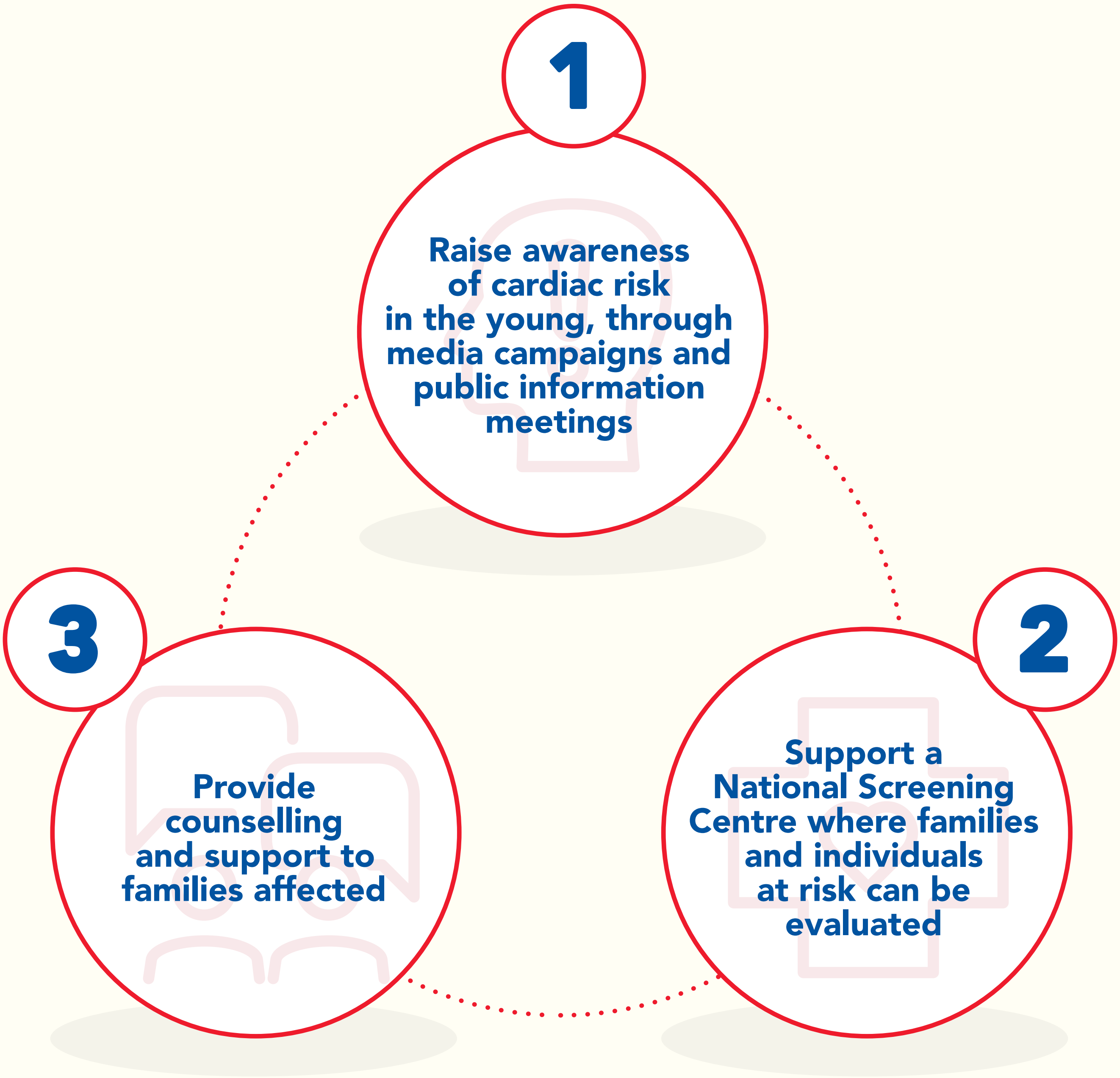
Michael and his team have done a magnificent job in raising public awareness about sudden arrhythmic death in the young, providing critical screening and much-needed family support. I simply want to build on that and ensure that we continue to provide quality support to families affected by SADS.

I am very excited about the partnership with Tallaght University Hospital and the HSE to provide a new, state-of-the-art fully equipped and staffed CRY Ireland Centre to be opened in 2019 at the prestigious location at the roundabout entrance to the hospital.

We have a challenging year ahead, and we welcome and appreciate the continuing support of the families, corporate, voluntary, state sponsors and individuals.

In September 2018 the Board of Trustees in recognition of the pioneering work of Michael & Marie Greene in founding and building the CRY charity voted to create the post of Lifetime President and Lady President in their honour.

Our Aims



1. Raise awareness of cardiac risk in the young, through media campaigns and public information meetings
2. Support a National Screening Centre where families and individuals at risk can be evaluated
3. Provide counselling and support to families affected

Our Team

Trustees of the Charity

- Geraldine Carter
- Walter Coakley
- Noelle Condon
- Tommy Fegan
  Chairman of the Board
- Dr. Katie Gallagher
- David Greene
- Marie Greene
- Michael Greene
- Deirdre Hanley
- Liam Herlihy
- Fionnuala Kelly
- Dr. David Mulcahy
- Brendan Mulligan
- Don O'Brien
  Secretary
- Regina Power
- Dr. Deirdre Ward

Centre Staff

- Deborah Blackburn
  CRYP Centre Administrator
- Helen Connaughton
  Clinical Nurse Manager II
- Ciara Honner
  Senior Cardiac Physiologist
- Ann Molloy
  Clinical Nurse Manager II
- Dr. Deirdre Ward
  Consultant Cardiologist
- Lucia Ebbs
  Business Operations Manager

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CRY National Screening Centre

It is estimated that between **60 – 80** people between the ages and **1 & 35** die of sudden cardiac death (SCD) every year in Ireland

Minister Patrick O'Donovan, TD, undergoing testing with Mark Russell, Senior Cardiac Physiologist in November 2018

Origins

Sudden cardiac death came to public awareness in 2004, following the unexpected sudden death of Cormac McAnallen, the Tyrone Senior Gaelic football captain at 24 years of age, and John McCall, an 18-year-old Irish rugby player who collapsed at the under 19 World Cup rugby tournament in South Africa.

The death of these two young men, elite sportsmen playing at the highest level in their respective disciplines, within 4 weeks of each other in March 2004, highlighted the fact that these conditions can strike unexpectedly, killing unsuspecting and previously healthy, young people who were not aware that they are at risk.

Sudden cardiac death (SCD) occurs because of a sudden change in the heart rhythm, from a normal organised electrical pattern, to a disorganised chaotic electrical pattern. The cause of the fatal rhythm change in older people is usually coronary heart disease, or hardening of the arteries. In those under 35 years of age however, the cause is more likely to be either a heart muscle condition (cardiomyopathy) or a pre-existing electrical disorder. The cause of death may not always be established even after the most thorough post-mortem, as structural heart conditions can be diagnosed, but electrical disorders are not apparent.

In the case of death due to electrical disorders, the term sudden arrhythmic death syndrome (SADS) is usually used. Well-recognised electrical conditions that can predispose to sudden cardiac death would include Long QT syndrome & Brugada syndrome.

It is estimated that between 60 - 80 people between the ages of 1 and 35 die of sudden cardiac death (SCD) every year in Ireland, which has a devastating and life-altering effect on their families, friends and communities. In up to 50% of these cases, the cause may be inherited. The genetic inheritance pattern of the heart muscle or electrical disorders is such that if someone is diagnosed with one of these disorders (in life or after death), then there is a 1 in 2 chance that their first degree relatives (parents, siblings and children) will also be affected. Over one in 500 of the population may carry a genetic defect that can cause the most common cardiomyopathy. At least one in 2000 of the population may carry a genetic defect that can cause Long QT syndrome. Therefore, almost 20,000 of the Irish population may be affected by inherited cardiac conditions, and many of them may not be aware that they are potentially at risk.

Many of these conditions can be diagnosed using non-invasive cardiac tests, such as ECG, ultrasound (Echo) and exercise tests.

The service at the Centre for Cardiac Risk in Younger Persons (CRYP) was developed in direct response to the lack of specialist services dedicated to the evaluation of young individuals and families at risk of sudden cardiac death. The service is a collaboration between the Cardiac Risk in the Young (CRY Ireland) and Tallaght University Hospital. The CRY charity which relies largely on the fundraising activities of affected families, has funded most of the equipment and staff salaries to enable the CRYP Centre to continue to see individuals and families at its dedicated facility on campus in Tallaght.

Other significant contributors have been the Tallaght University Hospital Volunteer Group and the Adelaide Society (who between them funded the bulk of the cost of providing the dedicated building on the Tallaght site), Pfizer Ireland, the Patches Trust, the Shabra Foundation, both TCD and UCD Med Days, and a confidential donor who facilitated the purchase of most of the equipment.

The running of the CRYP centre from day to day is still only possible because of the amazing contributions from the fundraising efforts of our patients and families, even while they themselves are often trying to live with an overwhelming personal tragedy.

Almost **20,000** of the Irish population may be affected by inherited cardiac conditions, many not aware that they are potentially at risk

Minister Patrick O'Donovan, TD, undergoing testing with Dr. Deirdre Ward, Consultant Cardiologist in November 2018

Since 2007 over **6,000** individuals have been seen at the CRYP, at over **10,000** patient appointments

Referrals

Patients may be referred to the Centre either by their GP or another Consultant for assessment because of a family history of sudden cardiac death, or a family member has been diagnosed with an inherited cardiac condition, to see if they themselves are affected and may be at risk of complications. Presently none of the ICC (Inherited Cardiac Conditions) are curable, but at-risk patients can usually be protected against the complications of their condition.

Patients may also be referred because they themselves have a definite or possible inherited cardiac condition, for ongoing management. Patients, and often whole families together, have their basic cardiac investigations (resting ECG, which is an electrical tracing of the heart), Echo (ultrasound of the heart), and treadmill (or bicycle) exercise test on the same day. They are also usually given a heart rhythm monitor to wear for 24 hours, which they can post back to us. The results, as well as an explanation of the family situation, and if relevant future management plans, are then discussed in detail with the Consultant before they leave. Patients are also given the contact details of the Centre and advised to contact our Specialist Nurse with any questions or concerns between appointments.

Counselling

Counselling is offered to all families affected by a sudden death, or patients struggling with a new diagnosis. This is provided either by Marie Greene, a co-founder of the CRY charity, or one of two Psychologist/Counsellors currently funded by CRY (one in Cork, one in Dublin).

The charity also provides a network of volunteers, who have themselves experienced a sudden death and are available for telephone (or if considered appropriate, face-to-face) support. This service is currently being reviewed to take account of increased activity anticipated by the opening in 2019 of the new All Island Centre.

When the service opened in 2007 Dr. Ward was the only staff member, and patients were seen and investigated on an almost ad-hoc basis. We then moved to out-of-hours evening and weekend clinics with Technicians performing investigations on a sessional basis. Clinics were also run in St. James' Hospital every fortnight to ease waiting list pressures. It quickly became apparent that such a model could not keep pace with an exponential demand for services, so CRY and Tallaght University Hospital agreed to develop a dedicated service with a modular building on the Tallaght site, with equipment and full-time staff funded by the charity. It was envisaged at the outset that this arrangement would stand for the first three years, and salary costs would transition to the Hospital / HSE.

At the official opening of the dedicated CRYP Centre in November 2008, by the late Dr. Garrett Fitzgerald, we had 5 full-time staff members, in addition to Dr. Ward – a (Candidate Specialist) Nurse, an Administrator, 2 Cardiac Physiologists, and a Research Registrar.

Since beginning operation in 2007 over 6,000 individuals have been seen at the CRYP Centre, at over 10,000 patient appointments (many patients require repeat visits, as often as every 3 months if they are affected by a condition, and every 1-5 years, if they appear to be unaffected, but a condition may develop over time). Patients and families have travelled from all corners of Ireland, and avail of the service free of charge. 10% of patients were aged 50 or over. 8% were under 10 years of age. Over 1/3 of our patients were referred following one or more sudden deaths in the family.

Over 25,000 cardiac tests have been performed, and over 800 patients have been referred for genetic testing. In approximately half of these the gene causing the condition in the family had been identified and they were being tested to see if they had inherited the gene. While a considerable number are still awaiting their genetics appointment or result, in over 150 individuals we have been able to confirm that they do not carry the gene for the family condition. This means that they, and any of their descendants, are not at risk and cannot develop the

10% of patients were aged **50** or over.

8% were under **10** years of age.

Over **2000** patients referred for electrical conditions, with up to **44%** of families have had one or more individual identified with an inherited condition.

Patient Screening

condition in the future, so they or their children never need to be tested again.

Since April 2012 we have also been running a Family Clinic in collaboration with our Paediatric Cardiology Colleagues, initially Dr. David Coleman and since 2015 Dr. Terry Prendiville. Since we opened this service, which caters for families of all ages, we have seen almost 300 patients ranging in ages from 3 months to 60 years. This service is the first of its kind in Ireland and (as is the case with our adult service), uniquely provides a same day evaluation where all necessary tests can be performed and the results discussed with one or both Consultants at a single clinic visit.

Outcomes/Results so far;

Patients who were referred because of a family history of cardiomyopathy (over 1,400 patients, representing 800 families) have had a positive diagnosis of one or more family members in almost 25%.

Patients referred for electrical conditions or SADS numbered over 2000 (representing over 1000 families), and up to 44% of families have had one or more individuals identified to be affected with an inherited cardiac condition.

192 patients have had cardiac devices implanted. 86 of these are internal cardiac defibrillators (ICDs – ‘shock boxes’ which can recognise life-threatening rhythm disorders and shock them out of them within 20 seconds). 23 are pacemakers. Of the ICD patients, 10 of these have already had appropriate, potentially life-saving treatment from the device.

It is likely that the presence of a pacemaker has prevented both sudden death and serious injury to a number of patients, but this is not possible to quantify. A further 83 patients have had heart rhythm monitors implanted and have either been reassured about their symptoms, or are still under investigation.

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Other activities carried out in the Centre, or by CRYP staff

Nurse Led Clinics:

Our Specialist Nurse (the only accredited Specialist Nurse in Inherited Cardiac Conditions in the 26 counties) sees patients who have commenced new medications, or who have been advised to make lifestyle modifications at Nurse-led clinics.

This allows us to assess tolerance and appropriate dosing in a timely manner, without taking up clinic slots intended for patients on our waiting list.

Our Nurse also provides detailed education sessions for any of our patients who are being recommended for an implantable device, so that they can be fully informed about what is involved before they consent to the procedure. Our Nurse has also been asked to extend this service to other Tallaght University Hospital patients who are being referred for a device if they are not attending a specialist service with sufficient expertise to provide such education. These sessions are universally well-received by patients and their relatives.

To date 70 patients have benefited from this 'extra-curricular' activity.

Research:

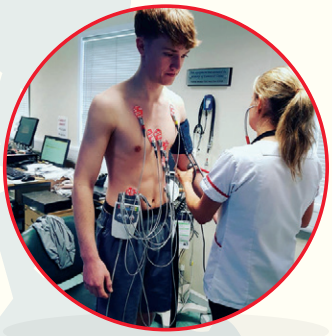
Staff at the CRYP Centre have been funded (by The Meath Foundation) for research into the clinical utility of Cardiac MRI in families with inherited cardiac conditions, and results of this study have been presented at prestigious American Scientific meetings.

A small number of our patients are also enrolled in pilot stem cell research.

We have been invited to join a European Network on rare cardiac conditions, and are currently planning a pilot study of implantable heart rhythm recorders in families affected by SADS.

CRY's Specialist Nurse is the only accredited Specialist Nurse in Inherited Cardiac Conditions in the **26** counties

Nurse Helen Connaughton



Patient Screening

We soon hope to deliver combined services on **3** sites, nationwide

Multidisciplinary and Transitional Clinics:

Staff from the Centre provide the cardiac expertise at multi-disciplinary clinics for inherited multi-system disorders, especially Friedreich's ataxia.

They have also in the past been involved in Paediatric multi-disciplinary clinics for inherited neuromuscular conditions, and transitional clinics for those Paediatric patients transitioning to adult services.

Dr. Ward also is a regular contributor to the monthly multi-disciplinary ICC case-conference currently hosted in the Mater Hospital.

Strategic Development:

Staff at the Centre have been working very closely with colleagues from Crumlin Children's Hospital (Paediatric Cardiology and Clinical Genetics) and the Mater Hospital, as well as patient representatives to develop services nationally for Inherited cardiac conditions.

The lead Consultants are meeting shortly with the National Clinical Advisor for Acute Operations in the HSE to discuss formal recognition of the combined services as a National Centre for ICC, delivered on 3 sites.

Patient and Health Care Education:

Patients of the centre are given information about their conditions at the time of diagnosis, and expanded upon on subsequent visits.

This is usually verbal and in the form of written booklets, with appropriate web-links for reputable and informative websites. Patients are also advised about the availability of patient support groups, and staff from the Centre regularly speak at information days for patient support groups.

Staff are also regularly involved in disseminating information on ICC to the wider public as well as other healthcare professionals. This has, over the last 10 years, included communities recently devastated by Sudden Cardiac Death, sports clubs, volunteer ambulance services, medical and nursing undergraduate and post-graduate students, GP meetings, sports medicine meetings and hospital grand rounds. Staff have also been invited to speak at several European cardiac Society conferences.

About CRY

CRY Ireland was set up as a charity in 2002 by parents Michael and Marie Greene who had lost Peter, their 15 year old son to a sudden cardiac death. At that time in Ireland there was no information, no awareness and no support for families.

In 2004 Cormac McAnnallen, captain of the Tyrone GAA Team, died suddenly at home one night. A few weeks later John McCall an 18 year old schoolboy playing international rugby for Ireland dropped dead on the pitch in South Africa. The Late Late Show covered it and the profile of CRY was raised. We got 64 phone calls from families who had lost sons or daughters in similar circumstances, many were told that they died of natural causes.

In 2006 a cardiologist Dr. David Mulcahy approached CRY with a view to starting a screening centre. Dr. Deirdre Ward, who had just completed her training at Heart Hospital in London, was appointed to run the centre. Prior to opening the Screening Centre CRYP Dr. Ward ran an out-of-hours service a few evenings a week from 5pm to 10pm using the Cardiology Department in Tallaght University Hospital seeing families from all over the country.

After endless fundraising and many corporate donations we had enough money to equip the centre. Staff were appointed and the CRY Centre, opened on November 8th 2008.

Following the Late Late Show's coverage of the deaths of Cormac McAnnallen and John McCall, CRY received **64** calls from concerned families


Dr. David Mulcahy


Dr. Deirdre Ward

Family Support

Marie Greene

Lisa Gannon
Psychotherapist

Cathy Spillane M.A.
Counsellor & Psychotherapist

We realised families and individuals also needed support in dealing with the trauma of grief. A very experienced facilitator led an information day, from which volunteers put themselves forward for training.

They met once a month in Dublin, and many volunteers leaving various parts of the country at 5:30am to catch a train to Dublin. We started with 10 volunteers and we matched them to those who needed support following a loss. Each was given a mobile phone to be used to phone their client. The client could also contact them and leave a message if they needed extra help. At first it was just telephone contact but eventually many volunteers met their client at least once. We found this helped and was more personal and worked well. Many families remained in contact for several years with volunteers sending cards for anniversaries or significant birthdays of their loved ones.

As time progressed we felt we needed to expand as we needed a psychotherapist to deal with more difficult cases, first in Dublin then in Cork a few years later. Presently we are hoping to engage three psychotherapists to cover the rest of Ireland. CRY pays them on a sessional basis. Our service is free to all and all our funds are raised by families and individuals who have been through the CRYP centre.

Our numbers have grown and the Government has agreed to fund extra staff for a new screening centre which will open in 2019. We thank all who have supported us to maintain our service to bereaved families and patients diagnosed with a possible life threatening heart disorder. Our volunteers know the pain of loss having gone through it themselves.

We are sincerely indebted to them for their continued support and thank them for bringing mums, dads, brothers and sisters through a most difficult time in their lives following the loss of a loved one from a sudden cardiac death.

Marie Greene
Co- Founder of CRY

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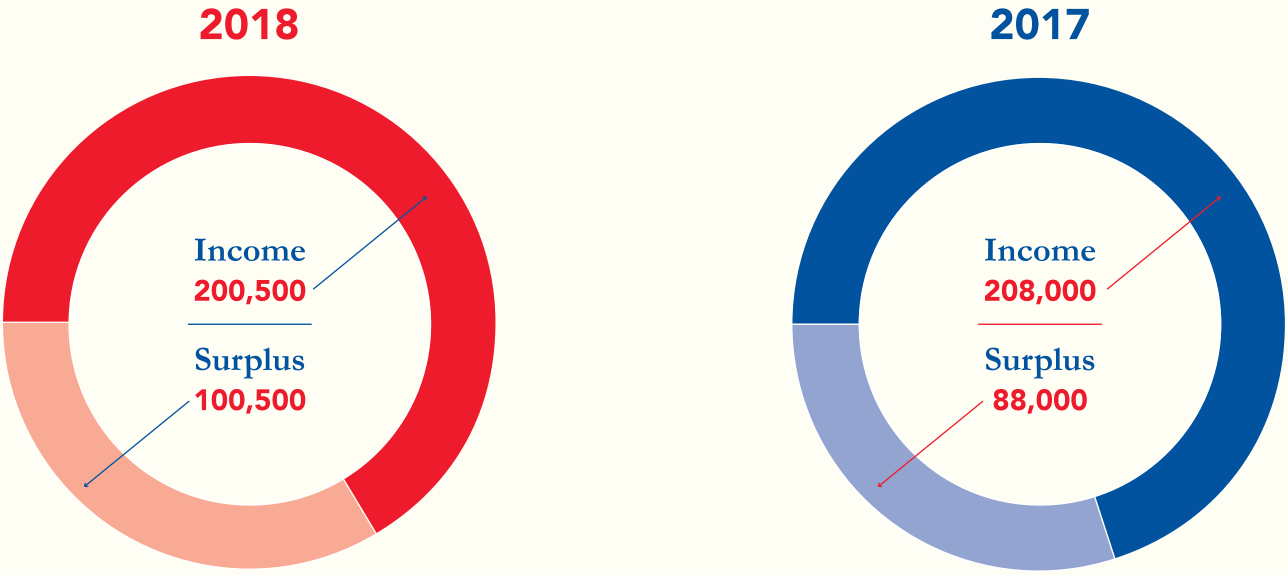
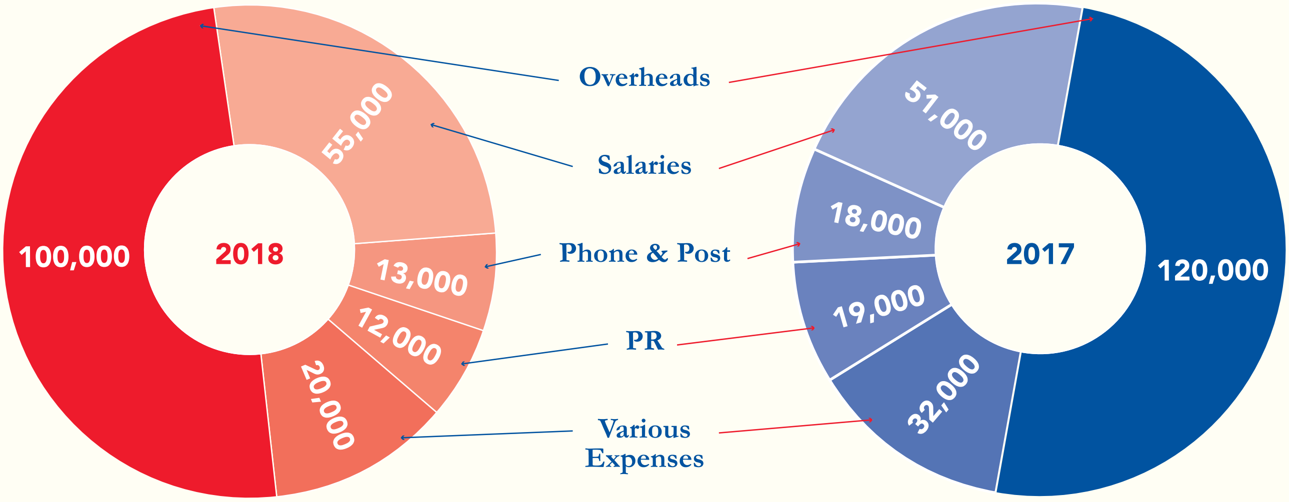
Finance

Notes on Accounts





**The surplus will be applied to the new development project in Tallaght University Hospital*

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Fundraising Activities

We have reached our 10 year anniversary and looking back we have had ten amazing years with the support of incredibly generous people & of course *#OurFantasticFamilies.*

We started with a car boot sale – we had a team cycle in South America and our first *#teamCRY* event was for the VHI Women's Mini Marathon – which remains central to our fundraising. Annually we run *Pure Style* – voted best Ladies Lunch in 2016 and we take a group on the Camino – 2019 will be our *5th Camino for CRY* and we have run a *Winter Ball* over a number of years.

Our personalised Wedding Favour Cards are always a popular way for people to donate to CRY, replacing Wedding Favours for many couples

Darby & Joan
have made a donation to CRY Ireland
in lieu of wedding favours
19th July 2019

CRYP Centre
Tallaght Hospital,
Tallaght,
Dublin 24.

Tel: (01) 4525482
Email: info@cry.ie
Web: www.cry.ie

Fundraising is vital are we are grateful to accept contributions of any size – we rely on public support to help support the CRYP Screening Centre and help us with our free counselling services and raising awareness for Sudden Adult Death Syndrome (SADS).

Our main source of fundraising comes from family organized events and 2018 saw 40+ family run events held for CRY everywhere from County Wicklow to Syria – from "Building a Beetle", Bag Packing, Non-Uniform Days, Coffee Mornings, our Corporate Sponsor BearingPoints' team who completed Hell & Back, and Cycles for CRY, to name but a few.

Our Fundraising Team is Lucia, our Pure Style Committee and every one of you who took the time to help us – so to everyone who donated to one of our countertop boxes, completed a direct debit form for CRY, organized an event, bought a ticket, sponsored an event, gave their time – **THANK YOU** – we couldn't do what we do without you.

Lucia Ebbs
Business Operations Manager

Pure Style Committee

- Geraldine Carter
- Lucia Ebbs
- Kate Farrell
- Marie Greene
- Frances Jones
- Aveen Harkin
- Pam Meehan
- Susan O'Connor
- Karen McGoldrick
- Davinia O'Donnell

Forever Part of Me

The song, Forever Part of Me, was written by Limerick man Tim Collins, who is a member of the Kilfenora Céilí Band and is a renowned national and international musician and composer.

Deirdre Scanlan, also from Limerick, poignantly performs the song. Tim generously offered to record and donate all of the proceeds from the song to CRY Ireland, and gathered a team of Ireland's leading traditional musicians, including members of the Kilfenora Céilí Band, who also volunteered to record the song in October. A patron of the charity, Tom Cavanagh sponsored the production and distribution.

The song was launched on December 1st 2018 in The Ballintemple Inn, Newcastle West, County Limerick, with the recording musicians, guest performers including members of the Kilfenora Céilí Band and other local and national artists, performed on the night and appearances from Limerick Senior Hurler and All Ireland Winner, Aaron Gillane. Speaking at the launch, where there was a very special performance of the song, songwriter Tim Collins said: "I donated the recording to CRY Ireland in memory of two young people and former neighbours, who both lost their lives as a result of SCD in recent years; Niamh Herlihy and Darra O'Donovan, nephew of Deirdre Scanlan."

Clare O'Donovan, mother of Darra who sadly passed away, expressed her gratitude to Tim saying, "The song is very well put together and sang beautifully. The words are full of images and Tim's recollection of growing up made me sad. I wish Darra had more time to experience life like that. Maybe he did; I don't know. After hearing it, I was very humbled and almost embarrassed that Tim had handed over his song to us and in memory of two people that to be fair he didn't know. I'm so grateful."

Tommy Fegan, Chairman attended the launch and said "Few, if any, events could surpass the most memorable musical event for the launch of "Forever Part of Me".

Observer News

Weekly Observer, Wednesday, 5th December 2018

A night to Remember in Newcastle West

By Helen Broderick

Tim Collins and Deirdre Scanlan.

Armagh native Tommy Fegan, Chairman CRY performing on the uileann pipes.

Limerick hurler Aaron Gillane.

Gerard Liston

The Flannery sisters entertaining the crowd.

iam Herlihy, Aaron Gillane and Deirdre Scanlan at the CRY fundraiser
st Saturday in Newcastlewest.

Con Herbert and local musicians.

Mickey Dunne and Oliver O'Connell.

The Kilfenora Céilí Band with guest Donal Lunny in full swing.

The song – superbly written and performed – was the focal point of an incredible evening of song, dance, music and recitations. All wrapped up in a tangible blanket of warmth and love exuding from the audience; a community bonded in support of two local families and their grief… and their vision of hope".

The song is available to download online from *cryireland.bandcamp.com/album/forever-part-of-me* at a cost of €5 plus VAT. The CD is also available to buy from *www.cry.ie* for €10.

Some CRY events from around the country


2WHEELS 4YOU
Remembering Niamh & Darra
WELCOME TO MONAGEA
CRY Cardiac Risk in the Young
SANTIAGO COMPOST
THE BANK
Pay C.R.Y.
One Thousand & One Hundred Euro
€1,100.00
Oct 2017
Theatre Box
National Centre for Cardiac Risk in Younger Persons
permanent tsb
euro euro euro
€5070-00
AIB
Pay CRY
Four thousand, two hundred and ten euro
€4,210.00
Date 27th October 2017

We would also ask that in 2019 you consider taking part in one of our events or organizing one of your own on our behalf?

You might consider joining our teams for the VHI Dublin Mini Marathon, Camino for CRY next September or the TCS New York City Marathon in November? Perhaps nominate CRY to be your company's Charity of Choice for 2019? Organise a Cake Sale, Pub Quiz, Coffee Morning or a Car Boot Sale? If you are getting married in 2019 you might choose to donate to CRY in lieu of Wedding Favours and let us print personalised Favour Cards?

Follow us on Facebook, Instagram or Twitter to see events happening locally and get involved.

Our Goal Chart

Our fundraising so far...

CRY Ireland continues to provide on-going support to families bereaved by the loss of a young person from Sudden Cardiac Death.

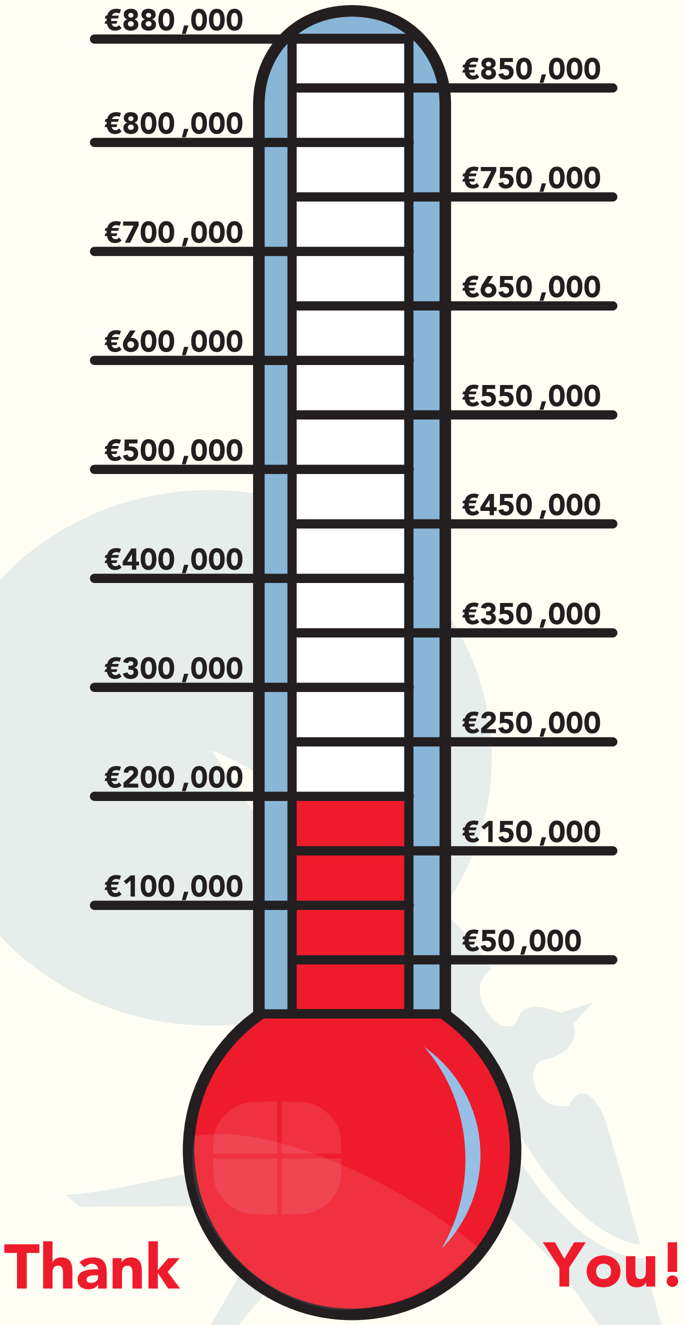
Sadly, increasing demand has outgrown our capacity at our current location, but by summer 2019, we will have moved to new premises at Tallaght University Hospital.

This will enable us to provide a more welcoming environment for families seeking assessment, expert care and on-going family support, through an innovative partnership between CRY, the HSE and Tallaght University Hospital.

CRY is committed to raising €880,000 of the €1.2m capital investment required. The HSE is funding the medical staff, and the Hospital is donating the premises, rent-free.

The image shows where we are in our fundraising as of going to print.

€880,000
Our Goal Chart



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Future Plans

Looking Forward – 2019 and Beyond

By early summer, 2019, CRY Ireland & the CRYP Service will have moved to new premises just off-campus at Tallaght University Hospital (TUH).

The CRYP staff numbers will increase from 3-5 to 11-13, and the location will be 3,700 sq. feet (almost 3x the current footprint) of purpose built modern outpatient facilitates. Increasing demand has outgrown our capacity at our current location, and we look forward to better achieving our aim to provide a welcoming environment for families seeking assessment, expert care and ongoing family support services.

> “The major expansion is the result of a dynamic public private partnership between Tallaght University Hospital, the HSE and CRY Ireland. **David Slevin, CEO, TUH**, described the arrangement as *“an innovative way of enhancing services by combining the ambitions of the Health Services, the Hospital Board and the Philanthropy”*. (Oct., 2018)”

The expanded resources will provide state of the art facilities for screening, comprehensive evaluation & treatment of the families who have lost a young person from Sudden Cardiac Death (SCD) or Sudden Arrhythmic Death (SADS), and anyone affected by inherited cardiac conditions (ICC).

The new All Island CRY Centre will be situated at the roundabout entrance to the hospital, offering high visibility to all hospital visitors. Waiting lists will be dramatically reduced and eliminated within two years. This partnership, by removing the burden of ongoing healthcare salary costs, will afford CRY the opportunity to develop more proactive outreach and awareness raising programmes, and a more comprehensive psychological support/counselling network, whilst maintaining our key role in providing rapid response screening and assessment to recently bereaved families.

We have already initiated a process of strategic planning that takes account of the new developments in 2018 – securing new premises and additional medical staff. Regional roadshows and closer partnerships will be central to our plans. The all island dimension to CRY’s programmes comes on the back of an agreement in 2018 by CRY (UK) to advise referrals they receive from Northern Ireland that the option of referrals to the CRY Centre at Tallaght University Hospital is available to them. Many families from the North have availed of these facilities since the opening of the centre in 2007, but these recent developments mean that we will be able to continue to offer, and extend the access to anyone from Northern Ireland who needs this support. All of this will require additional funds beyond the current fundraising campaign for the new centre, and sustainable fundraising programmes will be developed. CRY is committed to raising €880k of the €1.2m capital investment.

We have relied heavily on the support we have received from families since our inception. While we hope we can continue to avail our families fundraising, we need to develop additional sources of revenue to enable sustainable, planned growth. 2019 will be an exciting year in the history of CRY Ireland. However, it brings huge organisational challenges, and we welcome support from friends old and new in our endeavours.

Screening

The centre will enable us to continue to provide priority for screening for recently bereaved families, and to reduce and eliminate the waiting list for follow-up and other non-urgent screenings.

All Island Outreach

Increasing numbers of families from Northern Ireland have been availing of CRY's facilities at Tallaght University Hospital over many years. With the additional space and resources, we will be extending our outreaching out to communities in the North to avail of our services, free of cost, to all families throughout the island of Ireland.

Partnership

The major expansion is the result of a dynamic public private partnership between Tallaght University Hospital, the HSE and CRY Ireland. The expanded resources will provide state of the art facilities for screening and welcoming families for screening and support services.

Family Support

This increased activity will put pressure on family support service, and we have already started a review of that provision, including recruiting more volunteers, and making more specialist physiotherapists available on a wider regional basis throughout Ireland.

> "Being involved in CRY has really kept us going. Meeting amazing people on our CRY Camino with Marie Greene and in our normal days. Fundraising and trying to raise awareness about SCD while trying to help saving lives is a hidden blessing.
>
> There is very little we can say to the people involved except to say that your legacy will live on. Having the honor of being first family to be screened and we continue to count our blessings.
> **Elsa & Greg Leonard**"

Elsa & Greg Leonard

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Ambassadors

RTE

"When my cousin died of Sudden Adult Death Syndrome in 1997 there was so little support for families, who inevitably had so many questions.

I think what Michael and Marie Greene have done since the charity was founded is really incredible; both in building a community for those who need support in times of grief; and in saving the lives of family members, who may have an underlying condition they never knew existed. It's a truly special charity and one I'm delighted to be associated with."

Brendan Courtney
Fashion Designer

"I've been honoured to support CRY Ireland in my role as an ambassador helping to increase awareness of this amazing charity and the work that they do daily."

CRY
Cardiac Risk in the Young
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