# FOUNDATION

Providing financial assistance for children with a life limiting condition **Patron:** Miriam O'Callaghan Phone: 061 331 333 Email: info@clionasfoundation.ie Web: www.clionasfoundation.ie



# Cliona's Foundation NEWSLETTER | WINTER 2017

Working together to help struggling families in Ireland

Hello Everybody,

We hope you are enjoying the Festive Season 2017 and enjoying a restful period after a busy year.

Things have been quite busy at Cliona's Foundation since our Summer Newsletter. We had lots of fundraisers going on, a few of them were a "first" for Cliona's Foundation and then others were similar fundraisers as in previous years. A few of the "firsts" were:-

- \* we had 3 people walking the Camino de Santiago;
- Ring of Kerry made a donation to Cliona's Foundation;
- \* "Denim Day" in an office;
- 46 hikers up Galtymore on a cloudy, chilly October Bank Holiday Saturday morning but what camaraderie, fun, laughs and a terrific day out;
- Cliona's Foundation logo appearing on jerseys in 2 completely different parts of the country i.e. one on soccer jerseys in Limerick and the second on jerseys in a school in Belfast.

#### A flavour of some of the other fundraisers are:-

- \* We had a few cycles including Cliona's Foundation Cycle Club's Annual Cycle, Johnson & Johnson Annual Plant to Plant Cycle and Element 6 (Shannon) had their own first company cycle;
- \* Once again Greybridge Classic Club chose Cliona's Foundation as one of their charities to benefit from their Harvest Fair - it must have been one of the wettest days of the year but we had such fun !
- \* Adare to Survive was a successful and thoroughly enjoyable day out !
- Lots of lovely ladies in the Cook Women's Mini Marathon;
- \* 3 men and 1 lady in the Dublin Marathon;
- \* 1 young girl in Dublin cutting her ponytail for Rapunzel with sponsorship to Cliona's Foundation, all in memory of Ciara McCarthy.

At the end of 2017 we estimate we will have supported approx. 470 families in 29 Counties over the past 10 years. Close to 100 of those families will have been supported this year alone.

We are very proud of this achievement as it's completely down to your donations, fundraisers and support that has made this possible, and still without any State funding ! We are 10 years down the road since Cliona's Foundation was formed around a kitchen table. It's been enjoyable, rewarding, questioning, emotionally challenging, educational and more in between but worth it all to see the difference it makes to a family who receive a cheque in the post from Cliona's Foundation.

But we are seeing an increase in the number of families that are needing support and it is very difficult for us not to be able to turn around that support to them in a much faster time frame.

The challenge for Cliona's Foundation in 2018 will be to increase the awareness of the huge cost of caring for a child with life limiting condition and the need for families to be supported. Also to leverage large scale corporate support in addition to maintaining all our regular donations and fundraising events so that we can continue to support those families that need it most.

We are still the only Charity in Ireland providing this type of financial assistance.

We wish you a very Merry Christmas and all the very best for 2018.

Regards,

Terry, Brendan, Phil, Rachel & John



Brendan & Terry Ring CO FOUNDERS



# The Hospital Saturday Fund supporting Cliona's

The Hospital Saturday Fund have been very supportive of Cliona's Foundation over the past 2 years but we were delighted and honoured to be 1 of 26 Irish Charities that received an increased allocation for 2017.

The donation was presented at a special reception hosted at University College Cork on Monday 20 November 2017. In total, €115,000 was donated to the charities at the event, which was hosted by UCC in the Aula Maxima in the presence of the Lord Mayor of Cork and with special guest Dick Spring in attendance.

The grant which was specifically to assist families requiring specialized equipment enabled us to support 3 families and make daily living a small bit easier for their child and family. The impact on a family of being able to purchase a piece of equipment was highlighted for us in a family thank you letter as follows; "The ppod we were able to buy with the money you gave us has been life changing. It means she can sleep off a seizure safely in our kitchen while I make dinner and has her own chair to lie up in when we watch a family movie"

In 2017 the Hospital Saturday Fund will give €1.2 million in donations and grants to medical charities for care and research, hospices and hospitals across Ireland and the UK. Assistance will also be given to individuals whose illness or disability has caused financial difficulties.



# Keith Duffy Tee's off for Cliona's Foundation



Since the introduction of Terry & Brendan Ring to Keith Duffy over 2 years ago Keith and the Keith Duffy Foundation have become a fantastic friend and ambassador to Cliona's Foundation.

His support of and commitment to the Foundation has been once again evident this year from his attendance at our 10th Anniversary Annual celebration in January to our selection for the 2nd year running as 1 of 2 beneficiaries along with Fighting Blindness from the Keith Duffy Foundation Annual Golf Classic which took place in September in Roganstown Hotel & Country Club in Swords, Dublin. It was a massive success with many celebrities taking to the course including Brian Mc Fadden, Robbie Keane, Kenny Daglaish to name but a few. A great night's entertainment followed including a Charity Auction which saw extremely competitive bidding resulting in a very positive outcome for all the Charities.

Keith said, "the work that Cliona's Foundation do is very close to my heart as I have seen the financial burden on families caring for a critically ill child as part of my work with the Keith Duffy Foundation.

Not only has Keith's support resulted in a financial contribution to Cliona's Foundation but it has also increased our profile significantly to a much wider audience who we hope will be able to help us out in some way or another in the future.

#### WALKING THE CAMINO FOR CLIONA'S FOUNDATION



Walking a section of the Camino is now on everyone's bucket list but not being content with just doing the trek we were very grateful to 3 people that choose to fundraise for Cliona's Foundation as part of their expedition.

Aogan Mac Cormaic who became familiar with Cliona's Foundation and the work they do from travelling to Lourdes with some of our very loyal supporters, did the Camino Portugese in August walking 250Km over 11 days. He fundraised for Cliona's Foundation and the Mens Shed in Raheen

### IRELAND'S LARGEST RECRUITMENT AGENCY GOES PURPLE FOR CLIONA'S FOUNDATION

Cpl Limerick and their Director Graham Burns has been a loyal supporter of Cliona's Foundation for many years and we were delighted when the Cpl group decided to go purple on the 30th June. Cpl offices nationwide turned out in purple to raise awareness of Cliona's Foundation and to raise funds. From purple shirts and scarves to purple cupcakes and balloons, the staff really made a huge effort. We were also given the opportunity to share our story and the work we do with staff in the Limerick office on that same day.

We are delighted to have an association with Cpl and extremely grateful for their commitment to us as one of their charity partners for 2018. We wish to express our gratitude to Graham for his continuous support.



and we were delighted to accept a cheque for €310 from him.

Caroline Kenny from Bruff and her friend Deirdre Casey also did a section of the Portugese Way in September and over 5 days walked a total of 121km. Caroline raised the fantastic amount of  $\notin$ 1,175.

We are genuinely appreciative of the huge effort involved in the Camino challenge and also in the additional work associated with fundraising for Cliona's Foundation.









# **GETTING STUCK IN FOR CLIONA'S FOUNDATION AT ADARE TO SURVIVE**

There are not many that would swing from ropes, crawl through dark wet tunnels, wade through swampy ground, run through electric wires and climb over 16 ft high obstacles for Charity. But that is what approx. 60 members of the Purple Platoon did for Cliona's Foundation at Adare to Survive on the last Sunday in September.

This was the largest purple platoon we had since we became charity partners of the event 5 years ago and this year we were delighted to be joined by staff members of UBER who had selected Cliona's Foundation as their partner for this event.

It was also very special to have Kellie Ann Sweeney and a group of her family don the purple for Cliona' Foundation. We were able to help Kellie out a few years ago when her son was sick and since then she has been a very loyal supporter of the Foundation.

While challenging it was a fantastic fun experience with the Purple Platoon members literally pulling, pushing, lifting, dragging, slapping and clapping each other around the course through mud and water and up and under many obstacles.

As in previous years the Cliona's Foundation purple wall was the penultimate test for all the participants but thanks to John King and Brendan Ring no one was left hanging and everyone was helped if needed over the 16ft obstacle. There was a real sense of achievement crossing the end line, not only because of the physical endeavours but also knowing that the Platoons efforts and monies raised go directly to helping families of children. Cliona's Foundation would like to thank Ray Nash and Mark Touhy event organisers of ATS, and all the brave "Purple Platooner's" for taking part and donating €10 of the race registration fee to the charity A very special thank you to Saundra and Tracey from Morrisons Pub, Ballysimon for supplying the Platoon with very welcome refreshments afterwards.

Remember if you are considering doing an and endurance event next year – it would be great if you could do it for Cliona's Foundation.





#### WHAT WE'VE BEEN UP TO

# **CLIONA'S FOUNDATION 10TH ANNUAL CYCLE**







Cliona's Foundation Cycle club 10th Annual Fundraising Cycle took place in glorious sunshine on Saturday August 26th and once again cycling enthusiasts both experienced and newcomers took to the road in support of Cliona's Foundation.



With three routes including a 10km for kiddies, a 40km family/ leisure cycle and the 90km Cliona's Challenge there was something for everyone and it was fantastic to see the small kids taking off on their bikes to get the event rolling.



Once again Bruff Rugby Club was the perfect venue for the pre and post gathering and refreshments and coupled with the near perfect weather conditions there was a real party atmosphere throughout the event.



It is hard to believe that this event has been running successfully for 10 years and that is no small part due to the dedication and work of the Cliona' Foundation Cycle club members under the direction of Trevor Daly and also the many volunteer stewards on the day. We are extremely grateful for their support.

#### The 10th annual cycle raised an incredible €4,800 for the Foundation which allowed us to Support 3 families of children with a life limiting illness

Roll on the 11th Annual Cycle on Saturday August 25th 2018







# ELEMENT SIX PUT THEIR DIAMOND WHEELS IN MOTION FOR CLIONA'S FOUNDATION

We were delighted to receive news earlier in the year that we had been selected as the Element Six Charity partner for the year for 2017. It was particularly special as our selection was as a result of staff nominations and one of those staff members was Trevor Barry, dad of Fionn, whose family we have been able to support in the past.

Fionn is 3 years of age and was diagnosed with West Syndrome in 2015 and now requires 24 hour full time medical attention .

As one of their fundraisers the seasoned cycling enthusiasts in Element Six along with support of senior management and Executive Director Ken Sullivan organised a 50k cycle and encouraged all of their staff to participate regardless of their cycling experience and ability .

On Friday September 1st on what turned out to be a fantastic sunny morning and with a real party atmosphere on site staff members of all sections of the Company gathered for refreshments, banter and bike checks before hitting the road. Former Munster and Ireland player David Wallace set the cyclists off on their way and it was also great to see the beautiful Fionn there as well in the company of his mum & Dad Brenda and Trevor.

At a lovely leisurely pace the group of approx. 50 staff cycled together as they made their way through Shannon, Sixmilebridge, Kilmurray stopping off in Quin for light refreshments before hitting the road well fed and energised. An unscheduled but wonderful pit spot in Dromoland Castle allowed for further relaxation of the lungs before the group headed through Newmarket on Fergus, Carrigoran, Shannon Town Centre and finishing to great welcome and relief in Wolfe Tones GAA.

A wonderful staff night followed in the GAA Club where cyclists and others were fed and entertained for many hours afterwards.

It was a fantastic day out helped in no small way by the catering and support staff, and the experienced cyclists of Ed Hayes, Declan Coughlan and Dave Hanrahan who encouraged and motivated all the cyclists throughout. The whole day was captured on camera by Jack O'Shea and it was very touching to see the Purple Platoon wind it's way through the Clare countryside.Special thanks to Grainne Loonman who despite a very hectic work schedule coordinated the whole event and ensured it was an amazing success not only for Cliona's Foundation but for the staff of Element 6.

Thank you to everyone involved and all those who supported. You have made a difference.



## **FAMILY FEEDBACK**



To Terry & Bredon.

I don't know how to then't both of you's for what you's have done for our family when I opened my post I ceyed with day this much help us in So many way's we really appreciate everything you's have done Your thoughtfulness brought so much joy.

In the Enture when Company out of hospitalimic as a homing will do some Europaising for Clienc's Loundation Thank you very LALCE 28 JUL 27 From

# UBER



14.30 Hi, thankyou so much for the money we recieved. This has helped us so much my daughter has seizures every day and has to be with me around the clock so the ppod we were able to buy from the money you gave us has been life changing. this chair means she has somewhere safe and comfortable to lie downstairs in our house, it means she can sleep off a seizure safely in our kitchen while I make dinner (I have two other kids so these things have to be done) it means she she has her own chair to lie up in in the sitting room. while we're watching a family movie! Thankyou for this xxx Sent from my Huawei Mobile Slide to unlock i01 HUAWEI

It is always so special to hear back from the families that we have supported and when you receive special cards like those below it just reinforces for Cliona's Foundation that what we are doing with your support makes a huge difference

#### **UBER get moving for Charity**

UBER since their arrival in Ireland has had a very positive impact on business in Limerick City where over 200 staff are based in their fantastic ultra modern offices at the junction of Thomas Street and Catherine Street. They have also been making a positive impact on others as well, through their very innovative and energetic staff initiated charity fundraising events. Cliona's Foundation was delighted to be selected as the beneficiary in September and really enjoyed the opportunity to liaise with them over a number of weeks. Their main fundraiser saw members of staff cycle 200 km on a spinning bike which was based in the office for a day in the last week of September.

Staff battled against each other to see the distance they could manage in a specific period of time while attracting sponsorship for their individual achievements. Their efforts generated a whopping €1,176.10 which we were delighted to be presented with by Megan Mc Namara and her colleagues.

But not satisfied with just getting on their bikes 23 staff also registered to be part of the Cliona's Foundation Purple Platoon in Adare to Survive on the 24th September. Their presence hugely enhanced the Purple Wave on the day and helped all of our crew have a fantastic albeit dirty day out

# **OUR FAMILIES HELPING OTHER FAMILIES**



It is always very special and uplifting to Cliona's Foundation when we get support from families that we have been able to support. This could be in in the form of them sharing publicly their experience and the impact of the support received, nominating us as a beneficiary for a fundraising event or getting directly involved in raising funds for us.

Over the past year we have had a number of fantastic families who featured in national and regional media, and who spoke very honestly about their situation. While friends and family would have been familiar with the medical and emotional journey they were travelling, very few would have been aware of the financial difficulties they were experiencing on this journey. Opening up about this aspect of caring for their child is very brave for each of these families, but it also highlights the stress that non medical costs associated with caring can bring and how important it is to be able to get some help towards these costs.

We are extremely indebted to these families for their support and their honesty and openness has helped increase the profile of Cliona's Foundation and the necessity of the service we provide.

We have also over the past 6 months had a number of families organising and participating in various events that have generated funds for the foundation



Harrington Family and Lombardstown Community Council

In 2013 we were able to support the family of 7 year old Conor Harrington as he was being treated for a brain tumour. Very sadly Conor passed away in October 2016. In September we received a call from Conor's Dad Pat to say that his local community council were holding a table quiz in memory of Conor and he had put forward Cliona's Foundation as the beneficiary. We were very touched by this and were delighted to travel to Gortroe, meet with the Harrington family and members of Lombardstown Community Council and accept a cheque in the amazing amount of €3,175. What an amazing community that organised and supported this event.



Pauline Wallace goes running for Cliona's Foundation

Eoghan Wallace is a very bright and bubbly 4 year old. However when he was born at 30 weeks old with chronic lung disease his parents Pauline and Tony had a tough road ahead of them. We were able to support them at that time to get through the early stages of his care and his prolonged period of hospitalization. The Wallace family have been extremely supportive in return since 2013 and more recently when Pauline participated in the Cook Medical Women's Mini Marathon and raised €440 through her efforts. We had great fun with Eoghan when they called in to present us with their cheque.

#### Fabian O Callaghan's Last Birthday gift

In 2016 at 2 years of age Fabian O Callaghan was diagnosed with a brain tumour .Following surgery and facing treatment overseas we were able to support his family with their non medical costs. In September we received the most beautiful email from Fabian's dad as follows;

### **OUR FAMILIES HELPING OTHER FAMILIES**

On the 1st of September he celebrated his 3rd Birthday,this was a very special day for Fabian, ourselves and all who visited us to help celebrate. We asked our guests to make a donation to the Cliona's Foundation through a savings box that was in the house on the weekend in lieu of presents for Fabian, this we thought as at the moment he had not much interest in playing with toys apart from those already familiar to him would go some way to paying back the Cliona's Foundation for their help in recent times.

The total money raised was  $\in$ 515 which I would like to send to you today.

This was a most beautiful gesture from Fabians family that touched us deeply but we were then very saddened to hear of his passing only a few weeks later on the  $8^{th}$  of October. Rest in peace Fabian and we are honoured to have been the recipient of your last birthday gift



#### Fiona Duff and sisters doing it for Cliona's Foundation

It is not often that 10 sisters would run together as a group and raise money in the process. But that is what Fiona Duff and her 9 sisters did along with other extended family members when they participated in the Cook Medical Womens' Min Marathon in October.

We were able to help Fiona and her family out in December 2015 following the birth of her daughter Tess with the condition muscle myopathy. Tess had a lot of hospital admissions to both Limerick and Dublin and as Fiona said "your cheque removed one major burden from us at that time". Tess was unable to overcome her condition and unfortunately passed away in April 2016. Fiona wanted to give back to other families like hers so rallied the troops and over 20 of them donned the purple and completed the Marathon. It was fantastic to witness their delight and sense of achievement as they crossed the line with buggy and all in tow. A very special family moment.

Even more special was that their efforts raised a fantastic  $\leq 1,560$  which will enable us to support one of our waiting families. Thank you Fiona and all the Heffernan girls.



#### Kellie Sweeney talks and climbs for Cliona's Foundation

We were able to support Kellie back in 2014 when her baby boy Thomas was diagnosed with a terminal illness. After he passed away Kellie expressed her deep gratitude to Cliona's Foundation for their support when she most needed it and has shared her experience on local and national media. Not content with just talking about it Kellie has also raised funds through her participation in Adare to Survive and this year gathered a group of her family to partake and they raised a super €807 euros for which we are extremely grateful. Great fun in the office shooting bows and arrows when she called in with her two beautiful girls to present her cheque.

Big thank you also to Maria Fitzgerald who we supported in 2012 when her son Jonathon was unwell. Maria recently handed over €700 to Cliona's Foundation as a result of her fundraising efforts.



### **Galtee Mor Challenge 2017**

We had an early start on a very overcast and windy Saturday morning in October, where 41 determined walkers met at the foothills of Galtee Mor ready to face our Galtee Mor Challenge 2017.

The event was the brain child of David Ryan of DPack Packaging Ltd., and it is with great thanks to him that the event raised a massive €8,500. The hike was led by the charismatic hill walker and Galtee mountain expert Mike Moroney who kept us entertained along the way with historical facts and tales. For many it was their first time attempting Galtee Mor, which stands at 919m and is one of Ireland's highest mountains, but with regular stops to catch our breath and regroup we successfully made it to the summit together. Huddled up behind the shelter of the rocks, we bravely took off our gloves to enjoy our sandwiches and snacks sponsored by Carambola. Unfortunately due to the dense fog, we didn't get to enjoy the views described by Mike. After a quick group photo with the Cliona's Foundation flag

and a round of applause, we began our decent back down to the Blackroad. As we made our way down, the clouds lifted and revealed the stunning beauty of the Galtees, a great way to finish the 4.5 hour climb.

We have plans to continue our 'Mountain Challenge' series and look forward to revealing what mountain we will take on next year!

Thank you to everyone who completed the Galtee Mor Challenge and to those who supported us. In particular we want to thank Davy Ryan of Dpack Packaging, Crecora/Raheen/Mungret walking group, JT fitness and Carambola. We also have to thank to Mark Leahy who led us up and down safely and with no casualties due to his rescue experience.

It was a terrific morning; we hope more people will join us in next year's adventure.









10 years old Sadhbh Ni Chroinin made the ultimate sacrifice of any little girl with beautiful hair when she made the decision to donate her hair to Charity. " A small girl with a big heart" is how her uncle, hairdresser Niall Bennett of H2O Creative in New Ross described Sadhbh after he took 15 inches off her hair in a ponytail recently.

We were delighted and overwhelmed to take the call from Sadhbh's mother recently to tell us what they were planning to do and that while the ponytail would be donated to another fantastic Charity Rapunzel they were also fundraising for Cliona's Foundation as well. Even more special was to hear the reasoning and the connection to both. Niall Bennett had lost his younger sister to cancer a number of years ago but more poignantly they were fundraising for Cliona's Foundation in memory of Ciara Mc Carthy, a beautiful 7 year old from Limerick that also lost her battle with cancer a few years ago. Sadhbh's mum trained with Ciara's mum and Mary felt this was an opportunity to give something back to the Foundation that had supported the Mc Carthy Family during Ciara's illness.

The McCarthy family despite their heart breaking loss have with their family and friends been an unbelievable supporter of Cliona's Foundation since Ciara's passing. The funds that have been raised for Cliona's Foundation in Ciara's memory has helped us provide support to in excess of more 10 families who have travelled the same road as the Mc Carthys and we cannot thank them enough.

This wonderful and very generous gift from Sadhbh and her family raised an outstanding €1,650 which went directly back to a family on our waiting list

It was wonderful to see the images of Sadhbh before and after and I think you will agree that regardless of length of hair she is a most beautiful child with a fantastic smile. Well done to all involved.



# Greybridge do their fair share for Cliona's Foundation

The Greybridge Classic Club has done outstanding work for numerous charities over the past number of years and Cliona's Foundation has been privileged to be one of those charities on an annual basis. 2017 was no different and despite the weather people still turned for the Harvest Fair in Meanus on August 20th. Between showers they got to hear great singing in the marquee, fabulous model displays and got to see some old classics and some dyno testing. In addition to being one of the beneficiaries of the Harvest Fair we were also delighted to receive funding from the proceeds of the Classic Vintage run which ended in the Woodlands House Hotel on the 15th October. In total we have received €3,800 from the Greybridge Classic Club and we must thank Kieran Lillis and all his team for their efforts and support.



## Johnson & Johnson go plant to plant for Charity



Johnson & Johnson are a Company renowned not only for the range of products they supply but also for the very strong ethos of supporting charities and creating an environment where their employees very proactively organise and engage in fundraising activities.

With a very strong company cycling club one of those fundraising events for the past 5 years has been the Plant 2 Plant cycle. Staff sign up and commit to cycling from the plant in Limerick to the plant in Cork. 300km over a 2 day period travelling via Killarney. Each of the plants select 2 charities and staff in each of the respective plants raise funds for those selected. We were delighted to be selected as a beneficiary from the Limerick plant along with Our Lady's Children Hospital Crumlin. It was fitting that we would be paired given that a lot of our family applications would be from families who are spending prolonged periods of time in Crumlin with their sick child.

While the cycle is normally restricted to staff only, exception was made to allow our co founder Brendan Ring and Cliona's Foundation supporter Martin Hartnett participate. Brendan wanted to participate to acknowledge the huge efforts being made by Johnson & Johnson.

The event started out from Limerick in sunshine on the 18th August but conditions changed drastically on route. The group of 60 plus cyclists battled through torrential rain and high winds and were relieved to say the least to arrive safely in Killarney. Following a good rest and nourishment and thankfully under blue skies the group set out for Cork the following morning. All of the cyclists were lifted by the contrast in weather and thoroughly enjoyed this leg of the journey.

Through their hard work and efforts the Limerick plant raised a fantastic  $\leq 15,000$  and we were very humbled to accept a cheque for  $\leq 7,500$ . This will make a big difference to a number of our families. Huge thank you to all that cycled and supported and particularly Brian Molholly and the organising committee at Johnson & Johnson for ensuring this was a great success.



### **FAMILY STORIES**

## ADELE HUNTER SHARES HER STORY OF CARING FOR HER SICK SON ALEX

The mum of a seriously ill toddler has revealed she feared she would lose her home and have her kids taken from her.

Adele Hunter spoke candidly about the realities of having a sick child in Ireland and claims that parents are often left in vulnerable positions as she alleges there are a lack of supports available.

Adele's son Alex will turn three in October and has already spent the majority of his young life in hospital after being diagnosed with rare Pierre Robin Syndrome, which causes significant facial abnormalities, leading to other health issues.

"It's so sad. All Alex knows in his short life is hospitals and doctors. He's missing out on time with his sisters and being with his family at home."

Adele is his full time carer and is also a single mum to her daughters Alexi (9) and Ava (5).

Adele, from outside of Mullingar in Co Westmeath, said: "I find myself trying to be my three kids' voice and do what's best for them.

"Myself and his dad lived in a home for two and a half years, we completed 18 months of training including tracheotomy training, CPR, peg training, ventilator support. I feel that because we were so fully trained we were sent home and forgotten about." She said that as Alex gets older he seems to have more medical problems and she doesn't know what his prognosis is.

She explained: "Alex started having seizures this year after Christmas. His body goes into spasms, he shakes, his eyes roll, he goes blue and he sometimes requires CPR.

"Once this happened in front of my other two children, and in public. It was simply terrifying. You just don't want to leave the house it's so scary. The older Alex gets the more problems arise, I've never met another child like Alex, with the condition he has so I feel like we're all learning from him."

Adele and her ex partner were forced to spend time between Dublin to be near Alex and their family home in Westmeath and last year she feared they would be left homeless when money was tight. She was put in touch with Cliona's Foundation, to see if some assistance could be provided.

She said: "There is very little support out there, we couldn't work, we were living in the hospital and for the first two years we didn't even know if our son would live or not.

"Cliona's Foundation are fantastic, my goodness, we went to our social worker with our worries and our concerns and she put us in touch with them.

"Because I'd been let down so much I thought I'd be let down by them but I got home one Friday to see my girls and I came home to the cheque of €1,500 from Cliona's Foundation.

"Myself and Alex's dad cried but this time it was happy tears. It was the only support and relief we found, without them we probably would have lost our home, my kids would probably be in care and the whole family would have broken, then and there.

"With the help they've given us we've gotten this far.

"Cliona's Foundation kept a roof over our heads, our girls were able to stay in school and have that routine."

She said that she feels there isn't enough State support for seriously ill children and their families.

Adele said: "I feel that a lot of children are let down and if all of us parents got together our voices would be heard.

"I can understand why families don't speak up and it can feel like a losing battle but I'm willing to risk everything I have, my three children.



"No matter whether my son lives or dies I need to fight until all of our kids' voices are heard."



# **Going Long Distance For Cliona's Foundation**



Committing to participating in the Dublin Marathon is a huge challenge, which sees your work and personal calendar being defined by training schedules and your dietary intake dictated by what gives you the best output and maintains you through a heavy schedule.

But to also commit to fundraising is a massive undertaking which brings a whole new pressure in to the equation, a pressure that any marathon participant could happily do without.

So we were very grateful and overwhelmed to have 4 people that made that commitment to raise funds for Cliona's Foundation through their participation in this year's Dublin Marathon and worked tirelessly to raise as much money as they could in the process.

Each of the 4 chose Cliona's Foundation for very different and personal reason and we were only too happy to support and encourage them as much as possible on their marathon journey.

For **James Mc Carthy** this was his 2nd Marathon and he was running in memory of his daughter Ciara who passed away in 2013 aged 7 years of age after battling with cancer. The Mc Carthy family have been unbelievable supporters of Cliona's Foundation over the past 4 years and it was very special to have James running in purple.

It was also 2nd time round for **Karl Daly** who is Director of Metis Ireland and has been a loyal supporter on a personal and corporate level for a number of years . He has raised substantial fund for numerous charities including Cliona's Foundation over the past number of years through his participation in many other running events.

John McNamara is a successful confidence coach and also presents on local radio station Limerick City Community Radio . John had already committed to doing the marathon when he interviewed co founder of Cliona's Foundation Brendan Ring on the station. So touched was he by the work of Cliona's Foundation that he then committed to raising funds.

For our final runner **Geraldine Lyons** this was a significant personal commitment for her to make. Geraldine runs her own Life Coaching, Physical Therapy and Reiki treatment centre so to commit to do what would be her 1st marathon and also raise fund for Cliona's Foundation was a huge undertaking.

We are thrilled that each of our runners finished the marathon safely to a huge sense of relief and personal satisfaction. This was despite various medical conditions in the week leading up to the marathon (including doctors advice not to participate), physical problem during the race and mentally dealing with that invisible wall that meets each of the marathon runners on the route.

But for each of our very special runners what kept them going was people had committed monies to them to complete and they were not going to let them or Cliona's Foundation down.

We truly admire and are grateful to them for doing what they did for us and are blown away by the funds received in excess of  $\leq 12,000$ (and still counting). They have made a huge difference to families that need support.

# LOYAL SUPPORTERS



We have a large number of loyal and regular supporters that help us out throughout the year whether its volunteering at events, raising money for the Foundation or providing valuable advise and support.

These include Saundra Morrison of Morrisons Bar & Restaurant and Tracy Skehan of Whisps Hair & Beauty Salon, Castleconnell.

Both Saundra and Tracy have volunteered at events too many to mention sponsored and served refreshments to many of our purple platoon and also organised fundraising events in their respective businesses.

Morrisson's Bar & Kitchen ran a coffee week in September for Cliona's Foundation with all the tea/coffee takings in the amount of €487 being handed over to us

**Tracy Skehan** had a very successful coffee morning in her salon on November 17 and both she and we were delighted with the €492 that was raised from her very generous customers.

Leanne Moore has been an ambassador of Cliona's Foundation for a number of years and recently opened her own fitness centre, **Go Gym** in Limerick. Leanne selected Cliona's Foundation to be the beneficiary of the raffle at her official launch day and also for a Halloween





Spin in October. Both of these vents resulted is us receiving a cheque of €520 from Leanne.

**JFK School** on the Ennis Road under the direction of teacher Dolores O'Shea for the  $3^{rd}$  year running selected Cliona's Foundation to benefit from their colours and dress up day before the Halloween break. It is fantastic to get this annual support and it was great to visit the school and thank all the teachers and pupils for their contribution of  $\notin$ 400.

Employees at **Dell** continue to support Cliona's Foundation throughout the year and we are very grateful for their contributions

The staff of **Deloitte** who support us on an annual basis and this year donated the proceeds from their inhouse denim day in the amount of €300

**Frawley and Neville** for their continued support of and advice to Cliona's Foundation.

Carl Widger, Karl Daly and all the team at **Metis Ireland** for their encless support, encouragement and advice.



#### Thank You to all of these supporters

Wyeth of Askeaton and their employees who chose Cliona's Foundation as a recipient of €1,000 from their Christmas Charity Donation Scheme.

The campus community of the **University of Limerick** who nominated Cliona's Foundation to receive €1,000 from the University's newly established Christmas Community Celebration initiative.

The World Barbeque Association who selected Clionas Foundation as charity partner for the World BBQ competition in limerick from which we benefitted in the amount of  $\in$  500

**The Ring of Kerry** Cycle Committee who presented us with  $\in$  2,000 from their 2017 Annual Cycle

Our regular donors who make a monthly standing order contribution to the Foundation

The 5 couples who got married during year and in lieu of wedding favours made a donation to Cliona's Foundation.

Richard Lynch and his team at ilovelimerick.com for their great work at promoting the Foundation.

#### WEDDING FAVOURS

Are you getting married or know someone that is during 2018. If you really want to do something special to give to your guests why not consider charity wedding favours?

Donating in lieu of wedding favours is a unique way of thanking your guests but also supporting families of children with a life limiting illness. It is the perfect finishing touch and far more meaningful than traditional wedding favours.

In return we can provide you with tent cards per table and a personalised Wedding Notice letting your guests know you are supporting Cliona's Foundation.



# **HELP NEEDED**

By the end of 2017 we will have supported approx 470 families across 29 Counties. Every one of these families are different, with a range of heartbreaking circumstances. Cliona's Foundation is going to do everything that we can to support these families but we need your help. If you think that you might be in a position to organise a Fundraiser for Cliona's Foundation in 2017 we would love to hear from you and would greatly appreciate your support. You can call or email Phil at 061 - 331333or at phil@clionasfoundation.ie. You can also donate online at www.clionasfoundation.ie or by texting Cliona to 50300 to donate  $\leq 2$ 

#### **Collection Boxes**

Have you a business or location where you could display one of our new Cliona's Foundation Collection Boxes. Please contact us and we can arrange to send on to you.

#### IMPORTANT - Data Protection and You.

There is a major update of the data protection regulations underway in Ireland and across the EU. The General Data Protection Regulation (GDPR) is an update of the European wide Data Protection legislation. It will come into force on the 25th May 2018, replacing the existing data protection framework under the EU Data Protection Directive.

The GDPR emphasises transparency, security and accountability by data controllers (e.g. Cliona's Foundation sending you this newsletter), while at the same time standardising and strengthening the right of European citizens to data privacy.

If you receive this newsletter in the post and would like to continue receiving it then please let us know by contacting us on 061-331333 or by email at info@clionasfoundation.ie. If we do not receive a contact from you then we will remove your name and address from our system.

If you receive this newsletter by email and would like to continue receiving it then please click t he subscribe button on the cover email

that delivered the newsletter. If you do not subscribe we will remove your name and address from our system.

