

# Welcome



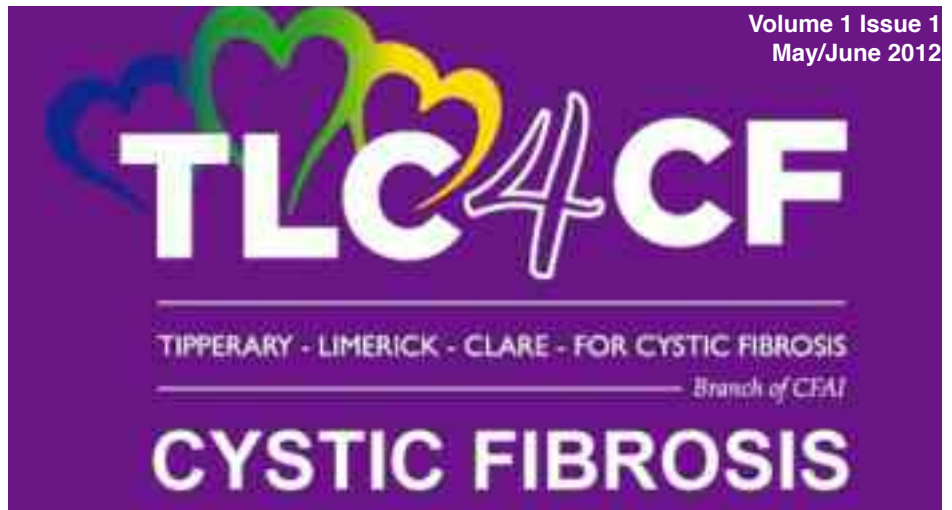
Katie Murphy

Dear reader,

Firstly, I would like to take this opportunity to formally introduce myself to the entire TLC4CF community. My name is Katie Murphy and I am the newest addition to the TLC4CF team, as the Regional Development Officer (RDO). As RDO my main objectives are; to advocate on behalf of the TLC4CF community, provide information and support to patients and families, to assist with and co-ordinate fundraising events and to assist with the building process of the new CF specialist unit at the Mid-Western Regional Hospital (MWRH), Limerick. As a blow-in from Mullingar, Co. Westmeath I wasn't fully aware of the extent of the work which has been going on in the region, but I have very quickly been brought up-to-date. I have been beyond impressed at the commitment of all members to the construction of the specialist unit, and I am privileged to be joining the team at such an exciting time!

Secondly, I would also like to welcome you to our first edition of the TLC4CF newsletter! As this is the first edition of this newsletter it is very much a trial run. If there is a topic/section you think would be beneficial to include in future editions, please let me know. In this edition we will be talking about the construction of the new CF specialist unit at the MWRH, up-coming fundraising events, and looking back at some previous events.

We have very busy times ahead of us, with many fundraising activities planned (more details are provided in this newsletter), the commencement of the building, addressing patient issues, and National campaigns, so as they say "Many hands make light work"! If you would like to get involved in TLC4CF in any way, shape or form please contact me and help to improve the lives of people living with CF in the Mid-Western region.



Volume 1 Issue 1  
May/June 2012

## New Adult CF Unit to open Oct 2013

**A**fter months of delays and setbacks, TLC4CF finally have the good news you have ALL been waiting for! Construction on the new adult CF unit has officially commenced, with an estimated completion time of October 2013!!!

On Tuesday the 20th of March 2012 the official construction contract was signed, sealed and delivered!! From this date the contractor now have 20 days to mobilise themselves on-site and begin construction. The official 'Turning the Sod' will take place in the coming weeks so watch this space!

Katie Drennan (PWCF, aged 21), advocate for TLC4CF has spoken about these recent developments.

"I am thrilled and delighted with the news that the building of our new units for all CF Adults who attend the Mid Western Regional Hospital in Dooradoyle has commenced at last. It's being a long time coming, and it's great to know that the building is started and will be complete by October 2013. This new State of the Art building, which will consist of 9 new Inpatient en-suite rooms and an Out-patient Centre with 5 individual en-suite rooms, together with a CF gym will be a fantastic development for everyone with CF attending the hospital." says Katie Drennan.

"At present we have a great adult CF team with Dr. Brian Casserly, and our CF nurses, Peig, Noelle and Samantha, and this new unit will be a great addition to the services that are so badly needed for people with CF." adds

Continued on back page



Katie Drennan

## Fundraising Continues

Fundraising for TLC4CF has been strong as ever even during these tough economic times! We are well on target to raising the money needed to construct the Adult CF Specialist unit. While we have received huge support in our fundraising campaign we are still falling short of approximately 1.2million euro to complete the project. So the fundraising continues.

### In this issue

- National Awareness Week
- Upcoming Events
- PWCF Committee
- CFAI Annual Conference
- A look back on recent events
- Our story so far - Photo gallery



## The Great Limerick Run, Sunday the 6th of May 2012

Sunday the 6th of May will see the third Great Limerick Run! The streets of Limerick City welcome over 8,000 runners and 30,000 spectators across the course. This event has something for everyone including a marathon, a half marathon and a 6 mile event.

TLC4CF have been very lucky over the past two years to have supporters raising money for TLC4CF by participating in The Great Limerick Run. We are hoping this year will be no different! So if you are interested in taking part in this year's run, why not take a TLC4CF sponsorship card and help contribute to the construction of the adult CF in-patient and out-patient unit for patients at the MWRH, Limerick.

For further information see <http://www.greatlimerickrun.com/> or contact TLC4CF on 087 1954213 project. So the fundraising continues...



## The 3 Ballingarry's Motor Bike Charity Run

TLC4CF in Association with Celtic M.C.C 'New York' Irish Chapter

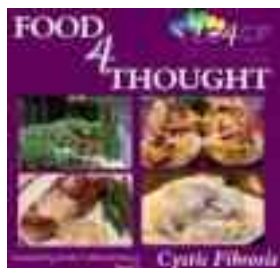
On Sunday the 6th of March 2012 a charity 'motor bike' run will take place across the three 'Ballingarry's' located in the Mid-West.

Route: Starts in Ballingarry, North Tipperary (just outside Borriskane) Continue to Ballingarry, South Tipperary (near Killaunaule)

Finally, on to the last Ballingarry, West Limerick (near Adare) All proceeds directly contribute to the construction of the new adult cystic fibrosis unit at the Mid-Western Regional Hospital, Limerick.

For more information please contact:  
John Baker: 086 8697383  
Liam O'Kelly: 086 2675963

## TLC4CF Cookery Book, Volume 2



After the great success of the first Cookery Book—Food4Thought, which raised over €110,000 for the building of the adult in-patient and out-patient unit for people with CF at the MWRH, Limerick, we have launched our second volume of the book!!

Volume 2 is again compiled by Breda O'Shaughnessy and she is very confident that having learned the basics in Volume 1, everyone is now ready to expand their knowledge and skills. Volume 2 offers just that with recipes that are a little more complex, but not Masterchef level!

ALL proceeds from the books goes directly to TLC4CF. The book is now available for purchase for €10 (€12.50 inclusive of postage and packaging). If you would like to purchase Volume 1 or 2 please contact Katie on 087 1954213 or at [katie@tlc4cf.com](mailto:katie@tlc4cf.com).



## 105 Marathon relay

On June 24th 2012 TLC4CF are giving both adults and children the opportunity to be part of a novel idea! Run 1 lap (400m) of the University of Limerick's running track and be part of a running Marathon.

We will require at least 105 people to complete 105 laps of the University of Limerick Running track to complete a 26.2 mile Marathon. This promises to be a great family day out with various side shows—bouncing castles, face painting, music, food and refreshments taking place on the day! You will also see a few famous faces participating on the day, so be sure not to miss out!! For more information or if you would like to participate please contact:

Jackie Gaffery—TLC4CF—087 6599194  
Liam O'Kelly—TLC4CF—086 2675963  
Dermot Kearns—Dooneen Athletics Club—086 6082516  
Joe Chawke—Dooneen Athletics Club—087 7533526

Sponsorship cards are available from the TLC4CF office so contact Katie alternatively

## Fundraiser Canter Ballycommon

On Sunday, 18th of March 2012 the North Tipperary Foxhounds held a sponsored horse ride in Ballycommon in aid TLC4CF, with all proceeds directly contributing to the construction of a specialised CF unit at the Mid-Western Regional Hospital in Limerick. The 16 mile ride, which included over 100 different types of obstacles and jumps, from stone walls to ditches, dykes, man-made jumps and rivers was an overwhelming success raising in excess of €8,000. Everyone at TLC4CF would like to extend our thanks and gratitude to all involved in the organisation of this event.

(Use images of event here)



## Solo Endurance Challenge, from Shannon to Dublin

Special thanks go to Kieran McCarthy who recently completed a solo endurance challenge from Shannon to Dublin in aid of two local charities – TLC4CF and Clare Crusaders. Kieran swam 3 km, then cycled 223 km to Dublin and then completed the Dublin Marathon!! He raised a staggering 13,600 for each of the two charities.

Kieran and his wife Sinead are pictured here with their Daughter Aoibheann (who is three and a half yrs and has CF) at the handover of the cheque for €13,600 to Linda Drennan TLC4CF. Also pictured is Shona Cullinan.

## National Awareness Week 2012

We would sincerely like to thank all who helped out during the National Awareness week 2012 in Tipperary Limerick and Clare. Much needed funds and awareness were raised all across the country with the Mid-West playing their part....

We're not quite finished yet though!!! The Crescent Shopping Centre has also been booked for the 17th-19th of May to sell CFAI pins and trolley coins. We will also use this opportunity to sell the TLC4CF Cook Book Volume two over the few days so all help would be greatly appreciated!!

If you are available and willing to spare a few hours over these few days please get in contact with Katie. You can call/text 087 1954213 or email [katie@tlc4cf.com](mailto:katie@tlc4cf.com)

# ECFS Conference 2012

The European Cystic Fibrosis Conference is taking place from the 6th-9th of June, in the Dublin Convention Centre. This prestigious international medical and scientific conference will bring together experts on CF from around the world. It will provide an important opportunity for those interested in CF including medical students and those involved in patient groups (including the CFAI) to hear some of the latest developments in CF research and care. The conference attracts around 2,000 participants and there is a huge amount of work in staging such an event. CFAI is committed to helping out as much as possible and will need at least 60

volunteers to help out over the four days of the conference and in the days leading up to the conference. Some of the tasks include helping with:

- Conference Bags Packing
- Self-Printing Terminals
- Conference Material
- Poster Helpdesk
- Entrance Control
- ePosters
- ePosters coner
- Social Events
- Speaker Preview Room
- Internet Café
- Helping to dismantle the conference
- General assistance to participants

In return for helping out, volunteers will be able to access some of the conference free of charge). T-shirts and meals will be provided on the days people volunteer and for particular tasks there will be training and support as necessary. The CFAI will be working with the conference organisers to co-ordinate volunteers and we need your help. We would particularly encourage volunteers who have an interest in the medical and scientific dimensions of CF. Application forms are available for download from the CF Ireland website or for more information please contact Helen Whitty: t: +353 1 4962433 / f: +353 1 496 2201 / e: hwhitty@cfireland.ie

# Condron's B Fest 2012

## Ballingarry


In aid of TLC4CF - A June Weekend with a difference.

**Friday June 1st**  
**9 pm Ballingarry**  
**All Star Mr. & Mrs.**  
with Special Guest  
How well do you know  
your better half??  
Dinner for 2 for the winning couple.  
80's Disco Theme Night. "Cocktails  
of the Decade" all night.



**Saturday June 2nd**  
**9 pm Final of The**  
**Voice of Ballingarry**  
with our judging  
panel  
Vote for your Favourites on the night  
Winner will perform with ZOO 2 live  
on Sunday from the roof.

**Sunday June 3rd**  
**Zoo 2** live from the rooftop down 8-10pm.  
Supported by Bad Penny 6-8pm  
4-6pm Traditional Music with Dancing at the Crossroads  
Junior Tractor Race, Donkey Derby, Face Painting,  
Ice cream van, BBQ all day.  
Entry by Wristband on sale now (€5) All proceeds go to TLC4CF.



**Monday**  
**June**  
**4th**  
Monster Draw  
9pm. Lines for  
Draw on sale all  
weekend

This promises to be a fun-filled weekend while raising much needed funds for CF care in the Mid-West. For more information you can contact Yvonne on 087 6450281 or Katie on 087 1954213.



Katie. "It is so important to have individual rooms when you are an Inpatient as the risks of cross infection are very serious. This new unit in Limerick will also enable patients to stay closer to home for most of their treatment, as being around friends and family when you are unwell is very important for your well being and peace of mind."

Katie has recently received a Person of the Year Award from the Ennis Parish, acknowledging her hard work and dedication to improving facilities for CF adults attending the Mid-Western Regional Hospital. The award was presented by Bishop Kieran O'Reilly.

We would like to congratulate Katie on her tremendous and well-deserved achievement. Katie is a great ambassador for TLC4CF and we are all very proud of her.

**Recently, there has been deterioration in the services being provided to CF patients attending the Mid-Western Regional Hospital, Limerick—primarily in the fields of dietetics and physiotherapy—with both dedicated specialists on sick/maternity leave.**

There have been numerous complaints made by patients and families about the lack of attendance of both the Physio and Dietitian at weekly clinics and for annual assessments. These issues illustrate the negative impact of the government policy on not replacing front line staff on maternity and sick leave.

"Once weight or lung function is lost it may never be regained and this directly translates into a worse outcome in terms of morbidity and mortality. One missed outpatient assessment can have a significant impact on patient

care". CF Consultants, MWRH—Feb 2012. TLC4CF and the Cystic Fibrosis Association of Ireland (CFAI) have been working relentlessly over the past few weeks to rectify this dangerous situation. An evidence-based report was prepared by CFAI/TLC4CF which outlines the deterioration of the services.

At the time of writing there was no Dietitian attending the annual assessments or weekly clinics of either children/teenagers or adults with CF. Furthermore, the only Physiotherapy service being provided to children/teenagers was a partial one through a rota of junior physiotherapists with little or no CF training/experience. In some paediatric clinics there were no physiotherapists at all present. The recent ministerial appointment of Ann Doherty as group manager of hospitals in the Limerick region was viewed as a prime opportunity to try and resolve out issues once and for all, so naturally we requested an urgent meeting.

On the 7th of March TLC4CF, CFAI, CF specialist staff members and hospital management all met to discuss our issues—which yielded positive results; A locum dietitian is being hired to cover the 10 month maternity leave of the dedicated CF dietitian. However, the new dietitian will not be treating CF patients. A permanent, full-time staff member will take on the role of CF dietitian for the duration of leave and will be attending annual assessments, clinics twice weekly, will treat in-patients and will also work with newly diagnosed families.

The selected dietitian will be receiving CF specialist training in Galway in the coming weeks, will attend Dietetic workshops/sessions being held at the CF European Confer-

ence and will also attend a week long training course in Brompton, UK, in September which is being sponsored by Novartis. The replacement dietitian will be in place at the beginning of April 2012.

The post of CF Physiotherapist Specialist at the MWRH has been unfilled since the post holder went on sick/maternity leave in November 2011, with the anticipated return date, not until April 2013. Three new physiotherapist posts within the MWRH are to be filled in the immediate future.

Two of the three posts are to be dedicated to the care of Multiple Sclerosis, with the third being recruited for COPD. At the moment, a Senior Paediatric Physiotherapist has taken on the role of CF specialist for paediatric patients; however she is not dedicated to CF care but attends as many clinics, annual assessments and in-patients as possible on a daily basis.

The service currently being provided has been deemed satisfactory, with the paediatric consultant reporting increases of up to 15% in lung function in some patients. The increase in the overall Physiotherapy work force at MWRH will hopefully allow for more dedicated time to CF care.

TLC4CF and CFAI will be meeting with hospital management on a regular basis in order to ensure a baseline of services is provided and maintained for CF patients attending MWRH.

If have any issues you would like addressed at subsequent meetings, please send on details to [katie@tlc4cf.com](mailto:katie@tlc4cf.com) or alternatively you can call TLC4CF Regional Office on 087 1954213.