

WINTER 2009

# Future Force

MAGAZINE OF THE CYSTIC FIBROSIS ASSOCIATION OF IRELAND

By PWCF For PWCF

New Nebs

The CF Advocate

# Contents

**Introduction** ..... 1  
Editorial -Tomas Thompson

**E-Interview** ..... 2  
Caroline Heffernan on being a CF Advocate

**Web Watch** ..... 3  
Physiotherapy, Advice and Research by Eleanor Walsh

**PWCF Group**.....5  
News Alert, future force e-mail address

**What Ails Ye** ..... 6  
HSE and the pharmacies? By Patricia Duffy

**Photo Gallery** ..... 8  
CF Conference 2008, Carol Brady

**Who wants to be on TV** ..... 8  
RTEs The Clinic By Patricia Duffy

**30th European Conference** ..... 10  
More on the Turkey Conference 2007  
Caroline Heffernan

**Patient Liaison Group** ..... 12  
Update on St Vincent's working group

**Bulletin Board** ..... 12  
Keeps you updated

**The Sound of Silence**..... 13  
A review of new nebs on the market by Tomas Thompson

**Letters to editor**..... 15  
PWCF Mixing

**Ingeminating Sisyphus** ..... 17  
By Nathan Swan

**What PWCFs have been up to ?** ..... 18  
A look around the country to see whats PWCFs have been up to in the last year



pg 5



pg 5



pg 13



pg 15

**H**i readers! As the saying goes we're back, and apologies for the delay. I have over the years like many PWCF eagerly awaited the postman arriving around this time of year with the latest edition of Future Force. Never did I think that one day I would end up as the editor!

A new Future Force team is now in place to write and research on issues related to CF in Ireland and overseas. The new team is made up of many old faces who have shared their expertise very kindly with the new young guns like me!

The team hopes to publish two Future Force issues each year as was the case in the past. To do this we require articles, photos and cartoons from as many budding PWCF journalists out there. So if you would like to follow in the footsteps of some of our past contributors like Orla Tinsley, now writing for the Irish Times, this could be your chance!

Also in this issue, Future Force launches its new e-mail address [futureforce@cfireland.ie](mailto:futureforce@cfireland.ie) for all communications. So get writing, drawing and get the camera out and start e-mailing us for with suggestions for the next issue.

Inside this issue we review every thing from the latest hi-tech nebs to Trish's debut on RTEs "The Clinic". The e-interview is with Caroline the new CF advocate, which is more or less the same job I also do for CF House. This year has also seen the re-development of St Marks ward to St Christopher's in St. Vincent's. We welcomed these new beds which is a taste of things to come for the new unit. You can see how it looks yourself, in the Patient Liaison Group update.

I am sad to report that we are still awaiting the publishing of the HSE working group report on CF. On the transplantation the Mater has still to carry out its second transplant on a PWCF which is very disappointing. Unfortunately organs are the limiting factor once again, so please don't forget to discuss organ donation with your friends and extended families and lets all push this important issue for 2009.

Excellent work is been done on the need for CF units outside Dublin with plans for new developments in Cork, Limerick and Galway as set out in the 2005 Pollock Report.

I take this opportunity to echo the words of the last editor Rory that, "Future Force needs your thoughts, views, articles, wit and wisdom to continue". I now know and appreciate all the hard work the Future Force team lead by Rory and Jean have done in the past. Last but not least I would like to thank all who contributed to this issue and encourage other PWCF and their family members to help us continue the good work into the future.

**Tomas Thompson**

**SEND ALL LETTERS/ARTICLES TO**

**The Magazine Group**

**Future Force**

**CF House**

**24 Lower Rathmines Rd.**

**Rathmines,**

**Dublin 6**

**Email: [futureforce@cfireland.ie](mailto:futureforce@cfireland.ie)**

#### CREDITS

Future Force is the property of:  
The Cystic Fibrosis Association of  
Ireland, CF House, 24 Lr  
Rathmines Road,  
Dublin 6

Tel: 01-4962433  
Fax: 01-4962201  
Lo-call: 1890-311-211  
Email [info@cfireland.ie](mailto:info@cfireland.ie)  
[www.cfireland.ie](http://www.cfireland.ie)

**EDITING STAFF**  
Tomas Thompson  
Rory Tallon

**DESIGN**  
Tomas Thompson  
Rory Tallon

**MAGAZINE COMMITTEE**  
Eleanor Walsh, Nathan Swan  
Maria Daly, Rosie Fitzgerald,  
Caroilne Heffernan, Patricia Duffy  
Brendan Lonergan

**PHOTOGRAPHS**  
Carol Brady, Caroline Heffernan

The views and opinions  
expressed in this magazine are  
not necessarily the views of The  
Cystic Fibrosis Association of  
Ireland.

# E-Interview with Caroline Heffernan on being a CF Advocate



*Caroline Heffernan*

## **FF. Can we have a brief background into your life?**

I am a 37 year old PWCF living in Galway with my family – husband Francis and two children Jamie and Anna, 9yrs and 6yrs respectively. Life can be very busy juggling CF treatments and physiotherapy, family life, working as CF advocate and training for New York marathon. It means everything has a time and place and has to run like clock work, in theory anyway.

My two children are very physically active which means I have to keep up, this is helpful for marathon training. (I always say there is no rest for the wicked)  
When I have spare time my hobbies involve all sports especially swimming, dancing, drawing, reading, watching musicals and going to the theatre mostly to see musical productions or comedy sketches.

## **FF. What does being an advocate entail?**

The CF Association has hired two PWCF to do the job of advocate, on a job share basis. We are both on a learning curve at the moment as nobody knows everything about CF from birth to transplant or everything in the middle from housing to financial difficulties, entitlements and having families etc...

To start with we are ringing all CF families to update the database to make sure all our PWCF details are correct, so it is more accurate, efficient and cost effective with postings. While we are talking to people we are hearing the difficulties and complaints from around the country which is giving us an insight into what the Association needs to be doing to help PWCF and their families i.e. information on entitlements, medical card, housing benefits, education, disability driving permits and mobility allowances, explaining cf to new families and schools, giving tips on physiotherapy to families, sharing experiences of CF to gain more knowledge.

In doing the database I am getting the opportunity to chat to lots of great characters, everyone has a different personal story to tell. The stories are amazing the courage of PWCF and their families waiting on the transplant list, the stress of not knowing must be enormous and yet these families continue with life and try to make the most of it.

Doing this job as CF advocate I learn something new or remember information I had filed away in the back of my brain about CF. I feel as PWCF we deal with our own CF in a very individual way; it's as if we are all in tunnels doing treatments and medications for ourselves in our own way to get to the light at the end. I think we should be more like trees each PWCF is the trunk but we learn from each of the branches attached to us so we now have a support network of a family tree instead of the isolation of a tunnel. Of course I don't mean for us all to start embracing each other physically but rather mentally and emotionally.

There are a lot of frustrations in this job but none to do with the people or work, it involves the difference through out the country in medical care, financial entitlements, housing etc... you can have all the criteria for aid from the government but depending on the person across the desk from you and their understanding of CF, how sympathetic to PWCF and the difficulties we face each day depends greatly how long and hard you have to spend fighting for your entitlements. It is very disheartening for me to say to people "well I know" people that have the entitlements you are looking for but you may and may not get it for reasons beyond our control.

I can get very frustrated when I chat to new families and the information some have received from medical staff is completely unrealistic and ridiculous, this causes these families more grief and anxiety than they need at this time in their lives. Thankfully from talking to a few of these people and from returned phone calls since our first contact I know that having spoken to them life has improved which makes living with CF bearable. This fills me with joy and encouragement as I know each and every PWCF could do the same, it's just that I am getting a direct opportunity through the advocacy job.



by Eleanor Walsh

The part of the job I find hardest is when I talk to families who have lost one or more PWCF, they are so strong and I just become an emotional wreck as I never know quite what to say, they give such great compliments and want to know about you and your life. They also get very upset and angry when they realise that facilities haven't improved for those of us still battling CF everyday.

#### **FF. What are the main skills you draw on as an advocate?**

I think my age is a benefit as you don't live for 37 years without gaining some knowledge and understanding of life. Our CF families are made up primarily of PWCF, parents and siblings. I have the knowledge of being a parent so I can understand the unconditional love and fear of not being able to protect my children from everything bad in this world. I can understand how parents feel in different situations of family life the difficulties we face in raising and supporting our family, I understand and can explain to parents what it is like to have CF how their children may feel about issues as they arise through life, and as it happens in my early days I was the healthy child in our family with a sick sister so I was the sibling also, it is the fact that I have been in all these situations I feel I can, be a benefit to PWCF and their families. Apart from these situational experiences I am also a very good listener; sometimes this is all people need.

#### **Is it weird working remotely from home - how were your techie skills before you started?**

The isolation can sometimes have you twiddling your fingers wondering what to do next, I think it helped that Tomas and I knew each other before we started working together as we got to know each others strengths and weaknesses quicker than if we were strangers. Tomas is definitely the stronger of the two of us when it comes to techie skills but I'm getting better, I'm not afraid to ask when I can't do something so therefore I'm learning all the time.

#### **Does part time work suit you/ how do you balance family and work life?**

At the interview for the advocacy job I was open to full time or part time work but I think the right decision was made by the Association to employ two PWCF on a part time basis. It can be difficult working from home in isolation but Tomas and I usually talk everyday about issues that arise on the Forum or from phone calls we receive.

[www.cystic-l.org/handbook/html/physiological\\_therapy.htm](http://www.cystic-l.org/handbook/html/physiological_therapy.htm)

This web page contains lots of information about chest physiotherapy and exercise. It covers the different physio aids including the vest, pep mask, and the flutter, giving an explanation on how each one works. It also covers autogenic drainage (AD) and exercise. It's not a bad web page for getting an overall view of the importance of physio aids and techniques.

[www.ecorn-cf.eu](http://www.ecorn-cf.eu)

Another useful CF site is [www.ecorn-cf.eu](http://www.ecorn-cf.eu) which provides expert advice to patients, partners, relatives, you can log on and ask the expert panel questions and they will try to get the answer for you and reply via e-mail directly to you. The main aim of the site is to provide easy access to expert knowledge and advice on cystic fibrosis.

[www.cfnewsnetwork.com](http://www.cfnewsnetwork.com)

The internet is an excellent tool for researching new developments in CF around the world. A useful CF website that you can subscribe to is the CF news network (CFNN) you log on and they send you e-mails on new e-publications on CF from around the world. see <http://www.cfnewsnetwork.com/newsletter/user/subscribe.php>

*IF YOU FIND A REALLY USEFUL WEBSITE YOU THINK OTHERS SHOULD CHECK OUT DONT FORGET TO EMAIL US THE LINK AND TELL US WHY IT WAS USEFUL- EMAIL FUTURE FORCE.*

[futureforce@ofireland.ie](mailto:futureforce@ofireland.ie)

## E-INTERVIEW

### **FF. So far in your role as an advocate what are the most frequent concerns you hear about from PWCF and from parents**

Most of the concerns from parents of young children are medically related - how do we get them to do physiotherapy, take the right amount of Creon at school, how to inform them about CF and the children's understanding of CF, will the facilities be in place when my child is an adult etc... When we get phone calls from the parent of an adult with CF it is usually related more towards the financial entitlements and the frustration of appeals and the length of time it takes for paper work to be processed for dietary allowances, disability allowances etc...

### **FF. CFAI is working hard to implement the findings of the Pollock report- trying to secure dedicated CF Units and Staff- what is the general feeling on the ground towards CFAI, the HSE and the Government?**

The statement - "seeing is believing" comes to mind when people talk about the HSE and Government, there is very little trust left so until we can all physically walk through the doors of Vincent's and other units and see the beds promised the powers that be wont be trusted.

I know the CFAI are doing a fabulous job and working very hard to improve facilities for PWCF but not everyone understands the demands and red tape that the staff in the office are trying to wade through every day.

### **FF. We know all in CFAI and the office staff in CFHouse particularly work extremely hard for PWCF but are there issues you think have not been looked into yet that could help improve quality of life for PWCF?**

I am not sure if the following is possible but the idea came up in discussions, Tomas and I would like to see a financial package offered by the Government for PWCF with out means testing where possible – so when you are diagnosed with CF you get medical card, dietary allowance, disabled parking permits etc... without having to spend hours in community clinics fighting and begging from welfare officers that don't understand CF, or battling each appeal individually.

### **FF. Brick walls- have you met any?**

The slowness of everything and red tape that seems to be wrapped around every issue related to CF.

### **FF. What is the general public's understanding/awareness of CF from your experiences?**

I was surprised at the amount of people that approached me after the Afternoon Show to

congratulate me on doing the show and explaining the treatments that we have to do daily, but in the next breath they would say that this wasn't their understanding of CF. People have said that they thought it was a blood disease or a muscle condition and wondered where we got the time to live a normal life. I think most families will admit to not knowing anything about CF until it knocks on your door, the families that openly discuss the difficulties of CF help to spread the awareness to the wider population. There has been much greater promotion of CF to the general public through awareness campaigns TV, radio, press and opportunities of presenting at public meetings.

### **FF. Favourite band**

I don't have an actual band that I like, I listen to a wide variety of music from the Sawdoctors to Classical music, and if a song has a beat that I can dance to I like it regardless of who sings it.

### **FF. Favourite Galway band?**

I have to say Sawdoctors as Dave is my cousin.

### **FF. Have you met any important politicians / professionals in your day to day work?**

When I was at the Transplant Conference I met Mary McAlise and shook her hand. I also met Mark Little (Prime Time) at the DFI conference.

### **FF. What was your school nick name?**

Ca or Car (not very inventive)

### **FF. Favourite Film**

Grease or any of the old musicals – Sound of Music, Singing in the Rain, Calamity Jane to name a few.

### **FF. What's your favourite (calorie filled!) food?**

My favourite part of any meal is the dessert but I like to have a selection profiteroles, pavlova, strawberry cheese cake and trifle with lots of cream.

### **FF. What three items would you bring to a desert island with you?**

Husband and two children don't need anything else.

### **FF. Describe yourself in three words.**

Optimistic, colourful and stubborn

### **FF. Three things always in your handbag...**

When I have my handbag with me I always check for wallet (can't leave home without credit card never know when you will find a bargain), inhaler and mobile phone.

# PWCF Group

## NEWS ALERT FOR ALL PEOPLE WITH CYSTIC FIBROSIS (PWCF)

Approximately 10 PWCF have come together to start up a network for communicating with each other in a safe, cross infection free way via phone and computer. It is similar to the old adult group which disbanded a few years back due to cross infection issues, but with a twist, you get to chat to other PWCF from the comfort of your own sitting room. If you decide to chat via the phone the CF Association will pick up the cost of the phone call, if you decide to chat via Skype it is free from computer to computer (if unsure how to do this someone will talk you through the procedure).

Why do we want people to join?

With approximately 50% of our CF population being adults, the knowledge and understanding we could share with each other is huge and who better to understand, give support, and encourage PWCF than another PWCF.



All other groups with disabilities or life threatening diseases say it's the support from others just like them that helps them through the hard days but with cross infection fears we can't be physically close but that doesn't mean we can't chat and support each other virtually. We meet on the first Monday of each month at 8pm for about an hour and a half, agendas are posted on the Forum the week before. Contact with Caroline and Tomas is needed by the Friday previous to meeting to ensure your position and to receive phone number and pass code.

**New**

### Future Force e-mail address !

We're excited to announce that we've moved to a new address- [futureforce@cfireland.ie](mailto:futureforce@cfireland.ie)! Send us your comments, photo's, suggestions and contributions to our brand new email address.

We'll also keep an eye on the old [futureforcemag@hotmail.com](mailto:futureforcemag@hotmail.com), just in case there are any stragglers left behind! Our big bright and shiny new Inbox is looking very hungry for your mails- so get typing now!!!



# WHAT AILS YE?

Is there something that's been bugging you for a while? Got something to get off your chest? **Future Force** invites you to have a good gripe and asks "*What Ails Ye*"?

**Can someone explain the dispute between the HSE and the pharmacies?**

**By Patricia Duffy**

## **Does a fair price for wholesale services mean cheaper medicine for everyone?**

In Ireland, the cost of wholesale services for medicines is double the European average, which means patients are paying too much for their medicine. On 1st March, after almost 2 years of preparation, the HSE will be reducing this cost from 18% to 8%, and saving patients' money.

Some pharmacies have told their patients that, because of this change, they may stop supplying medicines under various HSE funded schemes, like the Medical Card and Drugs Payment Schemes. What is this all about?

Pharmaceutical companies and manufacturers make medicines and drug products. They sell them to wholesalers, who then sell them to local pharmacies. When wholesalers sell medicines to pharmacies, that patients buy or the HSE buys for them, they add a margin of about 18%. In other European countries the average margin is 7-8%. The HSE would argue there is no reason for such a high margin.

## **So what is the HSE doing about it?**

On March 1st they introduced a new system that reduced the cost of wholesale services for medicines supplied to pharmacies to 8%. Now pharmacists can, on a purely voluntary basis, switch to a new higher fee (€5) for dispensing each medicine to you - this higher fee is also being independently reviewed to see if it needs to increase further. Its hope was that as a result of these changes the medicines that patients' buy, and that the HSE buys for them, will be cheaper.

## **Why is the Health Service Executive targeting Pharmacies?**

They would say they are not. This change is only affecting the wholesale cost of medicines. This cost, the wholesale cost, is what we pay for

moving medicines from the manufacturer to the pharmacy. It is about making the amount paid in this country the same as the EU average, rather than double that average. The HSE is not changing the dispensing fees paid to pharmacies - each pharmacist gets a flat fee for each item that they provide to you via your Medical Card or Drugs Payment Scheme card. These fees total about €320 million per year, and will not be affected. The Minister for Health and Children has set up an independent body to make sure that pharmacies receive a fair and reasonable dispensing fee for provision of pharmaceutical services.

## **Why does the HSE need to change what it pays for wholesale medicine services?**

The HSE spends in the region of €2 billion annually on medicines for patients in hospitals and in the community - spending taxpayers' money allocated to it by the Government. The HSE must ensure that we pay a fair and transparent price for all the services we purchase. Patients should also be allowed to pay a fair price for medicines.

## **Why did the Health Service Executive not discuss these reforms with the wholesalers and the pharmacies before introducing them?**

Firstly, the rate the HSE pays for wholesale services is not a matter for pharmacies - it would not be right for them to determine what the HSE pays for wholesale services. The HSE has over the last two years conducted extensive stakeholder consultation, including public submissions and an extensive independent economic analysis, the Indecon Report.

## **If this all about wholesalers, then why are Pharmacists involved?**

Even though wholesalers and pharmacists do different jobs, in fact, in a lot of cases, they are owned by the same people. For example, 400 pharmacists own the wholesalers Uniphar, the wholesalers Cahill May Roberts owns the Unicare Group of 72 shops and the wholesalers United Drug have invested €300 million in community pharmacies. Wholesalers pass on part of the current 15%-17.66% wholesaler mark-up to pharmacies by way of discounts, with larger discounts given to larger pharmacies.

### **Pharmacies say they will be out of pocket under the new scheme?**

This ignores the fact that extremely high wholesale mark ups are currently being passed on as generous discounts to pharmacies. The HSE reimburses Community Pharmacies for each item that they dispense to patients under the various schemes. The reimbursement price (the list price) is meant to cover the cost price of the medicines. A 50% mark up on this reimbursement price is paid to pharmacists for the Drugs Payment Scheme, the Long Term Illness Scheme as well as some other patients with further dispensing fees paid for all patients under all Schemes. Because pharmacies receive generous wholesale discounts, the reimbursement price currently paid by the HSE and patients is actually far higher than the actual price that the pharmacy pays to the wholesaler.

### **Pharmacies say that hundreds of pharmacies will close – is this true?**

This has been claimed before on other occasions but it has never come true. In fact, the numbers of pharmacies in Ireland has increased by 26% during the past 5 years. If it will affect pharmacies it will effect small local communities which have 2 or more pharmacies in a small community.

### **Can you reassure Medical Card and Drugs Payment Scheme Card Holders that they will still be able to get their drugs at their local pharmacy in the future?**

Pharmacies are bound by contract to give three months' notice of withdrawal from the community pharmacy scheme. The HSE have not received any such notices to date. The HSE would be surprised if any pharmacy denied a patient access to the medicines they need and are entitled to under various state schemes. Nevertheless, the HSE is putting in place contingency arrangements to respond to any instances where this may happen. From March 1st 2008, all patients will continue to be entitled to all their drugs and medicines under the various schemes, in the normal way, and can avail of this service at any community pharmacy of their choice. If a pharmacy indicates it will not supply medicines to a patient,

the patient can go to another pharmacy. The original pharmacy must give the patient any repeat prescriptions it holds and a copy of the patient's dispensing record.

### **HSE Advice to Patients**

If your pharmacy has told you that they will not supply medicine under the Medical Card or Drugs Payment Schemes in the future, what should you do?

- Go to your Pharmacist and ask them if they will be filling your prescription in the future.
- If they say no, then you should ask them to return your prescription to you
- Call the HSE info-line on 1850 24 1850, open from 8am to 8pm Monday to Saturday
- They will give you details of pharmacies in your area that will fill your prescription, or make alternative arrangements to ensure that you can get the medicines that you need.



**THE PRICE OF A PILL?**

## **CHALLENGE PWCF Group**

**Want to know about charity sky dives?  
Challenge Us!**

**Want to know about the latest in holistic  
medicine?  
Challenge Us!**

**If there is anything you want us to do, we  
will do it so you don't have to?**

**We are challenging you to...  
Challenge Us!**

# CF CONFERENCE 2008



# Who wants to be on TV?



In early 2008, and in the wake of the 'Joe Duffy' phase of awareness about CF, Ardmore Studios, the people behind RTE's successful medical drama 'The Clinic', contacted CFAI regarding a forthcoming episode. The producers and directors were planning to feature CF as a main storyline and they invited CFAI and PWCF to provide creative suggestions in terms of a storyline. Everyone seemed to jump at the opportunity to keep CF in the eyes and the minds of the public.



**The Cast of RTEs the Clinic**

The producers settled on the theme of a young woman with CF, leaving school and heading towards a more independent life at college with all its rewards and challenges. There was close liaison between the producers of the programme and their own medical and physiotherapy advisors in terms of the storyline, scripting and direction. The producers were eager to seek support with the practicalities of capturing CF as it is. Every effort was made to create an authentic picture of day to day reality of CF, including spirometers and nebulisers. They used photo's of actual medicine cupboards of PWCF!

To really drive this home, the producers agreed to use an 'authentic CF cough' for their scenes where the main character begins to feel the strain and is experiencing more significant symptoms. When they contacted me to discuss the difference between a CF cough and a 'non CF' cough, it was such a strange conversation. Over the phone, I offered to demonstrate it to them and then laughed-expecting them to think it a strange offer and politely hang up on me. I couldn't believe it when they jumped at the offer and began arranging a time for me to visit their production studio!



**Patricia in the production studio**

In early July, I travelled to their post-production studio in Dublin city centre for an unusual appointment. The artist/sound engineer and director played clips of the episode where coughing occurred, and asked my opinion. It definitely didn't sound like the actress had more than a tickle in her throat, and she looked like she had struggled to achieve that much! So they began recording my cough, and then playing it in synch with the clips from the episode. It was odd to hear myself, particularly when watching that sound 'coming from' the actress on tv! It took little more than half an hour, a small glass of water and a few tissues to achieve the elusive sound they were looking for. The finished product? You'll just have to go online to see!

[www.rte.ie/tv/theclinic/](http://www.rte.ie/tv/theclinic/)

## 30th European Cystic Fibrosis conference in Turkey 2007

*By Caroline  
Heffernan*

Hi all, This is Caroline and Grainne (PWCF ). We attended the European Cystic Fibrosis conference in Turkey in 2007 with Godfrey Fletcher (CEO) and Seamus Bohan (CF parent and NEC member). Our journey started in Tuam on Sun the 10th of June at 5.00am for us girls from Galway and we arrived in Belek, Turkey at 7.00 pm that evening, just in time for dinner. We had Monday and Tuesday off to recover and get our bearings and enjoy Turkey. While Godfrey and Seamus attended the CF worldwide AGM.

On Monday we investigated our hotel to discover beautiful pools, gardens, and a fantastic beach which Caroline promptly went to enjoy. In the afternoon we went to Antalya with our guide. We walked around the old town through Hadrian's Gate. The walls of the old town are kept together by the strength of egg whites! Yes seemingly the masons in the days past used egg whites as a strengthening agent. We visited the harbour, climbed steps to the top to be treated with a fantastic view of the Taurus Mountains. Shopping had to be on our agenda as girls will be girls, so the men patiently waited while we visited a diamond store and a leather factory. Even though diamonds are a girl's best friend we didn't purchase. Next stop on our trip were the beautiful waterfalls which were breath taking; also the salty mist from the waterfalls didn't do either of us any harm.

*Tuesday:* as the saying goes when in Rome do as....it was a must for us to visit the Turkish baths. We decided an authentic experience would be more fun than the usual pampering you get in the hotel. So we headed off, first impressions were a bit daunting but we soon relaxed and enjoyed the experience. The package included sauna, steam room, jacuzzi all optional, a body scrub, bubble massage and an oil massage to finish. During the course of the treatment icy cold water was thrown at us (needless to say you could have heard us in Ireland) Tuesday night was the CFWW president's dinner which was our first meeting with the CF conference group, who we found most friendly and despite language barriers we managed to have interesting conversations.

*Wednesday:* was off to an early start as conference began for us with the lay-persons meetings which were interesting and educational to all esp. the Turks who have very poor resources. It made us both think about our facilities and what we have and haven't got, even though in Ireland our journey is far from over and improvements are greatly needed we are not on the starting blocks either. The day was all work and no play so we felt it was only fair to let our hair down and enjoy the garden party at our hotel that evening. The Kenyan acrobats entertained us with death-defying stunts followed by a lively band. There were different activities for kids and adults to enjoy e.g. bull riding, human table soccer, sumo wrestling, face painting etc....

*Thursday:* the scientific conference began. we were a little apprehensive that we would comprehend the material content of some of the lectures. We all picked workshops of personal interest (some are listed below) but due to the scientific nature of these meetings some information was difficult to comprehend and translate.

*Friday:* we headed off again pens and paper to the ready, again we picked our workshops to attend and we hope you get some valuable information from the lectures we attended. The conference ended for us with a beach barbeque, where we enjoyed the company of our new Cystic Fibrosis acquaintances. We discussed all that we learnt from each other at the conference in an enjoyable relaxed party mode.

### **Now for the Science Bit**

Robert Beall talked about the changing face of CF, we are all becoming wrinklies. Quality of life, length of life and lung function is improving with each new drug treatment.

There are thirty new drugs in trials at the moment – drugs to treat the basic defect of CF as well as antibiotics to treat infections.

The discovery and research, development in preclinical trials and safety test and dosage efficiency and distribution of drugs to patient of just one drug can cost up to 72 million Euro

Preston Campbell spoke about the importance of hypotonic saline, he compared the lungs to a pot of stew if you let the water boil out it becomes thick and mucky just like the mucus in the lungs.

Jean Chevaillier spoke about physiotherapy, he said there should be no standard physio for all, the age and ability of PWCF should be a good guide to what techniques are to be used.

Upper airways to optimise nasal breathing warm up, moisten and filter inhaled air to eliminate bacteria. HOW – blowing your nose but not as we know it, inhale (sniff) through your nose and spit out through your mouth followed by nose rinsing with salt water.

Lower airways normalise relationship between different lung volumes. How using active and passive means choosing breath enhancing position, to regionalise ventilation into left and right lung separately.

### **Breathing**

Analytic breathing exercise - lay back inhale chest as big as possible and stretch out abdominals.

Functional breathing exercise - bouncing, swimming and all physical exercise. Relaxation breathing exercise and Yoga - improve body structure and autogenic drainage.

When do we start physiotherapy? As soon as diagnosis is known an active lifestyle helps greatly, become an expert in treatments tailored to your own needs, keep motivated and actively participate in your treatments.

Sports and oxygen supplements – always continue to exercise but take extra oxygen if needed. It's cheaper to buy new shoes than four new tyres for the car so walk whenever possible. Thursday morning parent patient education in nutrition, the dieticians play games such as snakes and ladders with food groups to encourage kids to understand and take control of their own nutrition and well being.

In Denmark they have a school where the CF team teaches strategies, increases the PWCF knowledge and coping skills. The school consists of three hourly classes, of three lessons over a period of three months. The purpose of this school is for the kids to be together, do physio together and take enzyme. The kids learn about the digestion and respiratory systems from their doctor. They learn practical things like swimming, physical exercise, cooking, play games and do quizzes about cf. They discuss responsibility of life and treatments, coughing hygiene, social topics and most important dreams.

This poses a question over cross infection guidelines which of course was asked of the speaker. People who are being treated for infections can attend school. People with MRSA attend the school with a non-cf friend so they get the benefit of the education and the fun element with their friend.

In Poland they try to motivate their patients with a "Life Club CF" program, the idea behind this is that if they encourage compliance over a period of time they hope it becomes a habit so by rewarding (with camera, laptop and even drugs and nebs) a healthy lifestyle and increased treatments. Most improvements occurred in the exercise program.

Thursday afternoon we attended the Aging Group meeting below is a list of the work being done by the group:

- \* they are putting a paper together of stories of people over forty
- \* they are collecting names for a registry of over forty year olds
- \* they think there are about two thousand pwcf world wide over forty
- \* from current information males are out living females due to BMI being greater in males.

### Promoting physical exercise in PWCF

All sports are good from swimming and soccer, to Yoga and Pilates to hip hop dancing all should be encouraged. Exercise increases secretion clearance, improves self esteem and quality of life. It also normalises life as well as being a benefit. Improving skeletal muscle strength and exercise tolerance also contribute to enhanced life.

### Adult Life with CF

It was a child psychologist that spoke about adult life as she felt it is the responsibility of paediatric team to prepare children for adult life by:-

- \* increasing responsibilities
- \* responsibility of paediatric CF team to prepare children for adult life
- \* stronger ties with parents – social maturity poor, emotionally demanding – attitudes
- \* need to change, over dependence on parents
- \* expect to live a normal life – marriage, old age
- \* exposure can increase understanding, seven to twelve year olds can learn health promoting behaviours
- \* children can be active in medical treatment
- \* children can be involved in making decisions
- \* children should understand correspondence from the CF team.

### Managing Adult Life

Make a plan of what you want to do with your life.

Monitor and adapt to change, the quicker you accept change the quicker you move on in life. Respond to all aspects of life and act on what life throws at you. Step back and take time out to view what's happening in life and reevaluate what's important. Everyone must make own mistakes learn from them and move on.

Personal relationships are the same for all adults, peer pressure, body image, sexuality and public attitudes.



**Caroline, Mitch (President of CFWW) and Grainne on a night out in Turkey**

The conference was very positive towards people with CF. All the professionals really showed enthusiasm for knowledge in improving the lives of PWCF. The professionals also realise that they can't help us if we don't help ourselves by complying with medications and treatments needed to keep us as healthy as possible.

# Patient Liaison Group

## ST VINCENT'S MEETING UPDATE

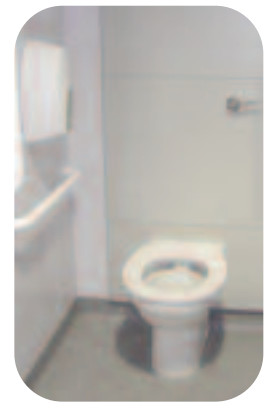
The cystic fibrosis Patient Liaison Group is an advocacy-working group for PWCF who attend St. Vincent's University Hospital (SVUH). This is a multidisciplinary group representative of all those with an interest in cystic fibrosis.

The cystic fibrosis Patient Liaison Group meets on a quarterly basis. In the past year the group has seen some exciting developments not least the re-development of St Marks Ward into St. Christopher's ward the CF 8 bedded ward, the re-development was not due to the work of liaison group, but we would like to take this opportunity to welcome the development.

In the last year the PWCF representatives have raised the concerns of other PWCF patients in relation to hospital admissions through A&E, waiting times for beds, the criteria for PWCF who are doing home IVs. Cross infection as always is high on the list of every meeting as we continue to work with the CF team and hospital staff to have sensible guidelines in place to deal with cross infection from the use of O2 stats machines on the wards to PWCFs mixing in the coffee shop. The need for access to the internet for PWCF is also being addressed by the group. The new 8 bedded ward St Christopher's now has internet access, TV and radio. The PWCF group plans to roll out data cards for patient with laptops to the rest of the hospital in 2009. All patients will now receive on admission a patient handbook highlighting the do's and don'ts of the hospital and will have a CF flyer for all PWCF inserted in the back with the contact details for the liaison group on it.

If you would like the liaison group to take up your concerns you can contact the present PWCF representatives who are Tomas Thompson and Rory Tallon; they can be contacted via e-mail [svuhreps@cfireland.ie](mailto:svuhreps@cfireland.ie). or phone @ 0879323930 and they will bring forward any items for discussion at the liaison meeting. Alternatively you can contact us through CF House - local 1890 311 211 or Email [info@cfireland.ie](mailto:info@cfireland.ie).

The photos on the top right of the page show the redeveloped St. Christopher's ward with TV/internet the toilet and shower.



## Notice Board

### Expert Patient Advisors

Caroline Heffernan and Tomas Thompson as your CF Advocates - they are working to improve things for us all and can be contacted by e-mail [tthompson@cfireland.ie](mailto:tthompson@cfireland.ie) or 0879323930 or [c.heffernan@cfireland.ie](mailto:c.heffernan@cfireland.ie) 087 9323933.

### PWCF Delegates 2007-2008

Nathan Swan, Brendan Lonnergan  
Maria Daly and Rory Tallon- anything you think should be done or improved and you dont know who to tell- well tell us and we will tell the Association. Contact us through CF House or through [Futureforcemag@hotmail.com](mailto:Futureforcemag@hotmail.com) or post your thoughts to the CF Community Forum.

### CFAI Conference 2008

Watch this years conference on your PC. Check out conference clips on [http://www.cfireland.ie/articles.php/news/\\_conference\\_clips](http://www.cfireland.ie/articles.php/news/_conference_clips)

### CF Christmas Party

The Castlegate Hotel in Westport host this years christmas party on the weekend of the 29&30th of November - in total 14 PWCF and partners attended and an excellent weekend was had by all. Photos will be in the next issue of future force.

# THE SOUND OF SILENCE!

BY TOMAS THOMPSON

Unlike conventional nebulizers, ultrasonic or mesh based nebulizer offers fast treatment times and yes its silent so no more noise! When you first see the mesh based you will ask your self how can they make them so small, you will also think its broken because it doesn't make any noise! Ultrasonic or mesh based nebulizer can do for nebulizer what broadband did for the internet. This article reviewed 3 ultrasonic or mesh based nebulizers on the market the Aeroneb Go, the e-flow and the I-neb. Two of them have been used by the author the Aeroneb Go and the I-neb with the e-flow being researched by a PWCF other than the author. The Aeroneb Go was developed in Galway and is an Irish product distributed by Oxygen Care in Dublin. It is simple to operate, works with either an AC wall controller or a battery pack, can be cleaned with soap and water or with the latest version you can boil the parts which is even better. The Aeroneb Go is for use for patients of all ages (infant through adult) and is approved for medications that are prescribed for general-purpose nebulizer. To date the Aeroneb Go has not been approved for use with tobramycin or pulmozyme, this is because trials of such medications have not been done on ultrasonic nebulizer, but may change over time as ultrasonic nebulizer become more common.



## The Aeroneb Go by Aerogen

I have had one for over a year and only use it when I am away as I just have the battery pack and not the AC adopter for the mains. There are many advantages to the Aeroneb Go as its much faster, silent, smaller has no tubing and can run on 3 AA batteries. One of the strong selling points to the nebulizer is the price you can get one with battery pack and the AC adopter for less than €290, which is a lot less than other nebulizers in it class. For more information and publications on the Aeroneb Go, see [www.aerogen.com/general.html](http://www.aerogen.com/general.html). You can purchase the Aeroneb Go from Oxygen Care in Dublin. ([www.oxygen-care.com](http://www.oxygen-care.com))

The e-Flow from Pari is the model sold in the US. The e-Flow rapid is the newer and better model sold in Europe there is a difference. The I-neb is made by Respiroics and can only be got if you are on the medication Promixin (colistimethate) which is the same as colomycin.

The e-Flow Rapid is light weight, silient, can run on batteries and is faster than older nebs and can cut treatment time. It is simple to operate, works with either an AC wall controller or a battery pack, can be cleaned with soap and water or with the latest version can also be boiled. The e-flow rapid is for use for patients of all ages (infant through adult) and is approved for medications that are prescribed for general-purpose nebulizer. The e-Flow uses VMT (vibrating mesh technology) which is silent and can deliver the medications much faster than older nebs. The e-Flow Rapid is sold by Pari see [www.pari.de](http://www.pari.de) and currently there is no direct supplier in Ireland so you must buy it from direct the UK.



## The e-Flow rapid by Pari

The biggest issue with the e-Flow is the cost and the fact that you must replace the membrane a number of times each year at additional cost to whoever purchase it! Its price is around €800 and you need to replace the membrane every 6 months and that's a Pari recommendation, but the experience is that this could be as low as every 2 months at a cost of €75 each time. Maintaining an e-flow could cost up to €200- 300 a year on top of the cost price.

I would say that the e-Flow would play a role for PWCF who travel a lot or when on holiday and only used when away, but it does not seem to be the solution for every day use yet. There are advantages such as it is silent and it has faster inhalation times, but it also takes much longer to clean 10-15 mins and must be cleaned very well to prolong the life of the membrane.

## THE SOUND OF SILENCE

There are other options out there for travel nebs such as the Freeway Lite and the Aeronex Go at 1/3 the price of the e-Flow Rapid and are fine for traveling.

The I-neb is also third generation nebulizer using AAD (Adaptive Aerosol Delivery) system. It is a small, battery powered, lightweight and virtually silent drug delivery device designed to replace the conventional nebulizer/compressor. The I-neb works by delivering a precise, reproducible dose of drug. The aerosol is created through VMT (vibrating mesh technology) just like the e-Flow, and the dosage of drug is controlled through an AAD Disc and specific metering chambers. I have used the I-neb and it is a huge advance in nebulizer technology. You don't need as much medication as little or none of the drug escapes into the environment around you, removing the need for filters and pipes out the window. It cuts the treatment time by up to 1/3 in some cases, It is simple to operate, works on battery which only needs to be recharged every few weeks. It can be cleaned with soap and comes with a case for cleaning each of the parts. The I neb can be used for patients of over 3 years of age and is approved for medications that are prescribed for general-purpose nebulizer, but not Tobi. You can use software to monitor the number of times you use it also!

The down side to the I-neb is that you cant buy it and if you could it would cost over €2,000, you can only get if you are on the medication called Promixin (colistimethate) as the company which makes the I-neb also owns the company that makes the Promixin.

On the question of what medications can be taken in the e-Fow is conflicting, Pari have done their own research (see [www.pari.de](http://www.pari.de)) on the use of medications such as Tobramycin, and say that it can be used in the e-flow. The manufactures of Tobramycin on the other hand are saying that you can't use Tobramycin in the Aeronex Go, e-Flow or the I-neb as it has not been approved and they are not convinced that it works 100%, 100% of the time. Other medication such as Pulmozyme and other antibiotics also have question marks over them but not to same degree as Tobi. Respirationics have also done some research on the use of Tobi and the I-neb and also say that the I-neb can be used for Tobi. The main reason that the manufactures of Tobi will not approve any new nebulizer is that they would have to redo medical trials for each one, at huge expenses of time and money.

**“Ultrasonic or mesh based nedulizer can do for nebulizer what broadband did for the internet”....**

On the other hand Tobi are working on their own new delivery device, which is currently on trial and will work just like a inhaler and should be available in the next 2 years which is welcome news.

As it currently stands and I would say for the foreseeable future if you want an Aeronex Go or e-Flow Rapid you will have to buy one yourself, as there are not approved for use in meds such as Tobramycin so clinics can't prescribe them, in turn the HSE won't pay for them. If you want an I-neb you can only get one if you are on Promixin which the HSE also won't pay for!



The I-neb by Respirationics

## Magazine Group Revival

**This issue of Future Force has been brought to you by the letter 'o' the number 6, no, just kidding, it's actually been brought to you by a Magazine Group. People like you- (sprawled on the couch etc.) spent some time using their various skills to put together this sparkling new issue of Future Force!! As you can imagine, a variety of jobs are involved and we uncovered some previously unknown talent in the process.**

**The best thing about being in the Magazine Group is the 'virtual' aspect- meetings are held every few weeks where people from the four corners of Ireland link up through teleconferencing. Some folks use their phone at home, some their computer via Skype and others their mobiles in hospital. You can't be more inclusive than that! These 'group chats' helped it come together nicely and even better- there's no need for any cross infection worries! Email us at [futureforce@cfireland.ie](mailto:futureforce@cfireland.ie) if you wanna join!!**

# LETTERS TO EDITOR



## *PWCF Mixing!*

It's really hard to understand what all the fuss is about with trying to get CF's not to talk to each other in hospital. When you're in and out a lot, the novelty (and the visitors!) wear off and there's not a lot for you to do. Going from one IV to the next, you'd go mad without chatting to someone else to keep you sane. You've got to get up and about and stretch your legs or you'll be adding bed sores to your list of things to feel crap about. There are some days when all you want to do is to get away from the old folks around you and talk to someone your own age. It's not as if there 's anywhere for you to go to get away from other people with CF. You're gonna bump into people and have a chat, that's the way it is. Sometimes you can even pick up little gems of info- about certain doctors/nurses to steer clear of! Some of the most useful info I've learned about antibiotics and I.V's were from other patients who were in the same boat as me and had been through the same stuff. Sure when the showers are out of action, you end up having to share the same facilities- what can you do?

### **Editor's Response**

#### **Dear reader,**

We completely understand, as long as it is the little gems and not the little germs that you pick up! There is a huge emotional strain that we all face when hospitalised. The routine of the assessments, the physio sessions, the early starts, the IV's -all these alone can make you miserable, yet we then have to contend with elderly and senile patients who through no fault of their own demand a lot of nursing care. The combined experience is extremely difficult especially given the young age of most PWCF in hospital. It's all particularly shocking and daunting for the even younger PWCF coming to the adult hospital for the first time. You would definitely go absolutely bonkers without speaking to others. We agree- you really do need to speak to someone- someone who knows how to survive the experience, someone that you can freely ask all the scary questions

you are afraid to ask the team. Let's face it the new interns you see on a daily

basis have difficulty even finding your veins so how can they even begin to appreciate what your life is like, all your anxieties, living with your illness and all the worries and questions inside your head which multiply when you are hospitalised? The solidarity of speaking to others who have been through the same problems, learning the coping methods they used and just sharing your anxieties to get through your day in hospital are of invaluable benefit to you.

Unfortunately what you must always remember too is cross infection. Remember that you present an infection risk to all other PWCF you meet in person and remember that they pose an infection risk to you. Remember also while in hospital on IV antibiotics that you have an active chest infection, so not only is your immune system already working overtime and your body's defenses weakened making you susceptible to even more infection, but you are even more of an infectious threat to the other PWCF you meet during this time too - more so than the risk you would normally pose to them when you are feeling well.

Be informed also that the bacteria causing the infections in PWCF are extremely good at developing resistances to the antibiotics you take to try to kill them. This antibiotic resistance can easily transfer from one bacteria species to the next. This is why close proximity of PWCF is very dangerous as it allows bacteria from one PWCF not only cross infect another PWCF but also allows your bacteria to pass on their antibiotic resistances to the other bacteria species colonising another PWCF. These are some of the reasons why, over time, the bacteria you grow in your sputum can become more and more resistant to a wide range of available antibiotics- your bacteria acquire new antibiotic resistances from other bacteria.

**Dear Editor,**

Recently I was waiting to be seen in the hospital and a woman sat down beside me. Since I am a bit paranoid about cross infection and I have some nasty bugs myself I got up and waited down the corridor. Subsequently I heard the doctor mention that she couldn't go for a PFT as she had MRSA!! I was shocked that a PWCF with MRSA would not know about cross infection issues. I understand that it is hard for many PWCF who are used to mixing to suddenly get out of those habits and it is easy to make mistakes. However it is important that we all work together to reduce the amount of infections that PWCF can pick up, especially from each other.

Yours,  
Concerned PWCF

### **Editor's Response**

Dear Reader,  
You were quite correct to try reduce the infection risk by moving away from the person as far as you could. You were an infection threat to them. As you subsequently learned they posed a huge infection risk to you also. If you encounter this again we suggest you explain the situation urgently to the CF team. They may need to test you for MRSA. Be sure to complain that this happened in the first place and seek assurances that this won't happen to you again. Don't be afraid to demand they tell you how they can guarantee that this won't happen to you again. This is a serious problem and could have had serious consequences for your health so do not be fobbed off by a simple response that this won't happen again. If you wish you can report the incident to the Director of Nursing within the hospital.

Unfortunately we will not always know who the other PWCF in the hospital are. Two PWCF could be sitting beside each other at the cafe for instance and it would be very likely the two PWCF would not even know the other person beside them has CF let alone whether they have MRSA or not.

It is unfortunate that some PWCF may not fully understand or appreciate the risk that the bacteria species which grow in their lungs can be harmful to other PWCF who have a completely different set of bacteria species. Cross infection occurs when the bacteria from one PWCF infects another PWCF who was in close proximity. PWCF with MRSA have bacteria growing in their lungs that are resistant to an antibiotic called methicillin. This antibiotic can be used to treat some infections in PWCF who don't have MRSA. However, if a PWCF was cross-infected with MRSA then this methicillin antibiotic is no longer an effective antibiotic treatment option for them.

If anyone with CF has any of the following 3 main types of bacteria they need to be very aware and careful about coming into close proximity with any other PWCF:

MRSA

Burkholderia Cepacia (B Cepacia) species

Multi-drug resistant pseudomonas species

If this is the case for you ask your CF Team what this means for you, what particular hospital restrictions are in place that you may need to follow and what this means for you meeting any of your friends with CF.

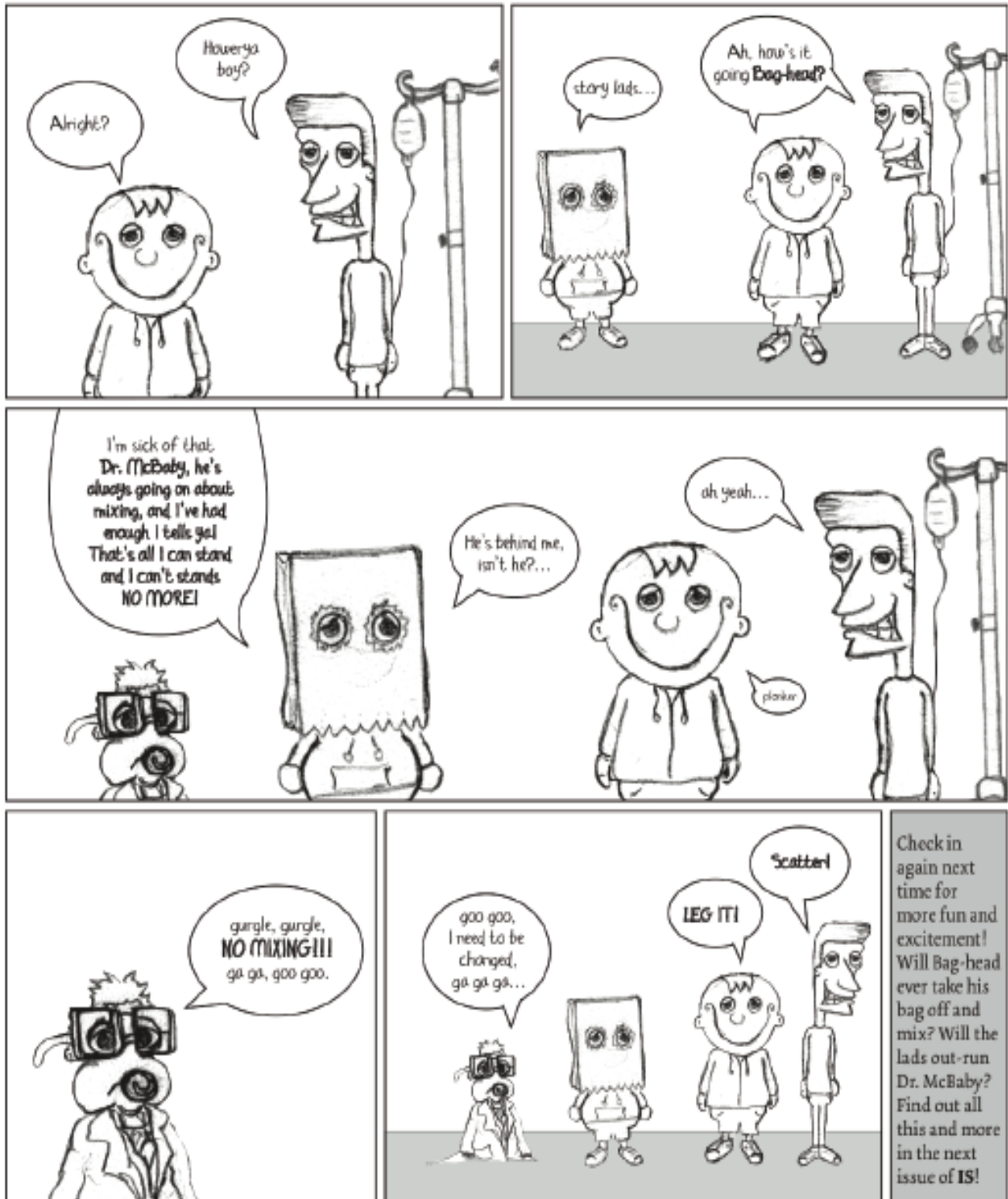
Also if anyone with CF does not have any of the 3 bacteria types mentioned above and does not have Pseudomonas species then they also need to be extremely careful and aware about coming into close proximity with any other PWCF, so that they don't acquire a new bacterial infection or colony.

The responsibility is on all of us to be conscious of other PWCF within our proximity that we know of and to take appropriate measures in an effort to "do as much as you can to reduce the infection risk as much as you can".

**Editors comment: If you have any concerns or questions for the Future Force Team please write to the editor by email to: [Futureforce@cfireland.ie](mailto:Futureforce@cfireland.ie) or by post to: Letter to the Editor, Future Force Magazine, CFAI, 24 Lower Rathmines Road, Dublin 6.**

# Ingeminating Sisypus

BROUGHT TO YOU BY PIDLEY & MRCSI



# What PWCF have been up to in the last year!



Training for the NY marathon



THE NEWLY WEDS



Enjoying the winter sun in France



Young Micheal Devaney son of James (PWCF) and Shana Devaney

Working hard at college



The new sport of shead jumping

How do i get home?

