



# ACF News

Regional Adult Cystic Fibrosis Newsletter  
St. James's University Hospital

## Welcome

Dear All,

I hope you are well and that you have a very enjoyable summer. We are presently working hard to improve delivery of information. This includes the development of a new website which will be launched in a few months' time. We have also installed three large TV screens on Ward 2 and in all the examining rooms which are designed to display your photographs that you have kindly sent to us as well as travel news, clinical information and video. I am very keen to receive more photographs and should be very grateful if you would consider sending them through to me at daniel.peckham@leedsth.nhs.uk.

I would also like to run an 'Art Exhibition' displaying pictures, paintings and other art formats for a period of one week as I think this would be inspiring to others and bring pleasure to the staff. Towards Christmas I would also like to run a one week period of music, videos and songs, which we can display. If this proves successful then we can repeat this on a regular basis. Therefore I should be grateful if you would send me CD's or DVD's of any music videos that you produce or alternatively a picture of yourself playing an instrument or singing of the music track then you should send it to Alison Anderson, Secretary, on Ward 2. All images should be emailed to me. If you have any information please do not hesitate to contact us.

Best wishes

Daniel Peckham

## Hi Everyone

Welcome to our summer newsletter which should (for the first time) actually reach you in the summer! I think the varied contributions will be of interest to you but we still wait in vain (mostly) for more bits and pieces from yourselves. This time, however, we do have columns from Andy Ward and Jackie Reid. Many thanks to them. Lastly can I reiterate Daniel's request for more photos to add to our TV screens on the ward. We are getting bored with the same old rotating display!! Enjoy the newsletter - it's for you.

Best wishes

Steve Conway

## Cystic Fibrosis Worldwide (CFW)

CFW is dedicated to improving the quality of life and life expectancy for people living with CF in developing countries. It has 52 member countries with a number of members coming from developing parts of the world.

CFW is aware of the desperate situation facing those who have cystic fibrosis, their caregivers and medical professionals in countries with poorly developed economies.

In May, we joined the CFW Educational Team which comprised four doctors (from France, the Netherlands and the UK), a nurse and a dietitian (from the UK), a physiotherapist (from Sweden), a patient (from the Netherlands) and representatives of CFW and CF Europe. The CFW Educational team delivered the 1st Balkans CF Conference in Skopje, the capital of Macedonia. For those who don't know, Macedonia is a country in the central Balkan Peninsular in southeastern Europe. It is a landlocked country and is bordered by Serbia and Kosovo to the north, Bulgaria to the east, Greece to the south and Albania to the west.

The Conference was opened by the Macedonian Minister of Health. It felt like being at the United Nations with headphones on whilst his speech was being simultaneously translated into English. The conference had three parallel programmes; one for doctors, one for allied health professionals (dietitians, nurses, physiotherapists, etc) and one for families and patients. It was an intensive two day programme. We gave over five hours of lectures and took lots of questions. Our sessions were translated into Macedonian for the audience which was a new and very strange experience for Alison. You can hear someone speaking in a foreign language as you are speaking in English and you always feel as though you need to wait for them to catch up!!

We were both shocked at the lack of access the patients in the Balkan countries have to some of the most basic treatments, ones that we would usually expect to be routine. There was not a single physiotherapist at the meeting as any physiotherapy is usually delivered by the nursing staff. There were only two nutritionists/dietitians present and it became apparent when Alison spoke to the parents group that most patients lacked even the most basic nutritional advice. This meant that we nearly missed the flight home as Alison's talk should have finished at 2.30 but she was still being asked questions at 3.20!



It was hard work preparing all the lectures, the travelling was long and tiring and it was a busy schedule whilst



get one pair of lungs so you may as well make them last as long as possible so remember, no pain, no gain and feel the burn!

Andrew Ward

We couldn't have put it better ourselves! Don't wait for us to ask you - if you are interested in the programme please speak to one of the physiotherapists who will be happy to discuss it further.

If you have a travel compressor at home, could you please return it as soon as possible. They are loan devices for when people are going on holiday. We do not have any left to hand out, and no resources to buy more. If you have issues with your current nebuliser system, please discuss it with the physiotherapist at your next clinic visit. Thank you.

Kim Pollard and Tracey Hughes

## Port Flushes

Just a quick reminder for all patients with either a P.A.S. Port or Port-A-Cath insitu. We recommend that P.A.S. Ports are flushed every 4 -6 weeks and Port-A-Caths every 6 - 8 weeks. You can request for this to be performed at your outpatient appointment, or alternatively you can arrange to have your port flushed on the ward in the evenings or at the weekend. It may be possible for us to flush your port at home if we are in the area. We are always happy to discuss the possibility of training someone close to home, i.e. a relative or practice nurse, to flush your port.

Please bear in mind over half our patients have ports. Therefore we ask that you remind us that your port needs flushing!

Thank you the CNS team.

## Cystic Fibrosis Parent Carer Group

As the parent of an adolescent with CF there are times when I struggle with the transitional process from child to adult and I'm sure I am not alone with this.

Due to segregation in clinics and on the ward it has become difficult for patients and parents to build links and friendships with other families going through the same everyday dilemmas, 'have you taken your neb' and then how many times do I remind him before becoming a nag!

With the support of Maria Phillip (Ward Sister) and Sharon Willson (Social Worker) we have organised a parent's group.

The aim of the group is to offer friendship and support to each other as parents/carers.

We had a good attendance at the first parent's group meeting held on Tuesday the 5th May 2009 at The Black Bull Inn, Birstall. We had the use of a separate room so we could chat in private. Maria and Sharon came along to offer their support which was very useful as they were able to share their knowledge and experience of caring for patients with CF showing an understanding

of the demands on patients and parents. A variety of issues were discussed from non compliance to starting university. Everything discussed in the meeting is kept totally confidential.

We are hoping to get together on a monthly basis and all parents/carers are welcome to come along and join us. The next meeting is planned for Tuesday 2nd June at 8pm at the same venue The Black Bull Inn, 5 Kirkgate, Birstall, Batley WF17 9HE.

If you would like any further details contact Maria Philip or Sharon Willson Ward 2, St James's Hospital 01132065702 or you can contact me via email on

jackie.turner4@btopenworld.com



## Gossip Column

Hi folks and welcome to this edition of Staff 'gossip' !!

Caroline one of our physio's has just got married and is off work for three weeks before she returns from honeymoon, (wedding photos to follow). We wish her and her new husband every happiness in married life.

Our social work student Emma has now finished her placement with us and has been a valuable addition to the team, assisting Sharon Willson with her caseload. Many of you who have recently received support from Emma I'm sure will wish her success with the rest of her career.

Chloe, who has been working along side Caroline Harris (our resident clinical psychologist) has also reached the end of her secondment with the CF Unit. Chloe has taken some of Caroline's clients during her time with us and been involved in some audit work on the Unit, looking at feedback from the patient questionnaires regarding the information screens, giving us a valuable insight into what you would like to see more or less of on the display screens.

Rachel Metcalfe (bravely) spoke at the recent Nursing and Midwifery Conference at Leeds Town Hall in front of a huge audience of people from across the Trust and from the Department of Health, to let the organisation know how proud we are of all your achievements and how the feedback shows that a huge percentage of you like to see photos and information displayed on the screens, (keep sending the pictures).

Nearly reached the end of the gossip column now, but some extremely exciting news to share with you that Sarah Huntington our pharmacist is expecting her first baby later this year, huge congratulations to Sarah and Tim.

Finally, we have recently held our first parent/carers support group (see parents review). This went extremely well and if anyone would like to discuss arranging a support group in another geographical area do not hesitate to contact us. We are aware as a Regional Unit that we may need to offer support to people further a field.

Take care and have a sunny summer,

Maria Phillip

we were there but we had fun with the other members of the team. We met some inspiring parents who were fighting to get better care for their children and it made us appreciate how lucky we (*and you!*) are here in Leeds.

**Steve Conway and Alison Morton**

## Annual Assessments

Those of you who have been attending our Unit for a number of years may have noticed that we have stopped doing the 'formal' assessments where you attended the ward for the large part of one day to have a full assessment including fasting bloods, CXR, abdominal ultrasound scan, lung function tests and a full physiotherapy and dietetic review. We would like to explain the reasons behind the change.

Firstly the assessments were not well attended. Unfortunately for the available slots we had (*usually 2-3 per week*) over 50% were 'lost' because people did not ring to cancel or failed to turn up on the day. Not only was valuable time for all members of the team wasted but also the many different departments within the hospital were left with empty slots for tests that other patients could have had. In addition when we moved from Seacroft Hospital to St James's it was almost impossible to arrange for all the tests to be done in a single day due to the much larger number of other patients attending the different departments in St James's.

By now you will almost all be familiar with our new computerised management system which you will have seen in out-patients and when attending the ward. This new system means that we are able to assess you on a 'continuous' or ongoing basis. The dates of your latest annual bloods, CXR, ultrasound and glucose tolerance tests and bone scans are all put in the system and the computer alerts us when it is time to arrange the different tests for you. The following will give you an idea of which tests we will be performing and how often they need to be done:

### 1) Annual assessment bloods

All of you need annual fasting assessment bloods. Previously when you had formal one day assessments we used to write to you with the results. However, we feel it is much more informative to go through all your results 'in person' at one of your clinic visits. We can also show you your graphs of lung function and weight etc and show you the trend in these and your blood results. On the day your bloods are taken we will put an alert on your records for the doctor to discuss all results at your next visit. The results usually take 4-6 weeks to come back. If you are concerned that you have had bloods taken recently and have not had them discussed please ask the doctor at any visit. Your GP will be told of any changes to medication based on the results of your assessment bloods. We hope that by doing things this way you will feel more involved and have the opportunity to discuss things in more detail.

### 2) Annual oral glucose tolerance test

Those of you who are not known to be diabetic will require an oral glucose tolerance test every year, unless you are taking long term steroid treatment.

Where possible we will arrange for this test to coincide with your fasting assessment bloods to avoid you having to fast twice. We can also do this on a limited number of patients in the out-patients department at Seacroft when you attend for a clinic visit.

### 3) Abdominal ultrasound scan

You will be booked for an abdominal scan every two years. You will need to attend fasting for this and again due to the facilities available 'next door' to our clinic at Seacroft we will always try to book this test to coincide with your clinic visit. For those of you who are admitted to the ward we can organise all of the above tests while you are an in-patient.

### 4) CXR

It is important to ensure you have a regular CXR. However, the timing depends on how well you are doing. We feel that it should be done as a minimum every 2 years but for some patients it may be that we will ask for one every year or more frequently when you are unwell. Please feel free to discuss this with the doctor at your next appointment who can tell you when you will next need to have one performed. Again this can be done at your routine clinic visit at Seacroft Hospital.

### 5) DEXA bone density scan

You will need to have a bone scan every 3 years to check that your bones are not getting thin. The test may need to be performed more frequently if any abnormality is seen. This test is performed at the LGI. The result of this test will be sent to you but feel free to ask questions when we see you in clinic.

### 6) Full lung function tests

We used to perform formal lung function tests as part of the previous one day full assessment. These tests were performed in the respiratory lab at St James's. After discussion within the team we feel that they are probably not giving us any additional information compared to the standard lung function tests that we perform as part of every clinic visit. We have thus decided not to do this test as part of your routine assessment. There may be circumstances however in which we feel that this test may be necessary and will discuss this with you when required.

### 7) Physiotherapy and dietetic assessment

We will not be doing the more formal assessments as part of your routine management. There may be circumstances when either the physiotherapist or dietitian may decide that a more formal assessment is required and they will discuss this with you on an individual basis. If you have any concerns please either contact the physiotherapist/dietitian on the ward or speak to them at your next clinic visit.

**Christine Etherington**

## Outpatient Clinics

Having recently completed an audit looking at the efficiency of our out-patient clinics in 2008 we felt it was important to share the results (*good and bad!*) with you and make you aware of some of the changes we have made as a result. Our total clinic population is

now almost 360 patients. As you know we run separate clinics depending on which bugs you grow in your sputum. These are:

- 1) *Non Pseudomonas*
- 2) *Intermittent Pseudomonas*
- 3) *Chronic Pseudomonas*
- 4) *Cepacia clinics*

In 2008 we ran the above clinics on Monday am, Friday pm and also introduced some clinics on a Wednesday morning. For the Monday and Friday clinics the total number of slots available for each clinic was 26. We had a total of 2,441 clinic slots available from 1st January to 31st December 2008. Unfortunately 1,139 slots were not used due to various reasons. This amounts to 47% of all slots being 'lost' for various reasons.

It is obviously important to look in more detail at the reasons for this. Out of the total number of appointments 'lost', 23% were due to slots being unfilled. We looked at our total population and how often each patient should attend and felt that we probably had too many slots per clinic. A further 22% of all wasted slots were due to patient cancellations and a further 22% were due to the patient failing to attend on the day of the appointment. The final percentage of slots 'lost' (33%) were due to cancellation/cutting down clinics by the hospital for various reasons e.g. insufficient staff, annual or study leave etc.

The point of any audit is to provide a better service and we do understand that at times certain circumstances may mean that you are unable to attend your clinic visit. What we would like to ask is that if you know in advance you are unable to attend that you contact us at least 1 week before your appointment to cancel so that we may be able to fill the slot before the clinic date. Ringing the day before or on the day itself does not enable us to utilise the available slot.

In view of the fact that there were too many total slots available we have reduced the number of appointments in each clinic. This also gives more time for all members of the team to assess you. We have also allocated an additional 2 'emergency' slots per clinic. Clinic appointment times will also be available from 8.30am on a Monday morning clinic. We will also aim to reduce the number of clinic slots that are cancelled by the hospital.

It is important that you are aware that for various reasons we will not be able to offer routine clinic visits on the ward if you fail to attend your allocated appointment in clinic. The ward is extremely busy on a day to day basis and under resourced. It is not always possible to ensure 100% segregation if too many patients attend the ward. In addition we cannot always ensure that you are seen by a senior member of the medical team. You will be therefore offered an appointment in the next available clinic.

We are looking in the near future to set up a system in which you will receive text or email reminders for your out-patient visits and would welcome any feedback you have regarding this facility. We are also aware that not all patients fail to attend appointments and that the majority of you are extremely diligent in attending. It is just a small proportion of patients who fail to attend on a regular basis.

We will be re-auditing the clinic data following the above changes at the end of 2009 and hope to have improved the efficiency of the service we provide to you all. If you have any comments please feel free to discuss them with us at your next visit.

**Christine Etherington**

## Feel the Burn

As a patient with CF who has always hated doing conventional physiotherapy due to finding it dull and time-consuming I instead chose to exercise regularly over the years which I find helps keep my chest clear AND keeps me fit. As my lifestyle has changed recently by greater day to day demands being placed upon me from studying at college I was finding it difficult to incorporate regular exercise into my treatment regimen.

In February 2009 the physiotherapy team led by Kim and Tracey announced that funding had been secured to run an after hours exercise programme on the ward, twice a week for a six week period and they asked me to be the guinea pig for them so I gladly accepted. The aim of the programme is to establish and maintain an individual exercise routine for each of its participants which can then be maintained at home or in a local gym. Former ward physiotherapists Vas and Andy are on hand as personal trainers to help and assist patients which I found to be a great advantage to me as local gym staff will have little or no knowledge of CF if I were to exercise at one of their facilities and a friendly face or two goes a long way!

At first I found the programme hard as I started it immediately after discharge from some in-patient care



due to a nasty virus which had knocked my lung function down a bit. I soon picked up though and my strength and fitness quickly returned within the first couple of weeks. Once I had established an enjoyable programme

of running, squats and weights combined with some postural exercises I began to feel fitter and stronger all round and my lung function started to increase. I also learnt some new information regarding how exercise and diet can be affected by CF so the whole experience was a positive for me.

Now the exercise programme is available for some patients within the local area so I would urge those of you that are offered the opportunity to grab it with both hands. Just think how much a personal trainer would cost twice a week at a normal gym and the benefits of regular exercise speak for themselves. It is proven to improve lung-function and energy levels and as a result aid in increasing weight and muscle mass. No matter how well or unwell you may be everyone can do something and the ward is a friendly and safe environment too which is another bonus. You only

