



Adult Cystic Fibrosis Centre Newsletter

Northern General Hospital,
Sheffield Teaching Hospitals NHS Foundation Trust
January 2015



Welcome to our annual newsletter. We hope you had a Merry Christmas and a Happy New Year. If you have any ideas that you would like to see included please let us know. We hope you find this helpful and we would value your feedback. The CF Team

Nursing News

We would like to welcome Robyn as Specialist Nurse to the outpatient nursing team. Some of you may remember her from the CF ward.



As many of you are aware we have introduced the telephone triage service in outpatients, this is a work in progress! We are currently trying to improve this service so please bear with us. We hope to allocate a couple of sessions per day when a member of the nursing team are able to deal directly with **urgent** queries. For other non-urgent calls you will still need to leave a message and we will get back to you. Having this service has freed up the nurses allowing them more time with patients.

Please notify us if you are unwell or unable to attend an appointment. **If you repeatedly do not attend or are late without good reason we will be writing to you. Also if you are more than 20 minutes late other patients will take priority and you may be turned away.**

Patients not attending or cancelling their clinic or annual review appointment cost the CF service around £150.00, for a half hour consultation.

Please also inform us if your contact details change i.e. phone number, address, and whether you need a repeat prescription in advance.

European CF Conference



Several members of the team were lucky enough to attend the Summer conference last year in Gothenburg Sweden.

We took a number of posters and both Rachael and Hui (Research Fellows) gave oral presentations highlighting our research.

Remember your flu vaccination

Please remember to see your GP for your annual flu vaccine. The flu vaccination will **not** give you flu, but it helps **stop** you getting it.

Protect yourself and others.

If you have not been contacted please enquire or let us know.



CONTACTS

Specialist Nursing Team-01142266281

If not urgent please leave a message.

Out of hours:

CF Ward- 01142266580

If an emergency please attend your local A&E Department.

Physiotherapy News



Congratulations to Charlotte (CF Clinical Specialist) who got married last summer. Her surname has changed from Rose to Carolan.

Following our peer review we were able to expand the physiotherapy team. Our staffing is now made up of:

Charlotte Carolan as the CF Clinical Specialist and lead for the physiotherapy team, Hannah Day (Senior CF Physiotherapist) who sadly will be leaving us soon to take up a post at the Children's CF Unit; and an annually rotating Respiratory Senior Physiotherapist. This post is currently being held by Marlene Hutchings who has been successfully appointed to a research post in our unit for 3 years, a rotating Junior Physiotherapist, Charlotte Hinchliffe the CF Technical Instructor, Ian Hardman our CF Physiotherapy Assistant. Thanks to this increase in resources we are now able to see patients more often.

As inpatients you can expect:

Daily exercise (Mon-Fri); Twice daily airway clearance; Weekly spirometry checks; Weekly nebuliser download checks.

As outpatients a physiotherapist will be present at every clinic or annual review should you need to see us.

We would also like to announce the addition of a state of the art treadmill to the physiotherapy gym on the CF ward. So don't forget to bring your joggers and trainers when you are admitted!



Many of you will have been sad to hear that due to the changes in Brearley outpatients the physiotherapists have been unable to undertake regular exercise testing. However..... we are going to introduce a new exercise test called the incremental step test. This takes only 12 minutes to perform and involves stepping at an increasing speed. We will be trying to exercise test patients yearly as a marker of your ongoing fitness.

Just a little reminder from physiotherapy—**please bring your physio equipment** (Flutters/Acapellas/PEP) and iNebis to clinic in case we need to review your treatment. Also **remember** to bring your devices to the hospital when you are admitted.

Psychology News

Some of you many have met Simon Ashe (Assistant Psychologist) who worked with us one day a week up until December. He developed a questionnaire for annual reviews.

Also, just a reminder that if anybody feels they would like to meet with Rachel Attfield (Senior Clinical Psychologist), they can contact her directly or ask any member of the team to arrange this.

Pharmacy News

Please try to pre-order your Nebis when attending clinic as this will reduce your waiting time, also **once a prescription has been ordered to be collected from the ward, or outpatients clinic, the prescription will be held for one week, then returned to pharmacy.**

If you are admitted to hospital please bring all your usual medicines with you in the original boxes. This helps us in different ways including making sure we have you on the correct medicines, and ensures none of your usual medicines are missing or delayed. It will also stop you from collecting lots of boxes of medicines at home.

Infection Control News

Some of you are unable to come on to the CF ward because of the types of bugs in your chest. This means admissions have been to Brearley 2 where the accommodation is not so good as the CF ward. Frank (CF Consultant) has arranged for the four side rooms on Brearley 2 to be modified and enlarged to have ensuite bathrooms, a sitting area, TV and computer/ WiFi access with fridge and hopefully space for exercise equipment too, very much like the CF ward. Snacks etc will continue to be supplied from the CF ward and the team will see patients regularly there. Meanwhile some Brearley 2 nurses will be working on the CF ward to improve their CF knowledge and training so people going there should get just as good an experience as on the CF ward. We hope they will open in March 2015. It will be for people with "cepacia" and "abscessus" bugs. A **new clinic** is also being run for "abscessus" on Friday afternoons which we hope will be convenient and successful.

Dietetic News

Some of you will be aware of the nutrition intervention study. This study has been running over the last year and some of you took part in it. This intervention offers more support to individuals through home visits, telephone calls and emails. It also gives individuals access to an online food diary to track intake and it gives you information about total calorie intake and compares this with your target. You can also track your weight through a graph. We are nearing the end of the intervention phase and will be beginning to analyse the results. Sarah will be asking those who participated for their feedback so that we can improve the process and study design.

We were really sad to see Jenna Samtaney leave us. Jenna worked in CF for the last year and she was an asset to the team. On a more positive note, Ellie Tidswell re-joined the team in September. You may remember Ellie as she worked with us a year ago. We are really lucky to have gained some funding from the Sheffield Hospitals Charity for a 2 year secondment with the main focus on improving the food and catering facility on the CF ward. She will be in touch to find out any ideas you have! As well as Ellie, the CF dietitians who will be staying in post are Sarah Thornton, Ailsa Milne and Sophie Robinson.



Research News

Many of you will have been involved in some of our research projects over the past couple of years. Thank you for continuing to take part and support us as we would not be able to do this without you. We are pleased that both Rachael and Hui have joined us again as Research Fellows and to develop further experience in CF. Rachael will soon be asking whether you want to take part in a study which will involve remote monitoring of spirometry, weight, and inhaled adherence. This aims to detect early decline in lung function and allow us to understand if we can streamline clinics to tailor slots and reduce waiting times. Hui has been awarded a National fellowship to undertake a PhD. He will be exploring how habits are formed in relation to inhaled treatment and how long this takes, to help inform adherence support.

Last year Martin (CF Consultant) was successful in securing a £2.5 million National Research Programme Grant, making us one of the leading CF Centres in Health Service Research. The ACTiF study will use technology to transform CF care. It aims to embed adherence measures in to routine CF care and develop an intervention to support adherence to treatment using a web-portal called 'cfhealthhub'. Marlene (Physiotherapist) will be undertaking the development work here in Sheffield with support from the group of National experts including a number of people with CF.



Charity News

A number of the team helped to raise funds for the Sheffield Hospitals Charity last year. Events included: the Sheffield Half Marathon despite the lack of water available on the day, a bake-off held at the Broomhill Festival, and a concert led by the Sheffield Philharmonic Orchestra, of which CF Consultant Frank is Chairman. These along with further donations raised £70,000 to pay for Ellie dietitian to work on transforming the food and catering systems currently used on the ward.



Little Corey-George Blackett from Birdwell, Barnsley (pictured with his grandfather Neil), was part of a group of family and friends all striding out to support the Adult CF Centre. They were raising funds to say thank you for the incredible support provided to Michael Blackett and his family. The family completed the 10km Walk for Wards charity event at the Longshaw Estate in Derbyshire earlier last year. 2 year old Corey walked a whole 5km in memory of his daddy. This raised over £1,300 for the



Sheffield Charity.

If you would like to find out more about raising funds for the CF Centre why not contact the Fundraising Team at Sheffield Hospitals Charity on 0114 271 1351 or at charity@shct.nhs.uk

Social Workers

We have a student social worker with us on placement. Her name is Aaminah Parveen. She came in October and will be with us until 23rd January 2015. She may have been in touch with some of you, to tell you about the work that we do and to ask you if you need any of our services. If she has not got round to you yet, or you want to ask for a call, please let any of our CF staff know and they will pass on the message. We hope you are all keeping toasty and warm this winter. Don't forget that many energy companies hold a 'priority register' which means that if they have to cut the power for any reason, they will not cut you off if you have a valid medical condition.

Louise, Dorothy and Aaminah

CF Ward News

We have had 2 new staff nurses join us Alison & Julie as well as a new support worker Rebecca. Marie the housekeeper joined us earlier last year, with the main focus of her job being to work with the nursing & dietetic staff to provide nutritious & appealing meals for you when you are in hospital. **If there are any particular requirements you would like to see available please let her know.**

The nursing staff have continued to fund raise for the ward to provide the additional food, quilts & pay for the up keep of the computer equipment, these have included Sister Sue doing a 10k walk for wards which she will repeat again this year, as well as a vintage tea party organised by Trish & running a craft stall at Handsworth Christmas Fair by Harriet, Sue & Chris selling homemade Christmas goods.

Finally Sharon Hill left us due to ill health, however she promises she will be back to torment us from time to time & we believe she will!

