

North West Midlands



Cystic Fibrosis Centre

Newsletter

Spring/Summer 2011

Welcome to this edition of the NWMCFCC newsletter. The summer has come around quickly again this year and the sun has been welcomed by the Team! The bad weather over the winter hasn't stopped you from fundraising and donating lots of money to the Centre to improve the patient experience in and out of hospital. There have also been a lot of changes in the Centre over the last few months with new members of staff and a new adult service in Shropshire.

There is puzzle section to this edition's Newsletter which I hope you'll enjoy while you relax in the summer sunshine. But don't forget to top up your salt levels whilst you're out and about!

Holiday season is upon us so please be prepared and remember to ask your Team for a holiday letter well in advance. Most of all have FUN!



, if you have an article or an event you want including in the newsletter, please contact Erin Stones, Cystic Fibrosis Co-ordinator, on 01782 552930 or email cf.team@uhns.nhs.uk.

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New Faces

Rosie Cormie -

Advanced Respiratory Physiotherapist in Respiratory Care



It sounds big and important doesn't it? Well please don't be fooled by the title, I am a normal down to earth person first and have just been doing my job for a few years! I have specialised in respiratory care since 1999. I began my journey in respiratory physiotherapy at Papworth hospital where I worked with a wide range of people including Cystic Fibrosis, people who had heart and lung transplants and who had other long term lung disease, to name just a few. I then followed my husband to work and managed a small hospital service catering for a population of

60,000 people in Guernsey which is one of the Channel Islands. I loved living there and worked with children and adults who had respiratory physiotherapy needs due to either respiratory conditions or as a result of surgery. I looked after the respiratory on call and weekend service and all the training and support of staff for this too - I was the lead of the service. I returned to the UK in late 2006 to be closer to family and to return to the NHS which had changed quite a bit while I was gone. I did a similar job as in Guernsey for 18 months at Stafford Hospital and also for 6 months here at the University Hospital of North Staffordshire. I then applied for the job that I presently share with Wendy Dale which is to work in either medicine or Cystic Fibrosis. After doing the Medicine side for over two years, Wendy and I have rotated. I am really enjoying the position and am slowly getting to know you individually. I really enjoy working with the rest of the team and am looking forward to developing the service further. If ever you want to discuss anything about any aspect of your physio routine I am always willing to discuss it either as part of a clinic visit, over the phone or as a separate appointment. You can contact me via the CF office on 01782 552930 or email cf.team@uhns.nhs.uk.

Shrewsbury Adult Cystic Fibrosis Service

An exciting new adult service will operate from Royal Shrewsbury Hospital (RSH) from May 2011. Organisation is underway for clinic rooms to be equipped and staff trained in cystic fibrosis care with support from the Stoke Team. Staff have been recruited and you will get a chance to read about them in the next newsletter:

Dr Moorcroft, Consultant Respiratory Physician
Sue Hunter, Secretary
Ana Ireland, Clinical Nurse Specialist
Amanda Taylor and Claire Trow, Physiotherapists
Michael Davies, Dietician

If you are an adult and you live in the Shropshire area, you may get asked whether you would like to be seen at RSH instead of Stoke. It is ultimately your decision about where you would like to be seen. The Team can be contacted on 01743 261240.

GOODBYE!



Goodbyes



Both **Dr Charles Pantin**, Consultant Respiratory Physician, and **Alison Heard**, Consultant Psychotherapist, have both retired in April 2011. The Team were very sad to see them go and they have put in a lot of work into developing the service over the years. We all wish them well and enjoy their retirements.

BUT the good news is Dr Pantin will be coming back in May 2011 to help Dr Lim with consultant cover in the Adult CF Clinics at Stoke.

Congratulations!



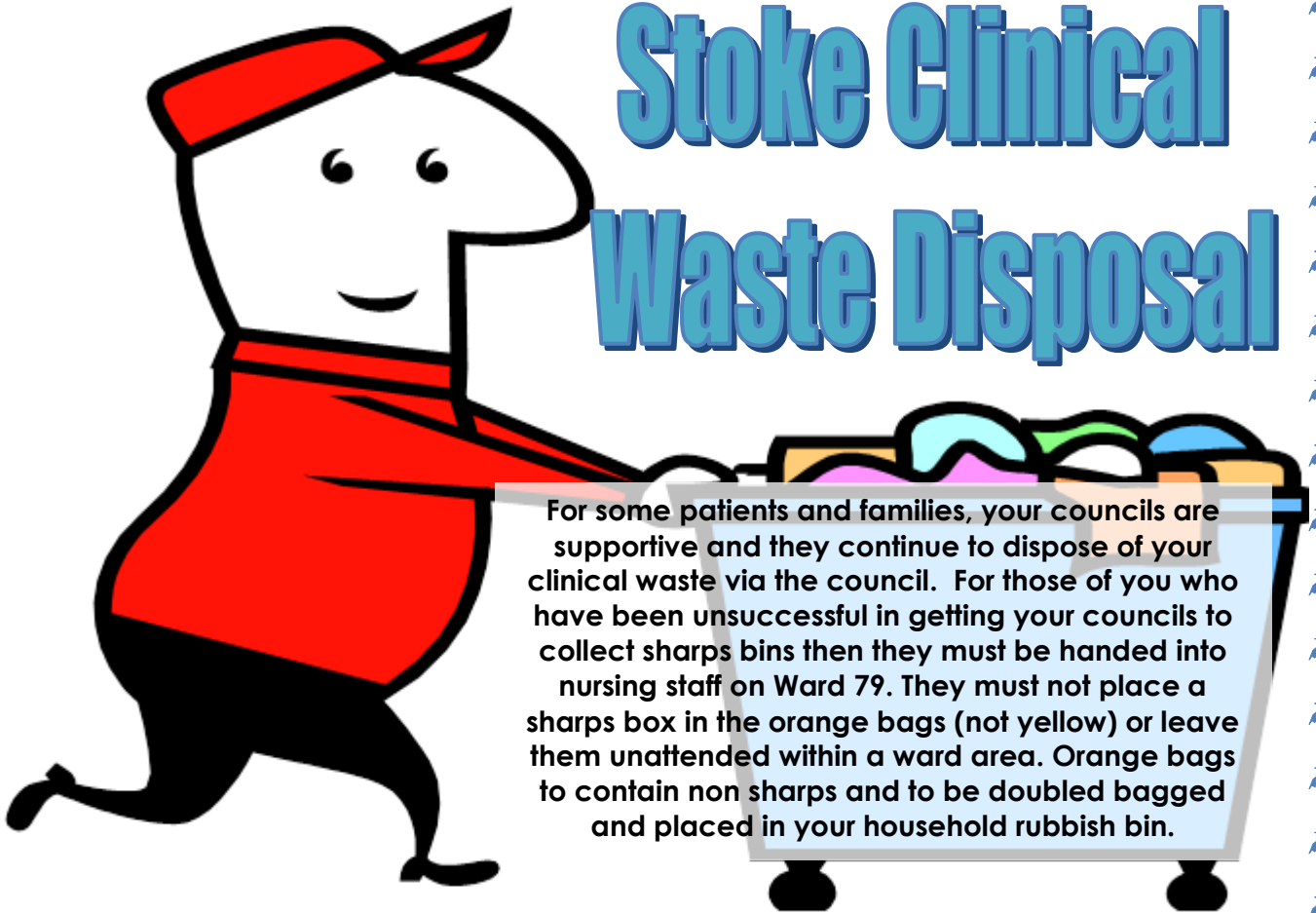
Rachel Berry, CF Pharmacist at Stoke, gave birth to a healthy baby boy on the 14th April 2011. He is named William John Berry and weighed 7lb 10oz. The Team wish her all the best with her new bundle of joy!

Contacting the CF Nurses

When contacting the CF nurses at Stoke during normal working hours, please remember they are very busy and may not be able to respond to you straight away. They may be tending to a patient on the ward, on a home visit, in clinic or at a meeting. In a **non-emergency**, please phone the CF Office on 01782 552930 and leave a message with Erin, the administrator or the answer machine. In an **emergency**, please contact the switchboard on 01782 715444 and ask them to page the relevant nurse. If you do not get an answer, please phone the office.
Have you utilised your GP? Could they help?



Stoke Clinical Waste Disposal



For some patients and families, your councils are supportive and they continue to dispose of your clinical waste via the council. For those of you who have been unsuccessful in getting your councils to collect sharps bins then they must be handed into nursing staff on Ward 79. They must not place a sharps box in the orange bags (not yellow) or leave them unattended within a ward area. Orange bags to contain non sharps and to be doubled bagged and placed in your household rubbish bin.

CF Trust Forum

The next time you are on the internet why don't you visit the Cystic Fibrosis Trust forum? You get chance to interact with people with CF, parents, carers, partners and friends. You can also speak to Dominic Kavanagh and the other Expert Patient Advisors in the country who are there to help improve the standard of care you receive.

The forum is continually regulated and reviewed to ensure the facility is utilised properly and appropriately.



Once Daily Tobramycin T34L syringe drivers (Stoke)



Please remember to bring your syringe driver back to the Cystic Fibrosis Office (Norton Unit, City General) once you have finished your course of intravenous Tobramycin. The devices are in high demand and we only have a small supply. Your help with this will ensure the next patient who needs the device won't have a delay in their treatment.

Cough swab/sputum results

If you have had a cough swab or sputum sample taken at an outpatient clinic, you will be contacted should there be a problem. However, please contact the office if you have taken a sample to your GP or directly to the Path Lab. This will then get flagged by the nurses to check the results.



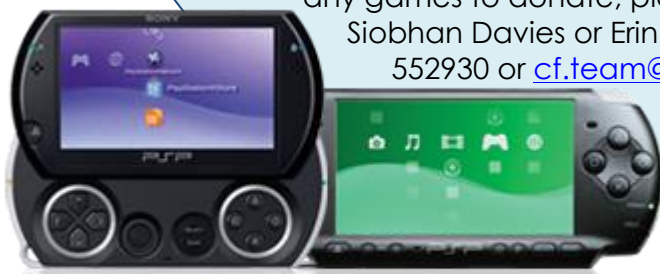
Travel insurance

Can you recommend a reputable travel insurance company?
We can then pass these details onto other people with CF who are finding it difficult to find a reliable insurer.

Please either phone the office on 01782 552930 or email cf.team@uhns.nhs.uk

Games Consoles

Do you have any old Nintendo DS or PSP games you no longer use? Johnson Titles, Browns Distribution and Dudson Ltd organised a fundraising event and have bought the Stoke paediatric service the games consoles for the children to relieve boredom during outpatient and inpatient visits. If you have any games to donate, please contact either Siobhan Davies or Erin Stones on 01782 552930 or cf.team@uhns.nhs.uk.



Patient Satisfaction Survey

You may hopefully remember that I conducted a patient satisfaction survey on behalf of the CF Trust and your Adult CF Specialist Centre at University Hospital of North Staffordshire back in October 2010. There was a 35% response rate to the survey which is actually a relatively good response, but equally it is always better if as many patients as possible respond to these surveys – thank you if you did! Remember, the patient voice is a powerful one in helping to influence developments and change in your CF service. It's a great chance to 'have your say'!

A full update from the survey will be given in the Autumn/Winter 2011/12 news letter however be assured that changes are underway to ensure your comments and suggestions are acted upon.

Please contact me if you have comments on your CF service, so that we can build a picture of the level of service provided. Only in this way can services try to match you expectation.

Remember your opinion might well be shared by others and together these opinions can be powerful when used by your CF team and by me in meetings with hospital management, local Commissioners and at national level to try and secure improved facilities, equipment and increased staffing, just as an example.

Dominic Kavanagh, Expert Patient Adviser (Midlands)
Tel: 0300 373 1057 Email: dkavanagh@cfrust.org.uk

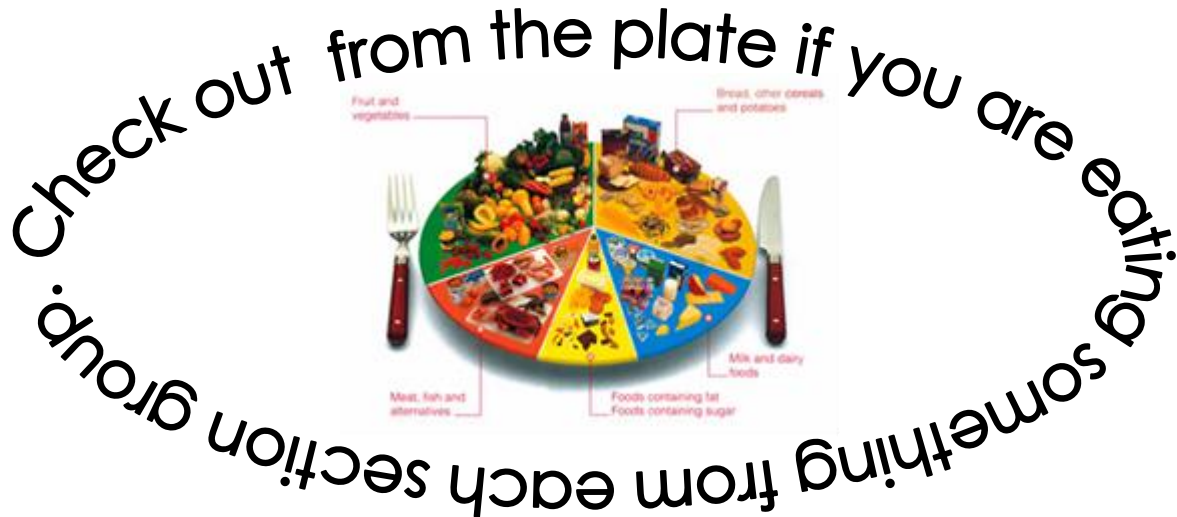
FOOD



Are you getting the balance right ?
In Cystic fibrosis, food is a constant thought - am I having enough ?



The newspapers talk about having a diet full of mars bars and cream cakes but this is not enough to have a good balance of foods!



- Meats, eggs, nuts and pulses give you protein and iron.
- The dairy group for calcium and protein.
- The bread potato and rice group for energy slow releasing (potatoes are in that group as they are high in energy).
- Fruits and vegetables are low in energy but high in vitamins and minerals, try to have at least 3 serves a day. Fruit and vegetables will give you extra vitamins, antioxidants and minerals that are not in your vitamin tablets.
- How can you try to eat more fruit and vegetables?

See if you are eating any of the colours below. Try for A RAINBOW

Colour	Fruit	Vegetable
Red	Strawberries, Watermelon	Red peppers, Tomatoes*
Green	Kiwi, Grapes, Honeydew melon	Peas, Beans, Spinach, Broccoli
Orange	Mango, Peaches, Cantaloupe melon	Carrots, Sweet Potatoes, pumpkin
Blue or Purple	Blueberries, Grapes, Prunes	Aubergine , Beetroot
White	Bananas, Pears	Garlic, Onions
Yellow	Pineapple, Star Fruit grapefruit	Butternut squash, Corn

Next time we will see how to add extra energy to your foods using every day foods

Best wishes: Sue and Heather, CF Dietitians



special days for seriously ill 16 to 40 year olds



The Willow Foundation was founded in 1999 by Bob and Megs Wilson as a lasting memorial to their daughter, Anna, who died of cancer aged 31. Bob Wilson is the former Arsenal and Scotland goalkeeper and TV presenter.

Anna battled cancer for five years. Yet it was during these years that she, her family and friends, experienced some of their most memorable moments and quality times - treats, days out, concert trips and time simply spent together.

The charity's name, Willow, stems from Anna's nickname and its aim is to replicate the positive impact special days had on both Anna and her family for other seriously ill 16 to 40 year olds throughout the UK.

Special days aim to give seriously ill 16 to 40 year olds a break from the stress and difficult realities of diagnosis and treatment. They offer the chance to spend quality time with family and friends doing something they will all enjoy and creating precious memories.

The charity defines seriously ill as any condition that is life-threatening. This includes cancer, motor neurone disease, cystic fibrosis, Duchenne muscular dystrophy, Huntington's, organ failure and many others. All applications must meet the charity's medical criteria and be endorsed by a medical professional involved in the individual's care.

Willow strives to create a unique and unforgettable day that is tailored to the needs and dreams of every beneficiary. He or she chooses exactly what they would like to do on their special day and Willow aims to meet and, wherever possible, exceed their expectations, making the day truly special and memorable.

Some of the most popular special day requests to date have included: West End shows and pop concerts; tickets to sporting events such as Premiership football and International rugby; trips to the country and city breaks; days at health spas; driving experiences and family days out to top UK attractions.

Following a discussion with the beneficiary and their family, the charity takes care of every arrangement, including transport, to ensure a stress free and enjoyable day for all.

To date, Willow has provided more than 7,000 special days for seriously ill young people.

Download the special day application form from www.willowfoundation.org.uk, or alternatively call 01707 259777 to request a copy to be sent to you in the post.



Future Events

Date	Event	Location	Contact
8-14 May 	CF Week		Martine Grainger 0300 373 1027
10 June 	Charity Disco	The Firs Conservative Club, Codsall, Wolverhampton	Janet Foster 07940 733 845
12 June 	Potter's Arf Half Marathon	Stoke on Trent, Staffordshire	Martine Grainger 0300 373 1027
25-30 June 	Hereford Triathlon Club's Three Peaks Yachting Challenge	Barmouth to Fort William	For more information please go to: herefordtriathlonclub.co.uk threepeaksyachtrace.co.uk
3 July 	Penkridge Fun Run	Penkridge, Staffordshire	Martine Grainger 0300 373 1027
8-10 July 	jogle50 - A 50-hour non- stop 6-man 850-mile cycle relay challenge	John O'Groats to Lands End	To sponsor Steve Rose and his team please go to - www.justgiving.com/jogle50 or contact Steve on 07776 014046 for more info on how you can help support
24 September 	Attingham Park Autumn Walk	Shrewsbury	Martine Grainger 0300 373 1027

For up-to-date information on events and events in other regions please visit:
www.cftrust.org.uk

Charity Skydive

Joanne Hughes has been hard at work recruiting local people to take part in a skydive and raise money for the Breath of Life charity. Joanne says:

'For years now I've wanted to get involved with fundraising for people with CF in order to improve quality of life for those around me and further afield. As I am very passionate and excited about this charity I hope to raise a lot of money for the CF Project with Breath of Life.'

'I am really excited about organising the event and I hope to get a group of about 20 people to do the Tandem Skydive. If everyone can make the target we can raise about £3,400. Obviously if we can raise more than this it will be fantastic.'

The skydive will take place on **Saturday 2nd July 2011** at the **Langar Airfield in Nottingham**. You can contact Joanne on her mobile 07944172318 or email joeyleese@sky.com if you would like to get involved or just be a spectator!



Supporting people with
breathing problems
in North Staffordshire

Breath of Life is a registered charity which helps people in North Staffordshire who have breathing problems or lung disease. Since 1997 we have funded research and provided equipment and facilities to help in the treatment and rehabilitation of patients in hospital, in clinics and at home, where statutory funding was not available.

North Staffordshire has amongst the highest rates of lung disease in the UK. Even though the area no longer relies on the traditional mining and manufacturing industries that may have contributed to lung disease in the past, the incidence of respiratory disease is still rising.

We help people with all lung diseases: asthma, lung cancer, COPD (the umbrella term for conditions such as chronic bronchitis and emphysema), Cystic Fibrosis, TB, Sleep Apnoea and many other less common respiratory conditions. Breath of Life will take an active role in supporting the development of new facilities in the area, including things that make life in hospital a little more pleasant and comfortable for young adults with CF. Currently Breath of Life is also funding gym places for some young adults, where regular exercise greatly enhances their physical and psychological wellbeing.

If you would like to help with fundraising or find more about the charity, please visit the new website www.breathoflife.org.uk or telephone their office on 01782 577124.

Fundraising



DUDSON

JOHNSON • TILES

browns
DISTRIBUTION

Thank you to all the staff and helpers from local companies who organised the **Firework Extravaganza** in October 2011. Joseph Davies, a child with CF, lit the bonfire and started the firework display which he thoroughly enjoyed. The organisers presented a cheque worth **£3000** to Siobhan Davies, Cystic Fibrosis Nurse, on behalf of the paediatric Stoke Team. The money raised has bought items for patients including a PSP with games, Nintendo DS with games, board games, iPad, eFlows, pill organisers and a special mobility bed. These items will be used to enhance the patient experience in the paediatric clinic and inpatient settings.

Good time had by all!



18



James Gibson never fails to think of others even on his 18th birthday! He invited his family, friends and members of the CF team to his birthday party where he organised a raffle to raise money for equipment on the adult ward at Stoke. James and his mum Joan presented a cheque for the sum of **£1500** to Dr Pantin along with Wendy Dale, Physiotherapist; Erin Stones, CF Co-ordinator, and Alison Heard, Psychologist.

**Last
but
not
least!**

The **Biddulph Community** pulled out all the stops and had a fun filled evening raising **£1000** for the paediatric fund at Stoke. The cheque was presented to Siobhan Davies, Clinical Nurse Specialist. The money has been used to purchase eFlow nebulisers.

Puzzle Page!

Wordsearch

All these words are in the grid. Words can run forwards, backwards, up, down and diagonally.

BEACH
FISH
FLIPPLOPS
HAT
ICECREAM
LOUNGER
PARASOL
SANDCASTLE
SUNSHINE
SWIMSUIT

F	E	L	T	S	A	C	D	N	A	S
A	L	C	E	G	I	P	K	T	M	U
O	F	I	S	H	R	A	T	I	A	N
I	G	T	P	E	E	R	C	U	R	S
R	A	I	N	F	S	A	L	S	E	H
H	U	T	R	O	L	S	N	M	G	I
C	T	S	P	O	M	O	K	I	N	N
A	U	B	D	F	H	L	P	W	U	E
E	S	P	N	L	J	H	F	S	O	D
B	I	C	E	C	R	E	A	M	L	B

Kriss Kross

All these holiday destination related words fit in the grid and there's only one way to do it.

3 LETTERS

USA

6 LETTERS

CYPRUS

FRANCE

GREECE

MEXICO

NORWAY

TURKEY

7 LETTERS

ENGLAND

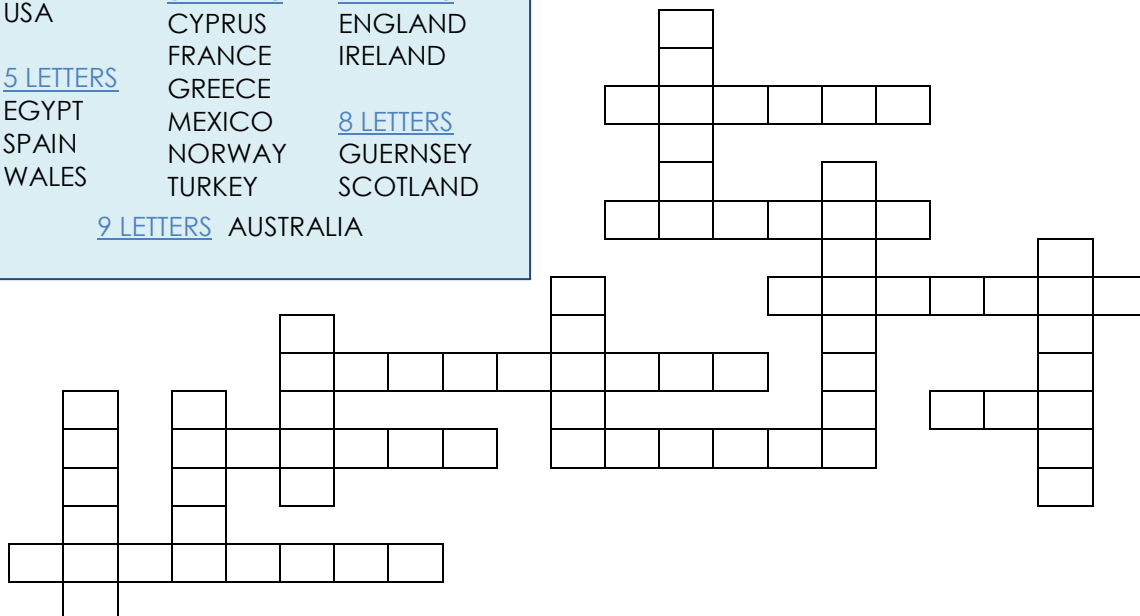
IRELAND

8 LETTERS

GUERNSEY

SCOTLAND

9 LETTERS AUSTRALIA



Contact Information

Department	Address	Contact	Contact Details
Stoke-on-Trent (regional centre)			
City General	Cystic Fibrosis Office, Norton Unit, Newcastle Road, Stoke on Trent ST4 6QG	Paediatric and adult services	Telephone: 01782 552930 Facsimile: 01782 552223 E-mail: cf.team@uhns.nhs.uk
Psychology Service	The Boat House, 1 Canal Arm, Festival Park, Stoke on Trent ST1 5UR	Michelle Edinburgh (adults) and Ruth Fishwick (paediatrics)	01782 408354/9
Shropshire			
Royal Shrewsbury Hospital	Paediatric Service, Mytton Oak Road, Shrewsbury SY3 8XQ	Dr Martyn Rees, Consultant Paediatrician	01743 261619
		Rachel Lugg, Community Nurse	01743 450855
		Christine Law, Physiotherapist	01743 450800
		Dr Abby Marr, Paediatric Clinical Psychologist	01743 608374
	Dietician	01743 261462	
	Adult Service, Mytton Oak Road, Shrewsbury SY3 8XQ	Dr Jim Moorcroft, Respiratory Consultant	01743 261240
Princess Royal Hospital	Apley Castle, Telford TF1 6TF	Paediatric Team same as above plus: Belinda Gower, Paediatric Respiratory Nurse Specialist	01952 641222
Burton-upon-Trent			
Queen's Hospital	Belvedere Road, Burton-upon-Trent DE13 0RB	Dr A Choules, Consultant Paediatrician	01283 566333 (extension 4367)
		Judy Veale, Clinic Nurse	01283 566333 (extension 4161)
		Angie Malkin and Stephen Tarpey (Community)	01283 511511 (extension 2303)
Cystic Fibrosis Trust			
Cystic Fibrosis Trust	11 London Road, Bromley, Kent BR1 1BY	Dominic Kavanagh, Expert Patient Adviser	0300 373 1057 dkavanagh@cftrust.org.uk