



## Parent's Support Group – Merry Christmas!!!

The next one will be **Wednesday 6<sup>th</sup> December at 7.30pm** in the Women's Health Building, Maternity Entrance, Seminar room 1.

This will be an informal, more social event – Christmas hats/jumpers optional. We will have a quiz, food and time to chat with each other. We will have our usual resources with us and will be on hand with any help and advice you may need, but no planned session other than a bit of Christmassy fun. We'll finish up around 9.30 ish, but no reason the evening couldn't carry on at a more cheery establishment for those who wish. **Please Text 07876 560546 to confirm your attendance**, or email [rde-tr.exetercf@nhs.net](mailto:rde-tr.exetercf@nhs.net)

## A Friendly Festive word from our dietician...

Getting your Creon dose right with the extra Christmas goodies can be a challenge. The table below gives you an estimate of the fat content of some of the additional things that we eat at Christmas. Working on 1 x Creon 10,000 for each additional 6g of fat can be a starting point! Meals tend to take longer and be more of a social event, try to spread your Creon out and keep some until the end of the meal. Drink plenty of water and non-fizzy soft drinks.

**Tips from Santa!** A ready to drink carton of juice with a straw, plus Creon attached by cling film to the chocolate item that that is likely to be eaten when the Christmas Stocking is opened can be helpful!

Food	Fat Content (average)
Shop Bought Minced Pie	10g
Christmas Pudding (100g)	5g
2 x Sausage & Bacon 'Pigs in Blankets'	6g
Stilton (30g)	11g
2 x Chocolates e.g. Quality Street	4g
Christmas Cake (100g)	5g
Trifle with Cream (170g)	16g
Chocolate Malt type Reindeer	9g
Solid Chocolate Tree Decorations	3 g
Irish Cream Liqueur (100mls)	13g
Clotted Cream (30g)	20g

## All in one ADEK preparation - an update

Unfortunately, the all in one vitamin prep ADEK did not get ACBS approval. We are still waiting to see next time around!

We will keep you posted.

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## RESULT trial - the "poo study"!



We now have approval and the green light to go and recruit appropriate patients to the RESULT (Reliable, Emergent Solution Using Liprotamase Treatment) study. This is very exciting from a dietetic point of view and Marie and Penny will be bespoking menus to meet both the needs of the trial and the individual patient choice!

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## Exeter CF Centre hosts CF Trust



The Exeter CF Centre was delighted to host delegates from the CF Trust on Tuesday. CEO of the CF Trust David Ramsden and Director of Clinical Impact Dr Keith Brownlee attended the Trust to meet with Suzanne Tracey, Dr Corinne Hayes and RDE Consultants who care for Adult and Paediatric patients with CF to understand more about the care delivered here at the RDE.

There were also presentations from the RDE Research Dept. who gave an update of the CF Clinical Trials currently running at the RDE, the Children's Health and Exercise Research Centre at the University of Exeter presented on 'Exercise as Medicine' and showed the work the teams from the University and RDE are doing to prescribe exercise as medicine. There was a presentation from the CF Physiotherapist Jayne Trott and Liz Lane CF Specialist Nurse gave an overview of the Patient Engagement work, updating the CF trust on the RDE CF newsletter, Parents Evenings and website.

It was also an opportunity for one of the CF patients and her partner to present the CF Trust with a cheque for £6000 that they had fundraised.

David Ramsden thanked all of the staff for their hard work in caring for patients with CF and for the support for the families.

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## All change for homecare deliveries!



Baxter has finally taken over the tender for Home Intravenous Therapy from Lloyds Pharmacy Clinical Homecare.

Lloyds Pharmacy Clinical Homecare continues supplying all high cost nebulised drugs (e.g. Colomycin, Pulmozyme, Manitol, Cayston not Caystom, Promixin, Colobreathe, Bramitob, TOBI Podhaler..) and Kalydeco.

### Creon 40,000

Creon 40,000 is available again and consistent supply should not be a problem.

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## Meet our new team members!



There have been a few changes to our staffing; we welcome Dr Lee Dobson who joins Exeter as one of our new Respiratory/CF consultants, our Torbay patients will know him as he currently runs the CF clinics there. He will continue to run CF clinics there as part of his new role at Exeter.

Charlotte Hawkins (Physiotherapist) has joined the CF team after working within the NHS for 5 and a half years. She has come from an adult and paediatric respiratory background and will be working full time within the adult and paediatric CF team as well as covering the Torbay clinics.

Rachel Rogers, CF Specialist nurse is back to work following her maternity leave and we welcome her return.

Those of you who have met Milly Dack, Rachel's maternity cover, will be pleased to learn that she has been appointed to a new role within the team; as a CF Health Hub Interventionist. Milly is working on a National Project which aims to improve outcomes for patients by using technology to assist patients in managing their nebulised treatments.

Clinical psychologist Dr. Guy Mizon has been providing a psychology service to patients throughout the RD&E for the last four years, and has now taken on a specialist role in the adult CF service. Guy has a special interest in how emotions affect health (and vice versa), and he has developed expertise in a variety of therapeutic approaches: "I'm really interested in ways to help people feel able to live the kind of life they really value, as well as ways to help people get past difficult life events that have been keeping them stuck." If any of our patients are interested in finding out more about what psychological work could offer them, they can contact Guy via the rest of the CF team, or leave a message for him at the psychology department on 01392 676376, and he'll call you back.

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## Merry Christmas and a happy new year from all of us in the CF team!



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Royal Devon and Exeter NHS Foundation Trust, Barrack Road, Exeter EX2 5DW, 01392 411611. **Exeter Cystic Fibrosis Team:** for advice regarding CF - 01392 402726; this number has an answerphone and messages will be checked regularly. For other numbers see your clinic letterhead. For **non-CF illness** please access healthcare as you would normally, and let your CF team know of your admission.