CF FAMILY NEWSLETTER

Spring 2022

UNC HEALTH Children's

Striving for Better Care

The UNC Pediatric CF care team is always working to improve the care for our patients and families. Recently, we have been focused on improving the experience for families who are new to our CF center. We understand that receiving a new diagnosis of cystic fibrosis or moving to a new center can be overwhelming. We aim to do everything possible to make patients and families feel supported and well-informed during that time. We have been working the quality improvement ("QI") team with the Cystic Fibrosis Foundation on this project. We greatly appreciate all the families who have helped shape the project by completing surveys and giving input on their experiences. Some of the changes to improve our care that we have been testing include: New patient welcome baskets, binders to collect and organize CF educational material, improvements to our sweat testing process, checklists for CF care team members, and "How to Contact" sheets for families. If you have any suggestions on your experience as a new family to our center, or feedback on these changes, please let us know!

Our Quality Improvement team has also been working on a project to improve video visits in our Pediatric CF Clinic. We aim to improve coordination and efficiency of video visits, so that they are better, more cohesive experiences for our patients. We would like to continue to offer video visits as an option for our patients. In order to help our patients and families better prepare for video visits, we have included a video visit instruction pamphlet in the newsletter (see pages 2 & 3). We hope this is helpful resource when it comes to expectations for these types of visits.

Submitted by Sara Abu-Nasser

Do you love to draw?

UNC has a virtual art gallery for those directly or indirectly affected by Cystic Fibrosis!

Submit Your Art to cfuncartgallery@gmail.com to be featured on the UNC CF Virtual Art Gallery Instagram!

Follow **@unccfvirtualartgallery** on instagram!

Preparing for Your Video Visit

Treat the appointment the same as you would an in-person visit. You are here to receive the same quality of care.

Before the Visit

Day Before the Visit

Choose a device that has audio and video capability
Find a location with reliable internet connection, preferably Wi-Fi
Review instructions for joining a video visit: https://unchealthcare.org/patients-families-visitors/my-unc-chart/video-visits/
Plan for your child to be present at the video visit
Make sure you are in the state of North Carolina, otherwise, reschedule the visit

Day of the Video Visit

Weigh your child or have a recent weight ready to share
Measure your child's temperature
Have your child's medications or medication list ready to review
Write down questions you or your child may have for the providers
Join the video visit 10 minutes before your scheduled appointment time

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During the Visit

Avoid eating, driving, or engaging in other activities

Make sure the room has good lighting
Please wait 10-15 minutes before disconnecting if your provider is late
    Send a message via MyChart or E-Mail your nurse before disconnecting

After the Visit

Review your After Visit Summary (AVS)

    MyChart: AVS will be sent through MyChart automatically
    Email: If you do not have MyChart, please provide your CF nurse with an e-mail to send you the AVS
Schedule your next appointment:

    Call 984-974-1401 or Reach out to your CF Nurse or Use FastPass option through MyChart if available

Preparación para la visita por vídeo

Considere la cita como si fuera una visita en persona. Usted está aquí para recibir la misma calidad de atención.

Antes de la visita

El día antes de la visita

- Elija un dispositivo con capacidad de audio y vídeo
- Encuentre un lugar con conexión a Internet fiable, preferiblemente Wi-Fi
- Revise las instrucciones para participar en una visita por vídeo: https://unchealthcare.org/patients-families-visitors/my-unc-chart/video-visits/
- Haga planes para que su niño(a) esté presente en la visita por vídeo
- Asegúrese de que está en el estado de Carolina del Norte, de lo contrario, reprograme la visita

El día de la visita por vídeo

- Pese a su niño(a) o tenga un peso reciente listo para compartirlo
- Mida la temperatura de su niño(a)
- Tenga los medicamentos de su niño(a) o la lista de medicamentos lista para revisar
- Anote las preguntas que usted o su niño(a) puedan tener para los profesionales de salud
- Únase a la visita por vídeo 10 minutos antes de la hora acordada para la cita

Durante la visita

- Evite comer, conducir o realizar otras actividades
- Asegúrese de que la habitación tenga una buena iluminación
- Espere de 10 a 15 minutos antes de desconectarse si su profesional de salud se retrasa
    - Envíe un mensaje a través de *MyChart* o un correo electrónico a su enfermera antes de desconectarse

Después de la visita

- Revise el resumen de la visita
    - *MyChart*: el resumen será enviado a través de *MyChart* automáticamente
    - Correo electrónico: si no tiene *MyChart*, dele a su enfermera certificada un correo electrónico para que le envíe el resumen
- Programe su próxima cita:
    - Llame al 984-974-1401 o
    - Comuníquese con su enfermera de fibrosis quística o
    - Utilice la opción *FastPass* a través de *MyChart*

UNC HOSPITALS

Translated by UNC Health Interpreter Services, 3/15/22

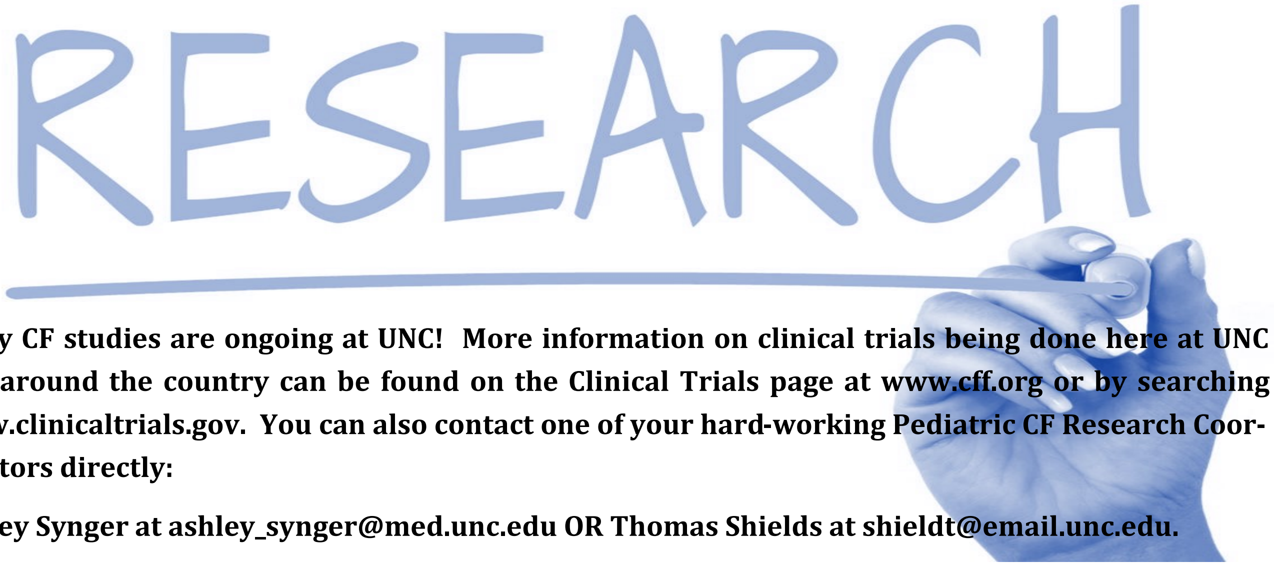
Healthy Fat Food Ideas for Kalydeco, Orkambi, Symdeco or Trikafta

Taking your CFTR modulator medicine with a fat-containing food increases your body's ability to absorb and use this medicine. There is no exact recommendation for grams of fat, but a goal of 10-15 grams should be adequate for most teens and adults. For younger children, a minimum of 5 grams of fat should be adequate.

Try these first (less saturated fat):
1 Hard-boiled egg (5g)
10 large black olives, pitted (5-6g)
1 whole-milk mozzarella string cheese (6g)
Black olive tamponade 2 Tablespoons with crackers (6-8g)
Hummus Tribe brand 4 tablespoons with pita (8g)
Peanut butter 1 Tablespoon (8g)
1 pack peanut butter and crackers, such as Lance (9g)
Avocado toast at Dunkin Donuts (11g)
1/5 of an avocado mashed on 8 tortilla chips (13g)
10 walnut halves (13g), or 18 cashews (13g)
1 banana with 2 tablespoons of peanut butter (16g)
Whole grain English muffin with 1.5 tablespoons of peanut butter (12g)
Wholly Guacamole 1 mini pack with carrot sticks (12g)
4 black olives and 1 tablespoon mayo on 5 thin slices turkey breast (13g)
Shredded cheese 1/4 cup on tortilla with 1 tablespoon of guacamole (14g)
Oatmeal 1 packet with 2 tbsp. of chopped walnuts with 2 oz. whole milk (14g)
Peanut butter or WowButter (soynut) 2 tablespoons with banana (16g)
Justin's single pack almond butter with graham crackers (19g)
Jif mini pack 1.5oz peanut butter with celery sticks (21g)

Still stuck? Give these a try:
5 Hershey kisses (5g)
1 cup whole milk (8g)
1 Eggo waffle with 1 teaspoon of butter (8g)
1 full-fat vanilla Greek yogurt, such as Fage Total (10g)
1 cup of breakfast cereal 8 ounces of whole milk (12g)
1 oz. cheese with 5 Townhouse crackers (13g)
1-2 slice of whole grain/wheat bread with a tablespoon of butter (14g)
1 cup of whole milk with Nature valley granola bar or CLIF bar (14g)
4 slices of bacon with 1 egg (15)
1 Bagel with 2 tablespoons cream cheese with 4 oz. of whole milk (15g)
1 cheese stick with 5 Ritz crackers with 1 cup Silk vanilla coconut milk (15g)
2 frozen wheat pancakes with 1 tablespoon of butter (16g)
1 egg cooked in 1 tablespoon of butter (17g)
1/2 of a large muffin, with butter (16-28g)

Websites for more Ideas:
https://www.trikafta.com/fat-containing-foods
https://www.symdeko.com/fat-containing-food-ideas
https://www.orkambi.com/videos-resources#recipes
https://www.kalydeco.com/fat-containing-foods



Many CF studies are ongoing at UNC! More information on clinical trials being done here at UNC and around the country can be found on the Clinical Trials page at www.cff.org or by searching www.clinicaltrials.gov. You can also contact one of your hard-working Pediatric CF Research Coordinators directly:

Ashley Synger at ashley_synger@med.unc.edu OR Thomas Shields at shieldt@email.unc.edu.

PROMISE Study Update

Hello PROMISE families and supporters! What a productive year we have had together doing research. On behalf of all clinic and research personnel, I'd like to thank all of you for your hard work and commitment to this study so far. We have officially completed everyone's Visit 4 (the 6-month mark after initiation of Trikafta), which is no small feat! With your help and the help of clinic personnel, we enrolled 11 pediatric patients within the first few months of Trikafta's approval for the 6-11 year age group..

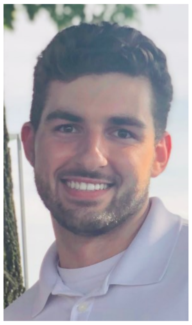
The PROMISE study has also extended the timeline of the study, adding in two additional visits (usually coordinated with your clinic visits). During your next study visit, the study team will ask if you are willing to conduct a visit at 36-months and 48-months; as always with research, these are voluntary as you discuss what's best for your family.

Last but certainly not least, we have received the Sweat Chloride results from pre-Trikafta and post-initiation of the new modulator. Our study team has sent all families their results and have begun sharing this information with their respective CF care team. If you have any questions, please contact your CF care team to discuss what this means for your child.

We look forward to seeing everyone in the next few months for their 1-year study visit! If you have any questions, please do not hesitate to reach out.

Submitted by Ashley Synger, MA & George Retsch-Bogart, MD

Introducing Thomas Shields, BS, CF Clinical Research Coordinator



I recently moved down to North Carolina after graduating from the University of Delaware and receiving my Bachelor's degree in Biological Sciences. I've been involved in different specialties of pediatric research for almost 3 years now, including research with cerebral palsy and the development of movement patterns in children. As an aspiring physician, I'm honored to have the opportunity to work in the pediatric pulmonology department here at UNC. In my free time, I enjoy reading and talking with my family in Delaware, including my 6 younger siblings! I have a passion for research, and working in pediatrics keeps me young at heart! Although I'm still learning, I'm excited to meet everyone that makes up the UNC cystic fibrosis community and help contribute to research for people with cystic fibrosis.

Want to Help Other Families Affected By Cystic Fibrosis?

Join the CF Family Advisory Board!

Who we are:

We are parents of children with CF who receive their care at the UNC Pediatric CF Center. We are dedicated to working with and getting to know the CF care team and each other in an atmosphere of trust and compassion and with the purpose of improving care and the quality of life for those with CF.

Mission:

We are dedicated to enhancing the medical care and quality of life for those with CF. Through collaborative efforts with the medical community; we seek to promote an open learning environment that results in personal empowerment and individualized care driven by evidence based best practices. In all we do, we seek to deliver the highest standard of safe and comprehensive care, provide compassionate support to CF patients and their families, and strengthen the collaboration between patients, family members and the health care team.

If you have interest in joining our monthly zoom meeting contact Jennifer Leandro at **leandro@email.unc.edu.**

Contact Us

Scheduling: 984-974-1401
(En Español: 919-966-6669)

Pulmonary Office:
919-966-1055 (8am-4:30pm)

CF Nurses:
919-966-1055 (9am-4pm)

Hospital Operator:
984-974-1000

Visit us on the web at:
www.uncchildrens.org/uncmc/unc-childrens/care-treatment/pulmonary-care/cf

UNC MyChart: https://myuncchart.org

uncpedscfcenter

Help Us Make the Newsletter Better!

If you would like to submit an article or have an idea for the next CF Family Newsletter, please contact Kelly Moormann at kelly.moormann@unc.edu.