



SALTY TIMES

CF News

CF Nutrition

Sandy Salzedo

The recent advancements in CFTR modulator therapy have led to a shift in the approach to nutrition for individuals with cystic fibrosis. Instead of focusing solely on weight, BMI and calorie intake, the emphasis has shifted to “eating for longevity” and promoting healthy eating behaviors and a positive mindset. Studies have shown that maintaining a healthy body composition, eating habits and exercise routine are crucial for overall health. By incorporating mindfulness and a deeper understanding of nutrition, individuals with cystic fibrosis can establish long term healthy habits and improve overall well-being.

Mindful eating is a practice that involves paying attention to one’s thoughts, emotions, and bodily sensation while eating. It has its origins in Buddhist teachings and has been popularized by Kabat-Zinn in the 1970s as a way to cultivate awareness in the present moment. For individuals with cystic fibrosis, mindful eating can be especially beneficial in addressing the unintended consequences of focusing solely on calorie and weight goals, such as not listening to their body’s cues and developing emotional eating habits. By taking the time to check in with one’s body and emotions during meals and slowing down to fully experience the food, one can establish healthy eating habits and a positive relationship with food and the body. It is important to note the importance of uncoupling weight with personal worth in this process.

Choosing nourishing, healthy foods is essential for overall well-being and nutrition. One useful resource for gaining basic nutrition knowledge is the USDA’s MyPlate guide, which divides foods into five main categories: grains, vegetables, fruits, protein and with a smaller circle representing dairy.

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CF Nutrition continued

Grains, such as wheat, rice, oats, and barley, provide important nutrients including complex carbohydrates, dietary fiber, B-vitamins, and minerals. Fruits and vegetables are rich in vitamins, minerals and dietary fiber and have been linked to various health benefits. Protein-rich foods, including seafoods, meat, poultry, eggs, beans, peas, lentils, nuts, seeds, and soy products, provide essential amino acids for building muscle as well as B-vitamins, vitamin E, iron, zinc, and magnesium. Dairy products, including milk, yogurt, cheese, and lactose-free options are a reliable source of B-vitamins, protein, calcium and vitamin D, which are essential for building and maintaining strong bones, particularly in children and adolescents

By combining an understanding of healthy nutrition with the practice of mindful eating, individuals with cystic fibrosis can establish a holistic approach to eating that promotes longevity and overall well-being. The field of CF nutrition is constantly evolving and utilizing both knowledge and mindfulness in one's approach to eating can be a powerful tool in improving health outcomes.



“By combining an understanding of healthy nutrition with the practice of mindful eating, individuals with cystic fibrosis can establish a holistic approach to eating that promotes longevity and overall well-being.”

SAVE THE DATE!

Family Education Day

That's right! We are back IN PERSON for our first CF Family Education Day since 2019.

**Date: Saturday,
September 23, 2023**

Time: 9am—1:30pm

Location: Rady Children's Main Campus

Keynote Speaker: Dylan Mortimer

Artist and adult with cystic fibrosis.

Trikafta Age Extension

Sara Cuevas



Elexacaftor/tezacaftor/ivacaftor (Trikafta) is currently available for patients 6 years of age and older with qualifying CFTR mutations. Vertex filed an application with the FDA last fall requesting for Trikafta to be approved for use in patients aged 2-5 years of age. The application was based on

data presented at the North American Cystic Fibrosis Conference (NACFC), which demonstrated safety and efficacy in patients aged 2-5 years. The researchers concluded that Trikafta “has a favorable safety profile and provides clinically meaningful benefits in CFTR function to people with CF as young as 2 years of age”. The most common side effects reported in the clinical trial were cough, fever, and runny nose.

We anticipate the FDA response this Spring. Will your child be newly eligible? Ask us at your next clinic visit if you are not sure if your child will be eligible. If you know your child has eligible mutations and you are waiting for the FDA approval, make sure your child is prepared with up-to-date liver labs (within the past six months) and an eye exam within the past year.

Getting Labs Done at Rady: Tips for Success!

Stacey Mount

Did you know you can get your labs done with a CF clinic visit?

Here's how:

Make an appointment ahead of time.

After scheduling your next CF clinic visit, call the Rady Outpatient Lab to schedule a lab appointment for the same day as your next visit. The sooner you call the better!

To schedule an appointment, please call **858-966-6776**.

No appointment, no problem!

Lab always accepts walk-ins, but the wait time can be unpredictable

If you are coming in for a CF clinic visit, you can check in with lab before your CF appointment check in time

If there is a long wait, you can come to your clinic visit and will not lose your place in line at lab! Just let the lab front desk staff know that you will be going to your clinic visit and will come back after – you may even be first in line when you check back in!

Need an oral glucose tolerance test? Get it done during your clinic visit!

You can start your oral glucose tolerance test at the lab and then come to your scheduled CF clinic visit while you wait!

You can plan ahead by scheduling your lab appointment for 30-60 min before your CF clinic check in time OR walk-in to lab 30-60 min before your check in time to get the process started

After the first blood draw, you can come to your CF visit and go back to lab for the glucola (sugar drink) and then the second blood draw.

The CF clinic nurse can help you coordinate while you are here. We even have handouts to give lab staff to let them know what's going on and who to reach out to if they have questions.



Outpatient Lab front desk located in Medical Office Building

A Fond Farewell! (and welcome back!)

We congratulate Laurie Brust on her retirement at the end of 2022! Laurie was our CF social worker for over 20 years and served our CF community with dedication and passion.

She will be missed by patients, families and team members!

Laurie plans on spending her retirement adoring her grandchildren and baking lots of treats!

Denay Gonzalez (featured on the next page!) has transitioned into Laurie's role. Welcome Denay! Denay will continue to be supported by Courtney Larson who has recently returned from maternity leave.



Max (6m), Courtney



Chloe (7), Laurie, John (9)

Get To know your CF Team:

Meet our Newest Members!

Meet Denay



Nice to meet you! My name is Denay, and I have recently joined the Social Work team at your CF center. I initially joined Rady Children's Hospital in the Fall of 2021, as a Social Work intern. During my time as an intern, I had the pleasure of working with families both inpatient and outpatient. I spent half of my time on the surgical floor, and the second half on the pediatric oncology floor, providing support to patients and their families. I am a graduate of San Diego State University, where I completed both my graduate and undergraduate studies as a major in Social Work. My undergrad

internship was with the County of San Diego, Child Welfare Services where I worked to promote the safety, permanency and well-being of children and families. Prior to that, I volunteered at the Dojo Café providing psychosocial support to youth in the City Heights community. It has been my honor to be able to serve children and families in these different capacities throughout the years.

When I am not working, you can find me exploring San Diego, reading, or studying for my upcoming law and ethics exam. I look forward to meeting you, and the opportunity to work with your family.

Meet Dr. Cymbaluk

Dr. Cymbaluk is a Pediatric Endocrinologist at Rady Children's Hospital San Diego.

Dr. Cymbaluk graduated from the University of North Dakota School of Medicine and Health Sciences in 2016. She completed Pediatric Residency at Cincinnati Children's Hospital in Cincinnati, OH in 2019 and went on to complete her Pediatric Endocrinology Fellowship at Texas Children's Hospital/Baylor College of Medicine in Houston, TX. She joined Rady Children's Hospital upon fellowship completion in July 2022. Dr. Cymbaluk treats patients with endocrinopathies, including diabetes, thyroid, growth, and pubertal disorders. She has a particular interest in CF-related diabetes, diabetes quality improvement, and socioeconomic predictors of health, as well as providing medical care for children in underserved communities. Dr. Cymbaluk will join cystic fibrosis clinic every other month, to help manage any CF-related endocrinology concerns that arise.



In her free time, Dr. Cymbaluk enjoys spoiling her niece and nephews, baking, and running marathons.

RT Corner

Cathy Glass

It is important to keep those neb cups clean!

When Using a Reusable Nebulizer:

After each use, clean and disinfect the nebulizer as soon as possible by following the CF Foundation's recommended nebulizer care.

Clean the nebulizer parts with dish detergent soap and water

Disinfect

Rinse

Air dry

There are two disinfecting options: heat and cold.

Heat Methods:

Place in boiling water and boil for 5 minutes

Place in a microwave-safe container submerged in water and microwave for 5 minutes

Use a dishwasher, if the water is 158 degrees or more, for 30 minutes

Use an electric steam sterilizer

Cold Methods:

Soak in 70% isopropyl alcohol for 5 minutes

Soak in 3% hydrogen peroxide for 30 minutes

Rinse off the cold-method disinfectant using sterile water, not tap water



Reusable nebulizer cups, tubing and masks should be replaced every 6 months.

You can get these from the durable medical equipment (DME) provider that gave you the nebulizer compressor. For questions or additional resources send us a MyChart message or ask in clinic!

Do you have a travel or emergency plan for airway clearance?



Ask your friendly respiratory therapist what you can do for airway clearance options if you do not want to bring your vest on vacation or if there is a power outage!

UCSD/Rady Children's Hospital

MyChart is a great way to communicate with your CF Team for non-urgent issues. You can also review lab results and after visit summaries!

Mychartatradychildrens.org

MyChart support:

877-902-4278

Contact us

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Dae Timog, Clinic nurse

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Sandy Salzedo, Dietitian

(858) 966-1700 ext 225016

Martha Lum and Cathy Glass, Respiratory Therapists

(858) 966-5982

Dr. Lim or Dr. Akong

(858) 966-5846, option 1

Lisa Ramos, Research Coordinator

(858) 966-1700 ext 224127

CF Foundation

San Diego and Imperial Counties

www.cff.org/chapters/san-diego-chapter

2023 EVENTS

- 4/25 Annual Meeting and Volunteer Celebration
- 4/29 Honolulu, HI Great Strides
- 5/11 San Diego Guild Luncheon
- 6/3 San Diego Great Strides
- 9/9 Surf for CF

