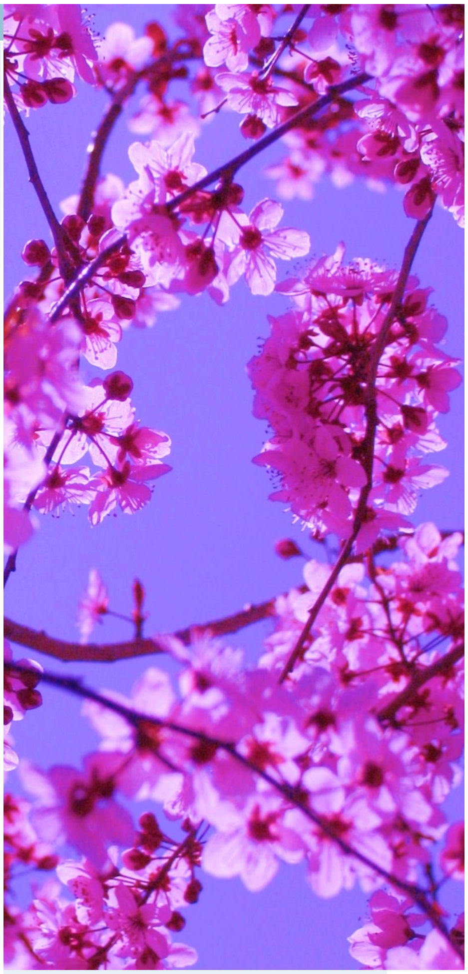
UCSD/Rady Children's Hospital

Spring 2024

SALTY TIMES

CF News



Exercise in Cystic Fibrosis

Dr. Patricia Lenhart-Pendergrass

Many families wonder about the role of exercise in the daily lives of their children with CF. Most children with CF can safely participate in a wide range of physical activities which can have both physical and psychological benefits.

<u>What are the benefits of exercise for my child with CF</u>?

Studies have demonstrated numerous benefits associated with exercise that are advantageous in CF. Some of these include:

Improved lung function
Increased mucous clearance
Improved cardiovascular health
Increased muscle strength
Improved bone health
Improved gross motor skills
Better mood, reduced stress
Higher sleep quality
Better focus in school
Increased opportunities for socialization with friends and family

<u>What should my exercise goals be for my child with CF</u>?

The American Academy of Pediatrics recommend that all children get a minimum of 60 minutes of moderate to vigorous physical activity each day, and in most cases, children with CF are no exception!

Toddlers usually do not exercise for 60 min continuously, but they can be given opportunities to do many shorter bursts of activity daily such as running and climbing. For school age children and older, exercise can take many forms ranging from outdoor play to organized sports.

In general, exercise should be vigorous enough for your child to get their heart rate up and to start breathing faster than usual, but your child should still be able to carry on a

Inside this issue

Special points of interest

- Luke Skywalkers Smoothie
- Airway Clearance Crossword Puzzle
- XoC: CFF Satisfaction Survey Info
- CFF San Diego and Imperial Counties info
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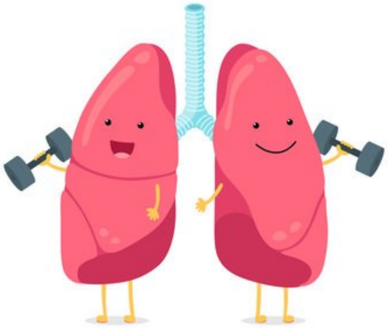
conversation.

In addition, there are many benefits to muscle strengthening activities. School age children can do body weight exercises, such as planks, bodyweight squats, or push ups. Teens can also do body weight exercises and can also begin to add in weights or resistance bands. Activities like yoga can also improve posture and core strength.



Special considerations for exercise in CF

- Stay hydrated. Fluid with electrolytes, like sports drinks, should be offered to children with CF who are doing vigorous exercise, especially in higher temperatures
- To improve airway clearance, you can encourage your child to do huff coughs during and after exercise
- Some children with asthma may need to use their inhaler before exercise
- Talk to your CF doctor about any other special considerations for physical activity for your child

What are ways to make physical activity more appealing?

- Make it fun for your child. One of the easiest ways to do this is to get the whole family involved. Go on a hike, take a bike ride together, or kick a soccer ball around at the park. Put on some music and have a family dance party. Getting in touch with your inner child and have fun together!
- Encourage your child to invite a friend to do something active.
- Team activities like sports or dance can be very motivating for school age kids and teens.
- Try lots of different activities to keep it interesting and find what your child enjoys.
- Start with small goals and build up as you go.

As a CF team, we are excited to help support you in making or continuing to make exercise a positive aspect of your child's day to day routine.

References

CFF.org, Healthychildren.org, Kinaupenne M et al. Eur Resp Review. Sept 2022, 31 (165) 220010.

NEW! Referral to Exercise Physiologist

To help support your child's exercise program at home, we are now able to make a referral to a exercise physiologist here at Rady Children's Hospital. An exercise physiologist is trained in how exercise can help people with chronic illness. This visit can provide information on exercise and create a program with goals for your child to use at home.

Resources to pay for activities

There are funds available to assist people with cystic fibrosis commit to a lifetime of regular physical activity. Grants can be used to pay for gym memberships, yoga, swim lessons, sports team registration fees or gear, exercise equipment, horseback riding, dancing, and other activities that promote physical fitness. Please contact your Social Work team for details about how to apply.

ROCK CF: KICKS BACK PROGRAM

BREATHE DEEP. RUN HARD. ROCK CF.

KICKS BACK DONATES RUNNING SHOES TO PEOPLE WITH CYSTIC FIBROSIS, AND REGISTERS THEM FOR A RACE OF THEIR CHOICE.

[Kicks Back — Rock CF (letsrockcf.org)](letsrockcf.org)

The Story of 65 Roses

In 1965, then 4 year old, Richard Weiss overheard his mother talking on the phone with numerous people, asking for financial assistance. This was shortly after Richard's mother, Mary, learned that all three of her children had cystic fibrosis. Volunteering for the Cystic Fibrosis Foundation, Mary was calling organizations asking for donations for CF Research. Overhearing his mother's conversations, but not knowing he had cystic fibrosis, Richard proclaimed to his mother that she was working for "65 Roses." Since then, the term 65 Roses has been used by children and adults alike to refer to cystic fibrosis. And the rose, a symbol of love, has come to represent the CF community.

Every year on June 5th, the CF community celebrates the legacy of the Weiss family and this heartwarming story.

Learn more about the CFF's 65 Roses Club by scanning the QR code

Recipe Corner

Luke Skywalker's AHCH-TO- Smoothie

By Sandy Salzedo

Nutrition plays a crucial role in managing Cystic Fibrosis, significantly impacting pulmonary outcomes. To support families in achieving their child's growth goals, I provide resources like high-calorie handouts, smoothie recipes, and cookbooks. Recently, I asked for your favorite recipes, and thanks to one of our patients who received Star Wars: The Padawan Cookbook by Jenn Fujikawa and Liz L. Heinecke as a holiday gift, we have a delightful recipe to share. Enjoy!

Prep time: 10 min
Yield: 1 serving
Ingredients:
1 banana, sliced and frozen
1 small avocado, peeled and pitted
1 cup soy milk* (substitute whole milk**)
2 tablespoons of maple syrup
½ teaspoon of vanilla
1/8 teaspoon of cinnamon

Into to a blender add the frozen banana, avocado, milk, maple syrup and vanilla. Blend until smooth. Pour into a glass. Dust the edge with cinnamon and serve.

*Nutrition analysis with soy milk: Calories: 530, protein: 11 g, fiber: 15g, carbohydrates: 77g, fat: 22g fat, vitamin A: 0.94 International units, vitamin D: 2.68 mcg, vitamin E: 0.39 mg, iron:1.2 mg, calcium: 350 mg

**Nutrition analysis with whole milk: Calories: 570, protein: 13 g, fiber: 11.2, carbohydrates: 77g, fat: 27g fat, vitamin A: 0.94 International units, vitamin D: 3.17 mcg, vitamin E: 0.3 mg, iron: 0.45 mg, calcium: 325 mg

FYI

Information and Reminders

Mask Reminder

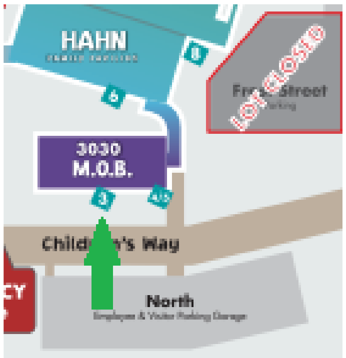
All persons with CF need to wear a face mask when in our hallways.

Mask may be removed once in the clinic room.

This is consistent with CFF guidelines for infection control and provides protection for your child. This rule applies to any of our buildings and indoor areas. Please make sure your child is wearing a mask when at lab, radiology or the cafeteria. If eating indoors at the cafeteria, masks should only be removed once sitting at a table to eat.

Construction Updates

Bridge Closure from North Parking Garage



The bridge that connects the north parking garage to the Medical Office Building (MOB) at the 2nd floor is now closed. The only way to enter the MOB is now through the main front doors on the ground level.

Access to the cafeteria from the north side of the MOB has also been closed.

During demolition, excavation and construction, all precautions are being taken to minimize dust and mold particles in the air. However, there may be increased levels of inhaled particulates in the air as you visit the Rady campus over the next few years. If you want to reduce your risk of inhaling these construction-related particulates, please consider wearing a mask outdoors as you walk around the campus.

A Special Thank You: Lilly Baker

By Rosa Baker

Lilliana, or Lilly, Baker is a super star fundraiser and contributor to the CF Clinic's Prize Closet! Lilly is 11 years old and the big sister and support to Lincoln (8 yrs), who has cystic fibrosis.

Lilly has raised hundreds of dollars for the CF clinic for the last two years by selling homemade bracelets and baked goods. She sells these items at an annual school boutique that focuses on having students build multiple different skills and the students get to keep any money they make. Lilly decided instead of participating to earn money for herself, she was going to use all the money for the CF Clinic. Lilly was inspired by her little brother Lincoln. She has seen firsthand how scary a CF appointment can be at times and has watched how her little brother struggles, especially with throat swabs. Lilly has never missed one of her brother's CF appointments and she knows that the only thing that brings a smile back to his face afterward is a small toy given at the end of his appointment for being so brave. Lilly uses the money she raises to purchase brand new toys and prizes for the CF clinic. She likes to pick toys that are easy, handheld, and enjoyable. She wants other children to have the same comfort and reassurance as she sees her brother have when he gets to pick a toy.

Since starting in 2022, Lilly has motivated friends and family to help her reach her goals. She has reminded her family that we aren't just here to find a cure, but to ensure that we are helping in all aspects of CF patients' lives. Lilly is one of the fiercest advocates for her brother and a great living example of how we get to change the world around us by seeing and filling a need. We are so proud of the heart that Lilliana has for her brother and other children with Cystic Fibrosis.

Lilly, the CF Team at Rady Children's thinks you are a STAR! Thank you for all you do!

RT Corner

Nebulizers

Nebulizers are essential to CF cares as they deliver important medications used for airway clearance. It is important to make sure you are taking proper care of both the compressor (the machine) and the nebulizer its (the cup, tubing, and if used, the mask).

The Compressor: The machine that you connect the tubing to is an air compressor. This machine works by pulling in surrounding air and then pushing it through the tubing to the nebulizer cup.

- May have a filter—check your manufacturer information to see if your compressor has a filter and how often it should be changed.

The Nebulizer: This is the cup that the liquid medication is placed into, the tubing that connects it to the compressor and then the mouth piece or mask that is used to inhale the medication. There are different types of nebulizers that create different sized mist particles.

- Reusable nebulizer cups and mouth pieces/masks need to be sterilized daily and replaced every 6 months.
- We do not recommend the use of disposable nebulizers at home, however, are the preferred product in the hospital.

If you need a instructions on how to sterilize nebulizers, ask your team!

Getting new nebulizers

You can get a new nebulizer (cup and tubing with mouth piece or mask) every 6 months—covered by insurance. This can be done by contacting the Durable Medical Equipment (DME) company that provided the machine.

Additional nebulizers can be purchased out of pocket. We recommend using the following websites:

Justnebulizers.com

Nebology.com

Contact your CF nurse for assis-

HealthWell Foundation

Get your out of pocket purchase reimbursed!

The HealthWell Foundation has a fund that will reimburse you for out of pocket costs for certain treatments and supplies. This includes nebulizers.

Please visit their web site for more information: https://www.healthwellfoundation.org/fund/cystic-fibrosis-treatments-2/

HEALTHWELL FOUNDATION®

When health insurance is not enough.®

Cross Word

Airway Clearance

S	P	A	C	E	R	S	S	A	T	L	R	C	R
X	T	H	C	C	R	R	B	I	A	E	E	H	N
M	H	L	E	N	B	E	H	U	L	C	B	O	C
F	G	K	L	G	S	O	Z	A	Y	C	A	P	C
L	U	R	E	R	O	L	H	I	E	M	T	H	E
O	O	R	L	P	E	N	U	Z	L	E	P	I	R
R	C	G	I	P	I	R	E	N	H	U	F	Y	A
E	F	E	M	Y	Z	O	M	L	U	P	B	P	E
T	F	Y	S	E	S	I	C	R	E	X	E	E	U
U	U	E	H	O	L	V	E	S	T	X	L	H	N
B	H	A	K	I	B	O	R	E	A	B	G	B	U
L	I	E	T	B	Z	I	A	O	U	P	K	M	R
A	I	O	R	B	L	T	H	O	G	E	N	L	P
P	C	E	S	E	T	E	F	T	H	H	B	T	E

EXERCISE
INHALER
SPACER
HUFF COUGH
CPT (chest physiotherapy)
PULMOZYME
NEBULIZER
AEROBIKA
VEST
ALBUTEROL

See back page for answers

Get to know your CF Team!

Meet Eva
New CF Clinic RN

My name is Eva Barton and I have been a nurse for 5 years. I started at Rady Children's Hospital in 2015 as a patient care assistant and in 2018 I was offered a position as a RN on 4 East. In 2020, I decided to move to Dallas, Tx and there I worked in the Pediatric Intensive Care Unit (PICU). I became a little home sick after about a year and decided to move back home to SoCal. I am a mother to a 5-year-old boy. He consumes most of my time, especially on weekends because he enjoys playing every sport. I also enjoy going to Barnes and Noble to drink Starbucks and browse through all the cool books. I am excited to meet you all and to be working with such a fantastic team.
Fun fact: I recently became a lash technician and I love it!

The Sweet and the Salty: Turning 16

Turning 16 is a big deal—for parents and 16 year-olds alike! It's a big deal at CF Clinic too. This is when we will start talking to you (the 16 year old) and your parents about becoming more independent in your CF Care.

Once you turn 16, the social work team will send a letter through your MyChart portal as well as provide you a paper copy during a clinic visit, introducing the idea and goals of CF independence. Together, YOU, your parents, and your CF social worker will create a plan to help guide you to independence in your CF care.

Get Involved with your CF Center

Become a Parent Advisor to the CF Team !

Interested? Email Stephanie at Slord@paloaltou.edu for more info.

Submit an article!

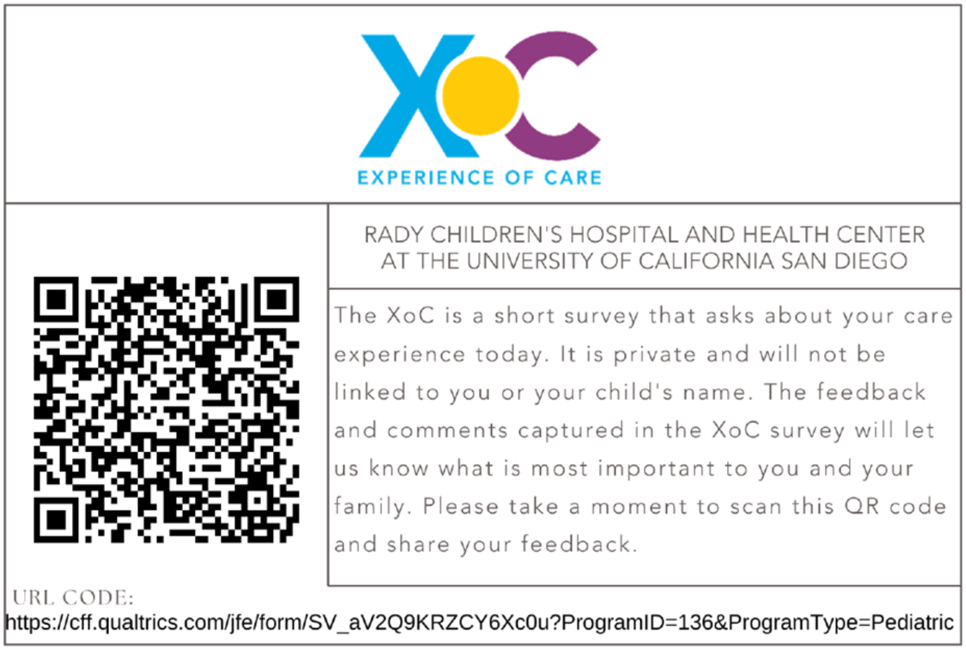
We accept submissions from families to share their perspective of living with CF.

You can also share a cool experience your child had or any of their artwork.

If interested, please send a MyChart message to your team!

Help us help you!

Please make sure to complete the CFF experience of care survey– called XOC—after your next visit. We would love to hear what's going well and how we can make your time at clinic better.



XOC EXPERIENCE OF CARE

RADY CHILDREN'S HOSPITAL AND HEALTH CENTER AT THE UNIVERSITY OF CALIFORNIA SAN DIEGO

The XoC is a short survey that asks about your care experience today. It is private and will not be linked to you or your child's name. The feedback and comments captured in the XoC survey will let us know what is most important to you and your family. Please take a moment to scan this QR code and share your feedback.

URL CODE:
https://cff.qualtrics.com/jfe/form/SV_aV2Q9KRZCY6Xc0u?ProgramID=136&ProgramType=Pediatric

PROGRAM 136: RADY CHILDREN'S HOSPITAL AND HEALTH CENTER
AT THE UNIVERSITY OF CALIFORNIA SAN DIEGO

CF Foundation: San Diego and Imperial Counties

CYSTIC FIBROSIS FOUNDATION
ADDING TOMORROWS

Scan the barcode for information on our local CFF Chapter
See Calendar of Events
Meet the Team
Get Involved!

CF FOUNDATION CARES | CYSTIC FIBROSIS FOUNDATION®

As a family member or friend of someone living with CF, we invite you to join others to connect, encourage, and share experiences. These dinners are free of charge and are not a fundraising event.

Register for a CF Foundation Cares event by scanning this QR code or visit www.cff.org/sandiego/.

Contact us

Stacey Mount, Program Coordinator

Eva Barton, Clinic Nurse

(858) 966-1700 ext 224562

Denay Gonzales, Social Worker

(858) 966-1700 ext 225340

Courtney Larson, Social Worker

(858) 966-1700 ext 224212

Sandy Salzedo, Dietitian

(858) 966-1700 ext 225016

Martha, Savannah and Cathy

Respiratory Therapists 858) 966-5982

Dr. Akong, Dr. Pendergrass, or Dr. Lim

(858) 966-5846, option 1

Lisa Ramos, Research Coordinator
(858) 966-1700 ext 224127

How to sign up for Mychart

Please visit: www.rchsd.org/mychart-information/enrollment/

Or

Sign up at your next visit at the check in desk

MyChart at Rady Children's

Cross word answer key

Airway Clearance

S	P	A	C	E	R	S	S	A	T	L	R	C	R
X	T	H	C	C	R	R	B	I	A	E	E	H	N
M	H	L	E	N	B	E	H	U	L	C	B	O	C
F	G	K	L	G	S	O	Z	A	Y	C	A	P	C
L	U	R	E	R	O	L	H	I	E	M	T	H	E
O	O	R	L	P	E	N	U	Z	L	E	P	I	R
R	C	G	I	P	I	R	E	N	H	U	F	Y	A
E	F	E	M	Y	Z	O	M	L	U	P	B	P	E
T	F	Y	S	E	S	I	C	R	E	X	E	E	U
U	U	E	H	O	L	V	E	S	T	X	L	H	N
B	H	A	K	I	B	O	R	E	A	B	G	B	U
L	I	E	T	B	Z	I	A	O	U	P	K	M	R
A	I	O	R	B	L	T	H	O	G	E	N	L	P
P	C	E	S	E	T	E	F	T	H	H	B	T	E