



Adult Cystic Fibrosis Center Quarterly Newsletter

Summer Travel Tips

Summer is here! Many of you are getting ready for your trips and vacations and we would like to give you some tips to keep you well cared for during your travels!

Always pack at least two standby antibiotics and pack an extra 4 days of medications in case of travel delays. If flying, keep your medications and nebulizer in your hand luggage rather than checking it in. When going through security its worth telling the officials that you have medical devices and medications in your hand luggage before it goes through the scanner - they appreciate being told and it may stop you from having to unpack everything to show them.

If you need a compressor while on vacation, take your own, or ask for a portable one that has a battery pack from your CF Care Team, if electricity is unavailable or unreliable.

If you are travelling out of the country, find out about the electricity voltage and frequency, and type of adaptor plugs needed. You will likely require plug adapters and voltage converters to avoid damaging your electrical equipment and to use it safely. Voltage adapters can be purchased at most electronics stores.

Have fun and enjoy the summer season !

How CF Affects Your Sweat Glands

Cystic fibrosis can lower the normal salt levels in the body, which can lead to many problems.

Sweat glands cool the body by releasing sweat. Sodium and salt help carry water to the skin's surface and then go back into the body. As the sweat evaporates, heat is carried away, and the body cools.

In people with CF, salt travels to the skin's surface with the water, but does not disappear with the water. This is why the skin of a person with CF is really salty.

People who have cystic fibrosis can become quickly low on salts, especially when the weather is hot, when they exercise, or when they have a fever. Low salt levels in the body can cause fatigue, weakness, fever, muscle cramps, stomach pain, vomiting, dehydration, and heatstroke. To avoid these conditions, people who have CF need to keep well hydrated and keep healthy salt levels in the body. Sports drinks like Gatorade contain electrolytes (such as sodium and potassium) that are good at replacing lost salts.

To help keep your salt levels up try our salt supplement (mix 1/8 of a teaspoon of salt in 12 ounces of water). Do not use salt tablets without talking to your doctor first.

Inside this issue:

Summer Travel Tips	1
How CF Affects Your Sweat Glands	1
2018 Gainesville Great Strides	1
Becoming a Parent with CF- An Adoption	2
More Travel Tips!	2
CF Recipe	2
Upcoming Events	2

Is finding a **CF Clinical Trial** close to your home what's keeping you from participating in research? If so, the CF Foundation has created a Clinical Trial Finder that can help you identify some studies that you may be eligible for. Click the link below to get started! <https://www.cff.org/Trials/finder?page=1>

2018 Gainesville Great Strides

This year's Gainesville Great Strides took place on Saturday April 14 in Westside Park, Gainesville, FL. The fundraiser past its goal raising \$43,626.00! The UF Adult CF Team attended, walking for a future cure for Cystic Fibrosis.



Becoming a Parent with CF- An Adoption Story by Chris Kvam

My story to parenthood starts in my late teens, when I learned of my CF-related infertility. Learning this was crushing and I struggled with it for a long time. I had always known I wanted to be a father. For a long time, I tried to convince myself that I didn't need to be a dad. Fortunately, I met my wife and started discussing becoming parents together. Little did we know that becoming parents was going to be a long process.

We considered IVF, other fertility options and adoption. Considering finances and the strain that hormonal treatments will cause, we decided to not attempt IVF and chose to pursue adoption. Arriving at that choice took about six months.

Once we decided that adoption was our desired means to parenthood, we began the process. We knew we wanted a newborn.

We found an agency about an hour away from our house and began the process of being "home certified" for adoption. This certification process involved an in-depth check of our house, personal finances, health, employment history and criminal background check. I was able, with the help of my Care Team to provide enough evidence to show the adoption agency that I was healthy and could reasonably expect to live to a child's "age of majority" and, was not required to disclose my diagnosis to a birth mother. This was a big deal and cleared a major barrier for our adoption process. We were also helped by the fact that my wife is in perfect health and having a "well spouse" and otherwise very supportive extended family decreased the ethical concerns around nondisclosure of my CF. Our home-study was completed and we were eligible for

matching.

The match process was the hardest, most vulnerable time of our lives. First, we had to select what we were open to. After we generated our "grid" of what we were open to and created a photo book showing off our house, ourselves and our family in waiting we waited to be chosen. It took years for our son to arrive. But when we met him, it was love at first sight.

I am worthy of being a dad. Overcoming the hurdles in our path to parenthood represents all of the work I have done to maintain my health. To be 37 and able to raise my son represents every treatment, every course of IVs, every surgery and the relentless approach I have taken to living my life with CF.

This article was adapted from the Winter 2018 CF Roundtable

More Travel Tips!

1. Always contact your airline if you need to take oxygen during the flight. Each airline has its own policy on oxygen transport and in-flight usage. Some supply oxygen for free or allow you to carry a compressor aboard as part of your hand luggage, while others charge a fee for supplying it.
2. Many medications are temperature-sensitive, so special care should be taken. Room temperature is generally identified as 15 to 30°C. Keep all drugs at the recommended temperature and keep them away from strong light and sources of extreme heat or cold (e.g. windows, automobiles and appliances). Enzymes should always be kept at room temperature. Be sure to store items that require refrigeration promptly so that they are not exposed to unnecessary heat, but do not freeze them!

CF Recipe

Easy Fudge Recipe (10 servings, 200 calories each!)

Ingredients:

- ½ cup coconut oil
- ½ cup cocoa powder
- ½ cup smooth nut butter (such as peanut or almond)
- ¼ cup honey or maple syrup
- ½ teaspoon vanilla

Instructions:

1. Melt coconut oil
2. Mix all ingredients in blender until smooth
3. Pour into silicone muffin cups (use paper liners if using a metal muffin pan). Fill about ½ inch each.
4. Freeze until firm (about 10 minutes) and enjoy!



Upcoming Events

CF FamilyCon invites people with CF and their families to connect, share, and learn from each other. June 3, 2018. Register here:

<https://www.cff.org/Get-Involved/Participate/Participate-in-an-Event/Virtual-Events/CF-FamilyCon/>

CF MiniCon: Transplant will provide adults with CF and their families the opportunity to discuss the transplant journey, whether considering a transplant, preparing for a transplant, or post-transplant. August 15, 2018. Register here:

<https://www.cff.org/Get-Involved/Participate/Participate-in-an-Event/Virtual-Events/CF-MiniCon-Transplant/>

Orlando's Finest

August 17, 2018 6:30pm

Location: TBA

Registration: <https://orlandosfinest.finestcff.org/orlandosfinest/event-info>

Gainesville Tailgate ~ Kick Off to A Cure

Date: Saturday October 13, 2018

Location: Ben Hill Griffin Stadium, Touchdown Terrace

Register and donate here: <https://gatortailgate2018.eventscff.org/>