Traveling for the Holidays?
Basic of Traveling with Cystic Fibrosis

What’s the best way to have a good trip?

Be prepared.

Start with this checklist of things to do three to six months before you travel.

- Check in with your CF center before booking your trip to make sure you get a travel note and to assess your medical status. If you are not feeling well, you may need to be treated prior to your trip. You also should discuss a plan for treatments if you become sick and any impact time-zone differences may have on timed medications.
- Check on immunizations required for international travel.
- Make lists of medication and supplies you will need on your trip ahead of time. (Check and recheck this list!)
- Make sure you request a refrigerator at the place you will be staying for medications that need to be kept cold.

Count all medications well ahead of your trip and get refills (order a month or so in advance if you use a mail-order pharmacy). You may need to talk with your insurance provider for refills needed prior to your trip; some will provide a “vacation

What to Pack

- Make a list of emergency contacts in case you become sick or have problems with such things as your luggage.
- Bring a list of doctors who specialize in CF so you can get appropriate care if needed. Check the CF Foundation's website (for national travel) and Cystic Fibrosis Worldwide (for international travel) for locations of CF centers.
- Bring your insurance information in case you need to visit a CF care center.
- Pack alcohol-based hand sanitizer with you for good hand hygiene.

- Bring a prepaid phone card to contact your own CF center for advice in an emergency. These cards also are good to have if your cell phone does not work. You also may want to ask your cell phone company for a loaner phone for international travel.
- Bring instructions for your medical equipment in case of a malfunction (e.g., problems with your insulin pump).
- Bring a calendar of times and details on taking your medications to help those with you if needed.
**Snack Your Way to Improved Lung Function** by: CysticLife.org

A Caloric Guide to Common Snack Foods

1 large apple | 5 oz. of grape juice | 1000 Calories
2-inch slice of angel food cake | 1 1/8 oz. of a Hershey bar | 200 Calories
1/2 of a small avocado | 1 c. of ice cream | 100 Calories
2 slices of bacon | 20 jelly beans | 100 Calories
1 medium banana | 1 jelly donut | 100 Calories
8 cashew nuts | 1 Lemon Zest Luna Bar | 200 Calories
1 slice of cheese | 2 tbsp peanut butter | 80 Calories
2 c. of dried apricot halves | 1/2 of a PB and J sandwich | 80 Calories
3 ginger snaps | 1/8 of a 14” pizza | 80 Calories

Burger King Whopper Jr.
10 oz. banana split | 5 oatmeal cookies with raisins | 3000 Calories
4”x6” brownie with nuts | 2 6” pancakes | 200 Calories
6 chocolate chip cookies | 3 tbsp of peanut butter | 200 Calories
5” eclair with icing | 6”x6” slice of pound cake | 200 Calories
1 slice of lemon meringue pie | 1 slice of pumpkin pie | 200 Calories
2/3 c. of macaroni and cheese | 2.5 oz. of Snickers bar | 200 Calories
McDonald’s cheeseburger | 1 c. of soft ice cream | 200 Calories
3 oz. of spare ribs | 2 tacos | 200 Calories

AbbVie made a donation to CFRI (Cystic Fibrosis Research Institute) for every recipe that was submitted. Thanks to the community, they received a check for $15,000!

Thanks to AbbVie for their commitment to providing nutritional support for the CF community.

Check out [www.chef4cf.com](http://www.chef4cf.com) to view the new recipes submitted by the CFRI community!
Cook’s Corner: Recipe for Success

Peanut Butter and Jelly French Toast

Ingredients
- 4 slices whole wheat bread
- 1/4 cup peanut butter
- 2 tablespoons jelly
- 2 eggs
- 1/4 cup heavy cream
- 3 tablespoons butter

Directions
1. Make two peanut butter and jelly sandwiches using the bread, peanut butter and jelly.
2. In a mixing bowl, beat eggs and cream together.
3. Melt butter in a frying pan.
4. Dip the sandwiches in egg mixture, coating both sides of the sandwich with the mixture.
5. Place in frying pan and brown on both sides. Serve with jelly or syrup.

Serving Size
- 2 servings
- 700 calories per serving
- Fat: 53 g
- Sodium: 722 mg
- Protein: 20 g
- Calcium: 99 mg

For other great CF high-calorie recipes check out: www.chef4cf.com

CF patient spotlight: Aubrey Powell
by: Kerri Powell, mother

Aubrey is almost 5! Her smile will light up a room :) Aubrey loves her big sister, playing dress up, and Barbies! She is becoming a good little soccer player too! She is obsessed with purple and any princess! Aubrey is so strong and is a trooper taking her meds and treatments! Sydney is 7 and in the 1st grade and also plays soccer! Syd is a great big sis that is always concerned about Aubrey!

We have been going to Cooks since we got her diagnosis at 3 1/2 weeks! I like that the entire staff is very caring and listens to all our concerns. Our dreams for Aubrey is for her to be happy, loved, and never feel different from other kids! Also for her to know how strong she truly is!
DON’T FORGET TO GET YOUR FLU SHOT

Make sure you protect your CF child, yourself, and your family this year from the flu! It’s not too late to get it!

CFF (FORT WORTH) CALENDAR OF EVENTS

Great Strides 2015

Change of Location

May 17, 2015

The Ft. Worth/Arlington CF Great Strides event has changed locations.

Quik Trip Park, Grand Prairie, TX.

FOR MORE INFORMATION

Executive Director: Melanie Hanna
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Vertex submits New Drug Application to FDA for Potential Combination Drug for the Most Common CF Mutation.

Vertex Pharmaceuticals Inc. announced Nov. 5, 2014 that it has submitted a new drug application to the U.S. Food and Drug Administration (FDA) for approval of the combination of ivacaftor (Kalydeco™) and lumacaftor. The potential drug is for people with cystic fibrosis ages 12 and older who have two copies of the F508del mutation, the most common CF mutation.

The company has asked the FDA for priority review of the combination therapy, which, if granted, could shorten the review timeframe from approximately 12 months to 8 months. The FDA grants priority review for several reasons, including when a potential drug is considered a major treatment advance.

The treatment is the first to combine two drugs into a single pill to address the underlying genetic cause of the disease in those with two copies of the F508del mutation. About 50 percent of people with CF in the United States have two copies of the F508del mutation and 40 percent have one copy.

“The CF Foundation is very pleased to see that this combination treatment is moving forward with possible approval in 2015,” said Robert J. Beall, Ph.D., president and CEO of the Cystic Fibrosis Foundation. “This is an exciting step forward in our efforts to speed development of new and effective therapies for all people with CF.”

Results released earlier this year from late-stage clinical trials of the combination treatment in those with two copies of F508del showed that those who received the drug had significant improvement in lung function and other important health measures, including weight gain, and a reduction in the rate of pulmonary exacerbations. The combination treatment was generally well tolerated by participants who took the drug, with few adverse events reported.

Vertex plans to begin a Phase 3b clinical trial of the potential combination drug in people ages 12 and older with two copies of the F508del mutation that have severe lung disease and may benefit from the treatment prior to its potential approval. The trial will enroll a limited number of people in the first quarter of 2015.
Dear Friends:

I have exciting news to share with you about a transformational moment in our shared journey to cure cystic fibrosis.

Today, we announced that our drug development affiliate, Cystic Fibrosis Foundation Therapeutics, has sold its royalty rights to CF treatments developed by Vertex Pharmaceuticals Inc. to Royalty Pharma for $3.3 billion.

The funds from this sale give us a tremendous opportunity to accelerate our mission as never before. We will expand our efforts to help develop lifesaving new therapies and work to ensure that the best possible care and patient programs are available for people with CF and their families. We will also pursue daring new research that we hope will one day lead to a lifelong cure that targets the disease at its genetic level.

Simply put, these new resources will allow us to “dream big” in ways we never could have imagined.

This historic milestone would not have been possible without the tireless dedication of the entire CF community. I am deeply grateful for the role you’ve played in today’s news. Together, over the last several decades, we have made enormous strides. Life expectancy has doubled in the last 30 years, and there is more hope and optimism than ever before that people with CF can live longer, healthier lives.

Working as a community, we will continue to forge a path of lifesaving progress that a group of devoted parents started almost 60 years ago. Thanks to you, we are now even better prepared to embrace the opportunities and meet the challenges that lie ahead. Your continued support will allow us to take bolder steps toward our shared goal. I am confident we will get there.

Thank you.

Robert J. Beall, Ph.D.
President and CEO
Cook Children’s Staff Bios:

Karissa Galvan, MA
My name is Karissa Galvan, I grew up here in Saginaw, Texas and have been with Cook Children’s for over 7 years. I have come to find a new home with the Pulmonary department as one of their Medical Assistants. I married my high school sweetheart and together we have 2 wonderful daughters and 2 dogs. I enjoy spending time with my family and doing ZUMBA!!

Esther Giezendanner, MS, RDN, LD
My name is Esther Giezendanner and I’m one of the new dietitians at Cook Children’s Pulmonary clinic. I completed my undergraduate degree at Wheaton College, IL, and worked for several years as a librarian before returning to school for an MPH in nutrition at the University of North Carolina at Chapel Hill. While there I got the chance to work in a WIC clinic, in a large hospital, and doing research in Africa—all fun experiences, but it’s nice to be settled now! In my free time I love to read, bake, visit art museums, and go on hikes. I’m new to Fort Worth but very excited to be here and to be working with CF patients and their families!

Brenda Blaker, MA
I have called Texas home for 20 years. I started with Cook Children’s in 1995 at CCPN Cityview. After 8 years I made the hard decision to leave. I have been back with Cook in some capacity for the last 4 years. My son is a freshman at MSU in Wichita Falls; my oldest daughter, whose life revolves around volleyball, is a high school sophomore; and my youngest daughter is in third grade. I just recently celebrated my 20 year anniversary.

GO STEELERS!!!

From October 9-11, nearly 4,000 clinicians, scientists and caregivers from around the world gathered in Atlanta for the Foundation’s 2014 North American Cystic Fibrosis Conference (NACFC). Live streaming highlights include the conference’s three plenary presentations and select symposia and workshops.

- **Plenary 1**: Michael P. Boyle, M.D., F.C.C.P., associate professor of medicine, The Johns Hopkins University School of Medicine, will provide a closer look at delivering the promise of transformational CF therapeutics.
- **Plenary 2**: John J. LiPuma, M.D., professor, associate chair for research, University of Michigan, will guide you through an exploration of CF microbiology.
- **Plenary 3**: Eugene C. Nelson, D.Sc., M.P.H., director, population health and measurement program, Dartmouth-Hitchcock Medical Center, will examine a CF care model fit for the future.

***The sessions are now archived and available for viewing on www.cff.org

Stay tuned for a special edition Cook Children’s CF newsletter. Our staff will share with us all the latest and greatest news that they gathered from the conference.
Winning with Cystic Fibrosis Teleclass

by Lisa Green, author and mother of 2 children with CF

Upcoming Teleclass for Parents of Children with CF
Winning with Cystic Fibrosis: Tools, Tips and Tactics for Raising Healthier, Happy Kids

Do you ever worry about your child not taking good care of him or herself when you’re not around? Or maybe your child is showing some frustration or resistance around doing all of the things it takes to stay healthy. Do you ever wish there was an instruction manual for parenting kids with cystic fibrosis? Good news—there is!!

Discover how to:
- Motivate kids to make wise choices about taking care of their bodies because they want to and not just because you tell them to...
- Put an end to power struggles, arguing, whining, and complaining.
- Prevent problems before they start by using effective tools early on.
- Promote responsibility without nagging, lecturing, yelling, or bribing.
- Talk about difficult issues such as life expectancy or negative medical information.
- Prepare your child for the transition into the real world starting in the early years.
- Raise confident, resilient kids with good coping skills and hope for the future.
- Increase the odds that your child will lead a healthier, happy life!

Dates: Six Session Teleclass: Jan 18 to March 8, 2015 (Skip 2/1, 2/22)
Times: Sundays, 4-6 pm Pacific, 5-7 pm Mountain; 6-8 pm Central, 7-9 pm Eastern
Location: In the comfort of your own home via telephone and/or computer
Cost: $59.00* per person/couple. Scholarships are available.

This is a six session, 2 hour teleclass for parents/guardians of children of all ages with cystic fibrosis. Tuition covers the cost of materials, live instruction, and interaction with other parents and guest speakers. This program was developed and is presented by Lisa Greene, MA, CFLE, a parent educator and mom of two teens with CF.

* Please note: The long-distance fees from your own telephone carrier are not included in the tuition cost.

One parent’s story...

I just want to let you know that I am finding this class very helpful. I have been struggling with a lot of the very issues you discussed. Having to follow the CF medical regimen, which is so demanding, can sometimes feel like child abuse.

One time I left the window open and the kids were yelling "I don’t want to do it, leave me alone" and my neighbors called the police! The patrol car pulled up outside my house with lights flashing. Two armed police officers came to the door. They asked to see what was going on so I brought them in and showed them all the medical paraphernalia. I explained that the kids did not want to do it. My wife and I were totally mortified. Fortunately, we don’t live in that neighborhood anymore.

The "sharing control" and "enforceable statements" concepts are very empowering. It is 100% on target. Thank you very much for this class.

To register or find out more information, visit:
www.WinningWithCF.com
You can also contact Lisa Greene at (425) 298-7197
Or email: WinningWithCF@gmail.com

Thank you to our supporting sponsor!
8 WAYS FOR PEOPLE WITH CF TO GUARD AGAINST GERMS IN EVERYDAY LIFE

Germs are everywhere, but there are things you can do to reduce your risk of getting sick.

The following tips are intended to keep you informed so that you can make the best decisions for yourself. These recommendations are based on the Cystic Fibrosis Foundation’s Guidelines for Infection Prevention and Control for CF. The primary goal of the Guidelines is to help people with CF preserve and protect their health.

Keep a Safe 6-Foot Distance
Germs can spread as far as 6 feet (2 meters) through droplets released in the air when you cough or sneeze. Try to stay at least 6 feet away from others with CF or anyone with a cold, flu or infection in all settings, both outdoors and especially indoors, such as in school or at work.

For people with CF who do not live together, avoid activities that may put you in close contact with others with CF or anyone who is sick.

Examples of activities to avoid are:
• Shaking hands, hugging or kissing.
• Sharing car rides.
• Sharing hotel rooms.
• Taking the same fitness classes.

Wash Your Hands
You can catch and spread germs when you touch something with germs already on it, like a doorknob or handrail, and then touch your eyes, nose or mouth. Wash your hands with soap and water or clean them with an alcohol based hand gel. Encourage your family and friends to keep their hands clean as well.

Everyone should wash or clean their hands:

Before
• Handling food.
• Eating or drinking.
• Beginning CF treatments.

After
• Coughing or sneezing.
• Using the bathroom.
• Touching shared objects, like pens or doorknobs.
• Touching or cleaning up after pets.
• Finishing CF treatments.

Cover Your Cough
You can spread germs to others when you cough or sneeze. Germs can remain in the air on tiny droplets – ready to be breathed in. They can also remain on surfaces long after you’ve coughed or sneezed on or near them.

Use a tissue when you cough or sneeze. Throw the tissue away immediately, then wash your hands with soap and water or clean them with an alcohol-based hand gel.

If you don’t have a tissue, cough or sneeze into your inner elbow. If you cough or sneeze into your hands, wash them immediately afterward.

Clean and Disinfect Your Nebulizer
It is important to always clean and disinfect your nebulizer since you can breathe in germs through your nebulizer and risk developing a lung infection. People with CF should have their own nebulizer and perform respiratory treatments in separate rooms to avoid spreading germs.

Don’t Share Personal Items
Germs can remain on surfaces of common objects like straws and utensils for hours. When you touch something with germs already on it, you can pick up and spread those germs.

Avoid Frequent Contact with Dust & Dirt
Some germs can hide in soil and be carried on dust or dirt particles. You can get these germs if you breathe them in or transfer the germs by touching your eyes, nose or mouth without first washing your hands.

Get Vaccinated
Pediatric CF Center Staff:

Center Physicians:
- James Cunningham, MD– Co-Center Director (Nurse: Stacy),
- Nancy Dambro, MD– Co-Center Director (Nurse: Karen & Danica),
- Maynard Dyson, MD (Nurse: Stacy),
- Sami Hadeed, MD (Nurse: Sharon),
- John Pfaff, MD (Nurse: Jessica),
- Karen Schultz, MD (Nurse: Paulette),
- Errin Newman, DO (Nurse: Lisa)

Adult CF Center Staff:

Center Physicians:
- John Burk, MD– Adult Center Director,
- Jack Gilbey, MD
- Stuart McDonald, MD
- Randall Rosenblatt, MD
- Cyndy Roget, ACNP-BC (Nurse: Laura, adult nurse and newborn screening)

CF Coordinators:
- Janet Garbarz, Carrie Stradley 682-885-6299

Dietitians:
- Staci Brummett, Rachel Hamik, Esther Giezendanner 682-885-7496

Respiratory Therapists:
- Deanna Pinckney, Alex Rasmussen, Crystal Thompson, Cindy Corne, Shonda Thompson 682-885-4189

Child Life Specialist:
- Alex Steward 682-885-4892

Social Services
- Aditi Prabhakar 682-885-3991

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Making CF stand for “Cure Found”