

CF Connection

Summer 2011

University of Florida Pediatric Pulmonary Center



Tips for a Fun and Healthy Summer

Well summer is here and with that, a change in routine. Here are some ways to make the most of vacation without letting care...and health, slide.

Stay wet and salty

People with CF lose more salt in their sweat and summer is a sweaty time. If you are outside a lot this summer, make sure you are replacing salt loss with a sports drink, salty snacks or just plenty of salt on the food you eat. Along with that, be sure you are getting lots to drink.

Sunlight...the good, the bad, and the ugly

Sunscreen! We know that a few minutes of direct sun exposure helps your body make Vitamin D. More than a few minutes and you need to remember the sunscreen so you don't burn. Now, that might seem like advice that isn't particular to CF care but it might just be. Some of the antibiotics you might need this summer create a "photo-sensitivity," making your skin more sensitive to the sun than usual. You should keep your skin covered from sun exposure if you are taking Cipro, Septra, Zithromax, or Levofloxacin. You may want to have your local pharmacist look at your full medication list to see if there are other things that might make the sun a hazard.

Keep 'em cool

If your daily regimen includes either TOBI or Pulmozyme, some advance travel planning is needed. Both of these

medications **MUST STAY REFRIGERATED** all the time, no matter what! We recommend that you only take along the amount needed for the trip so the remaining supply stays safely cool in the fridge at home. You might also need an alternative approach to disinfecting nebulizer kits. The choices for disinfecting are:

- Boiling for 5 minutes (either stovetop or microwave)
 - Dishwasher with water over 150 degrees
 - 3 minutes in a 1:50 mixture of bleach (roughly 1 oz bleach to 6 cups water)
 - 5 minutes soak in 70% isopropyl alcohol
 - 30 minutes in 3% hydrogen peroxide
- Do NOT use vinegar! It does not do the job.

Not in the car! Not in hot weather!

There are other medications that need some care. Your enzymes do not love being left in a hot car. They are not effective when overheated. Same goes for the inhaler you use before airway clearance, only in addition to the medication becoming "inactivated," the canister can actually burst! They would be happy at room temperature or if you are going to the beach, you could seal them in a watertight container and put them in a cooler. They will also appreciate that watertight container if you are doing the

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We Need You!

Please let us know if you have any tips or stories you would like to share. We would love to include them in our Family Corner! Send them to us at the address on page 4 or e-mail them to hillajb@peds.ufl.edu.

Summer (cont.)

water rides. The propellant in your inhaler loves water and will soak it right up, making your inhaler useless.

Keep food safe

One way to spoil your summer vacation is to eat spoiled food and get foodborne illness! Here are some tips to keep your food safe this summer:

- ✓ Plan ahead—keep perishable food in a cooler with plenty of ice or freezer packs. Keep drinks in a separate cooler so that the cooler with the food is not opened frequently.
- ✓ Pack safely—pack meat and poultry while it is still frozen so that it stays colder longer. Keep raw meat and poultry separate from other foods.
- ✓ When outside, keep the cooler in a shady spot and cover it with a light-colored blanket or towel to reflect the heat.
- ✓ Don't leave perishable food out of the cooler. Throw away food that has been out of the cooler for two hours or more (one hour when the temperature is over 90° F).
- ✓ Wash hands with hot, soapy water before and after handling food. If you don't have soap and water, use hand sanitizer.
- ✓ When grilling, use a meat thermometer to be sure the food reaches a safe temperature. Checking the color of the meat is not enough to be sure it is cooked to a safe temperature.
- ✓ Serve grilled meat on a clean plate—not the same plate that held raw meat, poultry, or fish.



Know Your Genes

The time has come when knowing your CF gene mutations is important, because some medications being researched are targeting specific gene mutations. The names of your gene mutations tell researchers just what needs to be fixed in order for cells to work correctly. It may even soon tell us

which bacteria you are more susceptible to so we can better treat you or your child.

There is a good chance you or your child has already had a genotyping test so we might already know the names of one or both of your gene mutations. If not, we will be recommending this test so that we will know if you might benefit from the medications when they are available. If you have health insurance, ask us for the test codes so you can check with your company to learn about co-pays for genotyping.

This is so important that every state now provides newborn screening for CF. If you or your child had a geno-

typing test done 10 or more years ago, we may have only identified one mutation. This means getting tested again could track down the second mutation.

If you are getting tested, it's helpful for the lab to know your heritage so they can be more efficient. For example, some mutations are more common in African Americans and others in those of Hispanic descent.

So if you don't know your CF mutation, ask us. If we don't know, let's find out!

Help us Help you!

It seems clinic reminders that worked "back in the day" (phone calls or mail) are not working so well in the technology age and we need you to tell us how to do a better job. We are also wondering about the best ways to offer information so you will have all you need to stay healthy and aware about changes in CF care. Please go to this link and complete the survey that will help us better serve your needs (it is quick!):

<http://www.surveymonkey.com/s/JQMVCYZ>

Welcome Back, Dawn Baker!

It is with great delight that I return to the University of Florida CF Center. As many of you know, I took an opportunity to practice at the University of Massachusetts. I have continued to work in CF research and am always amazed at the advances that have been made in CF, and also the commitment that patients and their families have in order to help in those advances.

Some ask why do you do research? To answer that, I only have to point to how the lifetime expectancy of individuals has continued to increase over the years. Communication between CF patients, families and their clinical team spurs researchers to ask important questions such as how can we make things better and what do we need to do to find a cure? Because of these questions, and the research that has taken place, the median current life expectancy for people with CF is in the mid-30's. In 1955, children with CF were not expected to live long enough to attend grade school. Data from the most recent CF Foundation Patients Registry shows that more than 45 percent of all people with CF in this country are 18 years of age or older. Still as researchers and clinicians, we want more.

If you were to take a snapshot of the research that has been done across the country you will see a combination of large multi-centered trials by companies that are invested in CF research as well as small independent studies that are led by collaborative efforts of pulmonary doctors and bench researchers that are attempting to take lessons learned from animal studies and incorporate them into human studies. It typically takes years for those research questions to be answered, but I can as-

Grand Opening

Opening July 1, the Pediatric Emergency Room at Shands Hospital for Children at UF will include a separate entrance, 13 private treatment rooms, and five observation bays with pediatric-specific equipment and technology. It will also offer two waiting rooms and two exam rooms specially designed to isolate children with communicable (infectious) diseases. Pediatrics After Hours will be moving from the Shands Medical Plaza to

sure you that the commitment is strong. The CF Foundation is our leader of that effort. I encourage you to visit <http://www.cff.org> regularly to find out what is going on in the CF community.



I encourage everyone with CF that has not been genotyped to talk with your care team about doing so soon. The Vertex VX770 and 809 programs and the John's Hopkins Twin Sib Study are but a few of the studies that are looking at specific mutations. The more we learn about CF the more we come to understand that there are modifying factors that help determine health care outcomes. Knowing your genotype will help your care provider achieve the best outcomes available. If you haven't already, check out the Genetic Information Nondiscrimination Act of 2008 <http://www.genome.gov/10002328>

So, I leave the snow behind and return to the sunshine state. I hope to see you soon in the clinic. I will be coming to clinic to introduce myself to those I haven't had the pleasure of meeting before and catching up with those I have missed. Our team is excited to re-start our research efforts in CF so I will be discussing what is going on in the community at large and what we are participating in locally. Remember there are a variety of studies to participate in if you are interested. Please let me know if you have any questions.

the renovated space and will include six exam rooms with a waiting room. The Pediatric ER will be located at the east entrance of Shands at UF on the north side of Archer Road. The Pediatric ER is the first phase of the newly planned Shands Hospital for Children. Existing space on adjacent floors within Shands at UF will be redesigned to create the 175-bed hospital.

University of Florida Pediatric Pulmonary Center

Family Corner

Top Ten Things a Patient or Family Member can do to Ensure Quality Care

Research has shown that patient and family involvement in their own health care improves outcomes and patient satisfaction.

1. Ask a nurse or doctor to answer questions that you have before, during, and after your care experience.
2. Learn about your health care insurance policy covered benefits.
3. Learn about scientific evidence and the most current treatment options related to your condition by reading articles or information on the Internet.
4. Make a list of questions in advance of your medical appointment to ask about your condition and care options.
5. Practice telling doctors about your symptoms, and how you are feeling. Practice asking questions when you need more information.
6. Keep a notebook of current medications, specialists, and other relevant information to discuss with a doctor. If hospitalized, be sure to ask every time you are given a medicine what you are being given.
7. Bring an advocate/friend who can listen, take notes, and help ask questions. Remember that family members are there to support you; inform them when issues are too difficult for you to handle alone.
8. Be honest with yourself and your provider about your needs, expectations, and feelings about your care. Be specific about what treatments you want or do not want. If you are unsure, ask for time to think about your decision prior to signing consent forms, and speak to your physician about those uncertainties.
9. Keep communication open at all times. Find out the appropriate channels so that questions and concerns may be brought to your care team when your main contact is unavailable. Make sure you have designated "power of medical decision making" in writing in the unlikely event that you cannot communicate those wishes — and give a copy to your doctor.
10. Ask for and review written discharge instructions for medications, return appointments, and information for follow-up and ongoing care.

(These "Top Tens" and Checklists are adapted from Jeppson, E. Thomas, J. (1994). *Essential Allies: Families as Advisors*, courtesy of the [Institute for Family-Centered Care](#), Bethesda, MD.)

Family Trainee Opportunity

Would you be interested in learning more about family-centered care at the institutional level? The Pediatric Pulmonary Center is offering a traineeship in Maternal and Child Health focusing on family-centered care. If you would like to learn more please contact Angela Miney, Family Partner, at 352-273-8508 or aminey@peds.ufl.edu.

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