



Summer's finally here! It's time for camp...



There are a variety of summer camps for kids here in Minnesota and Wisconsin. Sending your kids to camp, whether it's a day camp or an overnight camp, can be a scary experience for parents of children with CF.

It's hard to entrust your kids and all that comes with them (meds, nebs, vests) to counselors and hope that they can ensure your child stays healthy! As you're considering summer plans for your child, be sure to consider camps. Summer camps are a great experience for all kids, especially kids with CF.

Some of the positive benefits include:

- **Responsibility/Independence:** While there are counselors at camp to help children move successfully through their day, being away from home will give your child a strong sense of responsibility. Especially if they are taking more responsibility for their medications and treatments while away from their parents. At camp, in a controlled environment, kids get to feel that they're on their own and responsible for making their own decisions.
- **Team-work:** At camp, your child will learn to live and get along with other children from a variety of backgrounds. Many camps encourage team/group activities that boost your child's ability to work with other from diverse backgrounds.

The CF Breeze will be distributed electronically for patients and families of Children's Hospital and CRCCS.

To be added to the distribution list or to update your e-mail address, please complete a listserv form available in the lobby of CRCCS or by contacting Mary Sachs or Sandy Landvik.

- **Self-esteem:** When a child learns and masters a new skill, they feel good about themselves. Camp is all about learning new skills and having new experiences. When children with CF learn that they can successfully manage their treatment routine, their self-esteem increases.
- **Friendships:** Camps offer an opportunity for your child to branch out from their regular circle of friends and learn how to connect with other kids in positive ways.
- **Physical activity:** Camps are generally centered around activities, whether indoor or outdoor, that require the children to move and be physically active. This is great for all kids, but especially children with CF.

Before you send your child off to camp, it is important to prepare yourself, your child, and the camp staff. Here are some areas to consider when planning your child's camp experience:

- Draft a written plan and discuss it with the camp staff.
- Consider where the meds be stored? Is refrigeration required?
- Ensure that there are no other kids with CF attending while your son/daughter is there, or at least if there are, precautions can be taken to appropriately separate the children from one another.
- Educate your child about their meds/treatments. If your child is old enough, consider having them create their own treatment/medicine 'cheat sheet.'
- Be flexible with the times of treatment. Look at camp schedule ahead of time to find the least intrusive time for their treatments – the best time may not always be right away in the morning or right before bed in the evening. You don't want your child to miss out on fun early morning or evening activities, so plan ahead. Possibly, have a buddy come with your child to do their treatments, so they are not alone.
- Bring some of their own favorite snacks, water bottle, and salt.
- Let go! Even if the camp staff cannot take care of child as well as you can, remember it is only for a short period of time!



Research Corner

It is Children's CF Research Program's mission to improve the quality of care we provide and to improve the overall quality of life for the patients we serve. Thank you to all the CF families who have donated their time and energy participating in clinical trials. You are the key to finding a cure. Without your help, research cannot move forward. We need your continued participation to move promising therapies from the testing phase to the people who need it most.

Studies Open for Enrollment

- Vertex12-809-104: A Phase 3, Randomized, Double Blind, Placebo Controlled, Parallel Group Study to Evaluate the Efficacy and Safety of Lumacaftor in Combination With Ivacaftor in Subjects Aged 12 Years and Older With Cystic Fibrosis, Homozygous for the F508del CFTR Mutation
- Evaluation of Sleep in Children and Adolescents with Cystic Fibrosis for patients ages 6 -19 years old.
- STAR-too: Early MRSA therapy in CF – culture based vs. observant therapy (treat or observe) for patients ages 4 – 45 years old.
- Baby Observational and Nutritional Study (BONUS-IP-11) for patients less than 3.5 months old.
- A Long-Term Prospective Observational Safety Study of the Incidence of and Risk Factors for Fibrosing Colonopathy in US Patients with Cystic Fibrosis Treated with Pancreatic Enzyme Replacement Therapy: A Harmonized Protocol Across Sponsors

CF Listserv Update

Please remember to submit email address changes by completing a listserv form and handing it to your clinic nurse. These forms can be found in the lobby of CRCCS, or by asking Mary Sachs or Sandy Landvik.

CF Foundation Research Updates

If you would like to learn more about the CF Foundation research activities, please visit their website at <http://www.cff.org/research/>

Link to Vertex Research Press Releases:

If you would like to learn more about the Vertex research activities, please visit their website at

- <http://investors.vrtx.com/releasedetail.cfm?releaseid=743425>
- <http://investors.vrtx.com/releasedetail.cfm?releaseid=757597>

Research Contacts

To learn more about the Cystic Fibrosis Research contact:

- Mahrya Johnson: Office 612-813-6384; Email: mahrya.johnson@childrensmn.org
- Andrea Gruber: Office 612-813-6661; Email: andrea.gruber@childrensmn.org

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Nutrition Basics

It is that time of year again! Summer is right around the corner. Are you and your family planning on going camping? Having friends and family over for a cookout? Or maybe you're just looking for a quick snack. Either way, **food is the main event!** We have included a few summer snack ideas, recipes and ways to add calories to your menu.

When grilling, try adding avocado, cheese, or bacon for an instant boost in calories!

And remember to increase your salt and water intake while out in the heat or with increased activity. Watch for symptoms, which may include fatigue, confusion, abdominal pain, nausea or vomiting.

Featured Recipe

Protein Bars

Protein bars to make ahead of summer travel times. Good for your kiddos with and without CF.

Ingredients

- 2 cups peanut butter
- 1 ½ cups of honey
- 2 ¼ cups of vanilla protein powder (may substitute with chocolate)
- 3 cups steel cut oats or quick oats

Preparation Instructions

Melt two cups of peanut butter with 1 and 1/2 cups of honey

Mix with 2 and 1/4 cups of vanilla protein powder (may substitute with chocolate protein powder) with 3 cups of steel cut oats or quick oats

Stir all together and then spread in a 9 x13 pan

Refrigerate for 1 hour, makes 24 bars

Tasty Hint

Cut then into serving size, wrap them individually in baggies or Saran Wrap, freeze and then enjoy for a grab-and-go snack!

Summer Snack Ideas

NEW ITEMS!

- Yoplait Pro-Force Yogurt – It has 2x the protein!
- Chobani Champion Tubes –Try even frozen
- Reese's peanut butter bar – look in the candy or baking aisle!

MARSHMALLOW CRÈME

- 1 large jar marshmallow crème
- 1 8 oz package cream cheese
- 1 tsp vanilla



**Blend well and use with any kind of fruit!

S'MORES

- 1 graham crackers
- 1 jumbo marshmallow
- 2 squares chocolate



TRY THIS INSTEAD OF:

Graham crackers → Fudge cookies

Chocolate squares → Peanut butter cups

SUMMER SNACKS

- Nachos with melted cheese
- Trail mix
- Popcorn with M&M's
- Sunflower kernels
- Peanut butter rolls (tortilla, peanut butter & chocolate chips)
- Smoothie, popsicles
- Pudding made with whole milk and whipping cream



Clinic Changes

Expanded hours of Dietitians, Social Workers, and Respiratory Therapy

Good news! You may see these faces around more often! To better support our patients and families, the CF clinic has expanded the hours of the Dietitians, Social Worker, and Respiratory Therapist. They are available to meet with you **Monday, Tuesday, Wednesday, and Thursday mornings** on the 3rd floor of Children's Specialty Clinics. You can request an appointment by contacting them directly. Their contact information is listed below.



DIETITION

Mary Smieja, RD, LD and Megan Erickson, RD, LD

Dietitians can help with the following:

- Nutrition, enzyme, or vitamin question or concerns
- Weight Changes
- Meal or Snack Ideas
- Stool Changes

To schedule an appointment please call 612-813-7591 or 612-813-1154. You can also reach them via email

Megan.Erickson@childrensmn.org or

Mary.Smieja@childrensmn.org

SOCIAL WORK

Lacie Johnson, LICSW

Social Work can help with the following:

- Emotional Support around diagnosis
- Short Term Counseling
- Educational or Child Care Issues or Concerns
- Financial Assistance/Insurance Questions
- Community Referrals

To schedule an appointment please call 612-813-6839 or email

Lacie.Johnson@childrensmn.org.



RESPIRATORY THERAPY

John Plante, RRT

Respiratory Therapy can help with the following:

- Nebulizer Machine and Equipment Needs
- Vest Settings
- Vest Fit
- Equipment Cleaning

To schedule an appointment please call 612-813-6731 or email John.Plante@childrensmn.org

