Meet Our CF Providers:

Jennifer Lindwall, PhD

Hello! My name is Jenny Lindwall, and I have been working as a pediatric psychologist here at the Children’s Hospital of CO and an Assistant Professor at the University of Colorado since January of 2013. I grew up in Wisconsin, and received my undergraduate and graduate degrees in Psychology from the University of Wisconsin-Madison. My professional training enabled me to work with wonderful children and families at children’s hospitals around the U.S., including Wisconsin, Pennsylvania, and Tennessee. I am very grateful to now be in CO and have the opportunity to work with truly amazing children and families in the CF Center at the Children’s Hospital CO. I enjoy working collaboratively with the CF Team to support the positive emotional and social development of children with CF. I also enjoy the beauty that CO has to offer during my free time, and love to hike, bike, and snowshoe. I look forward to meeting and working with you and your family as a member of the CF Team!

Emily Muther, PhD

Hello, my name is Emily Muther and I am a pediatric psychologist at Children’s Hospital Colorado and Assistant Professor at the University of Colorado School of Medicine. I work in the departments of psychiatry and pediatrics and am very excited about working more closely with the CF team in both an outpatient and inpatient setting. I have a strong interest in and past experience working with patients who have chronic illness and hope to promote better quality of life for children living with CF and their families. As a pediatric psychologist, I work with patients to address the impact of living with CF, including increasing coping, addressing obstacles related to medical care, stress management, social challenges, and the difficulties managing CF at various developmental stages. I went to graduate school at the University of Denver and completed clinical training at the Children’s Hospital Boston. I have been back in Colorado for over 2 years and am excited to be working at Children’s Hospital and working with the CF team. I love spending time in the mountains with my family and enjoy reading, cooking, and anything outdoors.

Benefits of Pediatric Psychology in CF Care
By Jennifer Lindwall, PhD and Emily Muther, PhD

Pediatric Psychology is a specialized field of child psychology that focuses on promoting positive social and emotional development in children and adolescents who have a chronic medical diagnosis, such as Cystic Fibrosis. Pediatric psychologists working with children who have CF collaborate with other health care professionals on a multidisciplinary team, including physicians, nurses, respiratory therapists, dieticians, and clinical social workers, to support children and families as they are managing the challenges of medical care. For example, keeping up with respiratory treatments, medications, medical appointments, unpleasant procedures, and hospitalizations can be very demanding for children with CF and their families. These challenges can interfere with important things such as school, friendships, and family relationships, and often create additional stress. Because of these challenges, children with CF may be at-risk for having behavioral (e.g., acting out) or emotional difficulties (e.g., anxiety, sadness), and benefit from early intervention to address these issues. Pediatric psychologists specialize in talking with children and families about these challenges, and provide support and psychotherapy to promote positive coping, behavior, mood, and social development. They work together with children and families during medical visits and hospitalizations, and sometimes have additional psychotherapy appointments with children and families to provide on-going support. Pediatric psychologists recognize that different challenges may come up for children as they grow and develop that can affect a child’s emotional well-being. Therefore, they remain available to work with children and families throughout their treatment at pediatric health care settings. At Children’s Hospital Colorado, the CF Center is partnering with pediatric psychologists to provide comprehensive and collaborative care to our patients with CF, and their families, that includes treatment for both physical and emotional health. Our children and families are encouraged to talk with their CF team about concerns that they would like to discuss with our pediatric psychologists while receiving care at our CF Center.
The CF Foundation recently updated infection prevention and control recommendations for all CF care centers. Since 2003 when the guidelines were initially released, researchers have learned more about bacteria that infect people with CF and how these bacteria are spread. CF care centers offer many benefits to people with CF including experienced CF care teams, standardized approaches to preventing and treating complications of CF, and regular monitoring of lung and nutritional health. At Children’s Hospital Colorado, we are committed to providing the highest quality of care including ensuring that our CF clinics and the hospital are safe for everyone. Because of this, you will notice a few changes in our clinics and the hospital over the next few months.

In CF clinic and if your child is admitted to the hospital, all medical personnel will wear a gown and gloves when they see you. For certain infections, they may wear a mask as well. We will try to get you placed in a room as soon as possible to limit waiting room time. Most lung function testing will be done in your clinic room. We have also removed toys and books from the clinic rooms (see sidebar for more information). For people admitted to the hospital, you may be more restricted in where you can go in the hospital (for example, we are limiting the playrooms to one person with CF at a time). We continue to recommend that people with CF wear a mask when in the hospital facility (masks are available at the check-in desk), wash hands frequently, cough into a tissue or your elbow, and avoid close interaction (less than 6 feet apart) with other people with CF.

Many of the other changes we are implementing may not be noticeable, but are equally important. We are working closely with our infectious disease and epidemiology department to ensure that our current cleaning processes are of the highest standard. This includes clinic rooms, check in rooms, lung function equipment, hospital rooms, respiratory equipment (e.g. nebulizers, vest, inhalers), and the playroom/teen lounge.

All of these changes will allow us to provide the highest quality CF care while reducing the chance of spreading bacteria. We recognize that some of these changes may be challenging, and we are very interested in hearing from all of you about your experiences, concerns and ideas. Please feel free to speak with your CF provider with any questions. Also, plan to attend our upcoming family education night on April 10th to learn more about some of the common lung bacteria and how they impact people with CF.

For more information regarding the new CF infection control policies, visit [http://www.cff.org/treatments/CFCareGuidelines/InfectionControl/](http://www.cff.org/treatments/CFCareGuidelines/InfectionControl/).

We want to ensure that your child’s CF clinic appointments go as smoothly as possible, so to address the removal of toys and books being kept in clinic rooms, we will now have coloring pages and crayons available and craft bags donated by the local CF Foundation Chapter.

We have also received a very generous donation of new books for children Pre K-6th grade from the Alyssa Cares Foundation, and these books will be available on a case-by-case basis for children to take home with them.

However, we encourage you to bring toys or books from home if you anticipate that your child may get restless or fussy during their appointment.

The 27th NACFC, held in Salt Lake City, Utah, featured presentations by leading CF researchers and clinicians on topics including emerging therapies that target the root cause of CF, current research to address all CF gene mutations and treat the symptoms of the disease, and early detection and treatment of CF-related diabetes. We learned about how different classes of CF mutations cause the CFTR protein to fail in distinct ways, requiring different treatment approaches to fix the protein effectively. The first drug to successfully target or “modulate” the faulty CFTR protein, ivacaftor (Kalydeco™), was approved in 2012 for CF individuals ages 6 and older with the G551D mutation and is now being studied in more CF patient groups, as well as in combination with other potential drugs in people with two copies of the most common CF mutation, F508del. Using lessons learned from “first-generation” studies to treat the defective CFTR protein, the CF Foundation (CFF) is collaborating with several pharmaceutical companies, and has also established its own research lab, to help find new and more effective therapies for people with the F508del mutation, as well as those with less common mutations.

Based on the CFF vision of “no mutations left behind,” studies of CFTR modulators offer the promise of new breakthrough therapies for all people with CF. Despite the amazing progress and potential of CFTR modulators, we were reminded that modulators such as ivacaftor cannot reverse the organ damage caused by CF. Preventing lung damage, with antibiotic and anti-inflammatory and mucus-modifying treatments, is critical until lifesaving drugs that treat the underlying cause are available to 100 percent of people with CF beginning in infancy. We also heard a clinical and research update on cystic fibrosis-related diabetes (CFRD), one of the most common complications of CF, occurring in more than 30 percent of people with CF ages 18 and older. Research being performed in CF pigs and ferrets is leading to a better understanding of the early stages of CFRD which eventually should translate to new therapies and approaches to treat it. Early diagnosis and prompt treatment of CFRD can help people with CF improve their nutritional status, lung function, and overall health.

You can learn more about this meeting by visiting [http://www.cff.org/research/NACFC/](http://www.cff.org/research/NACFC/).
**Updates and Reminders From Our Center**

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**Save the Date For Our Next CF Family Education Night!**

Please plan to attend our next CF Family Education Night on **Thursday, April 10th from 6:00—8:00 p.m.**

Based on a suggestion from parents on our CF Family Advisory Council, the topic chosen for this event will be **“CF Lung Infections: Myths and Facts”** presented by Drs Edith Zemanick and Stacey Martiniano. A light dinner will also be served.

Space will be limited for this event and you will need to RSVP in advance, so be on the lookout for a postcard with further details on the agenda and registration instructions!

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**Become a Member of the CHCO CF Family Advisory Council**

Did you know that the Children’s Hospital Colorado CF Center has a CF Family Advisory Council? As part of our commitment to providing excellent, family-centered care, several years ago we established a group consisting of parents of children with CF and CF team members that meets monthly to discuss events happening at our Center, and to solicit feedback and suggestions from parents on ways we can provide better care to our patients.

Past FAC projects include a CF Hospital Handbook, creation of a pre-clinic survey to make clinic appointments more efficient, and a Facebook group that is managed by parents on the FAC to help CF caregivers connect with other families in the area.

If you are interested in joining the CF Family Advisory Council or would like more information, please contact staff administrator Lara Webb at [lara.webb@childrenscolorado.org](mailto:lara.webb@childrenscolorado.org) for further details.

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**Have You Signed Up For MyChart?**

MyChart is a free service offered by Children’s Hospital Colorado to help you receive personalized and secure online access to portions of your Children’s Colorado health records.

With this helpful tool, you can use the internet to view certain test results, request prescription renewals and medical appointments, and communicate electronically and securely with your healthcare provider.

If you are interested in participating in MyChart, please ask your nurse or healthcare provider at your next clinic visit to help you get an activation code. This code will enable you to log in and create your own username and password.

For more information, please visit: [https://mychart.childrenscolorado.org/mychart](https://mychart.childrenscolorado.org/mychart)

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**2014 CF Outreach Clinic Dates**

<table>
<thead>
<tr>
<th>Location</th>
<th>Dates</th>
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<tbody>
<tr>
<td>Colorado Springs, CO</td>
<td>February 3, March 3, April 7, May 5, June 2</td>
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<tr>
<td>Durango, CO</td>
<td>March 3 and 4, June 9 and 10</td>
</tr>
<tr>
<td>Grand Junction, CO</td>
<td>February 7, March 7, May 2, June 6</td>
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Call 720-777-6181 for appointments
Recipe Corner

Winter recipe idea...... This may become your new family favorite!

Submitted by Cathy Lingard, CF Dietitian (From Pillsbury.com)

Super Speedway Taco Pie

Ingredients:
- 1 to 1 ¼ lb. lean ground beef
- 1 (1 oz.) pkg. of Taco Seasoning Mix
- ½ cup water
- 1/3 cup sliced green or pitted ripe olives
- 1 (8 oz.) can of refrigerated crescent dinner rolls
- 1 ½ to 2 cups of crushed corn chips
- 1 (8 oz.) container (1 cup) sour cream
- 6 slices American cheese or 4 oz. (1 cup) shredded Cheddar cheese
- Shredded lettuce, salsa and avocado slices if desired

Steps:
2. Meanwhile, separate crescent dough into 8 triangles. Place triangles in ungreased 9 or 10-inch pie pan, pressing to form crust. Sprinkle 1 cup of the corn chips over bottom of crust.
3. Spoon beef mixture into corn chips in crust. Spread sour cream over beef mixture. Cover with cheese. Sprinkle with remaining 1/2 to 1 cup corn chips.
4. Bake at 375°F. for 20 to 25 minutes or until crust is golden brown. Cut in wedges. Serve immediately with lettuce and avocado. Store leftovers in refrigerator.

NUTRITION INFORMATION: PER SERVING SIZE: 1/6 of Recipe

<table>
<thead>
<tr>
<th>Nutrient</th>
<th>Amount</th>
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<tbody>
<tr>
<td>Calories</td>
<td>585</td>
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<tr>
<td>Fat</td>
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<tr>
<td>Protein</td>
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<tr>
<td>Fiber</td>
<td>2 g</td>
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<tr>
<td>Sodium</td>
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Good source of Vitamin A, Calcium and Iron

MODIFICATIONS to reduce calories and fat for those who don’t need a high calorie dish:
Use reduced fat crescent rolls, use ground turkey instead of beef, baked chips instead of regular and reduced fat cheese instead of regular cheese. OR make two pies, one regular and the other low fat.

Farewell From Janice Fordyce

To all of the wonderful CF families and patients I have worked with for the last six years:

It is with bittersweet emotion I inform you that I have taken a position within our Eating Disorder Recovery Program at Children’s Hospital Colorado. I started my new position November 4th, and have been working to foster a smooth transition. I will continue working with the Colorado Springs CF team through January 6th. After January, my colleague Cathy Lingard may step in as an interim dietitian for the Colorado Springs clinic.

I want to convey the tremendous respect I have for the patients and their families. All of you have taught me so much about living with cystic fibrosis, and more importantly, about living in spite of cystic fibrosis.

Thank you for six wonderful years!

Warm regards—
Janice Fordyce, MS, RD, CNSC
Sticky Icky Booger Bugs by Sherry Frith

Available on Amazon.com in paperback for $15.29 and on Kindle for $3.99

Icky Sticky Booger Bugs was released this past summer and is written by a mother of two boys with cystic fibrosis. It’s a simple, straightforward book appropriate for children in pre-K and grade school (my four year-old enjoyed it). It discusses the day-to-day basics of living with cystic fibrosis without getting into any of the complications or medical explanations behind the disease.

Icky Sticky Booger Bugs follows a boy named Kory through a typical day. He tells us about all of his treatments (inhalers, percussion vest, nebulizer, nasal rinse and enzymes). He also talks about taking enzymes at school, playing soccer and playing with his friends.

My son always seems to enjoy reading about other children with CF who do the same things as he does and this book filled that need. In many ways it is similar to Who I Am, which was released by Genentech and is available through the clinic. The two books complement each other and are both good additions to any child’s CF reading list.

Breathing Institute Team “Bikes for Breath” at the 2013 Courage Classic in Copper Mountain.

L to R: Steve and Edith Zemanick, Janice Fordyce, Cathy Lingard, Deb Liptzin

Associate CF Center Director, Dr. Edith Zemanick, was the team leader for the BI Bikes For Breath team, which raised over $3,000 for Children’s Hospital Colorado!


CF team members at the CF Foundation’s annual Gala event in November 2013.

Top Row, L to R: Jordana Hoppe, Jill Hammond, Lara Webb, Stacey Martiniano

Bottom Row, L to R: Ruth DeVoogd, Jill Levin, Heather Scazeske, Elin Towler
Please note that the name of the hospital has changed to Children’s Hospital Colorado

Website: www.childrenscolorado.org or www.childrenscolorado.org/conditions-symptoms/conditions/cystic-fibrosis
Send correspondence to cysticfibrosis@childrenscolorado.org.

{\textbf{CF Research: You are the key!}}

CF research is going strong here at Children’s Hospital Colorado and nationwide, with much more to come in 2014. Your participation and support have made it possible for us to continue our mission of finding more treatments while also targeting a cure. Thank you!

<table>
<thead>
<tr>
<th>Study</th>
<th>Description</th>
<th>Eligibility</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>AquADEKs-2</td>
<td>To study the antioxidant properties of a new formulation of AquADEKs and its effects on airway inflammation and oxidative stress.</td>
<td>10 years and older</td>
<td>6 months</td>
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<tr>
<td>Home monitoring</td>
<td>To study how PFT home monitoring and questionnaires help with CF care.</td>
<td>14 years and older</td>
<td>1 year</td>
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<tr>
<td>BONUS</td>
<td>A natural history study of growth and nutritional status in infants with CF.</td>
<td>1 month-3 ½ month</td>
<td>1 year</td>
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<tr>
<td>Kalobios</td>
<td>To study how well an antibody-based drug works against Pseudomonas.</td>
<td>12 years and older</td>
<td>Up to 22 weeks</td>
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<tr>
<td>Microbial Biomarkers</td>
<td>A study of biochemical measures in blood and sputum during clinical stability and pulmonary exacerbations.</td>
<td>10 years and older</td>
<td>14-120 days</td>
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<tr>
<td>MRSA</td>
<td>To study the effectiveness of an MRSA eradication protocol</td>
<td>4 years-45 years</td>
<td>6 months</td>
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<tr>
<td>N30</td>
<td>To study the safety and absorption of an anti-inflammatory drug for people with 2 copies of the delta F508 gene mutation.</td>
<td>18 years and older</td>
<td>6 weeks</td>
</tr>
<tr>
<td>GOAL e2</td>
<td>A natural history study of subjects on ivacaftor (Kalydeco) therapy.</td>
<td>6 years and older</td>
<td>Varied</td>
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</tbody>
</table>

There are many other active studies that we are working on. If you have any questions about our work or if you are interested in participating in a research study, please contact Churee Pardee at (720) 777-6162, or churee.pardee@childrenscolorado.org.