

The Cystic Fibrosis Center at Cook Children's Medical Center is one of more than 115 accredited CF centers throughout the nation. These centers are accredited by the Cystic Fibrosis Foundation, a non-profit organization founded in 1955 dedicated to funding research to find a cure for CF and improving the quality of life for people with the disease.

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# SCHOOL'S IN



As parents and children gear up for another school year, it is time for a review of 504 plans and IEPs. 504 plans and IEPs can be useful tools for children with Cystic Fibrosis. A 504 plan, which falls under the ADA (American with Disabilities Act), is a written plan between parents and the school district to make physical accommodations to help children be successful at school. Examples of accommodations that might be listed in a 504 plan are: extra bathroom breaks, snacks, being allowed extra time to get between classes, exemptions from some physical education classes, etc.



An IEP

(Individualized Education Plan), which falls under

the Individuals with Disabilities Education Act, is a written plan between parents and the school district that focuses on making educational accommodations to help children be successful at school. Examples of accommodations that might be listed in an IEP are: tutoring, special education classes, reduced homework load when a child is hospitalized/ill, etc.

Some school districts may be reluctant to do a 504 plan or IEP often because of the amount of administrative work involved. Instead, some schools would rather rely on a verbal agreement regarding accommodations that will be made for the child. Ultimately, as a parent, the decision is yours as to whether a verbal agreement will be sufficient.

Just keep in mind that without a written 504 plan or IEP, you have no way to ensure that the school district follows through with accommodations.

If you want to pursue a 504 plan or IEP for your child, first contact the school principal or counselor to start this process. Next, contact one of the CF Coordinators and/or the Social Worker to discuss possible accommodations that your child may need. You will want to have written recommendations from your child's Pulmonologist prior to meeting with the school.

The CF center staff is always available to assist you with questions regarding a 504 or IEP plan.

# Empowering the Family

## Cook Children's is dedicated to treating the entire family.

Now more than ever before, parents are playing a critical role at Cook Children's with the addition of three important programs

- Get Well Network®,
- Parents as Partners
- Parent Involvement in Nurse Shift Report.

### Get Well Network

After arriving at Cook Children's in the middle of the night, the Crim family spent the next day lying around their room, watching on-demand movies and playing video games.

But, this is no five-star hotel offering the finest in amenities for its guests. This is Cook Children's, which places an emphasis on caring for not just the child, but the entire family.

One of the newest tools to allow families treated at Cook Children's to feel more in control is GetWellNetwork, an interactive resource for patients and parents which can be accessed through their TV.

Families can view important educational information that covers a range of topics including asthma, cancer and diabetes through an exclusive partnership with KidsHealth®, which produces more than 160 pediatric patient education programs specifically designed for parents, and that are age-appropriate for the patient. GetWellNetwork offers age-appropriate movies, video games, Internet access and email.

Cook Children's is the only pediatric hospital in Texas to offer GetWellNetwork, which is available on all inpatient units of the medical center, including the Emergency Department and will be available in the Pediatric Intensive Care Unit within the coming months.

When Joshua Crim arrived at Cook Children's, he was feeling lethargic, not eating or drinking and he had only urinated once in the last 24 hours. Joshua was diagnosed with a kidney infection. After being treated for his condition, Joshua was feeling better by the next afternoon.

As 5-year-old Joshua steers his race car while he plays the classic video game Pole Position, his mother, Christie, gives him direction. "Get over! Oh no! He crashed." They laugh with one another as Joshua's mom snuggles next to him. It's her turn to play.

While GetWellNetwork helps families relax, it also serves as a valuable tool in educating them about important health matters.

"I think it's really neat. It's a really good interactive tool for the kids," Christie said, as daughter Olivia watched a movie she chose on-demand. "The kids today like video games and I think it helps them while in the hospital to enjoy their stay as much as they can. Even though we are here, we're trying to make the best of it."

Patients and their families can provide feedback and learn more about individual care members or departments. GetWellNetwork makes it possible to request a volunteer, a cleaning service or a temperature change. In times of need, parents can request a chaplain. They also can receive timely information about their child's care and learn more about their specific needs, such as finding a pediatrician in their area or even a nearby hotel.

A hospital never closes, but at most facilities, many services are provided only during normal business hours. GetWellNetwork allows Cook Children's to operate 24 hours a day for the convenience of the patients and their families.

GetWellNetwork is funded in part by Cook Children's employees. Through the annual Employees Care Campaign, employee gifts made it possible to upgrade all in-room TVs in preparation for GetWellNetwork, plus the installation and upkeep of GetWellNetwork throughout the medical center. As employees work with patients using GetWellNetwork they are able to see how their gifts directly affect the lives of our patients.

"I've heard from parents that when you feel out of control, you will do almost anything to gain it back," said Christy Ball, manager of Family Services at Cook Children's. "With GetWellNetwork, we are giving families some control back. We're allowing them to be actively involved and to make decisions about their child's care. We've done that before, but never as consistent as it is now.

"It may be something as simple as requesting that their trash be picked up. It may be researching their child's condition at midnight while their child is sleeping. It may be sending an email or updating their Facebook status. All of that can be done in their room. This is giving power back to the family when they thought they had none."

As a parent, Christie was able to use GetWellNetwork for her own personal use as well. She accessed her Facebook account to contact friends she couldn't reach by phone, to let them know she probably would not be able to make a scheduled trip to Canada.

After Christie takes care of her personal business, Joshua wakes up and it's time to play with her little boy.

"It's fun just selecting what movies we are going to watch," Christie said. "It really has been a nice experience. We're in a hospital, but we can still curl up in bed, and cuddle and watch a movie or play a video game together."

GetWellNetwork is one of many ways Cook Children's treats families like our guests. And with the new expansion, families will feel even more empowered in their choices.

## Parents as Partners

Research shows that family involvement helps patients recover from illness quicker. Cook Children's includes parents in a variety of programs to help better understand the patient and family experience through a program called Parents as Partners.

As plans were being made on the expansion project at Cook Children's, members of the Parents as Partners team were able to offer their suggestions. They were told to act as if they were given a magic wand and could make any changes they wanted.

So they made a list and much to their surprise, many of their wishes came true. Family lounges. Check. Family kitchenettes on every unit. Check. More family-based activities. Check. And on and on it went.



Family-centered Care Program Coordinator Tamela Grass said, “We want to make parents feel like they are part of the team. You kind of feel helpless and hopeless while staying at the hospital, like there is nothing you can do for your child. But these programs help to empower the family, educate them and strengthen them. It’s our honor and privilege to be a part of Parents as Partners. We are so thankful that Cook Children’s leadership was willing to listen to us.”

For Grass, her job holds special meaning. Her daughter Olivia was diagnosed with stage 4, high-risk neuroblastoma cancer at the age of 2. Olivia was given a 20-percent chance of surviving the chemotherapy after learning the cancer had spread throughout her body and into her bone marrow and lymph nodes. But today Olivia, who is now 8 years old, is cancer free.



Grass said immediately after her daughter’s treatment she had trouble driving by Cook Children’s, but as time went on she felt a calling to go back and wanted to give back in some way. After volunteering, she was nominated by staff to join the Family Advisory Council. When the opportunity came to hire a parent as

the Family-centered Care Program Coordinator, Grass applied, and was hired for the position. In this role, one of her responsibilities is to head up the Parents as Partners project at Cook Children’s.

“The best way to improve your company is to ask your customers,” Grass said. “It seemed to make sense and seemed like the right thing to do.”

### **Parents as Partners program offers a variety of ways parents can become involved:**

- Family Feedback Groups: Family partners give feedback in a one-time group setting.
- Parent Panels: Parents share their Cook Children’s stories and experiences with groups to provide family insight for educational purposes.
- Task Forces: Short-term, unit-based, departmental or system-wide work groups designed to address a specific project. Then they work with Cook Children’s staff to put the plan into action.
- Family Advisor/Representative: Members on a committee/board represent the family perspective and offer constructive feedback on a monthly basis at scheduled meeting times.
- Family Advisory Council: A group of Cook Children’s patient parents and staff meet monthly to review policies, initiate change and provide general feedback.
- Parent Mentor: One-to-one support and encouragement to newly diagnosed families or families with similar conditions or problems.

## Parent Involvement In Nurse Shift Report

It's 6:30 a.m. and time for the Epilepsy Monitoring Unit nurse on duty to go home. As she meets with the nurse taking over her shift about a patient, one more interested party is involved in the discussion.

A mom is up early to listen to what is being said about her child, ask any questions she may have and add a couple of suggestions.

This year, Cook Children's began a new program that uniquely involves the parents. Nurses now conduct shift-to-shift reports at 6:30 a.m. and 6:30 p.m., at the bedside, using the electronic medical record with the parents. This practice change offers parents a better understanding of the treatment plan and provides opportunities for parents to ask questions and give feedback. When appropriate, depending on age and ability to understand, the child also participates.



"During hospitalization, it is not uncommon for families to feel as though they are the visitors," said Kim Williams, RN, BSN, nurse manager of 4 Pavilion and the Epilepsy Monitoring Unit, the two units that piloted the program. "When you really think about it, it's the staff who are the visitors. Patient families are allowing us to care for what's most precious in their life – their child. This is a privilege and an honor. Bed-side shift report gives the parents a chance to have a voice for how we care for their child and to express their expectations and concerns."

Involving families in the report process has improved communication and helps families take part in the plan of care.

Immediately, this new program began to see results. Satisfaction survey results improved almost overnight.

"I have been a nurse for over 30 years and have never seen anything like this. You let me go over my child's medical record and I don't feel it is a big secret anymore," one parent wrote.

"Thank you for waking me up to participate in report. I learned information in report that will enable me to take better care of my child at home," said another parent.



## The Cook Children's Expansion Project

In the year 2020, the population of Fort Worth is projected to increase by an additional 800,000 people over the 2005 population. That's on top of the more than 38-percent increase since 1990. With that growth, expansion is a necessity for Cook Children's. As the largest expansion project in its history begins, an emphasis has been placed on Cook Children's meeting the needs of the entire family.

The Family Advisory Council, the Youth Advisory Council and other specific parent focus groups were consulted to help create the best possible patient- and family-centered care environment. Much of their work focused on what would make a parent's stay more comfortable and convenient.

In the North Tower, their suggestions will definitely be on display. The first level will be the public floor. This floor will have a skylit foyer to a new food court/cafeteria, interior dining space, interior playground, a Build-a-Bear Workshop®, access for families to exterior dining space and an exterior playground.

Highlights for families when the North Tower opens include:

- A central location for families to spend their time without having to be far from their child, as well as an opportunity to connect with other families.
- The Bomar Patient Library and the Matustik Family Resource Center combined in one location.
- A welcome center staffed with an ambassador to provide general information and directions and put the families at ease.
- An indoor playground for recreation connecting to an outdoor playground, offering a new basketball court, expanded play areas, a play lawn and even places to play checkers and hopscotch.
- A meeting space for parent education, as well as support groups.
- A new food court style cafeteria with chain restaurants such as Chick-Fil-A.
- An outdoor dining terrace.
- A celebration room for patient birthday parties and celebrations.



We are continuing to discuss additional ways to expand our family services. Initial ideas include:

- Extended Concierge services for patient families.
- A business center to offer our patients' families a place and the resources to handle work-related tasks.
- A new Cook Children's TV station/recording studio for patient programming.
- A centrally located school room.
- A centrally located teen room.
- Hair/nail salon.
- A new frozen yogurt shop.
- Retail spaces.

To learn more about our expansion project or to make a gift to the Cook Children's Fulfilling Our Promise campaign, please call 682-885-4105 or visit [www.cookchildrens.org/giving](http://www.cookchildrens.org/giving).



Help us make CF stand for Cure Found by recruiting your friends, family, colleagues and neighbors to join us in Downtown Fort Worth for the Inaugural Climb for the Cure.

**Website:** [www.fortworth.cff.org/ClimbForACure](http://www.fortworth.cff.org/ClimbForACure)

**Date:**

November 13, 2010, 9:00 am

**Location:**

Burnett Plaza, Downtown Fort Worth

Be sure to pick up a brochure at the information wall in the waiting room at Cook Children's.



## Cook's Newest Dietitian, Cristina Gonzalez



Length of Time at Cook Children's Medical Center – 7 months

Length of Time as a Pediatric Dietitian – 4 ½ years

Previous Experience: Graduated with a BS in Dietetics from TWU in 2004 and in 2006 completed Dietetic Internship at Baylor University Medical Center in Dallas. For the past 4 years, I have worked at Pediatric Hospitals including, Texas Scottish Rite Hospital for Children in Dallas, CHRISTUS Santa Rosa Children's Hospital in San Antonio, and currently at Cook Children's Medical Center in Fort Worth. I have worked within multiple specialty clinics, over the years, including: Gastroenterology, Genetics, Endocrinology, Feeding Clinic, and Pulmonary. During these experiences, I have obtained additional certifications and credentials including Board Certified Specialist in Pediatrics (CSP) and certificate for Pediatric and Adolescent Weight Management.

My first exposure to Cystic Fibrosis was at Santa Rosa Children's Hospital when I was training with the CF dietitian at the center. It was then that I learned so much about the diagnosis and the reward working with cystic fibrosis patients.

Hobbies: Soccer, Watching football and baseball, Muscle Cars, Photography, Running, Working out, Cooking



# On the Road to Good Nutrition

The Cook Children's CF center is embarking upon an exciting new quality improvement project. Starting this fall, we will focus our efforts on improving nutrition at the Cook Children's CF Center.

## Why is good nutrition important?

We know that good nutrition is important for people with CF because of the strong association between a healthy body mass index (BMI) and good lung function.

## What is the goal of this project?

The goal of this project is to improve weight gain and growth of children with CF at Cook Children's. We would like every child with CF to reach and maintain a BMI at or above the 50th%.

## How do we plan to reach this goal?

- **Step 1:** Classify your child's level of nutrition risk at every clinic visit:
  - Green:** Optimal (BMI  $\geq$  50th% and Weight > 10th%)
  - Green:** Acceptable (BMI 25-49th% and Weight > 10th%)
  - Yellow:** Concerning (Weight loss, No weight gain x 3 months, or downward slope of growth %ile)
  - Orange:** At Nutrition Risk (BMI 10-24th% or Weight 5-10th%)
  - Red:** Nutrition Failure (BMI < 10th%ile or Weight < 5th%ile)
- **Step 2:** Develop a personalized nutrition plan based upon your risk category. This plan may include:
  - More frequent visits to the pulmonary clinic
  - More time spent working with a Registered Dietitian
  - Regular screening for cystic fibrosis related diabetes (CFRD)
  - Referral(s) to an Endocrinologist or Gastroenterologist as needed

Please contact the CF coordinators if you have any questions or concerns related to this project. Stay tuned for projects specifically targeting improving adult and infant nutrition



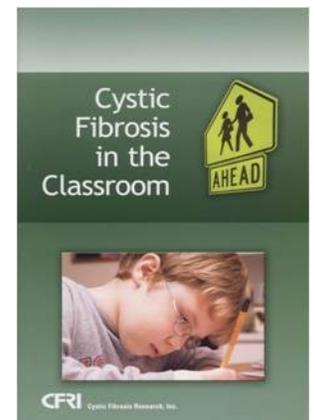
## Request a FREE "Cystic Fibrosis in the Classroom" Booklet

It's back to school!

Help educate teachers and administrators about CF and your child by providing them with educational booklets from CFRI.

If you would like to request a free copy of "CF in the Classroom," please visit the website:

[www.cfri.org/formbooklets.shtml](http://www.cfri.org/formbooklets.shtml)



# Breakfast! Jumpstart Your Morning School Routine

Mornings can be stressful, but with a little planning you can make breakfast part of your daily routine. Breakfast is important for many reasons. It can help improve your mood, allow you to focus in school and get better grades, plus it is an excellent opportunity to get the nutrition that will help you grow taller and stronger. If you are not used to eating breakfast, here are a few things to consider. Think about what you want for breakfast before you go to sleep and set your alarm 10-15 minutes earlier to allow yourself enough time. Keep convenient items on hand and prepare what you can the night before. Keep in mind that you don't have to eat breakfast foods for breakfast. There's nothing wrong with heating up last night's dinner! Once your body gets used to having breakfast daily, eventually it will come to expect it and you will wake up feeling hungry.

Here are some ideas packed with nutrition:

- Wrap scrambled eggs, shredded cheese, and salsa in a tortilla for a breakfast burrito. Speed the cooking process up by using the microwave to scramble the eggs!
- Make single serving oatmeal with milk and cream, then top with granola and dried fruit.
- Toast an English muffin or waffles and top with peanut butter, sliced banana, and honey.
- Spread butter on a large muffin or slice of banana, pumpkin, or zucchini bread.
- Microwave frozen biscuits or cinnamon rolls.
- Have your favorite cereal with whole milk and heavy cream.
- Grab a high calorie bar like PROBAR or Bear Valley Bar.
- Pair any of the above with a yogurt smoothie to drink and you have a complete breakfast!



## Recess and Physical Education...



### The Need For Extra Salt!

Children with CF lose more salt when they sweat than children without CF. They must replace salt and fluid when exercising or playing. Salt can be replaced by eating high-salt foods like pretzels or potato chips. Children with CF should drink fluids before, during, and after exercise. During aerobic exercise, it is estimated that children with CF should drink six to 12 ounces of fluid every 20 to 30 minutes. Sports drinks, with the added carbohydrates and salt, are great for children with CF to drink while playing during recess or during P.E. People with CF who play or exercise outside in hot weather may want to add  $\frac{1}{8}$  teaspoon of salt to 1 cups (12 ounces) of a sports drink, such as Gatorade. The carbohydrates give fuel to the muscles and help keep blood sugars up. The salt quenches thirst and prevents dehydration. Avoid drinks with caffeine during exercise since they can increase fluid loss.

# CookChildren's

## Cook Children's Medical Center Cystic Fibrosis Center

Pulmonary Services  
901 7th Avenue, Suite 420  
Ft. Worth, Texas 76104-2724  
Phone: 682-885-6299  
Fax: 682-885-1090  
Email: [www.cookchildrens.org](http://www.cookchildrens.org)

**Making CF stand for "Cure Found"**

### Pediatric CF Center Staff:

Center Physicians: **James Cunningham, MD**– Center Director (Nurse: Stacy), **Nancy Dambro, MD**– Center Director (Nurses: Karen & Charity), **Maynard Dyson, MD** (Nurse: Stacy), **Sami Hadeed, MD** (Nurse: Sharon), **James Pfaff, MD** (Nurse: Chrystal), **John Saito, MD** ( Nurse: Liz), **Karen Schultz, MD** (Nurse: Paulette)

### Adult CF Center Staff:

Center Physicians: **John Burk, MD**– Adult Center Director, **Steve Davis, MD, Stuart McDonald, MD**

#### CF Coordinators:

Janet Garbarz, Carrie Stradley 682-885-6299 (#6)

#### Dietitian:

Staci Brummett 682-885-7496

Cristina Gonzalez

#### Respiratory Therapists:

Deanna Pinckney, Alex Rasmussen,  
Ruthie Oney, Crystal Thompson 682-885-4189

#### Child Life Specialist:

Amy Kaufhold 682-885-4892

#### Social Services

Jamie Cole 682-885-3991

## The Cook's Corner: Recipe for Success

### Pack a punch with your school lunch

- 2 slices whole grain bread
  - 1 tbsp butter or mayo
  - 2 oz roast beef, bologna, or salami
  - 2 slices of cheese
  - Lettuce or tomatoes
  - 6 baby carrots
  - 1 tbsp ranch dressing
  - Small bag of potato chips
  - 2 sandwich cookies
  - 8 oz 2% milk
- Calorie count: 1,072 calories

