



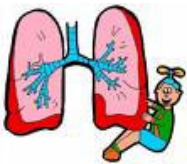
# The Cystic Fibrosis Care Center at Arkansas Children's Hospital

Issue 2

Winter 2007

## Building Bridges to Create Tomorrows

### Eat Well, Breathe Better



Have you ever heard the old saying, "Eat more and you'll breathe better?"

OK, so maybe it's not that old and perhaps you've never even heard it, but it's true! New research from the Cystic Fibrosis Foundation indicates that nutrition directly correlates with lung function. Plainly spoken, the better nourished CF patients have better lung function.

You may be thinking to yourself, "I was meant to be skinny" or "I'm just small-framed," but the truth of the matter is that ALL CF patients should strive to maintain normal growth and nutrition- that is a normal height, normal weight, and a normal BMI of around 50%. Once again, we have another factor that can be manipulated by patients and families in order to create the best scenario for both nutritional and pulmonary health!

While this may sound simple in print, you may well know that many factors affect nutritional status and it isn't always easy to stay in the "normal" range. Here are some reasons that CF patients sometimes fall behind in nutritional status and some tips for overcoming them:



**Diet-** You may have a hard time getting enough calories each day to gain weight and grow. Watch out for those low calorie, low fat, and "empty" calorie foods like candy & cokes and make those calories count! Adding butter, dressings, or sour cream to foods can boost your caloric and fat intake while adding very little substance to meals.



**Enzymes-** Is the enzyme dose prescribed appropriate? Have you had changes in bowel movements or abdominal discomfort? Are you taking your enzymes regularly? Remember: Enzymes work for about one hour after you take them & more fatty foods require more enzymes.



**Other Medical Problems-** Is there ongoing lung or sinus disease, diabetes, acid reflux, intestinal problems, or growth hormone deficiency? These factors can certainly impact nutrition and additional testing may be needed if you face any of these problems and are declining in nutritional status.



**Financial-** Are you having trouble paying for food, supplements, or medicines? The social worker or financial counselor can help determine if you are eligible for services that may help defray these costs.

All in all, don't forget that you're not alone in any battle that you face, including that of maintaining good nutritional status. Your CF nutritionist, pulmonologist, social worker, and all other members of "your team" are just a phone call away.

### Flu Shot Reminder

Influenza can worsen lung disease in CF leading to a decline in lung function or respiratory infection requiring hospitalization. Be sure your child receives his or her Flu Shot ASAP!





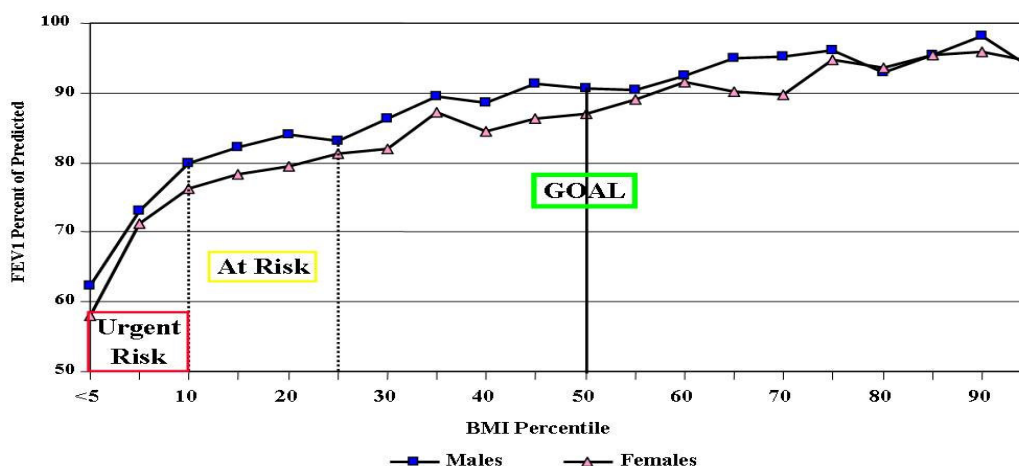
## A Note From Dr. Schellhase

We know that nutrition is important for the health of every CF patient. In fact, nutrition directly affects lung function. Better nourished CF patients have better lung function. Early and aggressive attempts to improve nutrition in infants, toddlers and young children can result in improved lung function later in life. We believe that all CF patients, regardless of age, should have "normal" weight, height and body mass index (BMI). "Normal" means that weight, height and BMI should be right in the middle, at 50%, average for age, not skinny, not short and not fat. What can you and the CF team do to make sure your child with CF is growing normally? You, your family, your doctor and the CF dietitian can be sure that your child eats a high fat, high calorie diet, takes her enzymes as prescribed,

takes extra supplements if needed and does not eat or drink the wrong things (like soft drinks, juices, candy, sweets). For those CF patients that are having trouble (and most have trouble at some time or other), we have developed a nutrition pathway to help us and you be sure we are doing everything that needs to be done to restore good nutrition and normal growth. Please ask questions, follow the recommendations of your doctor and the CF dietitian, help your child take his enzymes and supplements, know whether or not his growth is normal and demand help when he is not growing well. People with CF have a life to live! They need the energy provided by a high fat, high calorie diet to live it!



**LUNG FUNCTION (FEV1 PERCENT PREDICTED)  
CORRELATES POSITIVELY WITH BMI PERCENTILE (6-20 yr olds)**





## Corner For Kids!



Check out these great books about CF kids just like you!

Going to David's Party & Uncle Jack's Coming to Dinner by Kay L. Bartholomew- 1989

Two stories of children who almost forgot to take their enzymes!

Middle Childhood: Eating for Energy published by Baylor College of Medicine-1989, 1994

A two part story about two young boys, one of whom has CF, finding out how the digestive system and how enzymes help break down their food for energy. Includes activities and recipes.

A Day at the Outdoor Market published by Baylor College of Medicine- 1989

Lisa learns how different foods are good for you and how they help you grow!

Have you ever asked yourself or someone else the question...  
"Why do I have to pay attention to what I eat?"

Match the words below with their definitions, and learn how nutrition affects the body and CF.

Enzymes	Children with CF may need 30% to 50% more of these per day!
Lungs	A, D, E and K are part of this group
Heart	You need these to stay strong and healthy so you can breathe easier
Immune System	Helps deliver nutrition to the rest of your body
Calories	Helps the body digest food
Vitamins	The part of your body that fights infections and bacteria
Malabsorption	Eating healthy foods enables your body to do this
Grow	Difficulty in the digestion or absorption of nutrients from food

Play and explore this fun interactive website for children on nutrition!!!

[http://www.kidshealth.org/kid/closet/games/mission\\_nutrition.html](http://www.kidshealth.org/kid/closet/games/mission_nutrition.html)

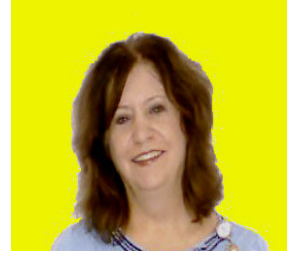


## Meet a Member of the Team!

Name: Mary Jo Chambers, LCSW

Job: CF Clinical Social Worker/Social Work Supervisor

- **How long have you been working with CF children?** 3 years
- **What do you like best about your job?** I love the patients and families that I work with and the fact that it's over the long-term and not just once or twice. It's also exciting to be a part of a team committed to ongoing improvement.
- **If you had to choose just one important thing to say to all CF kids, what would it be?** Dream big and grow into those dreams!
- **Tell us a bit about what your job encompasses.** My job as a social worker includes providing support to patients and their families, helping them to adjust to living with a chronic illness and with any concerns or conflicts that causes and providing resource information. My goal is to help our patients and their families to live as normally as possible so that CF does not become the focus of their world.



## Want an E-Pal?

The newsletter committee understands how difficult it is for Cystic Fibrosis patients to have contact with one another due to infection control guidelines. We would like to help match CFer's together who might enjoy corresponding via email and regular mail. If you are interested in the email option, please fill out the form below and send your responses to [cfnewslettercommittee@yahoo.com](mailto:cfnewslettercommittee@yahoo.com). If you are interested in the "snail mail" option, please send your answers to the questions below and your request to: Vickie Marshall-1112 W. Pecan Street-Rogers, AR 72756. Your information will be kept confidential and only shared with a potential e-pal match.

Name: \_\_\_\_\_

Email/Mailing Address:

\_\_\_\_\_  
\_\_\_\_\_

Age: \_\_\_\_\_ Grade: \_\_\_\_\_

Circle gender:    male        female

Interests/Hobbies: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

Would you like to be matched with a boy or girl?

\_\_\_\_\_

I understand that I am permitting the CF Family Advisory Board to match my child with another child. I am also aware of the dangers of the internet and will not hold ACH or the CF Advisory Board responsible for any unintentional email communication that my child may receive or send.

Our intent is to match children with similar interests and similar ages. Parents are encouraged to provide appropriate supervision or oversight regarding internet use as is being encouraged nationally. ACH and the CF Family Advisory Board join other groups in the country in encouraging safe internet activities for their child.

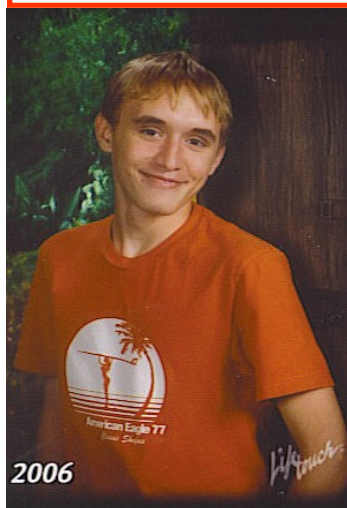
Parent Name: \_\_\_\_\_

Parent Signature: \_\_\_\_\_

Date: \_\_\_\_\_



## In the Spotlight!



**Name:** Chris Holsted

**City & State:** Alma, Arkansas

**Age:** 15      **Grade:** 9th

**Favorite School Subject:** Drama

**Siblings / Pets:** 2 brothers, 1 sister, and 2 dogs

**What do you like to do in your spare time?** listen to music

**Do you have any hints that you could give to other CF kids about their treatments, meds, etc?** Do them every time and don't cheat.

**If you could have one wish, what would it be?** for a cure to be found

**Awards and Accomplishments:** 2nd place science fair, Fiddler on the Roof

**What are your future plans?** to go to college

## Fabulous Food Find!

### Sweet Potato Casserole

**Prep time:** 60 minutes

#### Sweet Potato Mixture:

1-29 oz large can of yams, mashed

1 egg, beaten

1/3 c. butter, melted

1/3 c. brown sugar

#### Topping:

1/3 c. brown sugar

1/3 c. butter, melted

1 c. cornflakes, crumbled

1/2 c. shredded coconut

1/3 c. pecans, chopped

#### Directions:

Mix together yams, eggs, butter, and brown sugar to make the sweet potato mixture.

Bake sweet potato mixture for 15 minutes at 350 degrees.

While the sweet potato mixture is baking, mix together the topping ingredients. Once the sweet potato mixture is finished baking, put topping on top of sweet potato mixture.

Bake for another 30 minutes. Serves: 10

#### Nutritional Analysis (per serving) (Serving size = 3/4 cup)

326 calories

57 mg cholesterol

19 g fat

198 mg sodium

2 g protein

29 mg calcium

38 g carbohydrate

1.5 mg iron

2 g fiber

## Join Our Online Community

Join CF patients, caregivers, and support staff in an ALL NEW message board especially for the CF community in Arkansas and the surrounding areas. Arkansascysticfibrosisfamilies YahooGroup is a place where we can all come together to share stories, tips, and support in our common battle against CF. Just go to <http://groups.yahoo.com/> and type our group name in the search box and you're on your way to becoming a part of our online community of CF friends and families. We look forward to seeing you there!



## How to Reach the CF Team:

Pulmonary Office:	(501) 364-1006	Physicians, Specialty Nurses, Respiratory
Main Hospital:	(501) 364-1100	After-Hours Pulmonary Physician On-Call
Chaplain:	(501) 364-1824	Kenneth Myers
Child Life:	(501) 364-1412	Amelia Harris
Clinical Nutritionist:	(501) 364-7533	Heather Barkley
Education/Teacher:	(501) 364-1412	Kathy Robinson
Psychology :	(501) 364-1021	Dr. Anne Stermock
Social Work:	(501) 364-6537	Mary Jo Chambers

## CF Websites

[www.cff.org](http://www.cff.org)

[www.cystic-l.org](http://www.cystic-l.org)

[www.cforward.net](http://www.cforward.net)

Let us know if you have favorite CF sites that you'd like to share.

## We'd love to hear from you!

The Family Advisory Board would love to hear from you concerning this newsletter & other Cystic Fibrosis issues that are of concern to our fellow parents and patients.

Please send us an email @ [cfnewslettercommittee@yahoo.com](mailto:cfnewslettercommittee@yahoo.com) if:

- You have a newsletter story idea.
- You would like your child/yourself to be featured in our Spotlight section or patient pictures.
- You have questions or comments that you would like the family advisory board to address.

We look forward to hearing from you!

Please be aware that this information is provided to supplement the care provided by your physician. It is neither intended or implied to be a substitute for professional medical advice. Always seek the advice of your physician or other qualified health provider prior to starting any new treatment or with any questions you may have regarding a medical condition.

### Our Mission . . .

We, the Cystic Fibrosis Center Family Advisory Board at Arkansas Children's Hospital serve to build a bridge between the healthcare team, families and patients with Cystic Fibrosis.

### Our Vision . . .

Through communication, education, and self-reflection, we will provide personal insight to the CF team as well as to those dealing with the disease in their daily lives. Ultimately, it is our vision to further enable patients with Cystic Fibrosis to continue to "live well and prosper."

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