



# CYSTIC FIBROSIS CENTER

St. Vincent's Hospital Manhattan

## Highlights

WINTER 2008

The 21<sup>st</sup> annual North American Cystic Fibrosis Conference (NACFC) was held in Anaheim, California from October 3-6 2007. Dr. Berdella, Dr. Walker, Social Worker Amy Purdy, and Genetic Counselor Elinor Langfelder Schwind joined CF physicians, researchers, and allied health professionals from around the world to learn, think, and build collaborations.

The third session highlighted data from the CF Foundation's Quality Improvement Initiative. It emphasized how improvements in patient health result when patients, families, and healthcare providers work together to ensure access to and proper usage of standard CF therapies. (For more information on St. Vincent's quality improvement efforts, see page 6).

### CONNECTING THE DOTS: The role of genes, channels, sodium, chloride, and salt in CF.

As you know, cystic fibrosis is caused by mutations, or changes, in a gene. But how do gene changes lead to CF symptoms and the treatment approaches being researched?

Our bodies are made up of tiny building blocks called cells. These contain thousands of instructions for how we grow and develop, called genes. Some genes – which come in sets of two – determine what we look like, while others help the body function. Everyone has a few genes that don't work well. But while one copy may not work, the other is usually fine. When parents each carry a copy of the same non-working gene, their child could be born with a health problem. The "cystic fibrosis gene," or "CFTR," provides instructions for making an opening, or channel, for salt to move out of the cells. Salt is made of sodium and chloride. CFTR is mainly a chloride channel. When a person's CF genes have been altered by mutations, the channels are not made properly, movement of salt and water is not controlled, and we see CF symptoms.

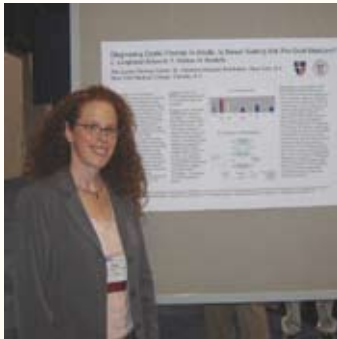
Researchers are looking for ways to help CF patients' cells do a better job of moving salt (or its components, sodium and chloride) as a treatment. There are three main ideas about how to do this:

- 1. Help the cells of CF patients get more CFTR chloride channels where they need to be,** such as Dr. Swiatecka-Urban's work described here.
- 2. Encourage cells to make other types of channels besides CFTR that can also move salt,** which is what Denufosal aims to accomplish.
- 3. Replace non-working CF genes with new copies and make new channels.** This "gene therapy" is still being researched.

The CF Foundation is aggressively working to find new CF treatments through these avenues, and more!

## CF CENTER ATTENDS ANNUAL CF CONFERENCE

The four-day conference had three major sessions which summarized CF research advancements and presented original research by over 800 investigators, including the St. Vincent's CF team. Staff were also updated on research collaborations in which St. Vincent's participates with scientists, caregivers, and pharmaceutical companies.



St. Vincent's Genetic Counselor Elinor Langfelder Schwind at the 21<sup>st</sup> annual North American Cystic Fibrosis Conference (NACFC) in Anaheim, California.



The first session focused on what has been learned about correcting the basic problem caused by the most common CF genetic mutation,  $\Delta F508$ . Some exciting data came from Dr. Agnes Swiatecka-Urban, a physician who was first inspired to cure CF during her residency at St. Vincent's. She has identified a key factor within cells that prevents  $\Delta F508$ -affected chloride channels from getting to the cell's surface, where they are needed. The second session described the CF research pipeline, including early reports of success with Denufosal, an experimental drug, from Inspire Pharmaceuticals. Denufosal addresses the salt transport defects in CF by stimulating other parts of the cell to work harder. St. Vincent's is one of the clinical research sites for this promising new CF therapy.

A major theme for this session was that the success of new trials depends on the Centers' ability to recruit patient volunteers. New drugs will only make it to the marketplace with your help. We are happy to review our current clinical trials with you in more depth during individual appointments and discuss which studies you or your child may be eligible to enter. (For more information on the Center's clinical trial participation, see page 3).

Staff also heard about progress in the CF Lung and Liver Genetic Modifier Study, the Aztreonam Study, and how to improve infection control practices.

Our own Genetic Counselor, Elinor, presented data on how best to diagnose adults with CF, showing the sweat test is still the most useful way to prove or disprove a suspected CF diagnosis. It does so more effectively and cost-effectively than genetic testing.

Conference attendees came away with a wealth of new information, ideas, and tools to use to provide our patients with the best CF care. It is our pleasure to answer your questions and review research findings in detail as it may relate to your – or your child's – situation. Be sure to ask a staff member when you come in for your next appointment.

Videos of all three sessions are available on the CF Foundation website:  
<http://www.cff.org/research/2007/NACFC>

*F*or any runner, completing the ING New York City marathon is a triumph. But for the 31 members of the St. Vincent's Hospital marathon team, this accomplishment meant even more as they raised over \$100,000 to benefit our Cystic Fibrosis Center!

# RUNNING MILES & RAISING FUNDS

For the second year, St. Vincent's joined the roster of charities participating in the marathon. The Hospital's President's Council designated our CF Center as a beneficiary of funds raised in recognition of the Center's 30<sup>th</sup> anniversary and in support of our renowned Exercise & Wellness Program.

Team members were selected from a large pool of applicants. Many were unfamiliar with Cystic Fibrosis and our Center. Others had a personal connection to CF that made their run even more meaningful:

**Alison Crichton-Stuart** (née Bruce) delivered her three children at St. Vincent's. She ran the marathon in memory of her childhood friend, Juliet Colley, who died of CF in 1975. Alison wanted to run the marathon for a charity and when she learned the St. Vincent's team would be raising money for the CF Center, all the pieces fit perfectly into place for her.

**Martha Murphy** is a fifth grade teacher in Fairfield, Connecticut. She ran in honor of her former student, Caitlin, who has CF. Martha says, "Caitlin is now in 8<sup>th</sup> grade and is doing well. I still see her and she looks great. She is a vibrant young lady who has never let CF stop her from doing anything!"

**Renee DeRubeis** finished the marathon in just 4 hours, 28 minutes. She dedicated her run to the memory of her close friend and high school classmate Jeanine ("Gigi") Roy, who died of CF one year ago after receiving a double lung transplant.

"I knew that Gigi was watching over me," Renee says of her run. "She was probably thinking I'm crazy for running 26.2 miles. Every time I struggled I'd think about Gigi and it kept me going. I knew she was smiling right back down on me!"

Renee's story even caught the eye of the media. An article about Renee and her run for St. Vincent's was featured in the *Star Ledger* and she was invited to be a guest on the Sunday morning program, *RealTalk*, on WWOR-MY9.

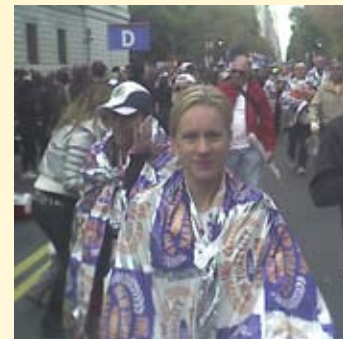
The CF Center was closely involved with the marathon team. At the first team meeting, we provided information about CF. We also told the runners about some of our patients, who had generously allowed us to share their personal stories. This helped to give the team a sense of the real lives their efforts would touch. Some of the runners even chose to dedicate their runs in the patients' honor.

The second meeting was held at the runners' specialty store, Jack Rabbit. Expert staff talked in detail about the marathon experience. Our own CF Center personal trainer, Emily Kritzler, was on hand, along with outpatient Physical Therapy Assistant, LaShanda Dandrich, to give a presentation on marathon survival tips. (For more on Emily and her role with the Exercise & Wellness Program, see page 4).

Jack Rabbit provided a generous discount for the runners to purchase any items they needed for the race. The CF Center presented each team member with a knapsack filled with PUMA running gear generously donated by the Parigi Group, a distributor of PUMA Kids products. Also included were St. Vincent's hats and water bottles as well as Power Bars, provided courtesy of Kraft Foods.

On Marathon Sunday, November 4, the President's Council reserved a room with a view at The Underscore at BarEast along the race route so the runners would have a specific location at which they could see their family members. And finally, a thank you runners' reunion party is currently in the works!

Center Co-Directors Dr. Patricia Walker and Dr. Maria Berdella gratefully note that proceeds from the race will be used to support and enhance the work of the Exercise & Wellness Program. The doctors commented, "We congratulate the runners on their tremendous efforts. We feel so lucky to have been a part of [their] momentous day!"



The family of one of our runners holds up an inspirational sign (left). Jeanne Gado smiles proudly after finishing the marathon in 4 hours 20 minutes (right).

“Every time I struggled I’d think about Gigi and it kept me going. I knew she was smiling right back down on me!”

-Marathon runner Renee DeRubeis

## Thank you to all of our outstanding marathon runners!

- |                    |                        |
|--------------------|------------------------|
| Megan Cassidy      | Timothy McElreath      |
| Sean Clifford      | Rohit Mitter           |
| Renee DeRubeis     | Martha Murphy          |
| Justin Flanagan    | Christopher Perri      |
| Glenn Fleishhacker | Amy Pournaras          |
| Jeanne Gado        | Christopher Quick      |
| Scott Guber        | Courtney Quick         |
| Michael Hattar     | David Sawyer           |
| Gary Housouer      | Kerry Skolkin          |
| Eric Huss          | William Sneddon        |
| Meaghan Joyce      | Jonathan Sobel         |
| Jason Keighery     | Jamal Stockton         |
| Janusz Kowalski    | Alison Crichton-Stuart |
| Christopher Laul   | Steve Watson           |
| Michael Leyden     | Kathleen Webb          |

**St. Vincent's CF Center has a long history of** participating in industry-sponsored clinical drug trials, from the early Pulmozyme trials to the recent Inspire (Denufosol) and TOBI studies. Historically, we've had excellent enrollment, completion, and compliance thanks to the dedication of our patients and families, and the hard work and perseverance of Carroll Anne Grece, the Center's research coordinator.

# CLINICAL TRIALS UPDATE: CF CENTER EARNS AWARD

In recognition of the CF Center's excellent research track record, the CF Foundation has granted our Center a Clinical Research Facilitation Award. This grant is meant to foster the Center's participation in CF Foundation-sponsored clinical trials through staff training and the purchase of research-related equipment. The success of the CF Foundation's substantial investment in a drug pipeline depends on the willingness of patients and families to participate in research.

Dr. Walker and Dr. Berdella attended two information sessions about implementing this award – one in Denver from September 3-5 and one at the North American Conference in Anaheim on October 3. This is an exciting development for our Center, as we anticipate this award will provide our patients and families with many more opportunities to participate in a wider range of research.

There are two new clinical trials approved for recruitment of patients at St. Vincent's – one on TOBI (TIP – TOBI Inhalation Powder, a newer form of the drug) and one on the effects of drug treatment for gastrointestinal reflux disease (GERD) on the lung health of adult CF patients. The GERD study represents an innovative and exciting new research partnership between our Center's Adult Program and the Adult CF Program at New York Presbyterian Hospital. Please ask your doctor about your eligibility for participation in these research studies at St. Vincent's.

LEARN. ASK. JOIN.

## THE CYSTIC FIBROSIS CENTER TEAM

### Co-Directors

Maria N. Berdella, M.D.  
*Co-Director, Pediatric Program*  
Patricia A. Walker, M.D.  
*Co-Director, Adult Program*

### Hospital Attending Physician

Lisa Forbes, M.D.

### Nurse Coordinator

Donna DiBenedetto, R.N.

### Senior Genetic Counselor

Elinor Langfelder Schwind, M.S., C.G.C.

### Genetic Counselor

Kara Gardner, M.S.

### Senior Social Worker

Amy Purdy, L.M.S.W.

### Nutritionist

Gail Zimmer, M.S., R.D., C.D.N.

### Senior Physical Therapist

Carroll Anne Grece, R.P.T., M.P.S.

### Physical Therapy Assistants (Inpatient)

Teresa Skarbek  
Warren Hope  
Guirlene Geneve

### Outpatient Exercise & Wellness Program

LaShanda Dandrich, P.T.A.  
Emily Kritzler, Personal Trainer

### Administrative Coordinator

Tema Roman

### Receptionist

Arianna Ortiz

### Intern

Lauren Shikowitz

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## SCHOLARSHIP INFORMATION

### 1. Cystic Fibrosis Scholarship Foundation

Contact: 847-328-0127  
Deadline: March 21, 2008

### 2. Boomer Esiason Foundation (BEF) Scholarship

Contact: Jerry Cahill, 646-344-3661  
Deadline: Quarterly, March 15, June 15, September 15 and December 15  
\* Information about other CF scholarships sponsored by the BEF can be found online at [www.cfscholarships.com](http://www.cfscholarships.com)

### 3. The Stony Wold-Herbert Fund, Inc.

Contact: 212-753-6565  
Deadline: Ongoing

Please contact CF Social Worker Amy Purdy at 212-604-8895 or [apurdy@svcmcn.org](mailto:apurdy@svcmcn.org) with any questions about scholarships.

Questions or comments about  
the information in this newsletter?

Contact us at 212-604-8895 or [cfcenterpatients@gmail.com](mailto:cfcenterpatients@gmail.com)

*I* "I am a big proponent of fun!" says personal trainer Emily Kritzler. Currently earning her Master's Degree and Doctorate in Exercise Physiology at Columbia University, Emily has joined the staff of the St. Vincent's CF Center Exercise & Wellness Program as a consultant/trainer.

Emily moved to New York to begin graduate studies. She knew her dream job would be to work with CF patients in an exercise program. A phone call to the CF Center resulted in meeting the doctors and LaShanda Dandrich, the Exercise & Wellness Program's Physical Therapy Assistant. It quickly became clear that Emily and our Exercise Program could be an ideal fit. "It was so wonderful that just as I was hoping to find them, the CF Center was hoping to find someone like me!" Emily says.

The biggest hurdle, she notes, is for individuals to commit to a regular exercise routine. "Especially in CF, where people are asked to make so many commitments already to their health, it is hard to ask for another," she explains. But Emily intends to lead by example and find activities that can get patients moving and having fun!

## WELCOME EMILY KRITZLER

### CF CENTER PERSONAL TRAINER

Since meeting her best friend, Samantha, in college, Emily has had a passion for working with people with CF. Emily witnessed Samantha's hospitalizations and rigorous daily regimen and, as a result, learned a great deal about CF.

Having always been involved in sports, exercise comes naturally to Emily. The first time she paired CF with exercise was to help her friend. Encouraged by her doctor to establish a regular exercise routine, Samantha did not know where to begin. Emily worked with her to develop more stamina. Together, the two friends trained for a half-marathon. Though Samantha "hated it," they stuck with their goal and did it! "Crossing that finish line with her was one of the most powerful experiences of my life!" Emily says. That year was the first since Samantha was nine that she had not had to endure an IV "tune up." The physical activity kept her well in a whole new way. Since then, Emily and Samantha have run an additional half-marathon. They are now preparing for the Rock and Roll Marathon in Phoenix, Arizona in Spring 2008.

"We have known for a long time in CF medicine that our healthiest patients are often our most active patients. Those who dedicate themselves to building their physical endurance and stamina frequently fare best," says Dr. Patricia Walker, Adult Pulmonologist and CF Center Co-Director. "We are thrilled that Emily has joined our team to help patients make that all important commitment to their wellness through exercise," she notes.



The CF Center is extremely grateful for the generosity of the non-profit organization, Families and Friends Supporting CF Care, in helping to fund Emily's work with our patients. If you are interested in working with Emily Kritzler, please speak with your doctor.

"We are thrilled that Emily has joined our team to help patients make that all important commitment to their wellness through exercise."

-Dr. Patricia Walker, Adult Pulmonologist and CF Center Co-Director

LaShanda Dandrich adds, "We have been looking for ways to bring new energy to our Exercise & Wellness Program. "Emily brings positive energy and contagious enthusiasm." Emily will be working with patients one-on-one, helping them reach their personal exercise goals. She hopes to show patients that exercise can be fun and can help them feel better.

#### Emily's Essential Exercise Tips:

- 1. Set specific and measurable goals.** Run a certain distance, do a certain number of push-ups, etc.
- 2. Make a regular appointment with yourself to exercise.**
- 3. Make it easy.** Put on your exercise clothes and give yourself permission to workout for just 10 minutes. When that time is up, allow yourself to stop if you need to or to keep going if you can.
- 4. Carry your workout clothing with you** so you can work out whenever you have the time.
- 5. Find an exercise buddy** – someone who can motivate you on tough days. Make the motivation reciprocal and make a regular workout date with your buddy.
- 6. Find an activity you enjoy doing and become passionate about it!**

### Save the Dates

#### CF Foundation's Great Strides Walkathons\*:

May 17, 2008 Manhattan, Battery Park  
May 18, 2008 Westchester, Rye Playland

\*Stay tuned for more information on the St. Vincent's CF Center "Exercise Rules!" Team Walk

*From the time she first worked with CF* patients nearly 20 years ago under the direction of Dr. Elisabeth Luder, a cystic fibrosis dietary expert at Mt. Sinai, Gail Zimmer, M.S., R.D., C.D.N., has been inspired by the patients and families she has encountered. "They were fighters!" she says of her first CF patients. "And more than just fighting the disease, they went on to live productive wonderful lives." Gail brings this same sense of respect and admiration for her patients to her work as the new St. Vincent's CF Center nutritionist.

Gail is very excited to report that she is currently applying to join the CF Foundation's "Nutrition Mentoring Program" through which she will have an opportunity to work closely with an experienced nutritionist at another CF center. Over the course of the next year, she will receive ongoing formal and informal consulting and will have a chance to visit her mentor's Center to learn more about best practices in CF nutrition counseling.

"I love [St. Vincent's]. This is a wonderful place to work. It is a place where I feel needed and valuable and know I can make a difference."

- Gail Zimmer, M.S., R.D., C.D.N., CF Center Nutritionist

## WELCOME GAIL ZIMMER CF CENTER NUTRITIONIST

Gail received her Master's Degree in Nutrition from New York University in 1986. She joins the Center staff after a long and distinguished career working with patients with diabetes and other chronic illnesses. She has done extensive research on renal nutrition including a National Institutes of Health Study on patients who are co-infected with HIV and Hepatitis C. Most recently, she worked as a clinical nutritionist at Cabrini Medical Center.



A proud mother of two grown sons, Howard and Michael, Gail lives with her family on Long Island. Her personal hobbies include skiing, attending opera at Lincoln Center, where she is a season-ticket holder, making silver and stain glass jewelry and, of course, cooking healthy and delicious meals. (Please

see sidebar for Gail's favorite classic winter chicken soup recipe).

She credits a Pancreacarb representative with making the initial connection between her and St. Vincent's. Several conversations with Center Co-Director Dr. Maria Berdella convinced Gail that our Center would be a great fit for her next professional endeavor. "Gail will be seeing patients at the CF Center three days a week," Dr. Berdella explains. "This marks a great increase in the nutrition services we now provide to our patients. We are thrilled to have her on board!"

Gail joined the St. Vincent's CF Center staff in mid-December. Of her first month as a member of the CF team, Gail says exuberantly, "I love it! This is a wonderful place to work. It is a place where I feel needed and valuable and know I can make a difference."

### From Gail's Kitchen: Chicken Soup for the Soul

*\*This classic chicken soup can be customized to your particular tastes. Beans, split peas, lentils or other favorite vegetables can be great additions!*

*\*Consider trying an organic chicken or a kosher chicken (which has been soaked in salt) to add extra flavor... and leave the skin on for an extra caloric boost. Excess fat will rise to the pot's surface during the process and can be skimmed off.*

Boil a small whole chicken or chicken parts in 6-8 cups of water  
Skim fat and foam as desired  
Add carrots and celery cut into 1-2 pieces  
Add a roughly cut onion  
Add parsley and dill – either chopped to eat or tied in bunches for flavor only  
Cook on a low boil or high simmer for 1 hour until chicken is well done  
Add 1-2 Tablespoons of salt

Serve with rice, noodles or matzah balls.



As you may recall from the last issue of this newsletter, our CF Center was chosen by the CF Foundation to participate in the Learning and Leadership Collaborative-V ("LLC-V"). The focus of this Collaborative is pulmonary care. The CF Center team meets weekly to work on quality improvement projects specifically relating to our global aim: "To slow the rate of decline of the median FEV1 for patients at the CF Center." We have implemented several projects toward achieving this goal.

At your next visit, expect to experience the results of these projects. For example, you may be asked about your current nebulizer use...Which type do you use for each medication? How do you clean it? The staff will review the correct practices and you'll take home a reminder of the proper procedures. When you are asked questions, be honest – this is for YOU. No judgments, we promise. Just ask Suzanne, one of the LLC-V patient representatives!

Participating in LLC-V meetings has been personally rewarding for both Fran and Suzanne...[they've] been integral to every aspect of LLC-V.

On an even more personal note, after all the discussions about proper nebulizer cleaning, Suzanne is much more diligent about following the correct procedures. But, she admits, she is still trying to live up to the level of perfection and diligence that Fran exhibits every day in caring for her son!

Suzanne and Fran are working with CF Center Social Worker Amy Purdy to develop the Center's parent and family advisory group. We have already received a terrific response to our last call for participants. We will report on our progress on this and all of our projects in the next newsletter.

# LEARNING & LEADERSHIP COLLABORATIVE-V

By Francine Fischer & Suzanne Joyce

Some of the projects we have worked on include:

- › **Improving office flow:** Reducing wait times to allow more time for patient education and visits with other staff members, in addition to the nurse and doctor. Thanks to all of you who filled out those time surveys!
- › **Developing standardized re-education programs for patients regarding proper use and cleaning of nebulizers and airway clearance devices.**
- › **Surveying and re-educating hospital inpatient staff regarding infection control.**
- › **Developing an "individual plan of care"** for each patient that includes, among other things, an assessment of the prior year's pulmonary and nutritional status, review of all airway clearance practices, medications, and list of annual tests.

Participating in LLC-V meetings has been personally rewarding for both Fran and Suzanne. From developing the aims and goals of the improvement plan to reviewing the documents, to leading meetings and discussions, Fran and Suzanne have been integral to every aspect of LLC-V. One of the meeting rules requires weekly rotation of the role of leader. Early in the LLC-V process, Fran dreaded taking her turn as leader. She was certain she could not run the meeting. Over time, Fran became more comfortable speaking during meetings and became more confident as she realized that her contributions were well respected. Now she says, "Bring it on!"

Suzanne attended the LLC-V face-to-face meetings in Maryland and California with the CF Center team as well as the staff from the CF Foundation and the other 15 Centers participating in the collaborative. She was impressed by the level of professionalism and sincerity of all the attendees. It was easy to see how hard everyone works and how much they care about moving forward the cause of improving pulmonary outcomes through quality improvement.



Amy Purdy and Elinor Langfelder Schwind with John Nash, Collaborative Coach and CF Social Worker, at Albany Medical Center (left). Amy Purdy, Dr. Maria Berdella and Suzanne Joyce at the Collaborative Meeting in Anaheim, California (right).

**ABOUT THE AUTHORS:**

Francine Fischer is a parent of a teenager with CF, 16 year-old Joseph. She lives in Manhattan with her husband and two other children. Suzanne Joyce is an adult with CF. She lives in Manhattan with her husband and two kittens.

On September 6, 2007, Jessica, 30, and her fiancé, David, visited the famed York Minster Cathedral in England. It was a beautiful day and Jessica was enjoying the fresh air. When David suggested climbing to the top of the Cathedral to take in the view, Jessica asked, "How far up?" David pointed to a spot far off in the sky.

Not until they reached the top did they learn just how many stairs they had walked – 275! Clearly, the climb is an achievement for anyone. The Cathedral hands out certificates to the hardy souls who make it all the way up. For Jessica, this meant so much more than it would to the average person.

"I am so proud of myself," Jessica says with pure joy. She admits that had someone told her in advance the amount of stairs there were to climb at the York Minister Cathedral or the conditions on the way up, she never would have attempted it. "It just showed that when you don't know what's ahead of you, you can push yourself to do anything!"

## THE GREAT CLIMB

Courageously, Jessica gave the go-ahead and the couple began the arduous climb. "The building was built in the 1300s," Jessica explains. So the stairs, which made a complete cylinder around the inside of the Cathedral, were "narrow, musty, and moldy." Along the way, Jessica and David realized the spot he had innocently pointed to from the ground was only halfway to the top.

"It just showed that when you don't know what's ahead of you, you can push yourself to do anything!"

-Jessica

This was the first trip Jessica took since experiencing more CF symptoms – a process which began in her late teens. Working with the CF team, she underwent three months of IVs, listened carefully to her body's calls for rest, good nutrition, and exercise, and a break from high dose antibiotics. All of that enabled Jessica to find her way to a better place – feeling well with lots of energy today.

Throughout the climb, Jessica remained undaunted. With David behind her and just two puffs of her Albuterol inhaler, Jessica completed the climb. At the top, the couple was greeted with a stunning view of all of York, including "The Shambles," an area of historic crooked homes built in the 1500s. "It was just spectacular!" Jessica recalls.

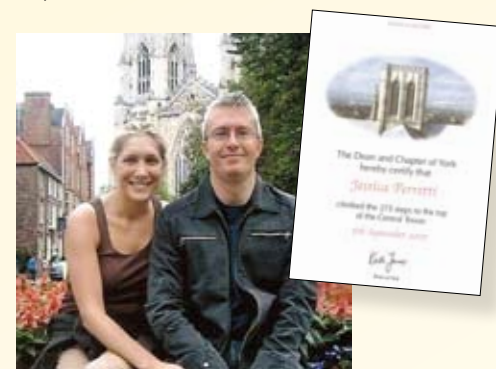
It all started with a few stickers hung on the hospital windows years ago by Lyndsey's Aunt Denise. "If you walk around the floor, you can still find them," says Lyndsey. Her whole family recognized that it is no fun to be stuck in the hospital. So gradually, they expanded their decorating efforts from stickers to a whole room décor.



Lyndsey's Irish-themed room at St. Vincent's.

years old. She has been receiving her care at St. Vincent's CF Center since soon thereafter.

Lyndsey is hospitalized two or three times a year and knows that fun distractions are key to passing the time. "I always have a goal while I'm in the hospital," Lyndsey notes. "I'm a big scrapbooker so I'll pick something to scrapbook before I go in."



Jessica and David in York, England.

This past time, I had just graduated from college so I scrapbooked that. My Aunt Donna and Uncle Steve always provide baskets of entertainment – little toys and art projects. I watch a ton of movies and catch up on TV shows that I always wanted to watch."

During her most recent hospitalization, Lyndsey's room had an Irish theme, designed by her mother, Donna. "I like having my room decorated because it gives me something else to focus on. It's a conversation starter," Lyndsey says. "I like that my room makes other people happy and I think it makes my family and friends more comfortable too."

Lyndsey graduated this past spring from the University of Delaware. She works at Elm Ridge

Capital Management, a hedge fund in Irvington, New York.

## LYNDSEY'S ROOM

After Aunt Denise brightened the atmosphere, Lyndsey and her family decided to make her room a tropical theme.

"It was like I was on vacation," she explains. "I always tried to explain to people that – even though I was in the hospital it wasn't like what you would think of as a hospital visit. I wore my own clothes and could walk around. I wanted to decorate the room so it didn't feel so hospital-like."

"I like that my room makes other people happy and I think it makes my family and friends more comfortable too."

-Lyndsey



# Highlights

## Highlights of the Fall 2007 Gala Season

It is our pleasure to share with you these snapshots which capture your CF Center team as well as members of our hospital administration and special guests all dressed to the nines in support of the hospital and in recognition of our Center for providing "Exceptional CF Care." It was a thrill to celebrate with our Center's beloved founder, Dr. Carolyn Denning and her husband, Dr. Peter Scaglione, as well as our dear former nurse, Sister Maureen Bernius, our former IV team nurse, Mary Anne Burnes, and our very own Maria Constantinedes.

