

C. F. Spirit

Central Connecticut Cystic Fibrosis Center

Winter 2008

February 2008

Clinical/Research Coordinator's Column

I hope that this finds you healthy and coping well with the winter season. By the time you read this, it will be February, which brings the hope that Spring is not too far behind!

There is a fair bit of news to report in this issue, so be sure to read every page so that you will not miss anything important. By now, most of you know that our long time nutritionist, Connie Galluzzo-Whitney, has left the CF center. Please see Dr. Lapin's article about this. Also, Jennifer Querim, our full time nurse, has left to await the arrival of her baby and the joys of full time motherhood. We wish both of them the very best in their new adventures. Finally, as we search to replace Jennifer, we have decided that it is time to think about training someone new for the Coordinator's position. I am not going anywhere for a few years, but I will be moving full time to the Research Coordinator job, once I have trained someone for my original position.

As you all know, the CF Center has been involved in Quality Improvement Initiatives since we were part of the Learning & Leadership Collaborative II in 2003 - 2004. We have accomplished much good work in collaboration with our Patient/Family Advisory Board. Working together, we have increased the pulmonary function and nutritional status of our patients, both pediatric and adult; improved clinic flow and communication; and started our Mentoring program. Currently, there are several other projects in the works and we are always open to having any one join with us in these endeavors.

Good work does not go unrecognized, and the CF Foundation is aware of what we have accomplished. In order for other centers to see what we have done, the CFF is bringing 16 CF teams from around the country to meet with us and observe our work. This will occur on June 2nd through 4th and is a huge undertaking for all of us - CF team members, Advisory Board members, and patients who will be seen in clinic during that time. Visiting team members - doctors, nurses, nutritionists, social workers, respiratory and physical therapists, will be learning from us and observing how our clinic flows. With so many people, it will be a tightly run program for the three days, but we also are hopeful that it will be beneficial and an enjoyable time for everyone. We will be keeping you all posted as the planning for this big event unfolds.

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Research Coordinator's Column

The research effort at the Central Connecticut CF Center has been moving along very well, in both the pediatric and adult centers.

In pediatrics, we have just completed the TIGER study. This new, but as yet not completed clinical trial, looked at Denufosol, a medication that opens alternate chloride channels in the cell, thus leading to improved water in the mucus, making it thinner and less sticky. We had 6 patients who participated in the study and we are most grateful to them and to their families for their willingness and effort to volunteer their time for this yearlong study. The trial is ongoing at other CF centers and will not wrap up until October of this year. Then the data will be analyzed and if the results are beneficial, as we expect they will be, then an application will be made to the FDA for approval of this medication. That is a lengthy process, so it will be a few years before we can expect this drug to be on the market.

Our current, ongoing study is the Azithromycin study. Participants in this study are children between 6 and 19 years old, who do not have *Pseudomonas* in their sputum. They are taking the medication or a placebo for the first part of the study - about 5 $\frac{1}{2}$ months. After that, they will move into the open label phase, where they will be taking Azithromycin for the last 5 months of the study. There are currently 10 children enrolled in this clinical trial and we can enroll more.

At this time, Dr. Lapin and I are looking at other studies and hope to have more information about new opportunities by early spring. We will keep you posted as the studies become available and will contact you if you are eligible.

On the adult side, Dr. Knauft and the Hartford Hospital study team are about to begin enrolling for a study on dry-powder TOBI. This will be given with an inhaler instead of nebulized and it will greatly reduce the time needed to take TOBI. Hopefully, the results will be good and we are all looking forward to anything that reduces the amount of time it takes to do daily treatments.

For pediatric patients and families, if you are interested in participating in a study, please call me, at 545-9440, or let me know during your clinic visits. For adult patients, please contact Sandy Trifiro, RN, who is the adult study coordinator, at 545-1249.



From Dr. Lapin

2008 will go down as a truly significant year of change for the Central Connecticut CF Center. I like to think we are the center that has thrived with change. Since participating in the Cystic Fibrosis Foundation's Learning and Leadership Collaborative, we have systematically looked at how we care for you and changed our care to improve health. This has resulted in improvement in pulmonary function and nutrition. We promised we would work to deliver exceptional care to you. I invite all of you to join us the night of March 11th to hear how well we (you and we) are doing! We will hold our annual CF Center Outcomes and Research Update evening from 7 to 9 p.m. on March 11th at CCMC. In addition to the CCCFC's center report, including comparison to national statistics, we will review the CFF's pipeline of new therapies being developed. The night will start with socializing from 6 to 7, hosted by CCCFC Patient Family Advisory Board (PFAB) with a light supper and beverages.

As you all know, we will be changing our pediatric CF nutritionist. Connie has left us and none of us can think of that without emotion. Connie has been part of us for so long, has helped us all so much, that it is impossible to put into words how much she is missed. Trust me too, when I say Connie will always be a part of the CCCFC. We will remember her fantastic care; her patients and families have and will continue to benefit from her nutritional skills; and we will remember all that she has done for us. People say "change is not easy", and that is certainly true. But... we will have a new nutritionist. Someone to bring into our CF family, who will build from the amazing foundation that Connie has given us. Someone who will get to know us, care for us, and bring his or her own skills into play, helping us to grow – in weight, in height, in BMI, and as a CF Team!

What else will change in 2008? We will start to change our CF Clinical Coordinator. Don't worry, Ginny is not going anywhere, but we need her as our CF research coordinator. Simply, we cannot overstate the importance of clinical research to the changing care of CF. In the next few years, there will literally be more medicines and therapies that will need people with CF to take part in clinical research trials. What does that mean? It means without change, without people like Ginny (or Sandy, our adult CF research coordinator), without people like you, there will be potential medicines or cures for CF that will be delayed because we will not know whether they work or not. **Please** consider participating in future research trials.

Change is an opportunity, and in the next few months we will start to train a new CF Clinical Coordinator. - someone who will become dedicated to you, to beating CF, who will deliver our center's high-level of care, and who will bring their own vision, excitement, and personality to the Center.

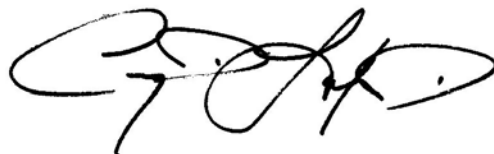
Anything else? Some of you may meet Rosi Bravo sooner or later. Rosi is our newest team member, an advanced nurse practitioner (APRN). Rosi is building her practice, and although she will not routinely be in CF clinic, Rosi helps us by expanding our ability to see sick patients. We are also actively recruiting for two pediatric pulmonologists, but unfortunately they do not grow on trees. As our new personnel join, we ask you to help train and teach them, helping them to grow as you have done for us.

From Dr. Lapin (cont''d)

Quality improvement (QI) is all about change. Changing things to be better. This year one of our initiatives is to make the transition process from the Pediatric to the Adult Program better. Our transition program is one of the first and most successful in the country. Ginny and Dr. Knauft have presented what we do and how we do it at the national CF conferences. But we know, and have heard from some of you, that things can always be made better. We realize that changing programs may be a time of uncertainty and worry. Teenagers are growing up and becoming adults. They may develop adult medical issues (not just CF ones) and also need to continue to become more responsible for their own care. These are the reasons that the CF Foundation and we support transition. The CF Center, in conjunction with the Patient Family Advisory Board, have formed a task force to look at our process of transition with "fresh eyes" from all perspectives – the teenager, the family, and the care provider – to help improve everyone's readiness for this event. This task force is open to any who wish to join; just contact Joanne or Amy, our pediatric and adult social workers. At the CF Center Outcomes and Research Update on March 11th we will give you an update, will keep you informed by posting on the website, future editions of this *CF Spirit*, and of course, in clinic.

I started with an invitation and will finish with one. The CCCFC website (<http://www.ccmckids.org/programs/cf.asp>) is up and running. There are parts of it that are still 'under construction'. So please, if it is a little rough bear with us, and check it out monthly. It will be a significant tool for us to stay in touch. It talks about who we are, what we do, and how we do it. It has downloads of the medication form (in case you want to fill it out before clinic), transition checklists, and self-help. Its information and education section has pieces on pulmonary function testing to airway clearance, x-rays to nutrition, tips for teens and much, much more. You can check out the research section to see what is being done at CCMC and Hartford Hospital, look at the Patient Family Advisory Board area to see our meeting schedules and what our task forces are currently attacking. We will have how our center is doing on major CF outcomes (like pulmonary functions, nutrition, diabetes screening to name a few). There will be links to the CFF, to Johns Hopkins CF Center, and to press releases and videos (e.g. 50 Years of Research, Progress, and Hope - a brilliant documentary video on CF). The website, like the CF Center, will be constantly changing and growing. Please feel free to send your comments and suggestions (on either the website or the CCCFC) to us at ucccfc@ccmckids.org.

Finally, I wish you all a very healthy, happy, and change-filled 2008!

A handwritten signature in black ink, appearing to be 'G. Lapin', written in a cursive style.



Central Connecticut CF Center Annual Meeting

Please be sure to mark your calendars for the upcoming CF Center Meeting. There will be an "Outcomes and News" report given by the CF team and members of the Patient-Family Advisory Board (PFAB). We will present our center specific data for 2006 and let you all know how we are doing compared to other centers. We will also share our upcoming PFAB projects with you and fill you in on the news from the NACFC meeting and the CF research world. It will be an exciting and informative evening and there will be time for food and socializing prior to the meeting. Please see below for the meeting information.

WHEN: Tuesday evening, March 11th
Light supper and social hour at 6:15 pm
Meeting from 7:00 - 9:00 pm

WHERE: Conference room F and D off the cafeteria at CCMC

WHO: Parents, friends and relatives of kids with CF
Please, no children.

Adults with CF, significant others, spouses, parents
Please do not come if you have a positive sputum culture of *B. cepacia*
Everyone will be asked to wear gloves for infection control and adults with CF will be asked to observe the "3 foot rule"

WHAT TO DO: *Please, please, please* call the CCCFC center at 860/545-9440 and let us know that you will be attending, and how many of you there will be. This is so we can plan for the right amount of food and beverages and will not have "too much" or "not enough".

We all look forward to seeing you on March 11th!!

PEER MENTOR PROGRAM

The Central Connecticut CF Center and your Patient and Family Advisory Board offer a **Peer Mentor Program** for all patients - pediatric and adult - and their families for one-to-one support during times of struggle or critical decision-making.

Whether a new CF diagnosis, first hospital admission, school or work entry, leaving the parental home, considering a G-tube placement or transplant surgery, or simply trying to fit CF care into daily life, patients and families can talk to others from our CF Center who have experienced similar challenges and events in their lives. "Peer Mentors" are professionally trained by PATH of CT (Parents Available to Help) to listen to your thoughts and feelings, without guiding or advising. Several parents and adult patients from our CF Center are trained as mentors and stand ready to provide support.

If you feel that connecting with another person living with cystic fibrosis might be helpful to you and your family, or, if you (or a family member) would like to become a Peer Mentor, contact PATH at 1-800-399-7284 or your CF Center Social Worker.

Amy Mueller, LCSW amueller@harthosp.org 860-545-4353
Joanne Stevens, LCSW jsteven@ccmckids.org 860-545-9675

PARENT SUPPORT, ANYONE?

The Patient and Family Advisory Board wants to know if parents of children with cystic fibrosis, both pediatric and adult, are interested in sharing information and support. Living with cystic fibrosis can present challenges in trying to squeeze CF care and clinic visits into days crowded by work, school, play and other responsibilities. Families can become isolated from one another which limits opportunities to draw support from each other and share solutions.

So, the Advisory Board wants your input. Would it be helpful for parents to gather on occasion? If so, how often would you like to meet - monthly, quarterly, once or twice a year? Would you want speakers at your meetings? What topics interest you? Would you want to meet on your own (hospital space could be made available) or would you prefer to have a social worker lead discussions with you? Do weeknights or weekends work best for you? Might you be able to help the Advisory Board launch some type of parent support?

Please share your thoughts and feelings with Joanne Stevens, Pediatric Social Worker, at jsteven@ccmckids.org /860-545-9675, or Kevin Burns, parent and Advisory Board member at keviniburns@sbcglobal.net. We look forward to hearing from you!

Noteworthy Updates/News

CHILD LIFE STAFF CHANGE

It is with regret that we announce that Ellen Buus, Child Life Specialist on MS6, has accepted a position as Director of Volunteer Services with The Hole in the Wall Gang Camp in northeastern Connecticut. Ellen has been expertly and compassionately serving our patients and families for the past nine years. She will be missed by all as she took a very special interest in tending to children with cystic fibrosis. We wish her the best in her new role!

Lindsay Ryder, another very competent, experienced and caring Child Life Specialist, will assume Ellen's responsibilities immediately in working closely with you and your children to ensure their physical and emotional comfort during hospital admissions. Let's all welcome Lindsay to MS6!



Book of Interest

The Power of Two: A Twin Triumph over Cystic Fibrosis written by twin sisters, Isabel Stenzel

Byrnes and Anabel Stenzel who were born in '72 is an amazing personal story of their struggles and family dynamics and finally their double lung transplants. There has been some interest in holding a book discussion for those who have read it. More information will follow in the future about setting up a date.

SCHOLARSHIPS FOR GRADUATING SENIORS AND COLLEGE STUDENTS

The Cystic Fibrosis Scholarship Foundation is for students with CF enrolling in an undergraduate college program or vocational school in the fall with scholarships of \$1,000 each awarded for tuition, books and room and board. Awards are based on a combination of financial need, academic achievement, and leadership. Applications must be postmarked by March 21, 2008 and sent to Cystic Fibrosis Scholarship Foundation, 1555 Sherman Avenue, #116, Evanston, IL 60201. For application forms, visit www.cfscholarship.org or call (847) 328-0127. (Note that this organization is not affiliated with The Cystic Fibrosis Foundation.)

CREON Family Scholarship Program is for students with CF enrolling or currently enrolled in higher education (undergraduate, graduate or vocational) in the fall with 40 scholarships of \$2,000 per year for up to four years of study. Awards are based on a combination of academic excellence, extracurricular activities, financial need, a creative presentation, and the ability to serve as a role model to others with CF. For specific application deadline (usually late June) and more information, visit www.solvaypharmaceuticals-us.com/products/cfscholarships or call (770) 578-5898.

The Elizabeth Nash Foundation Scholarship Program is for students with CF pursuing undergraduate or graduate degrees. Awards are based on demonstrated need and accomplishment (academic and other), clear academic goals and a commitment to participate in activities outside the classroom. For application, deadlines, and more information, visit www.elizabethnashfoundation.org.

The Elizabeth Lulu Scholarship Foundation is for students with CF pursuing undergraduate or graduate degrees. For application, deadlines, and more information, visit www.lizzielulu.com.

The Boomer Esiason Foundation Scholarship Program offers several award opportunities (listed below) for students with CF. For applications and more information, visit www.cfscholarships.com or call (646) 292-7930.

Scholarship of the Arts is for students furthering their education in the arts, including painting, sketching, and sculpturing. Application deadline is Friday, May 23, 2008 (postmarked).

Bonnie Strangio Education \$2500 Scholarship is for a student pursuing an undergraduate and graduate degree. Award is based on having an upbeat personality, "can-do" attitude and exemplary service to the prevention and cure of CF. Application deadline is June 13, 2008.

Exercise for Life Athletic Scholarship is for high school senior athletes seeking to pursue undergraduate degrees. Awards of \$10,000 are granted annually to one female and one male on the basis of demonstrated financial need, academic accomplishment, athletic ability in the area of running (should be jogging regularly and training for the 1.5 mile run; all candidates are judged on time), leadership, character, service to the community, and daily compliance to CF therapy. Deadline is Friday, June 27, 2008 (postmarked).

University of Phoenix Touchdown Mondays Scholarship awards 26 full-tuition scholarships for one degree program. University of Phoenix offers associate, bachelor, master, and doctorate programs. Each Monday during a NFL game, Boomer Esiason will announce a full-tuition scholarship for one of the University's popular degree programs – from business and education to health care, criminal justice and other areas of study. Application deadline is Friday, March 28, 2008. For more information on the University of Phoenix, visit www.phoenix.edu.

Boomer Esiason Foundation ("BEF") Scholarship offers awards quarterly for students pursuing undergraduate and graduate degrees. Awards are based on demonstrated need and academic accomplishment. Awards of 10-15 scholarships ranging from \$500 - \$2,000 are offered each year in March, June, September and December. Scholarships are for one year only. Application deadlines are March 15, June 15, September 15 and December 15, 2008.

SACKS FOR CF Scholarship awards \$1,000 to recipients based on scholastic ability, character, leadership potential, service to the community, and demonstrated commitment to maintaining a healthy lifestyle. Whenever a quarterback is "sacked" during the NFL season, \$1,000 is allocated to the **BEF Scholarship Grant Program**. Winners are announced on Super Bowl Sunday. *Deadline for this year was January 11, 2008, but keep in mind for next year!*

Anita Giampalmi Cystic Fibrosis Scholarship is awarded by the Resource Center for Persons with Disabilities (RCPD) at Michigan State University (MSU). The scholarship is for students currently enrolled or anticipating enrollment at MSU. For application, deadline and other information, visit www.rcpd.msu.edu/ or call (517) 355-1293.

The Angela Brooke Warner CF Scholarship is awarded annually and can be renewed for a maximum of four years for full-time undergraduate or graduate students at the University of Minnesota. Application deadline is usually late May. For more information, visit <http://ds.umn.edu/scholarships/Warner/index.html> or contact Sheila Fox-Wassink at foxwa002@umn.edu.

Page's Memorial Foundation Scholarship offers six scholarships totaling \$30,000 for students who are college-bound or currently in college. Applications are accepted between July 1 and September 20, 2008. Recipients will receive their awards at the 4th Annual Page's Run 5k on October 12, 2008 in Potomac, MD. For more information, visit www.pagesrun.com/scholarships/index.cfm or call Sharle Hussion at (301) 785-4707.

The Willard Bernbaum Scholarship helps students fund post-bachelor degree studies with a \$1,000 award towards tuition. Applicants are asked to submit a one-page letter describing both their educational program and financial need to: Robert Beall, President, Cystic Fibrosis Foundation, 6931 Arlington Road, Bethesda, MD 20814. Letters will be forwarded directly to the Bernbaum family for consideration.

For more information on financial assistance for college, vocational or graduate school, visit:

www.heath.gwu.edu (request publication entitled "Creating Options: Financial Aid for Student with Disabilities")

www.studentaid.ed.gov (request publication entitled "The Student Guide", which lists many financial resources)



Adult CF Clinic Survey Results

As most of you already know, we've been handing out and collecting surveys in Adult CF Clinic at each visit, for the purpose of getting specific feedback about how we are doing. We want to, first of all, thank everyone who has filled these out each and every time. Secondly, we are happy to report that as a direct result of this feedback we were able to do away with the need to register for clinic beyond the first visit! That was the one item on the survey where we received the lowest marks, so thank you for your honest input.

Thus far, most people have been completing the Surveys. We began distributing them in February 2007 and will continue to do so. Overall, the results have been positive; most (97.1%) respondents had either a "very good" or "good" impression of the services of the Adult Clinic, 100% said that the appropriate staff met with them during their visit, and 98.6% felt that "response to your questions and concerns by clinical staff" were "very good" or "good". 86.1% felt the length of their visit was "just right".

We have, however, been able to pinpoint areas that need improvement. Now that we've solved the problem of taking too much time to register, the next areas that receive less than "very good" marks are availability of convenient appointment time, waiting time in the reception area, and waiting time in the exam room. One or all of these may become the focus of our next "quality improvement" project as we go forward.

Finally, the Team would like to encourage you to continue to complete these surveys and please provide us with feedback about the surveys themselves. We will be revising the surveys by February or March, possibly to include questions such as timeliness of receiving calls back, responsiveness of staff to health concerns other than pulmonary issues, and communication of various test results. We rely on these surveys as guidance in order to continue to make tangible improvements. The staff can only make changes with your help! So, again, thank you.

New Vocational Assistance Tool Available

Remember those long Satisfaction Surveys we sent out last year and the year before? One of the topics people said they would like more information and assistance with was on the topic of vocational/ career planning. As a result, a Task Group was formed as part of the Patient Family Advisory Board to work on this. By the end of January 2008, this Group will wrap up, and we will have completed several "fact sheets" which will be available in Pediatric/ Adult Clinic, our website, and CF Information notebooks.

In addition, we now have a vocational tool to use to help people figure out what specific difficulties they are having with making decisions about a vocation or career. This tool, called "My Vocational Situation", is a quick, self-administered True/ False and Yes/ No list of questions that can be helpful to high school students and adults alike. The Social Worker can score it in less than a minute, and then we can identify problems in one of the following areas: 1. lack of information about jobs or training, 2. environmental or personal barriers, or 3. lack of a clear picture of goals, interests, personality, and talents. Once we have a better idea of where the problem exists, we can provide information and counseling to help resolve any difficulties.

Finally, our Peer Mentors may be helpful with this issue as well, so do not hesitate to ask us about how to connect with the PATH program. And remember that we have adults with CF and parents of children with CF serving as mentors. We are hopeful that these additions to the Center's offerings will begin to provide some assistance in this challenging decision-making process.

For more information about the "My Vocational Situation" tool or the Peer Mentor program through PATH, please contact either Joanne Stevens, LCSW (860) 545-9675 or Amy Mueller, LCSW (860) 545-4353.

Transition Task Group in Full Swing

As previously reported, our Center is in the midst of a Quality Improvement project focused on patient transition from Pediatric to Adult care. A Transition Task Group was formed as part of the Patient Family Advisory Board and a larger “focus group” was recruited to help us in creating “perfect transition”.

Thus far we have held an initial brainstorm meeting in which barriers to perfect transition were identified as well as the components of ideal transition. We are now prioritizing these items so we can choose specific problems to tackle. As anyone can imagine, the overall project is large and needs to be broken down into smaller pieces! We are very excited about all the energy and input thus far. What better group to solve the problems of transition than the people who have been, will be and are moving into Adult CF care! There are so many great ideas already, and we are very optimistic about the positive influence this will have on the project.

What follows is a copy of the Minutes from our initial brainstorm meeting. We invite anyone to email/ call either Joanne or Amy to add ideas, and we will provide updates in future issues of the Newsletter.

Jsteven@ccmckids.org
Amueller@harthosp.org

Transition Task Group – Meeting Minutes

CCMC – Conference Room E – Garden Level

Wednesday, December 5, 2007

6:00PM – 8:15PM

- **Purpose and Goal:** Quality Improvement Project –Meet between Adult and Pediatrics to envision an ideal Transition.
- **Rules:** Be courteous and respectful to members sharing thoughts and suggestions. Be truthful and honest. Do not be judgmental. Confidentiality outside of the meeting environment.
- **Assigned Meeting Roles**

Brainstorm Ideas of Perfect Transition and Barriers to Perfect Transition:

P E R F E C T	B A R R I E R S
Well-timed – Individualized	Unfamiliar faces, location and providers
Pre-educate parents	Differences on reading PFT reports
Checklist generate ideas problem solving	Different report results
Orientation to location and staff	Communication
Individualized care	Parent exclusion
Sub-specialty transition	Lack of patient choice
Parents well-educated in Adult CF	Individualized “one size fits all”
Medical Issues	approach
Expectations/Responsibilities understood by all and met	? whether transfer should be restricted @ 18 years

P E R F E C T	B A R R I E R S
Pre-appointment form concerned checklist	Inadequate support
Experienced dedicated health-care team	Complex medical picture
Joint program transition meeting	Provider bias re: family involvement and age group

Fishbone to Perfect Transition: Feedback constitutes an ideal transition. PFAB and Patient and Family Care Center would like to reach beyond the advisory board to individuals and families to partner into a smooth transition and not just provide service.

Feedback generated at this meeting will be sent to PFAB- generally to ensure confidentiality.

What's in place now for Transition: CCMC to HH at 18 years? Patient meets with alternating visits between pediatrics and adult team between ages 17-18. Task Group is looking for feedback if patient is ready at 18 years. Possibly start introducing your child into transitioning in junior high school.

Personal Objectives for Transition Goals:

- **Self Advocacy**
- **Continuity of care**
- **patient + family feels valued and respected**
- **readiness for work, college and “broad horizons”**
- **relieve/reduce parent/child anxiety**
- **provider know patient/family before age 18**
- **replicate family new diagnosis meeting @ transition**
- **disclosure of “CF” comfort levels**
- **financial/insurance readiness and education**
- **center specific care – same process across programs but with different providers**
- **no surprises**

Where do we go from here?

Teleconferencing and emailing between Quarterly Meetings. Meet 1/16/08 at 6:30pm, CCMC – Conference Room E – Garden Level

Please email ideas to: **Lisa Negro** lnegro@ctdhe.org
Diane Silliman silliman@hartford.edu
Roe VanEpps rtvanepps@cox.net

PATIENT AND FAMILY ADVISORY BOARD

MINUTES

Wednesday, January 16, 2008

6:30 – 8:15pm

Attended: Craig Lapin, Dee Rendock, Amy Mueller, Joanne Stevens, Rick Knauft, Ken Shove, Lyn Shove, Ginny Drapeau, Shannin Burns, Liz Nardi, Ruth George, Jennifer Gil, Dianne Silliman, Melanie Collins

Task Group Reports:

- A. **Transition** (DR,AM,JS,RK,KS,LS,LN,RG,DS) – The minutes for the December 5 Transition Task Force meeting were reviewed. This group brainstormed the placement of the Ideas for Perfect Transition and Barriers to Perfect Transition; as they are in the meeting minutes for the December 5 meeting. It was discussed that these ideas could be placed in categories of Patient, Care Provider, or Family. An email will be sent out to the broader group asking for their input on the categorization and then the ideas will be prioritized. There is a lot of energy from all, patients, parents and providers.
- B. **Communication With Specialty Practices** (CL,GD,SB,JG,MC) - Ideas were brainstormed for Barriers to Communication. A list will give attack points on improving the process for communication. Checklists will be generated to determine who will be responsible for communication of what is happening with the patient within the sub-specialties and the CF Center. A diary to help families and patients track their interaction with sub-specialties will be developed, the families and patients will bring these diaries to subsequent visits.
- C. **Adult Support** (AM, RV,SI) – Steve and Roe will facilitate this group on a rotating basis with the help of Amy. Permission was asked for to start an email exchange to get this group off the ground. One patient suggested a “Google Group” this would allow the patient to initiate and each participant would have a non-identifying address.
- D. **Communication With Schools** (CL,GD,SB,JG,MC,DS) – This group is planning to create a one page pamphlet for parents of children who are getting ready to start school. An example of what may be in the pamphlet; Who you speak to and what needs to be discussed. This idea will be expanded to create pamphlets for middle school and high school also.
- E. **Parent Support** (JS,KB) – An article has been drafted to put into the CF Spirit about how support is presented to parents; Do you need support? How do you get that support? How often would you like support?

Updates:

- A. **Web Design** – The website is ongoing in its development. A research page is in the process but not in place at this time. There have been some pictures submitted for the website but not many. Anyone wishing to submit a photo or photos can send them to Joanne Stevens (jsteven@ccmckids.org). Advisory Board meeting minutes are on the website as well as biographical information about the providers.
- B. **Peer Mentoring Program Use** – Referrals have been made and PATH will be contacted to get feedback on the use of their program. Mentors from the CF center are also members of the PATH program. The CF Spirit will have an “ad” about the program and how to access it.
- C. **Patient and Family Education Night** – There will be an education night at the end of March, however, the date has not been decided yet. On the agenda for this event will be the national conference, center outcomes and measures, and a social time for parents most likely at the beginning of the night.
- D. **LLC VI Site visit** – 96 people will be coming to our center to take part in the Learning and Leadership Collaborative June 2 – 4. These people will be here to observe and learn about the center and how it runs. There will be an Advisory Board meeting at a nearby hotel on June 3 with this group in attendance to see how our center runs the program.
- E. **Adult Advisory Board** – Equipment has been purchased to have teleconferences to hold these meetings. As soon as the equipment is in a meeting will be scheduled.
- F. **Social Event** – This event will have a ‘sports’ theme for families of patients with CF. A source of funding has been identified so “brainstorming” has begun on where and when to hold the event.
- G. **Agenda changes for February meeting** –
- Introductions
 - Task Groups at the beginning of the meeting
 - Updates - Book Club (Power of Two) Maggie Peterson
No website or Peer Mentoring updates

*Please note that our next few Patient and Family Advisory Board Meetings will be held on Wednesday, February 20, March 19 and April 16, 2008 from 6:30-8:15 pm.
Please join us if you can.*



Golfing Event

The 3rd annual Patrick Charles Burns golf event will happen on July 26, 2008 - all proceeds from the event are sent to the Cystic Fibrosis Foundation of Connecticut.

My son, Patrick, was born 21 months ago with Cystic Fibrosis. My wife, Shannin, and I, with the help of family and friends, are determined to be as active as we can be in beating this disease. To that end, we started an annual fundraising event in 2006 in Patrick's honor. I have recently published a newsletter that summarizes last year's event and looks forward to this year. What started out as an idea to get close family and friends together each year has turned into quite an event. We have raised over \$20,000 in Patrick's name to date - this year's goal is \$13,500.

The day starts with 18 holes of golf at Veteran's Golf Course in Springfield, MA. Last year we had 108 golfers - this year we hope to get 120 players. The golf is followed by a party at our house in Somers, CT. Any questions can be sent to Kevin Burns at keviniburns@sbcglobal.net - our home phone is (860) 265-2329. Everyone is welcome and we are looking to expand the fundraising this year with corporate sponsorships and donations to the event.

Mark your calendars!



GUESS WHO



I was born in Hartford, CT, and am quite happily, the youngest member of the CF team (except for the patients). I grew up in Somers, CT. In high school, I traveled across the United States competing in various vocal competitions (I'm a soprano) and performing with different choirs/recording artists. With the exception of a traumatic semester in France, all my education occurred at the distant location of the University of Connecticut. One of my majors was piano-and even though it's now overplayed, my favorite piece may still be Debussy's *Clair de la lune*. My interest in CF started very young when I saw the original airing of the movie, "Alex the Life of a Child" and continued while I did CF research with Dr. Michelle Cloutier. Please note, I would not recommend this film to other 11 year old children. Waiting for me at home every night, is my adoring spouse, 2 cats, Kitty and Lucifer, and 2 dogs Mia, a Bernese Mountain Dog, and Zeus, a wonderful mutt. In my free time (ha!), I enjoy taking care of my perennial gardens, watching old movies, going shopping and cooking meals for my extended family. Sometimes, if I have enough energy left, I will still sit down and play the piano-a far cry from the old concert hall though. In the future, I look forward to having children, horses and a grand piano (in no specific order).



Dear Friend,

We are pleased to announce that we have launched a **new online version of the CF Foundation's newsletter, *Commitment!*** It features the same great articles as our print publication in an easily accessible electronic format.

[Click here to view the most recent issue of Commitment online.](#)

The Fall 2007 issue features:

- key developments in cystic fibrosis research
- the top 10 reasons to participate in a CF clinical trial
- the latest news about volunteers working hard to raise critical funds
- the Foundation's advocacy efforts...and more!

To be notified when future issues are posted, please [register on our Web site](#) or [update your profile](#), and be sure to include "e-Newsletter" as one of your interests.

To help increase awareness of *Commitment* and the important work we do, please feel free to **forward this message.**

We would be interested in hearing **what you think** of *Commitment* online! You can contact us at commitment@cff.org.

Thank you for your commitment to our lifesaving mission. Together, we are adding *tomorrows* every day to the lives of those with CF.

Sincerely,

Cystic Fibrosis Foundation
6931 Arlington Road
Bethesda, MD 20814
(800) FIGHT CF
E-mail: commitment@cff.org
Web: www.cff.org
[Find your local chapter](#)

P.S. Remember—to be notified about future issues, please [register](#) or [update your profile](#).



2008 CALENDAR OF EVENTS

May 3 rd (Sat)	20th Annual Great Strides Walk-a-Thon , Manchester, Westport & Madison, CT
May 4 th (Sun)	20th Annual Great Strides Walk-a-Thon , Derby, CT
May (date TBD)	7th Annual Greenwich Marathon Golf , Tamarack Country Club, Greenwich, CT (Diana Siebold)
May 17 th (Sat)	20th Annual Great Strides Walk-a-Thon , Enfield, Avon & Torrington, CT
May 18 th (Sun)	20th Annual Great Strides Walk-a-Thon , Wethersfield, West Haven, Danbury, Granby, New London/Mystic & Watertown, CT
June (date TBD)	Expanding The Circle for Life , Ridgefield, CT (Diana Siebold)
June 30 th (Mon)	20th Annual Gillette Fusion Golf , Wethersfield County Club, Wethersfield, CT (Tracy Wu)
July (date TBD)	32nd Annual Cystic Fibrosis Golf Classic , Richter Park, Danbury, CT (Cassandra Davis)
July 26 th (Sat)	“65 Roses – The Summer Soirée,” DiNicola Residence, Guilford, CT (Diana Siebold)
August 23 rd (Sat)	Summer Roses III , Britnell Residence, Glastonbury, CT (Tracy Wu)
Sept (date TBD)	Nell’s Golf Challenge, TPC River Highlands , Cromwell, CT (Paul Drury)
Sept (date TBD)	9th Annual Comedy Night , Southbury, CT (Tracy Wu)
October (date TBD)	21st Annual Cystic Fibrosis Foundation Bike Tour , Sherwood Island State Park, Westport, CT (Diana Siebold)
October 3 rd (Fri)	Stand Up For a Cure , Marco Polo, East Hartford, CT (Cassandra Davis)
Nov (date TBD)	Jeans Gala (name and location TBD) (Cassandra Davis)
Nov (date TBD)	Sportscasters’ Super Ball , Rentschler Field, East Hartford, CT (Paul Drury)
Dec (date TBD)	Annual Meeting

Thank you for your support!

CONNECTICUT CHAPTER, 185 Silas Deane Highway, Wethersfield, CT 06109
 PHONE: (860) 257-6907 FAX: (860) 257-6903 Toll Free: 1-800-841-2828
 E-mail: conn@cff.org Chapter Website: <http://www.cff.org/chapters/connecticut>
 National Website: <http://www.cff.org/>

Please note: 2007 Event Calendar is subject to change

Central Connecticut Cystic Fibrosis Center
Connecticut Children's Medical Center
282 Washington Street
Hartford, CT 06106