

Inspire

Fall/Winter 2010

Exercise in Cystic Fibrosis

Dr. Rob Horowitz

We Need You!

Tuesday, 12/20 and Thursday,
12/22, 9am to 2pm:

LL Bean at Eastview Mall is allowing area non-profits to come to their store and provide FREE gift wrapping to their shoppers. Cystic Fibrosis Family Connection (CFFC) has been one of the lucky groups that was chosen. We will wrap gifts for FREE, and will have a donation jar for donations to CFFC. Stop in at LL Bean, do your shopping and come to the wrapping table to meet members of CFFC and make a donation.

Inside this issue:

NACFC update	2
Your Stories: Lizzie Hart, Eric Wright, Joanne Schum, Chris Kvam	2-4
New Faces at URMIC: Pat Lamarche, Nancy Jenks	
RT, RD, SW news	5
Nurses Nook and Research Corner	6
Recipes	7

Elsewhere in this newsletter, you'll read about Chris, a remarkable athlete whose comprehensive CF treatment regimen is centered on exercise. His experience is a dramatic example of the power of exercise in managing this complicated disease. And he is not alone: there are myriad others with CF, both in Rochester and around the world, who have recognized the power of exercise in their self-care regimen. Perhaps the most frequent example of this is the realization in many young adults who were exceptionally healthy during their high school athletic career, but upon graduation, when routine exercise ended, experienced a significant and upsetting decline in lung function. Certainly, this drop-off is multifactorial, but time after time, these folks recover "lost" lung function when they resume a regular exercise regimen. Similarly, many new exercisers with CF discover lung function and vigor they presumed was lost forever. What is the effect of exercise in CF lung disease?

The goal of routine lung treatments in CF is to reduce or eradicate the malfunctions caused by the CF protein mutation, and which lead to chronic, progressive deterioration: dehydrated, thick and sticky airway secretions; chronic lung infection; intense lung inflammation. These result in damaged lung tissue, and consequently, decreased functional lung volume. Wonderfully, we have medications and physical treatments that address these problems, including hypertonic saline, DNase, antibiotics, and airway clearance techniques. And even as thousands of researchers worldwide are investigating additional medical means of addressing each of these components of CF lung disease, exercise looms large as a readily available treatment, which, among its multiple benefits, appears to accomplish precisely these goals. Just last month in Baltimore, a panel of experts revealed these exciting findings:

HYDRATION OF AIRWAY SURFACE LIQUID: German physician-researcher, Helge Hebestreit, revealed compelling data suggesting that vigorous exercise actually hydrates the airway surface liquid in people with CF. This effect may be related to the stimulation of other ion channels in the lung that compensate for dysfunction CF ion channels, a result which may be similar to the impact of hypertonic saline, or such emerging therapies as denufosal.

ANTI-INFLAMMATORY EFFECT: California physician-researcher, Dan Cooper, reviewed the extensive body of research which implies the anti-inflammatory effects of exercise. It has long been known that each bout of vigorous exercise is briefly pro-inflammatory: it causes the body to release multiple inflammatory chemicals, almost as if it were preparing for attack. However, this effect is temporary (hours), and with repeated exposure to the exercise, the body appears to develop a sort of tolerance to this exercise-induced effect, such that the lungs may—note, this is speculative—actually develop more robust anti-inflammatory defenses.

LUNG FUNCTION: Exercise imposes demands on the muscles and heart and lungs. Unlike the muscles and the heart, the lungs do not have the luxury of growing bigger or stronger with exercise; scarred lung is not repairable. However, vigorous exercise demands use of portions of healthy lungs—this is called, "recruitment"—that otherwise are unused. What does this mean over time? The concept of exercise-induced lung recruitment is an example of the "use it, or lose it" phenomenon: regular exercise trains the body to utilize and retain its fullest potential. In a sense, lungs that are asked to do more, in fact can do more. Multiple studies unveiled in Baltimore last month demonstrate this effect:

A 7-year observational study in Toronto of 212 people with CF reveals a strong correlation between increasing activity and slowing decline in lung function.

A 12-week exercise training regimen in 17 British adults with CF yielded increased FEV1 (by 10%), strength (by 20-25%), and self-confidence.

A 2-month exercise training program in 58 Baltimore children with CF showed improvement in exercise capacity, and, among those with the most improvement, lung function also improved.

Exercise in CF

continued from page 1

Now you can understand why Dr. Frank Cerny, renowned Buffalo exercise physiologist and CF expert, says: “The drug companies are trying to produce medications that mimic the benefits of exercise!” In addition, exercise counts as airway clearance, because the alteration in air flow speed and volume in exercise mimics such powerful airway clearance techniques as autogenic drainage. Exercise also enhances mood and self-concept. Many people are pleased that this powerful CF treatment is unlike any other in CF: free of tubing and equipment and preparation or ingestion of medication. While medical treatments often remind people of their disease, exercise can be refreshing reminder of one’s health. Indeed, with exercise many people feel more in control of their lives, truly liberated.

Do you need to be a competitive triathlete to achieve these effects? Absolutely, positively no! We don’t know precisely how much exercise is optimal, but it is clear that some exercise is better than none, and excellent benefits can be achieved with a moderate amount of exercise, for example 30 minutes four to five days weekly. A reasonable goal is to select a pleasurable activity—vigorous walking, running, bicycling, swimming, yoga, aerobics, a racquet sport, among others—and start with 15 minutes three days weekly, gradually increasing duration and frequency.

What makes exercise vigorous enough? While daily activities like housework and walking on-the-job and gardening are worthwhile, the most beneficial exercise for lung health must be strenuous enough to elevate the heart rate and breathing effort, such that one feels challenged, but not exhausted. There are more precise means of measuring exertion, including heart rate monitoring, which can be wonderfully helpful guides. Talk with your CF team about your particular situation and identify reasonable goals and a suitable exercise regimen. You may wish to use the expertise of a physical therapist or exercise specialist to assist you.

So right here, right now, available to you is exercise, a powerful treatment that can bolster your lung health, and your general well-being in multiple ways. Remarkably, the benefits of exercise in all people, including those with CF, have been known for decades, and the evidence continues to mount. Unfortunately, rather than being a standard part of the treatment regimen, this powerful treatment is easily hidden behind the tradition and allure of medical treatments. But the two are complementary. Let’s together embrace this potent CF treatment!



NACFC Conference Update Drs. Clement Ren and Karen Voter

Every year we look forward to the North American Cystic Fibrosis Conference. This year the conference took place in October, in Baltimore, MD. We were fortunate to send many members of the team, to learn some of the new treatments and approaches to care that are on the horizon. Some of the new approaches we can use immediately, others will take more time to be able to use. You may see differences in infection control practices with providers more likely to wear gowns or gloves in some situations. We will probably change the way we look for diabetes in some patients as well.

One of the areas of research that is the most exciting is the possibility of medications to correct the underlying problem in CF. These medications could allow the CF transmembrane regulator (CFTR) protein to work more like it does in people without CF. These medications are still being studied, but are likely to be available within 2-3 years. Improvement in CF continues to rely on participation in research studies. There may be studies that you or your child can be involved in. During clinic visits, some of the members of the research part of our team may let you know about studies you could participate in. You should feel free to ask about research if you are interested.



Your Story: Lizzie Hart

Hi, my name is Lizzie Hart and I am 14 years old. I have Cystic Fibrosis which makes gaining weight hard, since I don’t absorb all the calories I need. Since I was in elementary school, I have struggled to gain weight. At my thinnest, I was in third percentile for weight! I got tired of going back to the CF Clinic month after month with no weight gain. So, I decided to really concentrate on finally gaining weight. I took some advice from my nutritionist and I began to follow my mom’s strict rules (see right). I began to gain weight right away once I committed to the plan.

Lizzie’s “No Pain Gain” Plan

- *Eat breakfast within one hour of getting up**
- *Eat everything on your plate or in your lunch box**
- *No candy before meals ONLY after.**
- *Drink milk with meals**
- *Make Scandishakes with whole milk and 2 scoop chocolate ice cream – have one with breakfast and one at bedtime**
- *DON’T SKIP ENZYMES!!!**

Within three months, I had gained six pounds. In the following six months, I gained an additional seven pounds. I outgrew all my clothes and got to buy all new ones!

This past summer, I got an iPhone app called “My Net Diary” that lets me track my calorie intake. It also lets me set a goal for weight gain and tells me how many calories a day I need to eat to reach the goal.

I am now in the 21st percentile for weight, and the 47th percentile for height. Last September, I was 76 pounds. This September, I weigh 95 pounds!



Your Story: Eric Wright

After receiving a double lung transplant in November of 2006 at University of Pittsburgh Medical Center, Pittsburgh, Pennsylvania, from Cystic Fibrosis, Eric Wright has waited to participate at the Transplant Games. The Transplant Games is held every two years and is run by the National Kidney Foundation, with several major sponsors and supporters for the event. This year the event was held in Madison, Wisconsin. Teams from every state participated. The athletes who participate in the events are transplant recipients. The event has fostered more opportunity for living donors to participate in activities, as well as Donor Families.

Team Upstate New York from Rochester fielded 12 athletes and was accompanied by supporters, ranging from family members, local area organ procurement professionals who are involved in transplantation, the Kidney Foundation, and most importantly a Donor Family. The games feature a variety of sporting events that mimic traditional Olympics; Track and Field, Swimming, Golf, and Bowling; including a new event Ballroom Dancing.

"The experience was very moving when we entered the Stadium at opening day ceremonies", says Eric. "There were over 5,000 people in attendance all celebrating life, the sacrifices made by living donors, and the ultimate

sacrifice made by the Donor Families." "When the Donor Families paraded in, the place erupted for 15 minutes, it was incredible; not a dry eye in the place." "I never experienced anything like it before in my life" says Eric.

As a first time participant, Eric played racquetball and tennis. Eric took the Gold medal in racquetball in age bracket 40-49. He got knocked out first round handily in tennis by the #1 seed. "Overall, I enjoyed the experience and camaraderie with our team" says Eric. "Looking forward to going again in 2012."

2010 NKF U.S. Transplant Games

Madison, WI July 30 - August 4, 2010

For more information about the Transplant Games visit

<http://www.kidney.org/transplantation/athletics/index.cfm>

To learn more about organ donation visit:

<http://www.rehpb.org/Page.asp?Script=1>

Your Story: Joanne Schum

With happy news I want to announce that I am now post bilateral lung transplant of 13 years, and I was fortunate to attend my 4th Transplant Games in the summer of 2010.

At the age of 33, I received my lungs at the University of North Carolina Hospitals, Chapel Hill, on September 12, 1997. It has been a joyous "journey".

Like the 2008 Transplant Games – I once again broke a bone before the games. 2008 I broke a shoulder, which meant that I could not attend the games. 2010, I broke my right arm, but... I refused to stay behind. My sister and I traveled to Madison, Wisconsin to enjoy the excitement, the people both recipients and donor families. My sister said after the first day in Madison, "I am exhausted. You recipients do not stop for a minute. Let's rest." My sister is a 5-10 mile walker, per day!!

This time I was able to cheer on our Upstate New York Team members in their sports, and cheer on all the recipients as they made great strides in finishing their competitions. One woman fell to the ground on the track, but refused

to stop and she hobbled with help of two emergency crew members, and crossed the finish line.

As Eric Wright mentioned, the opening ceremonies are something you will not experience anywhere else. 3,000 organ recipients of all kinds; basically people who would have been dead if not for living donation and those who take the step of being an organ donor filed into the stadium. Then 1,500 family members of organ donors paraded into the stadium. These family, friends are highly honored as they were part of organ donation, so that a total stranger in most cases, could live! Tears, goose bumps, are the norm at this time. Most are in awe of this group and an overload of emotions hits you hard.

This year, we "lungs" had the wonderful experience of watching and hearing, Isa Stenzel a young woman with CF, who had a lung transplant, play the national anthem on the BAGPIPES!!!! Bagpipes are not easy for anyone. When they announced what organ transplant she had....the crowd roared, applauded and were stunned at her ability. Leave it to a Cystic Fibrosis lung transplant recipient to manage

such a feat.

Again this year I organized the "Lung Gathering" which I have been doing since the 2000 games. What a great group. This was the most well attended one to date, about 75 people. We have social time to talk and share stories with the whole group, ask questions of others, admire medals that have been awarded (I will mention that the lung recipients are becoming more prevalent in winning their sports!!) We also sign a huge banner, and take many pictures. This year there was a film crew on hand, as Isa and Ana Stenzel, known as the "Stenzel Twins", both have CF and both had lung transplants had their film crew following them for a documentary they are making, called "Power of Two".

In 2012 I will be attending the games again. Lung Gathering again, and hopefully play some sports. I am aiming to do the long jump, 1/4 mile run, 5k run, and ballroom dancing!! My sister Dolores let me know she is most definitely attending again with me in 2012. She said we are exhausting people, but she was too moved by the people and stories not to be there again.



Your Stories: Chris Kvam

My name is Chris Kvam, I am 30 years old, and happen to have Cystic Fibrosis. I also happen to be a serious cyclist, and have made physical exercise the keystone of maintaining my lung function and general health.

When I was diagnosed in the early 1980's, there were no CF specific treatments, other than pancreatic enzymes. Faced with the scary diagnosis of CF, and the instruction to "treat him like a normal kid" my parents enrolled me in a variety of sports – tee ball, soccer, swimming lessons, even ice skating. I started cross-country skiing when I started walking, and spent countless hours outdoors in every season. As CF treatments became available, they were incorporated into my busy days.

I started running cross-country and track after being cut from my high school's soccer team. I was one of the slowest kids on the team, but stuck with it. From the start I was driven to compete with myself, and to make the most out of what little talent I had. I improved year after year, and by my senior year was fast enough to make the team at a Division III college. Running in high school and college taught me the importance of setting short and long term goals that necessitate adherence to my demanding medication and physical therapy routine. As an adolescent I was not focused on abstract ideas like living to X age, or being active at 30, but obsessed over running a personal best each Saturday. I knew that doing all my treatments would help me run faster, so I did them.

As my four years at SUNY Geneseo drew to a close, I realized that there was more to life than running. I had goals and desires that extended beyond the track, and

was driven to achieve them. As with running, fulfilling my potential academically and professionally required the same adherence to treatment that had enabled my running success. I earned a Masters degree in Public Policy from the George Washington University, and began to work full time in public policy research. Today, I am back in school as a third year law student at SUNY Buffalo. I am also happily married, which has added a dimension to my motivation for good self-care. It is no longer all about me, and the importance of maintaining my health goes far beyond maximizing athletic ability.

Scheduling events is a big part of my athletic goal setting, and how I motivate myself to train. If I name the event, pay the registration fee, and tell my friends and family that I'm going to do it, I'm much more likely to follow through. In the past few years, I've completed events including the Patriot Half-Ironman Triathlon, the Lake Placid Kort-Loppet, the Seacoast Safari cycling event for Cystic Fibrosis, and the GearUp4CF ride across the Canadian Rockies. Participating in these events gives me the opportunity to celebrate another year of hard work taking care of myself, relishing the continued ability to do the activities I love. I don't ride because I have CF, I ride because I can.

This past summer I completed two more significant bike rides. I had the opportunity to travel to the French Pyrenees to enjoy five days of cycling, including summiting the Col du Tourmalet, the highest pass in the Pyrenees, and a route rich in Tour de France history. In early September, I completed the 2010 Highlander Bike Tour "Death Before Dismount" ride through the Finger Lakes, a 128 mile route with over 10,000 feet of vertical gain. To

prepare for these rides, I rode my bike an average of 250 miles a week from April – August. I lift weights 3 days a week, and adjust my training to the seasons – I run more in the Fall and Spring, and do as much cross country skiing as I can in the Winter. I am also a part of TeamCF.org, a cycling team founded to promote exercise and cycling as a critical component of CF care.

I encourage everyone with CF to speak to your CF care team and give meaningful thought to incorporating an exercise routine into your daily life. Exercise isn't another drug or another hour tied to a hose – it is welcome break from the rest of our demanding treatment regimen. Be it walking, biking, running, or swimming, aerobic exercise has the potential to help us maximize whatever level of lung function we are capable of; to the benefit of everything else we want to do. For those with mild or moderate lung disease, it is important to recognize the difference between the difficulties in beginning an exercise routine that arise from simply being unconditioned versus those caused by lung involvement. Exercise is hard for everyone if you're not in shape. It takes work and dedication – don't let having CF be your excuse not to start, or reason to stop.



New Faces: Pat Lamarche, CPNP, and Nancy Jenks



As of 2009, the Cystic Fibrosis Foundation reported that there are an estimated 177 nurse practitioners and 12 physician assistants actively engaged in CF care in US centers. In August 2010, the CF Center at the Golisano Children's Hospital at Strong welcomed another pediatric nurse practitioner to the CF team. Pat Lamarche, CPNP has been a pediatric nurse with the Children's Hospital her entire nursing career. She spent many years in various nursing roles within the Neonatal Intensive Care Unit including being a staff nurse, nurse leader and clinical nurse specialist. While working as a nurse practitioner in the Division of Pediatric Hematology/Oncology, she developed an interest in working with children and families living with chronic illnesses.

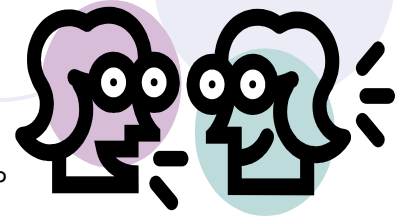
We also welcome Nancy Jenks who joined our research team in November. She will be working closely with Mary Platt on current and future research studies.

RT Talk

Help us help you!

Believe it or not, all of us here at the CF center understand that it's probably not possible to do every single treatment we ask you to do, every single day! When we ask you about your daily treatments, please be honest with us (and with yourself!) about which therapies are particularly challenging to get done. Often we can come up with strategies to help you complete the treatments, or in some cases provide alternate choices so you can work around difficult times. There are lots of methods of airway clearance and in some cases medications can be changed to something that's easier for your lifestyle. If you can't remember how a particular piece of equipment or therapy is supposed to work...ASK!... Kim and Donna **LOVE** to talk and educate our patients on the best therapies for their busy lives! We understand that we give a lot of information in each clinic visit and sometimes there are other distractions to keep you from absorbing it all. We have available a Respiratory Therapy 'Plan of Care' that we hope most of you have received over the last couple of years. The plan of care spells out all of your treatments, the proper order of therapy, cleaning and contact information. So if you don't have one and would like one, let us know, we would be happy to give you all the support we can!

So, please ask during clinic or give us a call and 'Help us help you!'



Nutrition Notes

Navigating the enzyme world has not been easy lately. Several years ago the FDA decided to regulate pancreatic enzymes to ensure that each capsule contained what it claimed to contain and work the way it claimed to work. This is a good thing but has caused some confusion and many have had to switch from their usual trusted brand to something new. Currently the only FDA approved enzymes available are Creon, Zenpep and Pancreaze. Approval is still pending for Ultrase and Pancrecarb.

Patient assistance programs for the available enzymes have also changed recently. Here's the gist:



Zenpep: Eligible patients may receive up to \$50 co-pay reimbursement for 12 months. Enrollment in Z Points program earns 100 points for each 1 month Zenpep refill. Points may be redeemed for SourceCF vitamins, a Pari LC Plus Nebulizer, a Pari LC Star Nebulizer, Pari Vortex Holding Chamber, Pari Masks (adult and children's), Nutra/Balance Protein Fortified Cookies (260cal each and very tasty!), Nutra /Balance 8 oz milk shake (400cal each and also very tasty!), a \$50 Amazon.com gift card.

Creon: Eligible patients may receive up to \$50 co-pay reimbursement for 12 months. Patients may also receive a free case of PediaSure, Ensure, Ensure Plus or Enlive Juice, as well as free SourceCF, AquADEK or Vitamax vitamins with each 1 month Creon refill.

Pancreaze does not offer these types of programs. All companies do offer free enzymes for those without insurance. Please call Melissa Berry, RD at 275-1457 if you have questions about these programs.

Social Work Bites

Caring for yourself while treating Cystic Fibrosis can be a daunting task. Many without the disease do not understand the financial stress from all the medications, hospital admissions and treatments that have to be performed. The Cystic Fibrosis Foundation estimated that the 1996 average annual cost of CF care was \$45,000 (S.C. Fitzsimmons, unpublished data). This data is over 10 years old so imagine the current average cost! But there is help available through various patient assistance programs. While many programs help only those *without* health insurance, there are some that realize that even those *with* insurance still need assistance and can help with co-pays.

One such program that helps adults in particular is the NYSDOH Adult Cystic Fibrosis Assistance program (ACFAP). The ACFAP fills the medical care reimbursement gap that has prevented many people with CF from reaching their maximum employment and life potential.

If you need help with co-pays or have any other questions please contact your Cystic Fibrosis Social Worker. Tiffany Passalacqua, Social Worker, Adult CF Center at Culver Medical Group 654-5432 ext. 1050
Christine Stokes, Social Worker, Adult CF Center at Culver Medical Group 654-5432 ext. 105
Marcy Odell, Social Worker, Pediatric CF Center at URM 275-9105

To learn more about ACFAP go to:

www.nyhealth.gov/diseases/cystic_fibrosis/docs/acfap_facts.pdf

And to apply:

www.nyhealth.gov/forms/doh-4390.pdf

Nurses Nook



The 2010 – 2011 Influenza Season

It is the time of year again to start thinking about the upcoming cold and flu season! Last year was unique because of the H1N1 influenza outbreak in early fall and the addition of a H1N1 influenza vaccine to the immunization schedule. You may recall that children under 9 years of age required 2 doses of the H1N1 vaccine in addition to the seasonal influenza vaccine (a.k.a. the regular flu shot) and therefore, some children received up to three or four injections. Because last year was unique, we are going to provide a brief update on influenza vaccine guidelines for this season:

Who should get the flu vaccine this season?

*The Center for Disease Control (the CDC) recommends that **all people age 6 months and older should be vaccinated**. This is a new and all inclusive recommendation for this season with the goal of protecting as many people as possible in the United States against the flu.

What does this year's flu vaccine protect against?

*The flu vaccine is updated each season based on research with three flu viruses that are likely to cause the most illness. Only one flu vaccine is being made this year and includes protection against the 2009 H1N1 virus (the virus associated with the outbreak last season) as well as two other influenza viruses (an influenza B virus and an H3N2 virus).

How many flu vaccines will you need to get this season?

*For all individuals age 9 years or older: one vaccine

*For children aged 6 months through 8 years of age who have never received the seasonal flu shot before (this includes children who received one or two doses of the 2009 H1N1 flu vaccine): two doses (spaced at least 4 weeks apart)

*For children aged 6 months through 8 years of age who received only one dose in their first year of vaccination (this may have happened due to age during the influenza season): two doses this season (spaced at least 4 weeks apart)

Points to remember:

*All patients with cystic fibrosis should receive the inactivated form of the virus (i.e. the flu shot) and **not** the live virus (i.e. the nasal spray)

*All patients are eligible to receive the influenza vaccine in our clinic assuming they do not have an allergy to egg and have tolerated the influenza vaccine in previous seasons without difficulty - this will be given as part of a regularly scheduled appointment. **The CF Center will not be offering "flu-shot only" clinics this year.**

As always, please call our office with any questions or discuss your concerns with your provider during a clinic visit.

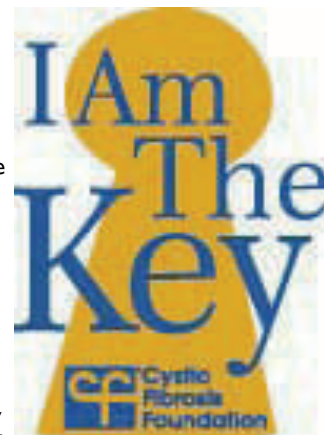
Happy hand washing and here's to a healthy fall and winter!

Research Corner

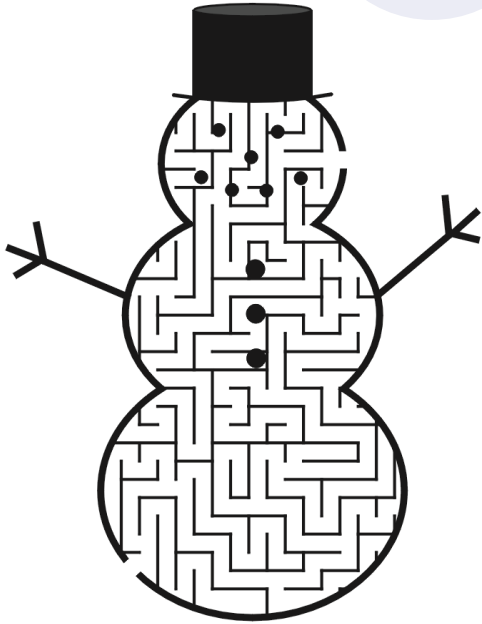
After being fortunate enough to attend the North American Cystic Fibrosis Conference in Baltimore this year, I could not help but be amazed at the many advances in CF that have been made over a relatively small amount of time. It was also hard not to think of all of the people with CF and their families who helped make most of these advancements possible by participating in clinical trials.

Your CF Center is a member of the Therapeutic Development Network. The Therapeutics Development Network (TDN) is a nationwide network of nearly 80 cystic fibrosis clinical research centers. These centers specialize in conducting clinical trials to evaluate the safety and effectiveness of new CF therapies. The TDN centers work together to promote quality, safety and efficiency in CF clinical trials by centralizing and standardizing the research process.

The CF Foundation at CFF.org, is a terrific resource for you and also has a lot of information about CF research, the Research Pipeline, and a clinical trial search tool. We are currently enrolling into the iCARE study with the goal of helping to improve medication adherence in our teen population and into the Vertex 809 trial in Spring 2011. We are also continuing the EPIC Observational Trial to study pseudomonas acquisition, and the Twin Sib Study which studies the relationship of CF in twins and siblings with CF. We are also finishing the ISIS clinical trial to study hypertonic saline and isotonic saline with our very young population. As always, we continue to consent our newly diagnosed patients' families, so that we may continue to input data into the CF Registry. Please call Mary Platt RN at 276-4123 if you have any questions about clinical trials. Many, many, thanks to all those who have been participating in CF clinical trials. You are the key!



Fun Page!!

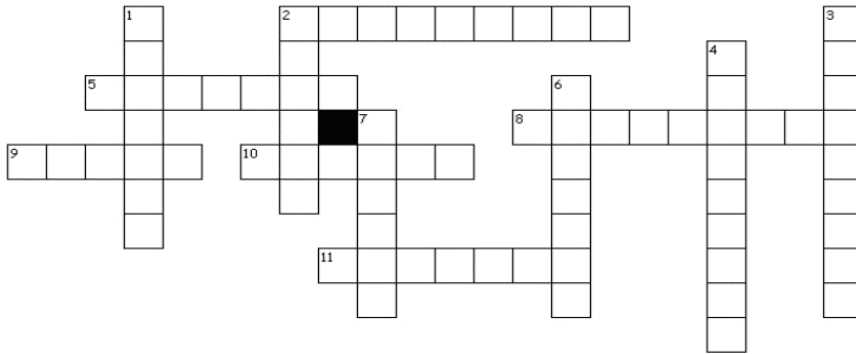


Winter Word Search



m h s l e d c s
 w a q j l l o n
 i t d n x w l o
 n b o o t s d w
 t m i t t e n s
 e c o a t g y o
 r s z s c a r f
 w k k i c e j m

Winter Crossword



boots mittens
 coat scarf
 cold sled
 hat snow
 ice winter

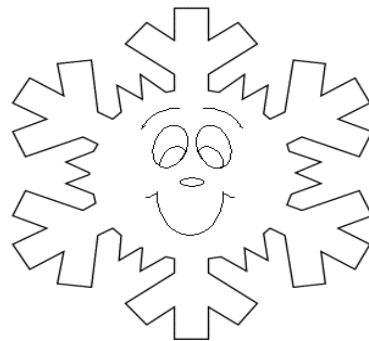
©1998 The Kid's Domain
 www.kidsdomain.com
 free for non-profit use

Across

- 2. no two are alike
- 5. tuxedo with feathers
- 8. light a fire here to keep warm on chilly days
- 9. winter's favorite color
- 10. twelve sticks and one puck
- 11. frosty fellow with a carrot nose

Down

- 1. grandma will knit you one to keep you warm
- 2. winter vehicle for off road travel
- 3. some animals do this all winter
- 4. white teddy
- 6. covers for cozy hands
- 7. strap two sticks on your feet and swoosh down a hill



 * "Prescription" for a cold winter day: *
 * * * * *
 * 8 oz whole milk (150cal) *
 * 1/3 cup Carnation Instant Breakfast *
 * powder (130 cal) *
 * 2 Tbsp heavy cream (104 cal) *
 * 2 Tbsp French Vanilla Coffee Cream *
 * (90 cal) *
 * * * * *
 * *Mix all ingredients well and micro-* *
 * *wave for 1-2 minutes. Add whipped* *
 * *topping for more fun! Can also be* *
 * *enjoyed cold.* *
 * * * * *



University of Rochester
Medical Center
Cystic Fibrosis Center

601 Elmwood Ave
Box 667
Rochester, NY 14642

Pediatric Phone: 585-275-2464

Pediatric Fax: 585-2758706

Adult Phone: 585-654-5432

WWW.URMC.ROCHESTER.EDU/
CHILDRENS-HOSPITAL/
PULMONOLOGY/CYSTIC-FIBROSIS



Save the Date!

The next Family Advisory Board Meeting will be *Wednesday, January 12, 2011, at 6pm*. Location to be determined. Please contact Marcy Odell at 275-9105 for more information.

The 31st Annual Kit Taylor Memorial Lecture is scheduled for *Tuesday, April 12, 2011*. Look for an invitation in your mailbox.



Get involved with CFFC!

Come join the newly re-formed Cystic Fibrosis Family Connection! CFFC was formed to help make life a little easier for CF patients and their families. We raise money to help pay for parking for both clinic and hospital visits, provide valuable coupons for area eateries and help those needing a phone or TV service while in patient. We also hope to restock the "Toy Closet" so our little ones can play with and take home a new toy after an inpatient stay. Become a member and help raise the awareness of CF by offering your resources you have in the community to raise more money for this very important benefit for our CF community. Members have a varied background in relation to CF. Are you a Mom or Dad of a child or adult who has CF? You can join CFFC. Are you a medical professional? You can join CFFC. Are you an adult with CF? You can join CFFC. We need everyone's input and help to make the lives of our area's CF'ers, more happy and fun filled. Please contact the following members if you would like to join CFFC or just learn more:

Lauren White at laurenwhite072807@yahoo.com

Joanne Schum at twoluckylungs@juno.com