University of Rochester Medical Center
Cystic Fibrosis Center

Inspire

Spring/Summer 2012

A newsletter for the Rochester Cystic Fibrosis Community

Hot Topic: Research

Mary Platt, RN & Nancy Jenks, RN

We wanted to update you on current research at our CF Center. Most everyone is aware of the recent FDA approval of **Kalydeco** (Ivacaftor), the CFTR potentiator for patients with cystic fibrosis who have the G551D CF mutation. About 4% of those with CF have this mutation. The drug sponsor, Vertex pharmaceuticals, and the CF Foundation are in partnership to help expedite more studies to try to find combinations of CFTR potentiators (VX 770 aka Kalydeco and Ivacaftor) and CFTR correctors (VX 809) that may be able to help correct the defective CFTR function in CF. There have been several studies at CF Centers around the world, some in progress, and more on the horizon. CFTR function and dysfunction can be difficult to understand. There is a YouTube video which displays computer animation that is helpful to explain it. It's called "FDA Approves KALYDECO™ (ivacaftor) ... to Treat the Underlying Cause of Cystic Fibrosis".

We are in the process of completing a Phase II trial of **VX809 and VX770** for those with one or two copies of the ^F508 mutation who are 18 years or older who also meet other requirements for the study. Nancy and I have been privileged to work with volunteers from the Adult CF Center. Since Phase II trials gather a lot of information for drug safety and efficacy, there were many long study visits and blood work. Thank you so much to our wonderful clinical trial participants and volunteers! We look forward to more Vertex studies in the future.

The **iCARE** (I Change Adherence and Raise Expectations) study is in its second year at the pediatric CF Center. This study aimes to help teens manage their CF therapies and find ways to incorporate positive changes to impact their health. Those involved are completing assessments on the laptop, are bringing in their respiratory equipment for checking with the RTs, and continue to do problem solving (brainstorming) sessions to find new ways (and time!) for therapies to improve their health. Thanks to all involved and we hope that you are continuing with those plans!

The **EPIC Observational** study is still under way. Enrollment ended a while ago but we continue to collect data in the form of surveys and annual labs to send to the sponsor, the CF Therapeutics Development Network. There are several sites around the country in this study and the data has proved to be a very valuable tool for researchers in learning about pseudomonas bacteria in the CF population.

Call us if you have questions about CF research:
Nancy Jenks, RN 275-8580
Mary Platt, RN 276-4123

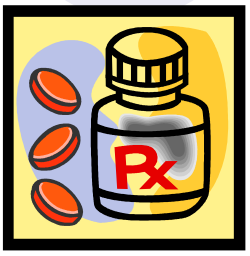
We are wrapping up our involvement in the **CF Twin and Sib Study** this year which involves questionnaires and blood work. Publications and other info related to this Johns Hopkins' sponsored study can be found at www.CFtwinsibstudy.net.

We have several other studies starting up soon. Nancy and I will be recruiting people as we determine eligibility. Please also visit the CF Foundation web site at www.CFF.org to find the new drug development pipeline. As one clinical trial participant said, "If no one cared or bothered to participate in a clinical trial, there would be no drugs available."

You are all the key to a cure.

Azithromycin (Zithromax): When An Antibiotic Isn't An Antibiotic

Stephanie Henning PharmD candidate, Jared Hill PharmD candidate, Angela Nagel, PharmD



Azithromycin (Zithromax) is an antibiotic approved by the FDA for use in otitis media (ear infection), upper and lower respiratory infections, as well as community acquired pneumonia. In addition to its anti-infective use, CF patients may use azithromycin as "add on" therapy for its anti-inflammatory effects. Azithromycin has been shown to decrease lung damage and number of exacerbations in CF patients regularly infected with the bacteria *Pseudomonas aeruginosa*. It has also been shown in some studies to improve lung function as measured by FEV_1. Its long-term use is currently recommended by the CF foundation for all patients at least 6 years of age with pseudomonas persistently found in their cultures.

Dosing for azithromycin, when used as an anti-inflammatory, is by mouth three days a week (typically Monday/ Wednesday/Friday). It is used in children over the age of 6, and is dosed based on patient body weight.

- Under 88 lbs: 250mg three days a weekpills
- Over 88 lbs: 500mg three days a week

Azithromycin may be taken with food. If you take antacids (such as Tums®, Mylanta®, Maalox®), take them two hours before or four hours after the azithromycin is taken. Azithromycin is generally well tolerated. Possible side effects include nausea, vomiting, diarrhea, wheezing, abdominal pain and headache. Anyone who is allergic to azithromycin, erythromycin or any macrolide-related antibiotic, should not take azithromycin. People with liver disease, pregnant women and those with a positive culture for non-tuberculous mycobacteria (NTM) need to talk with their CF health care team before starting azithromycin.

Helpful Hints for Phone Interactions at the Adult CF Center

When you call the Culver Medical Group and the Adult Cystic Fibrosis Program it is important to first identify yourself as a patient of the Cystic Fibrosis Program; doing this will insure that your call is directed in an efficient manner to the appropriate clinical staff. Secondly, if you are not feeling well or have an urgent medical concern please review this with the secretary, so that she can alert the nurse regarding the urgency of the call. If you are calling during normal business hours you can expect that a nurse will call you back about an urgent medical concern within 2 hours and non-urgent concerns by the end of the day. If for any reason you do not receive a call back in a timely manner please call the office again. If you call after the office is closed you can expect that the answering service will page the physician on-call and then the physician will call you back. Please call after hours for urgent medical concerns only.

Please call your pharmacy for prescription refills. They can then fax a request to the physicians here and the medication can be easily refilled. Requesting refills though your pharmacy will help insure that the medication is sent to the correct pharmacy. We ask that you allow a minimum of 3 business days for most prescription refills. If the medication requires prior authorization from the insurance company or needs to be shipped from a specialty pharmacy please allow additional time for those factors. With summer vacations fast approaching please request refills that you may need well in advance of going out of town.

Adult CF Center at Culver Medical Group:

913 Culver Road

Rochester, NY 14609

Phone:585-654-5432

Fax: 585-288-7871

Advance Directives in Cystic Fibrosis, Part II

Rob Horowitz, MD

Caution: The following paragraphs discuss dying and advance directives, sensitive subjects about which some people may choose to read no further.

In the last issue of this newsletter I began talking about a subject which is uncomfortable for many to discuss: serious illness, dying and advance directives for people with Cystic Fibrosis. You may recall, this discussion was inspired by the encouragement of patient-advocate Tiffany Christensen, who has CF, and by our adult patients, who have expressed the strong desire to learn more about these topics, ones which have often been avoided throughout their lives. We also know that children, with and without chronic illness, have a desire to talk about these issues. Yet we recognize this discussion can be difficult.

Here are common myths which are obstacles to discussing dying and advance directives:

1. **Advance Directives mean "giving up"**. In fact, Advance Directives are simply written records of your desires for medical treatment in case you are unable to make your own medical decisions. The **Health Care Proxy** form identifies the spokesperson you entrust to speak for you any time you are too ill to communicate your wishes. The **Living Will** states your wishes about medical care if you develop a severe and irreversible medical condition that prevents you from making your own medical decisions. These forms allow you to maintain control over your treatment and when seriously ill. Your wishes can range from continuing to provide every possibly helpful treatment, to withholding specific life support interventions (like CPR and mechanical breathing machines). We encourage our adult patients to review and complete advance directives as a testament of their wishes in the event of severe illness that prevents them from participating in important discussions about the goals of medical care.

2. **Talking about dying means I'm dying**. This concern is understandable, because unfortunately, too often medical professionals wait until their patients are gravely ill to talk about dying and advance directives. Specifically, some CF Programs have a policy to address these issues only when patients' lung volumes are very low. We believe this discussion is easier to have well before it is necessary, when the discussion is specifically NOT provoked by severe, end-stage disease. There is no conflict of interest in being prepared for severe illness, even as research improves the lifespan and the quality of life for people with CF. It is also important to know that prognosticating any individual's lifespan is a highly inexact science; we simply don't have a reliable means of predicting an individual's disease trajectory. Of course, if we fail to have this important discussion when patients are well, then there will come the imperative of doing so when they become very ill. Our goal is to encourage discussion about one's wishes about approach to care long before severe illness happens.

3. **Talking about dying will be intolerable to my family and loved ones**. Of course, loved ones are troubled when contemplating the death of their dears, and yet family members usually find a way to support this important discussion, one which naturally affects them and their emotions as well as the patient's. And what a valuable gift it is for family members to demonstrate their love by participating in this discussion, and validating the natural concern about dying which strikes most people with chronic illness. Taking control over one's future medical decisions is also a gift to loved ones, freeing them from the painful burden of wondering what the patient thought and wanted. We encourage and can help our patients and their loved ones to share this very challenging discussion, which is also often surprisingly gratifying.

4. **Talking about dying will take away hope**. There is no evidence from the many studies about discussing "bad news" in general, and dying in particular, that these cause depression or anxiety or reduce patients' quality of life. In fact, there is compelling evidence that an open discussion about such painful realities as progressive illness and eventual death can help people better prepare themselves and their loved ones, relieving some of the stress and pressure of concealing their real feelings. We encourage being both hopeful AND prepared.

Advance Directives in Cystic Fibrosis, Part II

5. **We should not talk about death with sick children**. Parents and physicians often avoid discussing difficult issues like prognosis and dying with children because they are concerned the child will not be able to cope with the information. However, even very young children often know when they are seriously ill, and they generally want to understand what is happening, and to talk about it. Often, children avoid talking about their concerns because they are worried about upsetting their parents. Adult attempts to protect the child and the child's desire not to upset the parents or physician often interfere with honest communication. We encourage and can assist in assuring developmentally appropriate, truthful discussion about such CF challenges as dying to patients of all ages, including children, when appropriate.

6. **Dying of Cystic Fibrosis is painful**. Most people who raise concerns about dying from CF lung failure wonder whether they will be in pain or suffocate or choke, all of which would make anyone anxious and scared. And the honest answer is: without medical treatment, people may suffer with these symptoms, but with medication and other treatments, these symptoms can be very well treated. There are experts in almost every hospital who can successfully treat all these symptoms, with medication, attention and compassion. This, in fact, is one of the things modern medicine is best at: assuring that the dying individual is aggressively treated with medications and other interventions to maintain comfort and dignity, and helping their loved ones through the process of grief.

We are committed to helping our patients and their loved ones talk about dying and prepare Advance Directives long before they develop severe disease. And since children with CF and their parents naturally have questions and worries about dying, we also encourage children and their parents to talk about these whenever they come up. Your CF team is committed to helping you be prepared by participating in this challenging and important discussion. As Tiffany Christensen, the patient advocate with CF says, talking about this often taboo subject is essential, it can lead to important decisions about your care in the future, and it can be enriching to both affected individuals and their loved ones.

Insurance Coverage

Bridget Platania, NP & Pat Lamarche, NP

The nursing group in the Division of Pediatric Pulmonology takes care of many of the medication refills, prior authorizations, and signing off on nutrition supplements. Over the past three to six months, we have encountered an increase in requirements by the insurance companies to meet patient needs in these areas. The Cystic Fibrosis Foundation (www.cff.org) offers some tips to understanding your health insurance—the Six C's of Insurance, reviewed below. We encourage you to review your policy and be aware of coverage benefits and some of the subtleties like what medications need to be filled via mail order (and which company) versus a local pharmacy, how often you can get new equipment (i.e. compressor / vest) and what the cost to you as an individual family will be. As your health care team, we do not have access to each individual's coverage details and will typically rely on you for this information. We advise you to contact a customer service representative from your insurance company (phone # often listed on the back of the insurance card) for questions and concerns specific to your coverage. We are also finding that some of the prior authorizations are taking several days for approval, so we encourage you to be proactive in refilling your medications in an effort to avoid days with no medication supply. We look forward to working together with you to navigate the insurance maze and provide you and/or your child with the best care possible.

Six Cs of Insurance

1. Coverage: Do the services covered match the services you need? Will the insurance provide the needed drugs and equipment? Are there any exclusions?

2. Co-pays: Few health insurance plans cover every expense. Out-of-pocket expenses are what you pay. They are called ***co-pays*** and ***deductibles***. It is important to find out what these will be for CF care. Is your CF care team part of

the insurance ***plan's network***? If the CF care team is outside the plan's network, ask about the yearly deductible amount and any charges you must pay beyond your normal co-pay to go to your CF clinic. What will insurance pay after you meet the deductible? Also, find out your prescription drug co-pay. With some insurance, you pay for the cost of the drug first and then fill out the paperwork before insurance will pay you back for the drug. With other insurance, you pay a percentage of the drug's cost. You may not be able to afford the drugs with these plans. (See Table 1.) Usually, there is a lower co-pay for a generic prescription drug, and a higher co-pay for a brand prescription drug. Know which brand drugs are covered by your insurance and what your co-pay is.

3. Claim Payment: Find out what you have to do before your insurance will pay the medical bill. Some insurance will not pay the bill until you fill out a form. With other insurance, you pay the bill first and then fill out a form before the insurance company pays you back.

4. Conditions That Affect Payment: Do you need to call the insurance company to get ***prior authorization*** or approval before getting certain prescription drugs, tests, or before being admitted to the hospital? Check to see if the health insurance company has a set timeframe to submit a claim or paperwork *after* services have been provided. Some insurance will not pay for services if a claim has not been filed within a certain time period, such as 90 days or six months. Check the insurance coverage for ***pre-existing conditions***. Does your insurance plan consider CF a pre-existing condition?

5. Caps on Benefits: Many health insurance plans will have dollar limits on the amount to be paid for medical equipment, physical therapy, or prescription drugs. Because CF requires a lifetime of expensive health care, see if the insurance plan has a yearly or lifetime ***cap on the benefits*** that they will pay.

6. Cost of Insurance Premiums: Be careful when changing to insurance with a lower premium. The insurance may have higher co-pays and deductibles. You could end up paying much more out of your own pocket in the long run. For example, insurance with a lower premium may only pay 50 percent of your prescription drugs. Think about what it would cost you if you had to pay for half of the total cost of your prescription drugs for one month. The better option may be to pay a slightly higher monthly premium for insurance that pays 80-100 percent of your prescription drug costs and/or one that requires a small co-pay.

Table 1. How to Compare Health Insurance

	INSURANCE A	**INSURANCE B**
Set co-pay vs Percentage	**Set co-pay** You pay…. • $30 for brand drug $15 for genetic brand	**. Percent co-pay** You pay…. • 50% of the brand price 10% of the generic price
Low deductible Vs High deductible	Low deductible You pay… • $500/year deductible • Co-pays for drugs, doctors visits, etc. do not apply to the deductible	High deductible You pay…. • $3,000/year deductible • Co-pays for dugs, doctors visits, etc do apply to the deductible
Coverage of Services	CF care center (in-network) You pay… A $15 co-pay for each visit	CF care center (out-of-network) You… • Pay for each visit • Are reimbursed 50% of your out-of-picket expenses for each visit

After several successful fundraisers, and plenty of elbow grease, the

Cystic Fibrosis Family Connection is back in action!

We're digging in and getting things done.

Our roots are spreading and our tree of support is growing strong!

CFFC has reinstated our Hospital Help Packets and improvements are in the works. If you or your child is admitted and you do not receive one, please ask the hospital staff to get you one. Also, please let us know if you have a problem so we can get our distribution system working smoothly. Help us better serve you.

Have you visited our website yet? www.cffamilyconnection.org

It's time.

Come see how we're supporting YOU.

There, you'll find ever changing news items, an increasing number of helpful links, a "Navigating the Hospital" section, a calendar full of Rochester Community Events (check out May, CF Awareness month!), and all sorts of goodies!

Bookmark us and visit often to stay informed of upcoming events, scholarships, fundraisers, and more!

Email us at info@cffamilyconnection.org if you have a question, a news item to share, or a suggestion for an improvement in our CF Community.

Also, send us a note if you would like to be included in our e-mail distribution list.

We grow stronger through you and for you. CFFC is here for YOU.

Rochester Chapter of the Cystic Fibrosis Foundation

Here is a list of upcoming events for the Rochester Chapter:

- Rochester Great Strides Walk: May 19 at Genesee Valley Park
- Geneva Great Strides Walk: May 20 at Seneca Lake State Park
- Hornell Great Strides Walk: June 2 at Steuben Trust Bank
- Cycle for Life: August 11 at SUNY Geneseo

To register for any of our walks, visit: http://www.cff.org/Chapters/rochester/GREATSTRIDES/

To register for Cycle for Life, visit: http://rochester.cff.org/biketour

For more info. about CFF in the Rochester area or volunteer opportunities, please contact Jessica: jregan@cff.org

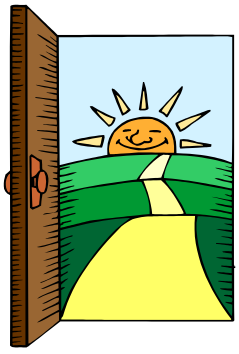
Equipment Check

Donna Germuga, RT & Kim Bordeaux, RT

With warmer weather approaching and people beginning to make travel and vacation plans, now is a good time to check all of your equipment for function and maintenance before you go to head off and discover your equipment won't make the trip and it's too late for us to order replacements. Also, be aware that some of the Pulmonary staff may be out of the office during the summer months and the sooner we receive requests, the more likely we can get them processed in a timely manner.

- Start by looking over the equipment in general; are there cracks, pieces broken off, a frayed power cord?
- Then, if there are filters, take them out and clean or replace them. The Home Care Company you got the product from should be able to order replacement parts for you.
- If your nebulizer compressor isn't working properly, ie: taking much longer than it should in spite of replacing the neb cups/tubing and cleaning the filter, the motor may be on it's way out and we should consider a replacement.
- Some people have very old Vest units. Check the integrity of the vest itself, the tubing that attaches to the vest and the power supply. If there is any problem with the equipment, call the company you received it from and ask them how to go about getting replacements. (The RTs also have the phone numbers for various companies if you need them)
- Some vest units may be old enough to allow for an "upgrade" to a newer, smaller unit. There is usually cost associated with this upgrade. (However, it is considerably less than purchasing a new unit) If you have changed insurance carriers since you got the original unit, you may be eligible to submit as a new claim and get it covered. The companies that supply the vest units can do a benefits investigation and let you know if you have a copay and how much it's likely to be. They also have patient assistance programs available if the financial burden is too great, so don't be afraid to ask for help if you need it.
- One of the things you may want to consider is calling your insurance carrier and checking out what your "DME" (durable medical equipment) coverage is if you don't already know. They will be able to tell you what percentage of the cost of any equipment ordered would be billed to you.
- Speaking of insurance, if you know what plans are available to you (from your employer or other source) it is well worth the effort to specifically look up the DME coverage of various plans in case you may want to change providers in the future.
- Finally, if the methods you use for airway clearance and nebulized medicines are not going to work for travel, please let us know so we can brainstorm alternate means of getting things done while you are away.
- Be aware that some airlines require a letter for carrying equipment with you, give us a call or let us know next time you are in clinic so you have what you need for a seamless trip!

HAPPY TRAILS!!



Your Stories

My son was diagnosed March 5, 1998 with CF, just before his 3rd birthday. I would bet every parent remembers that day. With the exception of sinus surgeries, we'd always been very "lucky". He had never been admitted to the hospital specifically for a tuneup until he was 14. It was a trying time and one of the most difficult as a parent that I had encountered since his diagnosis. In the months leading up to the admission my home turned into a battlefield. Every night one could predict the same scenario. "Do your vest." "I will." "When?" "Soon." This same conversation would go on for about an hour. I'd prepare the nebulizer and the conversation would start over again, only louder. I'd get angry, he'd get angry. The heart to heart talks didn't seem to make a difference, nor did the "You will end up in the hospital" lines. He was just being a normal teenage boy who felt fine and I was being a parent who knew what could happen by him not doing his treatments. I'd go to bed praying for help to get him through this. Just get him to the point where he is an adult and understands the importance. That was my job. And then I'd think, at what point does he take some responsibility managing his CF. Regardless, I couldn't take the constant battling day and night anymore. I was at my wits end and my 3 other children and husband didn't need to hear it anymore. I guess you could say I threw my hands up in the air. I never stopped telling him to do it and I never stopped handing him his nebulizer, but I did stop the arguing and I was always honest with his medical team about it. He just didn't want to do any of it. His pft's had always been over 100. Well, the decline began and weight gain was minimal but eventually became non existent. The 4-6 week checkups with Dr. Cheng turned into negotiating periods. He'd beg and promise her he would do his "stuff". She would say, "You keep telling me this, but you're not." He would do really well for a few days and then it'd go right downhill.

She gave him a few chances until January 2010, only 15 months since the last time he'd been in for sinus surgery and he was there for just a week. He had always only been in for a week when he had his surgeries. At this particular appointment, his lung function was at 83 and he had actually lost a few pounds. Dr. Cheng looked at him and said, "When are you coming in? I can have a bed tomorrow." My son said, "What? I'm not coming in, no way." Dr. Cheng looked at me, I looked at him and I said, "You don't get a choice this time." The tears started flowing and again he begged and pleaded. She said, "I gave you many chances and you didn't do it, no more chances."

The following week he was admitted. After his 1st week he had his hopes high that he'd be coming home, after all, that is what he was used to. Those hopes were shattered quickly when his pfts weren't back to normal. The news that he'd be there another week left him devastated, it left me hopeful we can get him back on track. And we did. And this changed him. He became much more compliant. He finally realized that this can be avoided for the most part, not forever, but more than 15 months. He's 17 now and was just in this past January for 12 days and sinus surgery. He went 2 years. I still fill the nebulizer, usually just in the morning when I wake him up at 5:00am to get started. Nighttime he does it himself. I still say, "Do your stuff." And occasionally when I get up in the morning, I can see he hasn't, but it's not often. I tell him he didn't do it...as if he didn't know. If he has plans at night, he has to do it before he leaves, and he does, no complaints.

I know that we will struggle with this again now that he's driving, has a girlfriend, and is in the best year's of anyone's life, but we made it through our biggest obstacle yet. He is taking responsibility for his own disease and I am very proud of the fine young man he has turned out to be.

We like to hear our patients stories and our patients like to hear other patient stories! We all learn from one another through our unique experiences. If you have something inspiring to share please consider allowing us to include it in our newsletter! Tell us about how you fit in your treatments or different ways to get your kids to do treatments. Teaching children how to swallow pills is a struggle so please share your experiences and ideas. Have a great recipe you would like to share? Does your son or daughter have an incredible talent you would like to show off? We would love to publish academic and sporting accomplishments as well! Graduating from high school or college? Get a new great job? Tell us!!! Send your stories to the attention of Donna or Melissa at URCFPULMF@urmc.rochester.edu

Enzyme Program Update:

CREON CF Care Forward:

- Anyone on Creon who does NOT have Medicare or Medicaid as their PRIMARY insurance may participate in the program.
- Offers 1 free bottle of Vitamax vitamins (chewable or liquid) or SourceCF vitamins (chewable, liquid or softgel) EACH MONTH
- Eligible for up to $50 copay reimbursement for each Creon refill
- Offers the choice of one of the following free nutritional products EACH MONTH:

Product	Size	Calories	Flavors
Ensure	8 fl oz (24 bottles)	250	Vanilla, Chocolate, Strawberry
Ensure Plus	8 fl oz (24 bottles)	350	Vanilla, Chocolate, Strawberry
Pediasure	8 fl oz (24 bottles)	240	Vanilla, Chocolate, Strawberry
Pediasure 1.5 Cal	8 fl oz (24 cans)	350	Vanilla
Ensure Enlive	6.7 fl oz (32 boxes)	200	Apple, Mixed Berry
Similac Advance	12.4 oz (4 cans)		
Myoplex Original Shake	17 oz (24 boxes)	300	French Vanilla, Chocolate Fudge
ZonePerfect Bar	12 bars	210	Chocolate Peanut Butter, Fudge Graham
Myoplex Carb Control Bar	12 bars	260	Chocolate Peanut Butter
Myoplex Strength Bar	12 bars	280	Chocolate Chocolate Chip

- You must fill out an order form each time you fill your Creon prescription.
- If you need an initial enrollment form or a reorder form please call Melissa at 275-1457.

Zenpep Live 2 Thrive:

- Newborn to age 2 are eligible to enroll in program regardless of medical coverage—even if they have Medicaid or Medicare.
- Age 2 and up are eligible only if Medicaid or Medicare is NOT their PRIMARY insurance.
- Offers 1 free bottle of AquADEK vitamins (chewable, liquid or softgel), or SourceCF vitamins (chewable, liquid or softgel) EACH MONTH.
- Offers the choice of one of the following free nutritional products EACH MONTH:

Product	Size	Calories	Flavors
Scandishake	24 packets	440 cal in powder 150cal in 8oz whole milk = 590cal shake	Chocolate, Vanilla, Strawberry
Scandical	8 oz shaker	35 per tablespoon	Taste free
Carnation Breakfast Essentials Lactose Free VHC	9 oz (24 cans)	560	Creamy Vanilla

- Eligible for Live2Thrive Loyalty Card for up to $50 copay reduction for each Zenpep refill.
- Enrollment includes a Rewards Program to earn points that can be redeemed for electronic prizes, gift cards, exercise tools, or 7% hypertonic saline.
- Go to www.live2thrive.org or call 1866-520-8032 to enroll.

University of Rochester Pediatric Cystic Fibrosis Center

601 Elmwood Ave Box 667
Rochester, NY 14642
Phone: 585-275-2464

University of Rochester Adult Cystic Fibrosis Center

Culver Medical Group
913 Culver Road
Rochester, NY 14609
Phone: 585-654-5432

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greatstrides®
TAKING STEPS TO CURE CYSTIC FIBROSIS

Rochester Great Strides Walk: May 19 at Genesee Valley Park

Geneva Great Strides Walk: May 20 at Seneca Lake State Park

Hornell Great Strides Walk: June 2 at Steuben Trust Bank

Save the Date:

The next Pediatric Family Advisory Board is Wednesday, July 18th, 2012, at 6pm. If you are interested in attending please call Marcy at 275-2464.