



HomeLine

Brought to you by Cystic Fibrosis Services, Inc.

A Subsidiary of the Cystic Fibrosis Foundation

The medical contents of this newsletter express the opinions of the guest author(s) and are not necessarily the opinions of Cystic Fibrosis Services or the Cystic Fibrosis Foundation. Please consult with your caregivers at your local CF care center for guidance.

HomeLine Archive

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are available at
www.cfservicespharmacy.com



**Cystic
Fibrosis
Services, Inc.**

PHARMACY SERVICES

**A Subsidiary of the
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Vital Enzymes Will Now Be Regulated By The Food And Drug Administration

With urging from the Cystic Fibrosis Foundation, the Food and Drug Administration (FDA) has issued a new rule regarding pancreatic enzymes to help ensure safety and standard dosage with this vital cystic fibrosis (CF) therapy.

The FDA announced to all manufacturers of pancreatic enzyme products that they must conduct clinical trials and obtain FDA approval for their enzymes, within the next four years, to keep them on the market.

This new ruling was a result of an FDA review, which revealed substantial variations among currently marketed products. The variations affect the overall potency and effectiveness of these enzymes. In 1938, the FDA enacted a law, which required new drugs to be reviewed by the FDA to ensure safety. Pancreatic enzymes, which predate the 1938 law, were exempt from FDA review and have been allowed to stay on the market because of their lifesaving benefits.

“Variations in potency are unacceptable. Patients with pancreatic insufficiency disorders rely on these supplements to provide the enzymes they need to digest food properly. If the label contains an inaccurate statement about a particular product’s potency, then the patient is at risk for receiving too much or too little of the medicine,” said Lester M. Crawford, Ph.D., acting commissioner of the FDA.

The CF Foundation anticipates increased FDA oversight will help reduce the inappropriate substitution of one enzyme product for another by pharmacists, which can lead to insufficient absorption of nutrients by patients who consume them. The CF Foundation urges physicians to write prescriptions for brand name pancreatic enzymes by indicating “dispense as written/DAW.” Individuals should not accept substitution at the pharmacy level and should check the label and packaging to ensure that the enzymes dispensed are the ones prescribed by their physician. The CF Services Pharmacy does not substitute pancreatic enzymes.

A press statement and a question-and-answer document for patients and families are available on www.cff.org. Click on the “Living With CF” tab on the home page, then click “Patient and Family Education” on the left side and scroll down to “CF Therapies.”

The CF Foundation applauds the FDA’s new rule and believes it will help ensure that people with CF are getting the maximum benefit from their pancreatic enzymes. More than 90 percent of the CF population relies on enzymes for good nutrition. ❁



Adult Corner

Helping the Student With CF Prepare for College Life

By Joan Finnegan Brooks — Special Contributor to *HomeLine*

Having CF does not make us different from other people, but it makes it necessary for us to prepare differently for college life. Here are a few tips to consider as you get ready.

1. “CF Health 101” is your most important class and must be your top priority. Actively schedule time to do the “ABCs” of your normal CF routine: airway clearance and aerosol treatments, daily medications and supplements and exercise. Also, do not neglect the basics of eating and getting enough sleep. Choose your academic class schedule *after* you have scheduled these important activities into your daily routine. It is important to get an “A” in this class!

2. Evaluate and discuss your potential circumstances and requirements with your CF care center team and school. Can you select your class schedule to ensure adequate time to get to the next class? Is there a shuttle service you can use to get around campus? Is campus housing located close to your class buildings? Can you select classes that start after your morning CF health treatments are completed? If you miss class time due to illness, can your professor provide lecture notes or can there be a class note-taker? Can you reschedule exams and paper deadlines if you are ill? Are there nutritious food choices available in school cafeterias at reasonable hours? Can you select campus housing next to dining facilities to ensure you have easy access to food? Can you obtain a single room without a roommate, so that you can perform your medical treatments privately? Is air-conditioned campus housing available? What types of services are available at the school’s health services center? How does your insurance coverage work while you are a student? Is there a CF care center near school?

3. Never hesitate to ask your school for assistance or accommodations in anything associated with your academic or campus life. Be explicit in your requests to accommodate your CF health care needs and find the resources at school that can advocate on your behalf (often this is the college’s Office of Student Life).

People often remark that their college years are among the best of their life. My recommendation is to enjoy everything that college has to offer in moderation and be diligent about maintaining a healthful CF routine. And yes, you can do both! Good luck!

If you have comments on this topic or would like to see another specific topic covered in this forum, please e-mail us at comments@cfserv.com. ❀

Happy Birthday CF Services!

In October 2004, CF Services will celebrate 16 years of service. We thank patients, families and caregivers for their support over the years and remain committed to providing quality pharmacy services to the CF community. ❀

Customer Support Survey Results Are In!

A special thank you to everyone who responded to our yearly Customer Support Survey. Our response rate of more than 27 percent (approximately 1,500 surveys received) serves as a testament to the strong relationship we have with our patients and families. On a scale of 1 to 4, CF Services received an overall score of 3.7, which is our highest customer satisfaction score ever! We thank you for your valuable support and feedback, which assists us in developing exciting new programs and services. ❀

CF Services To Support EPIC Trial

As part of its support of CF research endeavors, CF Services will be supporting the **Early Pseudomonas Infection Control Study (EPIC)**, a clinical trial that will study the effectiveness and safety of intermittent antimicrobial therapy for the treatment of new onset *Pseudomonas aeruginosa* airway infection in young patients with CF. CF Services will serve as the central fulfillment pharmacy for the clinical trial, which will involve 300 patients at 60 CF care centers and will last three years. Ask your physician if your center is participating. ❀



Back-to-School Basics

The following resources are available to help prepare children and families for going back to school:

- The CF Foundation's new brochure, "**Day-to-Day: School and CF,**" provides information on legal rights for getting health needs met at school. It is available online at www.cff.org, in the "Education and Scholarships" section of "Living With CF" or by calling **(800) FIGHT CF**.
- The CF Services guide, "**Back-to-School Basics,**" is published in the August 2002 issue of *HomeLine*. Among the topics covered are: school/daycare, college/graduate school, scholarships, exercise, nutrition, health care and infection control. Available online at www.cfservicespharmacy.com/homeline_newsletter/archive/ or by calling **(800) FIGHT CF**.
- Axcan Scandipharm's publication, "**Cystic Fibrosis in the Classroom,**" provides information to share with teachers and children in the classroom. Available by contacting Axcan Scandipharm at **(877) 657-6737**.
- Digestive Care's publication, "**CF in the Classroom,**" highlights important issues related to children with CF in school. Available online at www.digestivecare.com under the "Literature" tab or by calling **(610) 882-5950**. ❀

Open Enrollment: Evaluate Your Coverage

Open enrollment is the time to review existing insurance coverage and evaluate insurance coverage options. It is a critical decision, so take the time to carefully evaluate your coverage options. The following resources are available to help individuals select an appropriate insurance plan:

- The CF Foundation's publication, "**Day-to-Day: Know Your Health Insurance Coverage,**" is an extensive guide on understanding and choosing your health insurance plan. Among the topics covered are: health insurance coverage laws, drug formularies and important questions to ask about your insurance. Available online at www.cff.org under the "Insurance and Assistance Programs" section of "Living With CF" or by calling **(800) FIGHT CF**.
- The CF Services "**Policy Checklist,**" provides guidance for reviewing and selecting an appropriate insurance policy. Among the topics covered are: access to care, benefits and limitations and claims and costs. Available online at www.cfservicespharmacy.com/insurance_providers/policy_checklist/.

If you have questions about whether or not CF Services participates with your plan or to update us with your new plan information, please contact the CF Services Customer Support Department at **(800) 541-4959**. ❀

CF Services: Your One-Stop Pharmacy

Customers are often not aware that CF Services is a full-service pharmacy and carries a variety of prescription medications. Almost anything available at a local retail pharmacy, also can be obtained from CF Services.

CF Services offers an extensive line of products, including but not limited to: *nebulized medications and supplies, diabetes medications and supplies, inhalers, pancreatic enzymes, transplant medications, nutritional items and a variety of other prescription medications*. However, CF Services does not compound medications, nor does it dispense controlled substances. CF Services requires a prescription for all items dispensed.

To inquire about the availability of a specific medication, please contact the CF Services Customer Support Department at **(800) 541-4959**. ❀

Join CF Services' Birthday Club

The Birthday Club is our way of saying "thank you" for using the CF Services Pharmacy. By joining the Birthday Club, individuals will receive a birthday card and a small token of appreciation during the month of their birthday. Participants must be active CF Services customers. To enroll, e-mail CF Services at comments@cfserv.com and provide the following: the patient name, account number and date of birth. ❀



GREAT STRIDES 2004 Sets New Fund- Raising Record

greatstrides



Taking Steps to Cure Cystic Fibrosis

GREAT STRIDES 2004 was nationally sponsored by American Airlines® and Solvay Pharmaceuticals.

Thousands of volunteers across the country “pulled out the stops” to make GREAT STRIDES 2004 the most successful fund-raising event to date. Thanks to our dedicated volunteers, it is expected that well over \$23 million will be raised — a nearly 15 percent increase over 2003! Thank you and congratulations to everyone who participated. ❁

Tell a Friend

Are we doing a good job? If so, tell other CF families about our pharmacy and the services we provide. Your word is the best way to help us reach others with CF. CF Services is committed to providing quality pharmacy services and we thank you for your continued support! ❁

CF Foundation Reaches Out To CF Community Through Cutting-Edge Technology

The CF Foundation developed an interactive forum designed to answer a previously unmet need — to provide information to patients while also creating a sense of community with others battling this disease — the Virtual Patient Education Day Web Cast.

Almost 950 people with CF and their families “tuned in” to the most recent free, live Virtual Patient Education Day Web Cast in June to learn about CF nutrition and the latest in nutrition research. In a nutshell, good nutrition can be the best “secret weapon” an individual with CF can use to fight this disease. The CF Foundation, in collaboration with Washington University (St. Louis Children’s Hospital and Barnes-Jewish Hospital), hosted this latest Web cast.

Mark your calendars, the CF Foundation has set a date for the next Virtual Patient Education Day Web Cast — “Go for the Gold Standard of CF Care.” This live Web cast will be held on Tuesday, September 21, 2004 at 7:00 p.m. (Pacific Time) and 10:00 p.m. (Eastern Time) at Stanford University. Experts will discuss what it takes to best tackle this disease and to attain the best health possible. To participate in this Web Cast, visit www.cff.org to register.

To date, there have been three Virtual Patient Education Day Web Casts. Archived versions of all Web casts are available on the CF Foundation’s Web site at www.cff.org. This program is supported by an unrestricted educational grant from Genentech, Inc. ❁

CF Services Expands Its Providership Network

CF Services is constantly working to expand its providership network and recently has become a provider with the plans listed below. If you have primary or secondary coverage with any one of these plans, please contact CF Services at (800) 541-4959 to update your insurance information.

- Community Health Group (MediCal HMO)
- Health Net (MediCal HMO)
- HealthTrans (MediCal HMO)
- Crippled Children’s Services of New York (CCS of NY)

*CF Services participates with approximately 5,000 insurance plans and almost 40 state programs. A **partial** list of the major insurance plans and prescription cards that CF Services accepts is available online at www.cfservicespharmacy.com. If you do not see your insurance plan listed or you wish to inquire about a specific plan, please contact the CF Services Customer Support Department at (800) 541-4959. ❁*

CF Services Texas Celebrates One-Year Anniversary

In July 2004, the CF Services Texas Pharmacy celebrated its one-year anniversary. Because of an in-state requirement that necessitates pharmacies servicing individuals with state coverage to be within the state’s borders, CF Services opened a subsidiary in San Antonio, Texas. CF Services continues to expand its providership network to ensure that more patients and families have access to its pharmacy services. ❁