CF Foundation Creates Pharmacy Alliance with Walgreens

The Cystic Fibrosis Foundation has entered into an alliance with Walgreens that gives the national chain a significant ownership stake in Cystic Fibrosis Services Inc. The CF Foundation remains a partial owner and CF Services will keep its name and remain based in Bethesda, Md.

The alliance provides the CF community with greater access to affordable medications and expanded pharmacy services. It will also allow the Foundation to expand its patient assistance programs with a new Patient Assistance Resource Center (PARC), which will help people with CF and their families access the treatment and care they need.

CF Services members will continue to use the same toll-free number to order medications and interact with the same knowledgeable and caring professionals. The pharmacy will still offer customer-friendly services, such as free shipping and monthly invoices for out-of-pocket payments.

In the longer term, CF Services expects to provide many new services and benefits to its customers, including unique programs to help CF patients better manage their treatment regimen and improve their health.

The CF Services team is excited for what our future holds with Walgreens by our side, and we look forward to providing the same quality service to all people with CF and their families!

For more information on the alliance, visit www.CFServicesPharmacy.com or call 1-800-541-4959.

The CF Foundation and Walgreens, the nation’s largest drugstore chain, entered into an alliance to operate CF Services Pharmacy.
CF Services at NACFC 2012

The 26th Annual North American Cystic Fibrosis Conference (NACFC) was held in sunny Orlando, Fla., Oct. 11 – 13.

While the CF Services team didn’t meet Mickey or Minnie, we did devote our time and energy to greeting some of the world’s finest CF caregivers and sharing exciting news on a new nebulizer available to people with CF in the U.S.

Front and center at the entrance of the conference hall, we showcased the exciting U.S. launch of PARI’s eRapid® Nebulizer System, which CF Services will distribute exclusively.

The eRapid is a portable, compact and noiseless inhalation treatment system, and operates up to twice as fast as current systems. The eRapid Nebulizer System contains an eBase® universal controller, two eRapid handsets, nebulizer connection cord, international power supply with U.S. plug only, carrying case and instructions.

Customers will also receive an EasyCare® cleaning aid separately — at no charge — when they purchase the eRapid Nebulizer System.

For an additional charge, customers can order the CF Services Nebulizer Cleaning Kit, which includes a baby bottle sterilizer, clear detergent, Ziploc containers, an instructional DVD and a backpack.

For more information on the eRapid and CF Services Nebulizer Cleaning Kit, visit “Products and Prices” at www.CFServicesPharmacy.com or call 1-800-541-4959.

Make the Most of the Winter Season Indoors

By Mary Sullivan, pharmacy coordinator, CF Services, and CF parent, special contributor

We all know it’s coming. That time of year when moms all over the country walk outside and feel the first crisp air signaling that winter is upon us.

Along with it comes the cold, harsh reality that school holidays are looming but a trip to the pool is out of the question.

It’s time to retreat indoors.

As a CF mom, cold weather presents a challenge to maintain treatments and avoid the increased risk of infections. But it also presents an opportunity to pack some extra pounds on your CF kiddo.

Regardless of your family’s traditions or religious observations, winter probably means time in the kitchen: cooking, baking, burning, over-cooking and putting out flames on occasion.

We search for new and interesting recipes to add to our time-honored ones and we get down to business. We eat what we can and we package the rest. We “Boo!” neighbors around Halloween and take treats to them on other days, sometimes for no reason at all.

My girls, their cousins and all the neighborhood kids love these times. It’s nothing for me to look up and find a dozen kids (only seven of whom I can identify) in my kitchen covered in flour.

Sound familiar? If so, my suggestion is: forget the mess. Enjoy your time inside and stick to the treatments surrounded by a houseful of kids you may or may not know. Spring will be here soon enough to present its own set of problems.
Cook Healthy Meals the Whole Family Can Enjoy

By Eileen Potter, M.S., R.D., CF nutritionist, Ann & Robert H. Lurie Children’s Hospital of Chicago, special contributor

Many of us can count on the holidays to bring the comfort of special, traditional foods. Although holiday eating is usually a bonus for those with CF, it may be a challenge to other family members who don’t want the plentiful calories from decadent foods.

Good nutrition is more than meeting calorie goals (high or low). Everyone’s diet should be “nutrient-dense.”

Here are some tips to make the holidays more healthful for the whole family:

• If your holiday tradition includes a green salad, try adding baby spinach; fruit like mandarin oranges, sliced apples or berries; and almonds, walnuts or sunflower seeds. These add extra vitamin E, protein and other antioxidants to the salad, making it a nutrient-dense addition to any meal (without taking up too much room in your stomach!).

• Try substituting whole grain bread for white bread in part of your stuffing recipe.

• Consider incorporating more nuts into your meal by adding chopped pecans to the marshmallow/brown sugar topping on baked sweet potatoes and serving rolls with blackberry or blueberry jams, which are rich with antioxidants.

• Offer kale (a “super-food” rich in vitamins A, K and C, plus antioxidants) as a vegetable choice along with the green bean casserole.

For those with CF, remember to have a good supply of enzymes in your pocket. If you take a large dose of enzymes when you arrive, you won’t be able to break down the foods that you eat an hour or two later.

Take some enzymes when grazing on appetizers, then take your meal dose when you sit down at the table and some more when dessert is served. Ask your CF dietitian for specific dosing advice.

Just remember: healthy eating is not always about eliminating foods from your diet if you don’t have CF, or choosing only high-calorie, high-fat foods if you do.

It’s about choosing your foods wisely to include nutrient-dense ingredients as often as possible throughout the year.

This green rice recipe is an example of boosting the nutritional value of a common staple dish.

Green Rice
(Serves 4-6)

Ingredients:
2 tablespoons olive oil
2 cups short grain rice
4 tablespoons butter or margarine
3 ½ cups hot chicken broth
1 cup minced green onions or scallions
1 ½ teaspoon salt
1 cup minced parsley (optional but recommended)
¼ teaspoon black pepper
1 ½ cups coarsely chopped fresh spinach (or 10 ounces frozen chopped spinach, drained)
½ cup grated Parmesan or Romano cheese

Directions:
1. In a 2 quart saucepan with lid, heat the oil and butter.
2. Add the onions, parsley and spinach; cover and cook on low heat for 5 minutes.
3. Stir in rice and cook until translucent.
4. Add chicken broth, salt and pepper. Cover and cook over low heat another 20-25 minutes, or until the rice is tender and light.
5. Gently mix in the cheese, saving 2 tablespoons for the garnish.

Nutrient Analysis:
1 serving contains: 400 calories; 9 gm protein; 16 gm fat; 100 mg calcium; 3.7 mg iron.
How Active Lifestyles Can Help People Maintain CF Treatments

By Brian Callanan, founder and executive director, Cystic Fibrosis Lifestyle Foundation

As a 36-year-old adult with CF, I have lived with the physical, psychological and social adversities of chronic illness since being diagnosed at birth.

I know firsthand that living with CF can take quite a toll. It can intrude on our daily lives, cause feelings of isolation and create a financial strain — all of which often lead to nonadherence to our CF treatments.

However, I’ve also found that financial and personal support can provide incentive and motivation for the development of an active and healthy lifestyle, which is why I started the Cystic Fibrosis Lifestyle Foundation (CFLF).

The CFLF is a nonprofit organization that provides financial support to people with CF for recreational activities. It focuses on patient education — specifically, the psychosocial challenges of living with CF on a daily basis and how those challenges can lead to nonadherence with medication and treatments. It also educates people with CF on the importance of a positive attitude and healthy lifestyle and helps them afford recreational activities.

Lending a Helping Hand to People With Adherence Challenges

Participating in physical activity and learning about success and empowerment can have lifelong positive effects on an individual. The CFLF seeks to support these activities by awarding recreation grants to people who have demonstrated a need and desire to improve their physical, emotional and social well-being.

For many people with CF, experiencing what it is like to feel good — physically, emotionally and socially — can be a critical turning point; but the cost of recreational activities often gets in the way.

These small grants can be the spark that ignites a passion for focusing on achieving health, as opposed to avoiding illness. A person’s mindset can help determine not only the ways they accept CF, but also how they can harness it as a driving force to become stronger and live longer.

Breanna Schroeder, left, 2012 grant recipient, and her “Peer Support” dive into better health by having fun.
Vicki Thompson, grant recipient in 2008, 2011 and 2012, doesn’t let CF hold her back when she’s on the slopes.

CFLF Grants for Activities

The CFLF provides direct financial assistance for activities like gym memberships, sports or summer camps, yoga, dance or karate classes, horseback riding and swim memberships or lessons.

People with CF can apply for a grant at www.CFLF.org.

They will need to identify which activity they want to pursue and explain how they feel it will benefit their well-being.

The grants provide up to $500 toward the cost of a recreation activity, and the CFLF sends the payment directly to the activity provider.

Applicants can also request funds for a “Recreation Mentor” or “Peer Support” who will participate in sports and activities with them.

Recreation Mentors provide a formal relationship, including training, goal setting and committing to a meeting schedule; Peer Supports accompany, motivate and encourage grant recipients in their activities.

Please note: The purchase of exercise equipment is typically not funded, as the spirit of the program is to encourage participation in activities that “get you out there”; however, we occasionally make exceptions for special circumstances.

Living Xtreme: Beyond Cystic Fibrosis is a short documentary film on the lives and stories of people with cystic fibrosis who engage in extreme sports and active lifestyles.

The film highlights individuals who not only choose to be empowered by their disease, but who also demonstrate how exciting, active and rich life with CF can be. The film was co-produced by CysticLife, the Cystic Fibrosis Lifestyle Foundation and Essential Image Source Foundation, and can be found at www.LivingXtreme.org.

DVDs will also be sent to CF care centers for in-clinic patient education. A full-length documentary is scheduled to follow the film.
Find New CF Clinical Trials Resources Online

By Cynthia George, M.S.N., F.N.P., B.C., director of clinical research resources, Cystic Fibrosis Foundation

Translating scientific knowledge into tangible benefits for people with CF and their families is the driving force behind CF research.

A major part of that research is clinical trials, which test potential drugs and therapies in people with cystic fibrosis. Over the past decade, new drugs have been discovered because people with CF have volunteered to participate in clinical trials. But more clinical trials and participants are still needed until a cure is found.

Choosing to volunteer in research is a personal decision that is best made when you are informed. Check out the Cystic Fibrosis Foundation’s website — www.cff.org — for these new resources to help you learn more about CF clinical trials.

- **Get Answers to Your Questions:** The Foundation’s booklet, “About Clinical Trials: A Guide for People with CF and Their Families,” answers questions frequently asked by people with CF and their families. The booklet goes behind the scenes to explore key steps in a clinical trial, the informed consent process and how the health and safety of study volunteers are protected. It also offers general information to help you begin a conversation with your CF care team about whether participating in a clinical trial is right for you or your child. Visit www.cff.org/research/ClinicalResearch/FAQs to download the booklet or read it online.

- **Watch New Webcasts on CF Clinical Research:** Hear an adult with CF, parents of a child with CF and research team members discuss questions to ask when considering joining a trial; what happens before and during a clinical trial; and how to learn about the results. Watch the webcasts at www.cff.org/LivingWithCF/Webcasts/ArchivedWebcasts/Research.

- **Sign Up for Clinical Trial Alerts:** Receive email alerts when new trials or trial results are posted on the Foundation’s clinical trial search tool. It’s quick and easy to sign up at www.cff.org/research/ClinicalResearch/Find/ClinicalTrialAlerts.

Ask your CF doctor and care team for more information, and join in the effort to develop new treatments by volunteering for clinical trials.

Award-Winning CF Documentary Available on DVD

The Power of Two, a documentary featuring twin sisters with CF who have survived double lung transplants, is now available on DVD, for digital download and streaming, and for community screenings.

Inspired by Anabel Stenzel and Isabel Stenzel Byrnes’ memoir, The Power of Two: A Twin Triumph Over Cystic Fibrosis, the award-winning film offers an intimate portrayal of the bond between Anabel and Isabel, their ongoing battle with cystic fibrosis and their advocacy on behalf of others with the disease.

With the help of community partners like the Cystic Fibrosis Services pharmacy, The Power of Two uses personal storytelling to inspire awareness of CF and action around organ donation and transplantation. For more information, visit www.ThePowerOfTwoMovie.com.
Stay Healthy During Cold and Flu Season

By Mary Lester, R.R.T., Medical University of South Carolina in Charleston, special contributor

Winter is fast approaching, which means shorter days, chilly weather and cold and flu season. For people with CF and their caregivers, increased awareness and preparedness for this time of year is important for helping maintain lung health.

Below are several ways you can help stop the spread of germs and stay as healthy as possible during the winter months:

• The most important way to minimize the spread of germs is through **good hand washing**. This can be accomplished by using soap and water or bottled hand gels that contain at least 60 percent alcohol. Dirty hands that come in contact with the mucus membranes of the mouth, nose or eyes are the number one way that germs are spread.

• Another preventive measure includes **practicing proper and safe coughing techniques**. Everyone should be taught to cover their nose and mouth when coughing and sneezing and to wash their hands afterward. The flu virus spreads from person to person by coughing, sneezing or talking to someone with the flu.

• The flu virus can also spread when people touch something with the virus on it. **Clean public surfaces with sanitizing wipes** prior to their use (such as computer keyboards) and always provide children with tissues and hand sanitizer to use at school.

• **Keep all respiratory equipment cleaned and disinfected** prior to use to stop the spread of germs for people with CF. All nebulizer cups should be washed in hot soapy water and disinfected after every use.

There are several ways to disinfect equipment. You can place nebulizer parts in a pot of boiling water for 5 minutes, use a baby bottle sterilizer or disinfect them in a dishwasher if it reaches 158°F. Check with your CF center staff to find out about other disinfection methods and develop a plan that works best for your household.

According to the Centers for Disease Control (CDC), flu season peaks in January and February. It is recommended that people with lung disease and their caregivers should receive a flu vaccine as soon as they become available. If you haven't received the vaccine yet, contact your CF center today.

So let's all load up with hand sanitizer, be super diligent about cleaning respiratory equipment and clean our hands after coughing and sneezing so we can have a mild flu season this year!

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Learn More about Living with CF as an Adult

The CF Foundation has launched a new section of its website created specifically for adults with CF: [www.cff.org/Adults](http://www.cff.org/Adults).

This continually expanding, one-stop resource provides accurate information and practical advice on all aspects of living with CF, such as working with the CF care team and using the right therapies, and also offers insights from other adults with CF.

The Adult Guide is written by people with CF and CF health care professionals and aims to give the reader the “big picture” along with key takeaways on a range of topics in an easy-to-read format.

Topics include:
- Respiratory
- Nutrition
- Gastrointestinal
- Germs
- Insurance and Finances
- Social life/relationships
- Daily work/school life
- New diagnosis
- Transplantation
- Other health issues

If you are interested in contributing to the guide, please contact resources@cff.org.
How I Combat Feelings of Isolation During the Winter Months

By Joan Finnegan Brooks, special contributor

The winter months are here again and, for people in northern climates, it heralds a season when the activities we enjoy during the warm months either stop completely or change significantly. As a result, many of us find ourselves feeling more isolated during this time of year.

Although I’ve lived through the cold winters of New York and New England my whole life, I must admit that I’m facing this season with some uneasiness.

While I suspect this stems partially from the difficult winter I had last year, I also dread the feelings of withdrawal from seeing less of the people whom I spend time with in the warmer seasons for activities like biking and running. Winter weather forces most of those activities inside, dispersing us to different gyms and fitness clubs.

It’s also the time for cold and flu season. As I’ve grown older, I find I am much more selective and deliberate in deciding whether to go somewhere that may be crowded. I try to go to public places like the grocery store, gym or shopping mall during off-hours to reduce my chances of contracting viruses. While this helps me avoid catching a cold or the flu, it also adds to the feeling of isolation.

To avoid this, it’s important to have plans to stay connected to friends despite the weather and flu season and find activities that everyone enjoys. I try to schedule social time with friends and family in small groups at one of our homes. Since they are aware of my challenges with CF, they let me know ahead of time if anyone is sick with a cold, giving me the opportunity to control my exposure to sickness.

I also try to plan vacations and other fun activities to look forward to and set fitness goals for myself. This year I’m focusing on building endurance and strength. Exercise is key to keeping our lungs clear and contributes to our general sense of well-being. Although it’s tempting to skip taking a brisk walk or going to the gym when the weather isn’t very nice, I’ve learned that doing so doesn’t help my body or my spirit. Regular physical activity helps combat depression and feelings of isolation, and generally boosts my mood and attitude.

While it can be challenging to prevent feelings of isolation during winter, staying engaged in activities that you enjoy and taking extra precautions for keeping healthy will make the season pass more quickly.

Joan Finnegan Brooks, a 52-year-old market research consultant with CF, can be reached at joanfbrooks@p-fmr.com or 617-312-0931.

Live Webcast Available Soon: “New Horizons for CF Research”

The Foundation recently hosted the CF Education Day webcast, New Horizons for CF Research, featuring Steven M. Rowe, M.D., M.P.H., from the University of Alabama, who presented a summary of his North American CF Conference plenary presentation, “Reversing the Basic Defect: A Vision for the Future.”

Dr. Rowe was joined by the CF Foundation’s Robert J. Beall, Ph.D., Preston W. Campbell, III, M.D., and Bruce C. Marshall, M.D., who talked about current CF research and new drugs on the horizon. They also answered questions from the CF community during the live December 13th broadcast.

Check back in January to watch the archived two-part webcast at www.cff.org/LivingWithCF/Webcasts under the “Research” section.

Watch New Webcasts Online

New webcasts on the CF Foundation’s website explore lung transplantation, clinical research, quality improvement in CF care, infant care and CF diagnosis in adulthood:

• Partnering for Improvement of CF Care
• CF Infant Care: The First Year of Life
• CF Diagnosis in Adulthood Lung Transplantation: Risks, Benefits and Care
• What Might Happen in a CF Clinical Trial
• Behind the Scenes of a CF Clinical Trial
• Thinking about Joining and Enrolling in a CF Clinical Trial
• The CF Clinical Trial Is Done, Now What?

View these and other webcasts on the CF Foundation’s website at www.cff.org/LivingWithCF/Webcasts.