

# Network News

A Publication for the CF Foundation's Care Center and Clinical Research Networks

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| Adding *tomorrows* every day.

## New Study Compares Aerosol Characteristics of Nebulizers

By David Geller, M.D., director, pediatric CF center, Nemours Children's Health System, Orlando, Fla.

There are a number of inexpensive, portable aerosol delivery systems on the market that may appeal to CF patients.

A recent study compared the aerosol characteristics of the "gold standard" PARI LC<sup>®</sup> PLUS nebulizer with the Omron CompAir<sup>®</sup> Elite, a battery-operated, portable jet nebulizer, as well as with the Home Aide Ultra Neb<sup>™</sup> nebulizer (Model CE-331), a portable, perforated-mesh nebulizer.

In the aerosol lab, researchers tested the delivered dose, droplet size, calculated lung dose and treatment time in the PARI LC PLUS run with a Proneb<sup>®</sup> Ultra compressor. They did the same tests in the Omron CompAir Elite and the vibrating mesh nebulizer from Advanced Health Care when run with albuterol inhalation solution.

Results suggest that the dose of drug most likely to reach the lungs was remarkably similar in the three aerosol delivery systems.

- The PARI LC PLUS, despite having the highest dose left in the nebulizer, achieves efficiency by being a breath-enhanced nebulizer that reduces drug loss during exhalation.
- The Ultra Neb mesh device had a very low residual dose in the medication reservoir, and similar particle size to the LC PLUS, but other inefficiencies in design meant a slightly longer nebulization time.
- The Omron CompAir Elite uses a small, portable, battery-operated compressor, which should be less forceful than the Proneb Ultra compressor with a longer nebulization time (about 5½ minutes longer than the LC PLUS). Despite having a lower total inhaled dose, the Omron produced a median particle size that was smaller than the LC PLUS, which was very surprising. Thus, when calculating the expected lung dose, the Omron came out the same as the other devices.

In summary, for the parameter that matters the most — expected lung dose — all three systems were equivalent.

The PARI LC PLUS was the fastest device, while the Omron and Ultra Neb are very portable. These results may differ if a drug with different physicochemical properties (viscosity, surface tension) is used — for example, albuterol or dornase alpha, which are effective at low doses and do not show much dose dependence beyond a minimal amount. Further testing would be necessary for other drugs, like TOBI<sup>®</sup>, that differ in fill volume and viscosity.

If patients decide to substitute these devices for the LC PLUS, they may experience similar clinical benefit. Care center staff are urged to share this information with patients when determining which nebulizer is best for specific medications.



## Foundation Launches New Patient Assistance Resource Library

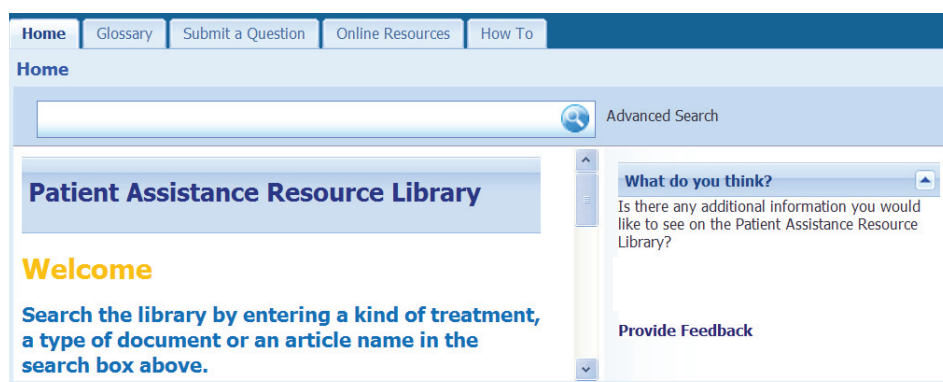
The CF Foundation recently launched the [Patient Assistance Resource Library](#) on its website. The CF community can now use this unique library's online resources when faced with health care coverage and reimbursement challenges.

The information includes:

- Sample letters of medical necessity and prior authorization
- How-to guides for navigating common insurance obstacles
- Templates for insurance appeals and exceptions
- CF care guidelines
- Medical journal articles
- White papers for medical professionals

Visit the library at [www.cff.org/LivingWithCF/AssistanceResources/Library](http://www.cff.org/LivingWithCF/AssistanceResources/Library).

If you have materials that you would like to add to the library, please contact Maria Thomas at [mthomas@cff.org](mailto:mthomas@cff.org).



## Teams Share QI Knowledge and Skills at NACFC

Four teams that recently completed the QI Self-Study Program shared their work in a collaborative meeting at the 2011 North American Cystic Fibrosis Conference in November.

The self-study program enables CF care teams to either start their quality improvement initiatives or refresh their knowledge and skills of QI as they launch new initiatives. Participating teams work with a CF Quality Coach — a member of a previous collaborative who has been trained to coach.

For more information, please contact [Kathryn.A.Sabadosa@Dartmouth.edu](mailto:Kathryn.A.Sabadosa@Dartmouth.edu).

### Self-Study CF Care Team

Saint Barnabas, Livingston, N.J.

University of Michigan, Ann Arbor, Mich.

Joe DiMaggio Children's Hospital, Hollywood, Fla.

Mary Bridge Children's Hospital, Tacoma, Wash.

### CF Quality Coach

Bob Zanni

Albin Leong

LaCrecia Britton

Judy Hollingsworth

## Second Adult QI Collaborative to Convene in January

The Adult Quality Improvement collaborative (AQI2) will convene in January 2012 at the University of Minnesota for a two-day benchmarking site visit. Jordan Dunitz, M.D., and his team will open their adult program to observation by the 13 adult care teams and 10 CF Quality Coaches participating in AQI2.

In addition to observing care processes in the CF adult clinic, teams will participate in sessions on survey design, co-designing care with people with CF and their families, effective strategies for inpatient and home care and advanced measurement for improvement.

For more information about the AQI2 site visit, contact [Kathryn.A.Sabadosa@Dartmouth.edu](mailto:Kathryn.A.Sabadosa@Dartmouth.edu).

## New Bulletin Covers Top CF Policy Issues

The CF Foundation recently launched [The Cystic Fibrosis Policy Bulletin](#), a targeted, easy-to-read summary of the major policy issues important to CF care and treatment.

Available in the [Advocacy section](#) on the CF Foundation's website and issued quarterly, this bulletin provides up-to-date information on such topics as Medicare, Medicaid, health reform, federal and state budgets, as well as how changes impact the care and coverage available to people with CF.

If you have information on policy changes or would like to receive quarterly issues of *The Cystic Fibrosis Policy Bulletin*, please contact Jackie Erdo ([jerdo@cff.org](mailto:jerdo@cff.org)).

## Awards Showcase Partnerships Between Chapters and Care Centers

CF Foundation care centers and chapters nationwide worked hard this past year to build partnerships and fulfill the Foundation's mission: "To assure the development of the means to cure and control cystic fibrosis and to improve the quality of life for those with the disease."

Each year, local chapter staff members nominate care centers to be recognized as fundraising partners. This year's recipients are:

### Outstanding Partnership Award

- Emory University CF Center and affiliate program at Children's Hospital of Atlanta – Scottish Rite (Georgia Chapter)
- Johns Hopkins Cystic Fibrosis Center (Maryland Chapter)
- Lewis H. Walker CF Center, Akron Children's Hospital (Northern Ohio Chapter)
- Medical University of South Carolina Cystic Fibrosis Center (South Carolina Chapter)
- Primary Children's Medical Center Intermountain CF Center, University of Utah Health Sciences Center (Utah/Idaho Chapter)

### Fundraising Innovators of the Year Award

- University of North Carolina at Chapel Hill (Carolinas – Raleigh Chapter)
- Children's Memorial Hospital & Northwestern University (Greater Illinois – Chicago Chapter)

Congratulations to these centers and thank you to all CF care centers for your continued commitment to our shared goals.

To learn more about these awards, contact your [local CF Foundation chapter](#).

## Give a Warm Welcome to the Newest Member of TEAM CF — Chris Dowd



Please join us in welcoming Clinical Research Program Manager Chris Dowd to the CF Foundation's clinical affairs group. In this new role, Chris will be working to move Phase 4 clinical trials forward in an expeditious manner.

Chris previously worked for PMG Research, Inc., a private clinical research company in North Carolina, as a clinical research coordinator and then as the manager of clinical operations.

In his free time, Chris is an avid traveler. To date, his passport boasts such destinations as Vietnam, Cam-

bodia, Scotland, Italy and Mexico, and a trip to Peru is currently in the works. He considers himself a die-hard fan of both the New York Giants and Yankees.

When asked what drew him to the CF Foundation, Chris responded: "I wanted to be a part of this team that is dedicated to making a real difference in peoples' lives. My role is just a small part, but I feel I can make a real contribution to getting better/more efficacious/higher-quality therapeutics to the market (hopefully quicker) and to people who need them the most."

### Public Data Preview Period Quickly Approaching

Preparations are under way for the upcoming release of public data on [www.cff.org](http://www.cff.org). Data reported to the public will be updated to reflect current CF Foundation Care Guidelines.

Care centers will receive an email detailing the data preview period as well as planned changes. The data preview period will allow each center to review its adjusted data prior to it being made public. For more information, contact [CenterReporting@cff.org](mailto:CenterReporting@cff.org).

### Got Education Materials?

The CF Foundation's Education Committee will begin its 2012 submissions in January. Centers seeking the committee's review and potential approval of education materials can submit materials January 1 through March 31. Feedback will be given in July.

For more information, refer to the "Submission for Review Guide" in PortCF Resources: Education/Education Committee folder.

### New CF Family Education Program Module Available

The newest module of the CF Family Education Program, "Lisa and Jason: Family, Friends, and Everyday Life," is now available. This module uses stories, games and activities to help preschool children learn the basics of CF.

To order a hard copy, email your name, street address, phone number and quantity to [resources@cff.org](mailto:resources@cff.org). There is a maximum of 20 books for all orders. The module and additional game pieces are also available in PortCF Resources/Education/CF Family Education Program folder.



## New Webcasts Now on [www.cff.org](http://www.cff.org)

If you missed the most recent live webcast on CF-related diabetes, or would like to see it again, you can now find it on the Foundation's website.

The CFRD webcast series features Antoinette "Toni" Moran, M.D., and Carol Brunzell, R.D., C.D.E., of the University of Minnesota, who discussed "[Diagnosis and Screening](#)," "[Daily Management](#)" and "[Illness, Transplant and Pregnancy](#)." Additionally, "[Living with CFRD](#)" features Tim Tolaas, an adult with CF and CFRD, who spoke about how he manages CFRD on a daily basis.

Other newly released webcasts include:

- [Constipation and DIOS](#). Learn about symptoms of constipation and DIOS (distal intestinal obstructive syndrome), treatments and the latest research.
- [GI Overview: Stomach and Pancreas Problems in CF](#). Learn about stomach and pancreas problems, such as pancreatitis, gas and bloating, small bowel overgrowth, gastroparesis and GERD (gastroesophageal reflux disease).
- [CF Liver Disease](#). Learn about staying healthy and what causes CF liver disease.

For a complete list of archived webcasts, visit the Webcast Library at [www.cff.org/LivingWithCF/Webcasts](http://www.cff.org/LivingWithCF/Webcasts).

## Care Centers Recognized for QI Commitment

At this year's North American Cystic Fibrosis Conference, 11 care centers were honored with a 2010 – 2011 Quality Care Award, which recognizes sustained quality improvement work that helped achieve better health outcomes for people with CF:

- Long Beach Memorial Medical Center, Adult Program
- Yale University
- Helen DeVos Children's Hospital, Pediatric Program
- Monmouth Medical Center
- [Steven and Alexandra Cohen Children's Medical Center of New York/Long Island Jewish Medical Center](#)
- Akron Children's Hospital
- Cincinnati Children's Hospital Medical Center/University of Cincinnati University Hospital
- Nationwide Children's Hospital
- Children's Hospital of Philadelphia, Pediatric Program
- Children's Hospital of Pittsburgh of UPMC/University of Pittsburgh Medical Center
- Seattle Children's Hospital/University of Washington Medical Center

Recipients of this year's awards were chosen by the CF Foundation Center Committee from the care centers visited in fall 2010 and spring 2011.

The Foundation instituted the Quality Care Awards in 2008 to honor centers that excel at



*Continued on page 5*

## FDA Releases Updated Warning for Reclast

The FDA released an update to the Reclast (zoledronic acid) label regarding the risk of kidney failure. The revised label states that Reclast is contraindicated in patients with creatinine clearance less than 35 mL/min or in patients with evidence of acute renal impairment. The label also recommends that health care professionals screen patients prior to administering Reclast to identify at-risk patients.

For more information, visit <http://www.fda.gov/Drugs/DrugSafety/ucm270199.htm>.

## Report Adverse Events and Side Effects to the FDA

Health care professionals and patients are encouraged to report adverse events or side effects related to the use of drugs and other medical products to the FDA's MedWatch Safety Information and Adverse Event Reporting Program.

Filing a report is easy:

- Complete and submit a report at [www.fda.gov/MedWatch/report.htm](http://www.fda.gov/MedWatch/report.htm).
- [Download a form](#) at the MedWatch site or call 1-800-332-1088 to request a form, then complete and mail to the address on the pre-addressed form, or fax to 1-800-FDA-0178.

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## CF Foundation Pushes for Access as States Review Preferred Drug Lists

States periodically review drugs on their Medicaid preferred drug lists. These include all pancreatic enzymes and coverage of inhaled antibiotics, specifically Cayston®.

It is essential for CF care centers to engage with state review committees. Linking CF care center physicians with state review committees has resulted in fewer restrictions for Medicaid patients, and less bureaucratic burden for care center staff.

When the CF Foundation learns of drug reviews, we will ask for help to address the committees and to testify on behalf of people with CF. Typically, attending a review meeting requires very little time commitment and the Foundation will provide assistance throughout the process.

Please contact Jason Ranville at [jranville@cff.org](mailto:jranville@cff.org) if you learn that a state review committee is holding a hearing on enzymes or CF-related drugs.

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## Care Centers Recognized Cont. from pg. 4

meeting the following quality improvement performance standards:

- Actively uses clinical outcomes data to identify opportunities for improvement and documents results of improvement efforts.
- Aligns improvement efforts to result in measurable improvement in important clinical outcomes.
- Consistently and actively involves patients and families in identifying, designing and/or implementing improvement efforts.
- Employs innovative strategies to improve care processes and outcomes.
- Implements system changes that result in high reliability of care processes.

Learn more and view photos of the awardees in the [News and Events](#) section on the CF Foundation's website.

### "CF Infant Care: First Year of Life" DVD Now Available

The new DVD "CF Infant Care: First Year of Life" features CF parents sharing personal stories about how they cared for their infant during the first year, as well as perspectives from CF care team members. The parents talk about how they manage nutrition, giving enzymes and doing chest PT and how they balance life with the demands of CF care.

To order a hard copy, send your request to [resources@cff.org](mailto:resources@cff.org) and provide your name, street address, phone number and quantity. There is a maximum of 20 DVDs for all orders.

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### Mandatory Managed Care May Limit Patient Access

As states seek to cut health care costs, some are transitioning Medicaid beneficiaries from a more traditional fee-for-service structure into managed care. The Foundation is concerned that some patients have had difficulty getting coverage for their prescribed treatments or accessing their care center.

If you hear of patients who are no longer able to get their medications or use their care centers due to a change in their public insurance plans, please contact Jason Ranville at [jranville@cff.org](mailto:jranville@cff.org) or 301-841-2617.

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