

# Network News

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

SUMMER 2015

## Table of Contents

Clinical Research Resources	2
OneCF Center Update	2
CF by the Numbers	3
Recruiting Adult and Family Advisors	3
Publication Watch	4
Town Hall Webinars	4
Updated CFRD Manual	4
Registry Roundup	5
Mentorship Work Group	5
President Highlights CF Advances	6
Meeting to Improve CF Care	6
Clinical Trials Legislation	6
Clinical Care Guidelines Update	7
State-Level Advocacy	7
In the Spotlight	7
Achievement Awards Recipients	8
Care Model of the Future Update	8
Award Program Deadlines	9
Great Strides	9
Important Fundraising Reminder	9
2015 NACFC News	10
Golf Events	10
Cycle for Life Events	10
CF Finest Events	10
Communications to Patients and Families	11
Patient Resources Update	11



The multidisciplinary team at the Cystic Fibrosis Center at Women and Children's Hospital of Buffalo

## Integrating Mental Health Screening into CF Care: One Center's Successful Approach

Care teams are preparing for the publication of the recommendations for depression and anxiety screening by strategizing about ways to effectively integrate mental health screening into CF care.

The care team at Women and Children's Hospital of Buffalo, N.Y., has successfully prepared for the recommendations by developing treatment algorithms, referral patterns and educational materials. The team also developed a guide for depression screening in CF centers that is being adapted as a supplement to the CF Foundation and European Cystic Fibrosis Society's (ECFS) mental health guidelines.

The secret, according to the center's psychiatrist, Beth Smith, M.D., is the involvement of the entire team in the screening process. "Our motto is, 'it takes a village,'" Smith says.

### Putting a Process in Place

The first step toward implementation was to ensure that all team members received baseline knowledge about depression, its prevalence in CF and its effect on disease management and health outcomes.

By acknowledging a shared belief that screening for depression is important for the health and well being of their patients, the multidisciplinary team had full ownership. This enabled them to better support each other through the process and, in turn, successfully implement mental health screening.

Continued on page 2

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The team created a plan that identified which person would conduct the screens, score them, respond to positive screens and enter the data into the charting system. The knowledge and skills needed to effectively carry out the new roles were clearly outlined, helping the team assign the new roles to the appropriate team member.

### Barriers to Implementation

The team was originally concerned that the additional time required for mental health screening would pose a barrier to implementation. However, this concern dissipated after the planning phase. "Prior to the start of screening, we had strategic meetings to establish protocols and to determine the most efficient way to screen in our busy center," explains Dr. Smith. Once the screening process began, the team found that clinic time and flow was not disrupted.

Many thanks to the team at Buffalo for developing and sharing their resources to help other care centers implement mental health screening. These tools will be posted on PortCF when the recommendations are published. Feel free to contact any member of the Buffalo team with questions on implementing a similar screening process at your center:

Carla A. Frederick, M.D.  
Lynn M. Fries, P.A.-C., M.P.A.S., D.P.T.  
Danielle M. Goetz, M.D.  
Kimberly Rand, L.M.S.W.  
Christine M. Roach, R.N., B.S.N.  
Beth A. Smith, M.D.

[cfrederick@upa.chob.edu](mailto:cfrederick@upa.chob.edu)  
[lmfries@buffalo.edu](mailto:lmfries@buffalo.edu)  
[dgoetz@upa.chob.edu](mailto:dgoetz@upa.chob.edu)  
[krand@upa.chob.edu](mailto:krand@upa.chob.edu)  
[croach@upa.chob.edu](mailto:croach@upa.chob.edu)  
[balucas@buffalo.edu](mailto:balucas@buffalo.edu)

### OneCF Center Update

The second OneCF Center Learning and Leadership Collaborative (LLC2) kicked off in November 2014 and will run until March 2016.

Six teams and six quality coaches convened as a group in Baltimore for a face-to-face meeting with teams from the first OneCF Center LLC, and coaches have conducted a site visit with their participating teams. Teams will travel to the University of Minnesota in June 2015 and the groups will convene again at the 2015 North American CF Conference.

For more information, please email Margie Godfrey at [margiegodfrey@gmail.com](mailto:margiegodfrey@gmail.com).

### Clinical Research Resources

Never before in the history of CF have there been so many research opportunities. This year, nearly 20 clinical trials will be conducted across all categories of the pipeline. This means that 2,500 people are necessary to reach target enrollment for these upcoming trials.

#### You Can Help!

Please spread the word about the many opportunities to participate in CF clinical trials using the using the **I am the Key** materials. You can order these materials via [resources@cff.org](mailto:resources@cff.org).

The Foundation also has many great online resources for people interested in clinical research:

- **Clinical Trial Search Tool:** Conduct a tailored search for clinical trials based on various fields
- **Drug Development Pipeline:** See the status of drugs currently in the pipeline
- **Clinical Trial Email Alert:** Receive an email notification of all new trials posted

If you have any questions, please email Christina Román at [croman@cff.org](mailto:croman@cff.org).

## Patient Registry Data: CF by the Numbers

### Associations Between Anxiety and Depression with CF Outcomes

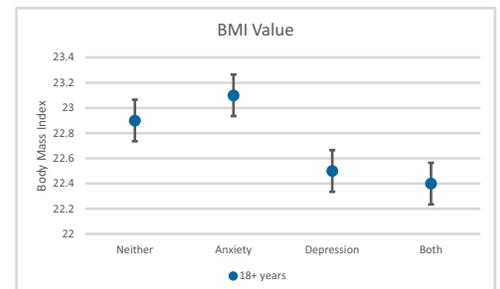
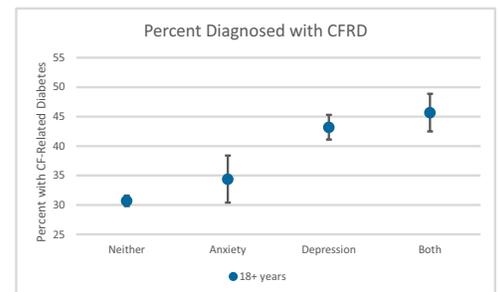
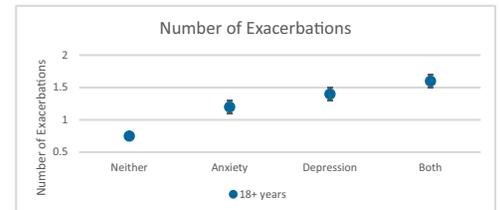
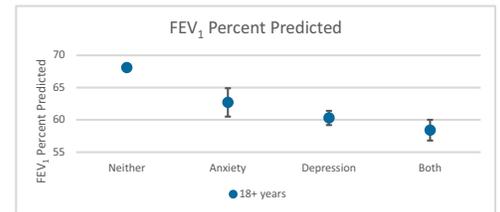
The interdependence of physical and mental health has been well established. The association between these domains in individuals with CF was assessed by evaluating health outcomes by age and by whether anxiety, depression or both were documented as complications.

In pediatric patients, documentation of anxiety, depression or both was 1 percent, 2 percent and 0.5 percent, respectively; in adult patients, it was 4 percent, 15 percent and 7 percent, respectively. The true prevalence of anxiety and depression may be underreported due to the variability of mental health screening protocols.

The figures to the right show the data for adults with CF. Similar patterns were observed in pediatric patients. Patients with any indication of a mental health disorder had lower FEV<sub>1</sub> percent predicted, more exacerbations and lower BMI and were more likely to have CF-related diabetes (CFRD).

Overall, depression appears to have a more significant impact on outcomes than anxiety. This cross-sectional look at the data does not allow us to attribute causality or disentangle the direction of the effect — e.g., does depression lead to more CFRD or does CFRD result in depression? Nonetheless, these data do highlight the importance of considering both physical and mental health in the care of individuals with CF.

If you are interested in obtaining aggregate or record-level data from the Foundation’s patient registry, please email [datarequests@cff.org](mailto:datarequests@cff.org). If you have any questions about this figure or using patient registry data for research, please contact Aliza Fink at [afink@cff.org](mailto:afink@cff.org).



### Recruiting Volunteers: CF Adult and Family Advisors Program

Help us get the word out! The CF Foundation is still looking for volunteers to provide input and feedback on a variety of projects and topic areas. If you know a person within the CF community who may be interested in providing his or her unique perspective on CF care, research or quality of life, please refer them to the CF Adult and Family Advisor group.

We have received over 145 applications since the beginning of the year and are looking forward to furthering our collaboration with the CF community.

The application link will be sent to clinic coordinators and center directors, so keep an eye out! For more information about this recruitment process or the projects and topic areas we are recruiting for, please email [communityaffairs@cff.org](mailto:communityaffairs@cff.org).

## Publication Watch

This column highlights recently published work derived from the Foundation's care center network or patient registry data. We congratulate the authors of these manuscripts and sincerely thank the many contributors who made this work possible.

### Development and Evaluation of a Palliative Care Curriculum for Cystic Fibrosis Healthcare Providers

Linnemann RW, et al.

*Journal of Cystic Fibrosis*, in press, available online March 25, 2015

This single-center study reports on the impact of a newly developed palliative care curriculum tailored to the nuances of CF. Using a pre- and post-training survey, researchers found that the 18-hour, CF-specific palliative care training was well received by CF health care providers and significantly improved self-assessed comfort with core skills, including the use of supportive care resources, pain management, non-pain symptom management, communication and psychosocial skills.

### Air Contamination with Bacteria in Cystic Fibrosis Clinics: Implications for Prevention Strategies

Zuckerman JB, et al.

*American Journal of Respiratory and Critical Care Medicine* 191.5 (2015): 598-601.

This study assessed the contamination of air with bacteria in exam rooms and spirometry rooms at seven CF Foundation-accredited care centers across the country. Environmental samples were compared to respiratory culture results from 308 subjects with CF ages 6 years and older. Air contamination was most frequently observed in association with spirometry, with a trend towards higher cough frequency at those encounters with documented air contamination. These findings support the greater emphasis on mitigating safety risks in PFT labs in the recently published Infection Prevention and Control Guidelines.

### Experience of Care From the Perspective of Individuals with Cystic Fibrosis and Families: Results from 70 CF Foundation Accredited Programs in the USA

Homa K, et al.

*Journal of Cystic Fibrosis*, in press, published online Jan. 30, 2015

This study reports the aggregate findings of an experience of care survey deployed at 40 pediatric and 30 adult Foundation-accredited CF programs in the U.S. Twenty-nine percent of potential respondents completed the survey, for a total of 2,090 people. Both adults with CF and parents of children with CF reported the same five positive attributes of experience of care: courtesy and respect shown, easy to understand explanations, involved in decision-making, their questions were answered and enough time with providers. Potential areas for improvement included assessing mental health and improving patient hospital staff's knowledge of CF. Results of this study suggest that the experience of care survey will provide a means to systematically collect and learn from individuals with CF about their impression and observations of CF health care delivery.

*Continued on page 5*

## Town Hall Webinars

Thank you for your enthusiastic response and positive feedback regarding our care center town hall webinars. This format has proven to be an effective way to communicate about exciting initiatives and programs available to the CF community, and we look forward to sharing more information with you in the next webinar on June 4.

Invitations to the town halls are sent via email to all center directors, coordinators and listservs. All team members are invited to join and encouraged to submit any questions they may have. [Watch the March 3 town hall here.](#)

If you have any questions, email Paula Lomas at [plomas@cff.org](mailto:plomas@cff.org).

## Now Available: Updated CFRD Manual

The 6th edition of the [Managing Cystic Fibrosis-Related Diabetes](#) manual is now available to download and order. The manual is a guide to treatments and daily management of CFRD for people with CF and their families.

To view the manual on PortCF, go to the PortCF "Resources" tab, then click on the "Education/Nutrition" folder.

To order a hard copy, send your request to [resources@cff.org](mailto:resources@cff.org). Please provide the name of the resource, your name, street address (including building/room number), phone number and quantity requested.

Continued from page 4

### Cystic Fibrosis Foundation and European Cystic Fibrosis Society Survey of Cystic Fibrosis Mental Health Care Delivery

Abbott J, et al.

*Journal of Cystic Fibrosis*, in press, published online Jan. 12, 2015

The CF Foundation and ECFS mental health guidelines committee sought input from care center personnel to assess the current provision and barriers to mental health care. Many centers reported not having someone on staff trained in mental health issues and 20 percent had no one on their team whose primary role was focused on assessing or treating these issues. Insufficient resources and a lack of competency were reported in relation to mental health referrals. Seventy-three percent of respondents had no experience with mental health screening.

### Prevalence of Symptoms of Depression and Anxiety in Adults With Cystic Fibrosis Based on the PHQ-9 and GAD-7 Screening Questionnaires

Quon B, et al.

*Psychosomatics*, in press, published online June 1, 2014

The investigators of this study conducted at a single large Foundation-accredited adult program used the Patient Health Questionnaire – 9 (PHQ-9) and General Anxiety Disorder – 7 (GAD-7) survey to screen their patient population for depression and anxiety, respectively. Based on the “symptom definition” (moderate-to-severe symptoms as defined by > 10 on the PHQ-9 or GAD-7 survey), 15 of the 153 patients (10 percent) had clinically-significant depression or anxiety symptoms. Using the “composite definition” (i.e. moderate-to-severe symptoms on PHQ-9 or GAD-7 or the long-term and active use of psychiatric medications for the treatment of depression or anxiety), 42 of 153 patients (27 percent) had clinically-significant depression or anxiety symptoms, and seven patients (5 percent) had evidence of co-morbid, clinically significant depression and anxiety symptoms. Of the 153 patients surveyed, 5 percent expressed suicidal ideation. This study supports the recommendation in the CF Foundation and European CF Society guidelines on mental health: systematic screening for depression and anxiety using the PHQ-9 and GAD-7 symptom questionnaire.

### Mentorship Work Group

A workgroup has been established to develop a pilot peer-to-peer formalized mentorship program for adults with CF. The workgroup consists of clinicians, Foundation staff and people with CF. We expect to pilot this program early next year. For more information, contact Danielle Lowe at [dlowe@cff.org](mailto:dlowe@cff.org).

### Have Comments?

If you have comments or suggestions for *Network News*, please contact Jackie Thompson at [jthompson@cff.org](mailto:jthompson@cff.org). We welcome your comments and ideas.

## Registry Roundup: Updates to PortCF

A section titled “Mental Health” was added to the 2015 annual review form under “Socioeconomic Status” with the following questions:

- Was the patient screened for symptoms of classic depression using the PHQ-9 or other valid depression screening tools?
- Was the patient screened for anxiety disorder using GAD-7 or a similar tool?

A new field was added in the “Medications” tab of the encounter form to capture open-label combination therapy ivacaftor/lumacaftor (i.e., Kalydeco/VX-809). The corresponding drug frequency responses are Full Dose BID, Half-Dose BID and Other Regimen.

On the “Complications” tab of the encounter form, the functionality that carries forward previously entered complications into the current form was changed to only apply for chronic or permanent complications. For further details, please refer to the PortCF announcements page.

If you have any questions about PortCF or the implemented changes, please email [reghelp@cff.org](mailto:reghelp@cff.org).

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## President Obama Highlights Advances in CF Research

It has been an exciting year for cystic fibrosis advocates across the country. The incredible progress in CF treatments and research was highlighted nationally by President Obama during the 2015 State of the Union address, as well as at an event introducing the White House's Precision Medicine Initiative.

William Elder, Jr., a medical student with cystic fibrosis and long-time advocate for the CF community, was invited to both events. The president shared [Elder's personal story](#) and described the role ivacaftor has played in changing the face of drug development, not just for CF but for many other diseases with an underlying genetic cause.



[Learn more about the Precision Medicine Initiative.](#)

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## CF Foundation Spearheads Meeting to Improve CF Care

On Feb. 4, the Foundation hosted an event for private insurers, state Medicaid officials, care center providers, health experts and people with CF and their families to discuss innovative ways to continue improving the quality of CF care.

The group identified opportunities for greater collaboration, improved utilization of the CF patient registry, supporting access to treatment and care, standardizing improvements to care, and minimizing administrative burdens placed on care center providers and people living with CF.

Various themes, such as the cost of care, the importance of shared accountability among patients, families, providers, payers (including private insurers and Medicaid) and the Foundation, and quality improvement metrics were identified as potential avenues for exploration. Each stakeholder at the meeting agreed that the ultimate goal is effective, quality care delivered in a timely manner.

The CF Foundation will continue to collaborate with payers and providers to find ways to work together to create better patient outcomes and improve the quality of care. [Read more here.](#)

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## Legislation to Remove Barriers to Clinical Trial Participation

The Improving Access to Clinical Trials Act (IACT) is scheduled to expire in October 2015. This important law allows those with rare diseases, like cystic fibrosis, to participate in clinical trials without fear of losing vital health benefits. In response to the pending expiration, members of the U.S. House and Senate have introduced the Ensuring Access to Clinical Trials Act of 2015, which would remove the expiration date from IACT and allow it to become a permanent law.

The bill has not yet been scheduled for a vote, but the Foundation is cautiously optimistic that it will progress successfully through the legislative process. The CF Foundation will continue working with partners in the House and Senate to ensure the bill passes before IACT expires in October.

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## Clinical Care Guidelines Update

### Nontuberculous Mycobacteria (NTM)

The Nontuberculous mycobacteria consensus statements have been submitted to *Thorax* for peer review.

### Screening and Treatment of Depression and Anxiety

The depression and anxiety manuscript is being finalized for submission.

### Clinical Care for Preschool Age (2-5 years old) Children

The committee, chaired by Stephanie Davis and Thomas Lahiri, has reviewed the public comments and has submitted the manuscript to *Pediatrics*® for peer review.

### GI/Nutrition-Related Topics

The enteral feeding committee, chaired by Sarah Jane Schwarzenberg and Amanda Leonard, met for the first time at the end of March. Also meeting for the first time was the colorectal cancer screening committee, chaired by Albert Lowenfels and Alexander Khoruts; they met in April. Consensus statements from both committees are a joint collaboration between the CF Foundation and the American Gastroenterological Association.

For more information about the clinical practice guidelines, contact Sarah Hempstead at [sarah.e.hempstead@dartmouth.edu](mailto:sarah.e.hempstead@dartmouth.edu).

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## Foundation and Care Centers Advocate in States

As state governments across the country began crafting their budget agenda, the CF Foundation reached out to decision-makers to advocate for robust funding for health care programs that help people with CF access specialized CF care and treatments.

State legislators in Ohio, Texas, Illinois, New Hampshire, Oregon, Georgia, Wisconsin, Colorado and New York have been engaged by the Foundation through advocates to protect Medicaid, Children with Special Health Care Needs programs and CF adult assistance programs. This effort will continue in all 50 states.

In addition, the Foundation and care center providers have advocated for open access to life-saving therapies on behalf of people with CF in 20 states this year. Providers and the Foundation have presented both written and oral testimonies before Medicaid's Drug Review programs to ensure all FDA-approved drugs remain on Medicaid's Preferred Drug List.

## In the Spotlight



Chris Kvam, an adult with CF, shared his experience as a member of the mental health task force and international guidelines committee with *Network News*.

"I was invited to join the guidelines committee as a person with CF in 2013. The writing of the guidelines themselves was left to the professionals on the committee, but it was a collaborative process and when I read them, I see my fingerprints on many parts of the end result.

"I viewed my role on the committee as using my personal story to elevate the profile of mental health issues, generate buy-in from clinicians and illustrate the need for resources from the Foundation to enact the guidelines and enable clinicians to provide the best possible care for all people with CF. These issues cannot be ignored, and I am incredibly proud and humbled to have had the chance to contribute to that conversation."

## Three CF Care Professionals Honored with Achievement Awards

The 9th annual CF Nutrition and Social Work Consortium was held in St. Louis, where three CF care center professionals were recognized for their excellence in CF care.

### CF Dietitian Achievement Award

Congratulations to Eileen Potter, M.S., R.D., L.D.N., for receiving the CF Dietitian Achievement Award! Eileen has served as a CF nutritionist, center coordinator and research coordinator at Ann and Robert H. Lurie Children's Hospital of Chicago since 1998. She is active in Foundation initiatives, serving as a CF mentor in the nutrition mentoring program and a member of the adherence project steering committee and patient engagement advisory committee. Additionally, she is the contributing editor for the continuing medical education program, "Cystic Fibrosis @Point of Care." Eileen is known for her expertise in tube feedings, patient- and family-centered care and constipation/distal intestinal obstruction syndrome.



### Social Work Achievement Award

This year, two CF Social Work Achievement Awards were presented. Congratulations to Charlotte Lemming, M.S.W., L.I.S.W.-S., and John Nash, M.S.W., L.M.S.W.!

Charlotte Lemming, of the CF center at the Children's Medical Center in Dayton, Ohio, has been a senior medical social worker for more than 35 years. She is a member of the multidisciplinary pulmonary team that treats patients with CF and asthma, and is also part of the pulmonary treatment team for children with tracheostomies and ventilator support. Charlotte was the psychosocial chair for NACFC and a board member of the Foundation's **Greater Cincinnati/Dayton Chapter**, and is currently the social work representative for the CF patient assistance advisory board.



John Nash has worked as a medical social worker and clinical instructor of pediatrics in Albany Medical Center's pediatric CF and genetics programs since 2001. He has been credentialed as a quality improvement consultant and coach through the Dartmouth Institute Microsystem Academy coaching program, and has provided coaching and education in quality improvement to hundreds of health care team members across the country. John is also a mentor in the Foundation's social work mentoring program and has been active with NACFC in multiple capacities.



## CF Care Model of the Future: Project Update

As mentioned in the Winter 2015 issue of *Network News*, Cincinnati Children's Hospital Medical Center and the Dartmouth Institute are leading a pilot project sponsored by the CF Foundation to co-design a peer-produced Learning Health System. This system would enable individuals with CF, families, clinicians and researchers to collaborate and learn from every interaction, conduct research and implement the findings to produce optimal health.

Since the January meeting at the Foundation's national office, the workgroups have added new members, with 60-plus stakeholders now participating in the design process. An empathy building exercise, "CF for a Day," and ethnography research were also completed. A second meeting was convened in May at the National Office and the design team completed a prioritized roadmap and developed recommendations for pilot testing a CF care model of the future. Look for more details in the next issue.

If you are interested in participating or learning more about the roadmap and pilot testing, contact Michael Seid, Ph.D., at [Michael.Seid@cchmc.org](mailto:Michael.Seid@cchmc.org).

## Upcoming Deadlines: CFF and CFFT Award Programs

Award Program	Letter of Intent (LOI) Deadline	Application Deadline
Research Grant	4/1/2015	9/2/2015
Pilot and Feasibility Grant	4/1/2015	9/9/2015
Clinical Research Award – Fall Cycle	6/15/2015	10/6/2015
Utilizing the CFFT Biorepository to Identify and Validate CF Biomarkers	6/1/2015	9/15/2015
Newborn Screening Quality Improvement Program	-	6/1/2015
Repairing CFTR Genetic Mutations for Research Tools and Therapeutics – Research; Pilot and Feasibility; and Postdoctoral	-	7/15/2015
Delivery Technologies for CFTR Gene Replacement and Repair – Research; Pilot and Feasibility; and Postdoctoral	-	7/15/2015
3rd, 4th, and 5th Year Clinical Fellowships	-	9/2/2015
Postdoctoral Research Fellowship	-	9/2/2015
Leroy Matthews Physician/Scientist Award	-	9/10/2015
Harry Shwachman Clinical Investigator Award	-	9/10/2015
Therapeutic Development Award (Rolling deadline)	1/1/2015 – 10/31/2015	1/1/2015 – 10/31/2015
CFF/NIH-Unfunded Grant Award (Rolling deadline)	1/1/2015 – 10/31/2015	1/1/2015 – 10/31/2015
1st and 2nd Year Clinical Fellowships (Spring 2016 cycle)	-	To be announced.

Applications are accepted [online](#). Locate the listing under “Cystic Fibrosis Foundation” or “Cystic Fibrosis Foundation Therapeutics.” Guidelines may be downloaded on that page by clicking on the document icon next to the program name.

For more information, call the Foundation’s Grants and Contracts office at [301-841-2637](tel:301-841-2637), or email [grants@cff.org](mailto:grants@cff.org) with the name of the program in the subject line.

## Help us Make Great Strides

Calling all CF friends, families, caregivers and companies throughout America: We want you to help us make Great Strides! With walks around the country, you can be a part of the largest and most successful community activity for CF in the world. There is a place for everyone — whether you are a long-time participant or you are interested in organizing your first walk team. Visit [greatstrides.cff.org](http://greatstrides.cff.org) and help us continue to do great things!

## An Important Fundraising Reminder

Please keep in mind when fundraising that, as a care center employee, you should follow the rules and guidelines set by your organization regarding solicitation, patient privacy and other related issues. If you’d like to share a photo of a person with CF that was not provided by the Foundation, it is important to always obtain their written consent prior to using the photo.

Thank you for everything you do to better the lives of all people with CF. We hope to see you at a Foundation fundraiser!

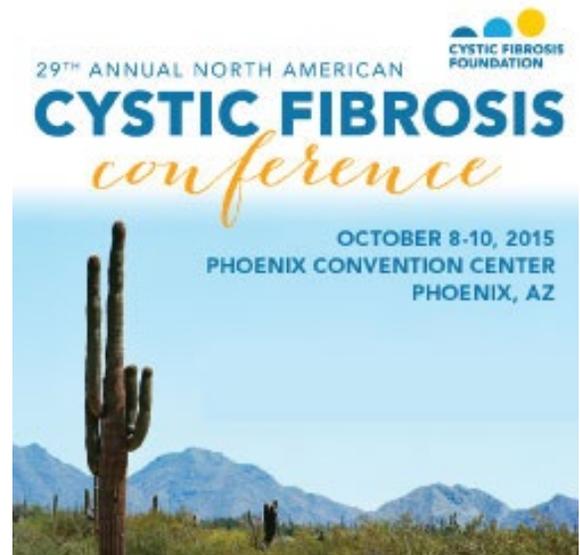
## NACFC News

The 29<sup>th</sup> annual North American Cystic Fibrosis Conference (NACFC) will be held in Phoenix, Oct. 8-10, with pre-conference sessions beginning Oct. 7.

Start planning your adventure to Phoenix. Visit [www.nacfcconference.org](http://www.nacfcconference.org) for information about housing, programming, special classes, short courses and much, much more!

### Mark Your Calendars!

- **Housing will open on June 8.** Register and book your hotel rooms early to ensure your participation in a short course or special class (held Oct. 7), limited attendance sessions and the official conference hotel of your choice! It is critical that you book your hotel room at one of the official conference hotels and through the NACFC housing website to guarantee the CF Foundation's credit for room blocks.
- **Fellows case submission will open on June 15**, and cases must be **submitted no later than July 13**.
- **Registration will open on July 14.** Attendees from the past four years will receive an email notification with registration login information on July 14. If your email address has changed, please send updated information to [nacfc@cff.org](mailto:nacfc@cff.org).



Those who are unable to attend the conference in person will have the opportunity to view the live-streamed plenary sessions and select workshops and symposiums online. For more information about which sessions will be available and how you can join a session, please visit [www.nacfcconference.org](http://www.nacfcconference.org).

For more information, please email [nacfc@cff.org](mailto:nacfc@cff.org) or call **301-907-2513**.

### Like to Golf?

Join the Foundation for a fun-filled day of beautiful courses and friendly competition. Every chapter hosts a golf program; with 70 golf events across the country, there's bound to be an event near you! To learn more, [contact your local chapter](#).

### Actavis + Allergen CF Cycle for Life

Start your own national cycle team by signing up as a national team leader! Teams can consist of co-workers, friends and family members. To learn more visit [cycle.cff.org](http://cycle.cff.org) and click on the "National Team" tab.

### Honor Worthy Young Professionals

Finest events honor up-and-coming young professional leaders. Honorees are selected based on their extraordinary contributions in their place of employment and through philanthropic endeavors in their community. To learn more or nominate a candidate, visit [finest.cff.org](http://finest.cff.org).

## Communications to Patients and Families

### "Share with Those Who Care" Animation

Inspired and informed by the CF Adult Advisory Council, the Foundation released an animation that helps adults with CF explain to family and friends why health reasons may keep them from attending certain social gatherings. **"Share with Those Who Care"** is the third animation in the "Get Germ Smart" educational series.



### Video Release for "Living Today, Adding Tomorrows"

The **"Living Today, Adding Tomorrows"** video series gives a glimpse into the everyday lives of adults with CF and the remarkable people in our community who help add more tomorrows for those with the disease. Following the initial video, which featured Kaitlyn, a 25-year-old whose buoyant spirit helps her overcome personal challenges with the disease, are the stories of 39-year-old Brent, 17-year-old Mara and 20-year-old Rachel.



### 2014 Annual Report

The theme of the Foundation's 2014 annual report — *Courage. Innovation. Focus.* — is a tribute to the collective efforts of the care center teams, researchers, volunteers and people living with CF and their families, to continuously drive improvements in the length and quality of life for those with CF. Copies of the annual report will be distributed to all center directors and can be accessed online at [CFF.org](http://CFF.org).



### Re-Envisioning CFF.org

Coming out of the Foundations's strategic plan to better address the needs and concerns of the CF community is the launch of an expanded and empowering online experience through CFF.org. The site has been re-envisioned based on what we've heard matters most to people living with the disease and how CFF.org can help.



Not only will the site be more intuitive, with an improved search function so visitors have an easier time finding the information they're looking for, it will also support print-friendly pages while delivering a more dynamic experience with the integration of education, news, blogs, community comments, videos and photography.

With a summer launch date, the site will continue to incorporate updates to existing information as new material is created. Select patient resources may not be available at the time of launch, but will be saved on [PortCF](http://PortCF) until the migration of all relevant topics has been completed. For more information, contact Paula Lomas at [plomas@cff.org](mailto:plomas@cff.org).

## Patient Assistance Resource Center Update

### Cystic Fibrosis Patient Assistance Foundation (CFPAF) Expansion

As of May 15, the **CFPAF**, a non-profit organization that provides financial support to people with CF, has expanded its assistance to include all CF-specific, FDA-approved drugs and paired devices. In an effort to make financial assistance available to more people with CF, the maximum amount of assistance that will be provided for each enrollee is \$15,000 per enrollment year. This amount is subject to change upon review and is contingent upon the availability of funds.

### Case Management Help

Did you know the Patient Assistance Resource Center (PARC) helps care centers locate in-network providers, request network exceptions and file appeals? **Contact the PARC** to learn more at **1-888-315-4154**, Monday – Friday, 8:30 a.m. – 5:30 p.m. ET, or email [parc@cff.org](mailto:parc@cff.org).

### Community Outreach

In 2015, the PARC expanded its community outreach efforts to care centers. Through site visits and webinars, the PARC is assessing care centers' needs and providing informational trainings on the Foundation's access programs. For more information, contact Sierra Stites at [ssites@cff.org](mailto:ssites@cff.org).