The Patient and Family Experience of Care Survey offers care teams a glimpse into the care center experience through the eyes of individuals with cystic fibrosis and their families. The survey, developed in 2013 with input from people with CF, their families and health care professionals, helps care teams improve quality of care through insights from patients and families. The University of North Carolina at Chapel Hill pediatric care team has been excited about the data it received from this process.

When team members first heard about this survey, they looked forward to its deployment and what they could learn from their patients and families. They realized that in order to improve the experience of care at their center, they needed to work on what patients and families thought impacted their experience at clinic. The team also felt that families would prefer a survey that asked questions specific to CF.

“The information from the experience of care survey is so helpful,” said Dr. Margaret Leigh at a recent Quality Improvement Learning and Leadership Collaborative meeting. Dr. Leigh told the room of clinician leaders that she liked being able to view the data from their center’s responses to the survey. “The data is displayed in a way that makes viewing quick and easy. In addition to our own scores, we can easily see how we compare to other CF centers.”

The information showed the team areas in which their patients and families felt it excelled, such as rapid response and infection control — both of which team members had worked hard to improve in the past. Survey results also highlighted areas to focus quality improvement efforts in the future.

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The pediatric care team at UNC-Chapel Hill has shared its data within its community in multiple ways: Parent Education Day, combined pediatric and adult team meetings, advisory board meetings and on the data board in its clinical area. The team also plans to share the data in its next newsletter, while also thanking patients and families for taking the time to respond to survey questions.

Care teams can also give their advisory boards access to the experience of care survey data in an effort to partner in the improvement work. Some centers have already used their results to bolster discussions about infection control with their administration.

To have actionable data, teams should submit visit date information at least monthly. Some of the survey questions ask about the patient’s most recent visit; all survey results are reported by visit date. The pediatric team at UNC-Chapel Hill assigned this responsibility to its registry coordinator, who submits data to Quality Data Management (QDM) monthly.

To learn more about Patient and Family Experience of Care Survey deployment or data retrieval, please contact QDM Client Service at 877-QDM-SUPPORT (877-736-7877) or via email at clientservice@qdmnet.com. You can also view CFF webcasts about survey implementation and data retrieval.

A Message from Preston

Dear friends and colleagues,

It is a privilege to have the opportunity to share a few words with all of you in my new role as president and CEO of the Cystic Fibrosis Foundation and at such an exciting time for the CF community.

In the 1960s, when we established the care center network, the median predicted age of survival was 10. Today, people with CF are living well into their 40s and beyond, thanks in large part to your collective efforts and commitment to our shared mission.

I am determined to build on and increase the momentum that our CF care programs have gained under the leadership of Dr. Bruce Marshall and his incredible team here at the Foundation. Not only will we continue adding more tomorrows, but we will also sharpen our focus on improving the quality of living today for all individuals with CF.

Based on what we’re learning — especially from the adults who are changing the face of the disease and experiencing new challenges — we are making significant new investments to support critical programs and ensure care teams are adequately staffed and trained and have the resources they need to provide comprehensive and timely care.

As members of multidisciplinary care teams, you know there is a lot of hard work ahead of us and you also have ideas on how we can best move forward. You can help us understand what you’re learning from your patients, their families and your colleagues, both within the CF community and beyond. Please send any comments or suggestions to info@cff.org.

I am deeply grateful for your dedication, every day, to providing the high-quality, individualized care that makes it possible for people with CF to lead healthy and fulfilling lives.

Sincerely,

Preston W. Campbell III, M.D.
President and CEO, Cystic Fibrosis Foundation

“As an adult with CF, I know the pros and cons of my CF center all too well. The Patient Experience of Care Survey offers the opportunity to give feedback on what works well and what does not … I found that the survey focuses on practical topics ranging from clinic appointments, communication with your care team, cross infection and keeping up with recent CF developments. It also asks about my health, compliance and exacerbations. Completing this survey honestly gives me the chance to help improve the quality of care I receive at my care center.”

– Rich DeNagel, 47
Center Committee Chair Corner

2015 was a busy year for the Cystic Fibrosis Foundation Center Committee. The accreditation process is one of our core functions. Last year we visited 50 programs, a record-breaking accomplishment, and approved core center status accreditation for two affiliate programs: the Geissinger Medical Center in Danville, Pa. and the Greenville Hospital System UMG in Greenville, S.C.

The Center Committee continues to focus on efforts to improve the care of people with CF. Primary areas of focus for this year include:

1. **Strengthening relationships between core centers and affiliate programs:** Currently, 52 affiliate programs provide care for more than 3,300 adults and children with CF. The core centers provide guidance and oversight for their affiliates.

   Based on feedback from center and affiliate directors, we learned that there is a fair amount of variation in this process. To bring greater strength and consistency to this relationship, the updated affiliate criteria require a formal site visit every other year and encourage a reverse site visit on the alternate year for networking and education. The CF Foundation will provide additional resources to support these visits in the upcoming center grants.

2. **Facilitating core center applications for the largest affiliates:** About a dozen affiliates care for more than 80 patients each. Affiliates of this size no longer fit the affiliate model well. With recent changes in the center criteria, most of these affiliates are now eligible to apply for full center status. Over the coming year, the Center Committee will work to facilitate these applications.

3. **Refining the site visit process:** Based on feedback from centers, the committee is planning more advanced notification for site visits (12-18 months) and timelier turnaround for the accreditation decision and evaluation.

Please send any questions or comments for the Center Committee, chaired by Jordan Dunitz, to cffcenterassist@cff.org.

Registry Roundup

The 2015 database will be locked Feb. 29, 2016. Here are a few things to keep in mind as you continue data entry in PortCF:

- Be sure to enter all data for post-transplant patients! Continuing to capture data on these patients is important.
- Enter all hospitalizations and home IV treatments that occurred in 2015 into Care Episodes.
- Enter a death date for individuals who passed away in 2015.
- Complete an Annual Review for every patient seen at your center in 2015.
- Remember to mark all Annual Reviews, Encounters and Care Episodes as complete!
- Review the Grant Criteria for Full Data Sets and Bonuses. This document is available in the Resources section of PortCF.

If you have any questions, please email us at reghelp@cff.org.

CF Foundation Compass Materials Coming Your Way

Helping your patients get and afford care.

CF Foundation Compass is launching later this month. Formerly the Patient Assistance Resource Center (PARC), Compass is our specialized, personalized service that helps you and your patients resolve complex insurance, financial, legal and other issues they may be facing, including getting coverage and benefits and finding resources to pay for CF therapies and medications.

Soon, care centers will receive their Compass Sample Boxes, which include a starter set of Compass pens, magnets, patient brochures and clinic posters, among other items, to help you inform your patients about this important service.

Care centers also can order more materials for free by contacting compass@cff.org.

If you were unable to join our Town Hall, you may learn more about Compass through our recorded webinar.
Creating Partnerships to Sustain Daily Care

In 2012, inspired by the drive and vision to work collaboratively, the CF Foundation partnered with representatives from across the CF community to create a multi-pronged strategic plan addressing the complex issue of adherence to CF therapies. Core components of this program include promoting a national and local dialogue about adherence; establishing objective measures to identify and assess barriers; and designing and testing interventions for sustaining daily care.

To us, involving the community is integrally connected to the successful development, dissemination and implementation of resources in these core components. Since beginning the partnership, we have gained valuable insight from the CF community suggesting changes to the language and approach to conversations about adherence. Based on this input, we have reframed the initiative from “adherence” and “patient engagement” to “partnerships for sustaining daily care.” Through this change in language, we seek to emphasize the importance of non-judgmental problem-solving conversations between care teams and individuals with CF and their families about the CF treatment regimen.

In this issue of Network News, we re-introduce this initiative as the Partnerships for Sustaining Daily Care Program and provide you with an inside look at two pilot projects currently underway. We will continue to update you in future issues of Network News about these and other projects within the program.

Promoting a Dialogue

Designed by individuals with CF and members of care teams across the country, our pilot project tests materials in care centers to trigger conversations between patients and providers about the difficulties in balancing complicated care plans and busy lives. The results from this initiative will inform our efforts to further develop and refine resources for the care centers and individuals with CF to use in these conversations.

The materials were piloted from November-January 2016 at six CF care centers:

- Boston Children’s Hospital/Brigham and Women's Hospital
- Johns Hopkins Hospital
- Lurie Children's Hospital/Northwestern
- National Jewish Health
- University of Kansas Medical Center
- Women & Children’s Hospital of Buffalo

Establishing Objective Measures

Establishing a set of objective adherence measures is an important part of helping people with CF, families and care teams understand how well treatments are completed and sustained in daily life. Because prescription refill data is one widely available objective measure of adherence, the CF Foundation has contracted with Walgreens to pilot the use of their MedGap solution. The MedGap solution displays prescription refill histories in a dashboard, making complicated lines of data easy to understand. Four care center programs are currently using MedGap at the point of care to learn how this data may facilitate communication between people with CF, families and care teams about medication usage.

Our team is excited to continue partnering with members of the CF community in current and future endeavors. Our Partnership for Sustaining Daily Care Program team members are Cindy George, senior director; Chris Dowd, senior program manager; Katherine Raymond, program specialist; and Ali Sue Patterson, senior program coordinator.

We invite your questions and feedback by contacting us at PSDCteam@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.

US Cystic Fibrosis Foundation and European Cystic Fibrosis Society consensus recommendations for the management of non-tuberculous mycobacteria in individuals with cystic fibrosis

R. Andres Floto, et al.
Thorax, published online December 14, 2015
This comprehensive document covers risk factors, screening, microbiology, diagnosis and treatment of NTM pulmonary infections. Read more here.

IV-treated pulmonary exacerbations in the prior year: An important independent risk factor for future pulmonary exacerbation in cystic fibrosis

Donald R. VanDevanter, et al.
Journal of Cystic Fibrosis, published online October 22, 2015.
This report of an analysis of the CF Foundation Patient Registry confirmed that past behavior is indeed predictive of future performance with respect to pulmonary exacerbations. Of the 13,579 patients with 1,2,3, or 4 prior-year exacerbations treated with IV antibiotics, there was a 1.6, 2.4, 3.6, and 6.0 (adjusted) higher hazard of exacerbation versus those without prior-year exacerbation (p<0.0001). This has important implications for study designs that use exacerbations as an endpoint. Read more here.

Improvements in Cystic Fibrosis Quarterly Visits, Lung Function Tests, and Respiratory Cultures

Jamie L. Wooldridge, et al.
Pediatrics, published December 2015, 136(6):1611-6
This report from Cardinal Glennon Children’s Medical Center showed the impact of a multi-pronged quality improvement intervention in increasing number of clinic visits per patient and percent of patients meeting guidelines recommendations for 4 clinic visits, 4 respiratory cultures and spirometries. Read more here.

The 6th edition of the CFRD manual is now available in Spanish! The manual is an introductory guide for people with CF and their families about CFRD diagnosis, treatment and daily management.

To view online: Spanish Version CFRD Manual
To view on PortCF: Go to the PortCF Resources tab, then click on the Education/Nutrition folder.
Please note: Hard copies of the manual are not available. Feel free to download a PDF of the manual from the website or from PortCF.

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**Newborn Screening for Cystic Fibrosis in California**

Martin Kharrazi, et al.

*Pediatrics*, published online November 16, 2015

This comprehensive report of the first 5 years (2007-2012) of newborn screening (NBS) for CF in California is a “must read” for those interested in NBS. With their unique 3-step model (IRT, 40 mutation panel, DNA sequencing), they report a program sensitivity of 92%, positive predictive value of 34% and CF prevalence of 1 in 6,899. Read more here.

**Advance care planning in cystic fibrosis: Current practices, challenges, and opportunities**

Elisabeth P. Dellon, et al.

*Journal of Cystic Fibrosis*, Published online September 8, 2015

This study reports the findings from a chart abstraction of adults with CF who died of respiratory failure between 2011 and 2013. Advanced care planning (ACP) was found to occur late in the course of disease and often during a hospitalization for acute illness. Significant variation in ACP was found across the participating adult CF programs. Opportunities were identified to improve this important aspect of clinical care. Read more here.

**Early Life Growth Trajectories in Cystic Fibrosis are Associated with Pulmonary Function at Age 6 Years**

Don B. Sanders, et al.


This CF Foundation Patient Registry analysis of 6,805 infants born between 1994 and 2005 showed that within-patient changes in nutritional status were significantly associated with FEV1 at ages 6-7. This study reinforces the importance of promoting optimal nutritional status early in the life of individuals with CF. Read more here.

**Baseline Ultrasound and Clinical Correlates in Children with Cystic Fibrosis**

Daniel H. Leung, et al.


This report from the PUSH (Prediction by Ultrasound of the Risk of Hepatic Cirrhosis) study detailed the initial ultrasound findings of 719 enrolled subjects with CF between 3 and 12 years of age. The findings were normal in 82.1%, heterogeneous in 8.9%, homogeneous in 5.7% and cirrhosis in 3.3%. Subjects with an abnormal ultrasound (and matched normal controls for those with a heterogeneous pattern) are currently in the long-term follow-up portion of the study. Read more here.

**Learning and Leadership Collaborative Activities Continue and a Second Fundamentals Collaborative to Start in 2016**

The second OneCF Center Learning and Leadership Collaborative (LLC2) continues with six teams supported by quality coaches. Teams are focused on improving transition and transfer between pediatric and adult care. This Collaborative will close with an in-person meeting in Boston in April 2016.

An additional 15 teams are participating in the Fundamentals LLC, which kicked off in May and continues through October 2016. This group convened an in-person meeting with faculty and quality coaches in November 2015 in Baltimore and will travel for a benchmarking site visit at Boston Children's Hospital in April 2016. Twelve teams are participating in the Virtual Improvement Program, Fundamentals (VIP-F). This first-of-its-kind program kicked off at NACFC and engages teams via asynchronous learning through May 2016.

A second Fundamentals LLC is slated to start in April 2016. Look for a call for applications in early spring. For more information about current and upcoming collaboratives, email Margie Godfrey, Ph.D., at margiegodfrey@gmail.com.
Clinical Care Guidelines Update

Recently published in *Thorax*

Collaboration between the United States and European cystic fibrosis communities has produced two sets of guidelines, both recently published in *Thorax*. The manuscript, including consensus recommendations for management of *Nontuberculosis Mycobacteria*, and its executive summary are available online. Consensus statements for Screening and Treatment of Depression and Anxiety have been available with open access since October 2015.

Supporting the Implementation of Guidelines

The CF Foundation issued a Request for Applications (RFA) for an award for a mental health coordinator in early October. The Foundation received applications from 154 CF programs, more than double what had been anticipated. A multidisciplinary review committee chaired by Beth Smith and Michael Schechter included an adult with CF and parent caregiver.

To fund as many of the applications as possible, the Foundation had asked some programs to share resources within their centers, and decreased the funding requests to small centers. The Mental Health Task Force recommended that a mental health coordinator position be staffed at 1.0 FTE for every 200 patients. This recommendation served as the basis for determining which programs would receive reduced funding. In total, the CF Foundation will be funding a mental health coordinator in 84 programs. Another mental health coordinator RFA will be announced in 2016.

Accepted for publication in *Pediatrics*

The Clinical Care for Preschool Aged (2-5 years old) Children manuscript has been accepted by *Pediatrics*. The care center network will be notified when it is published.

Clinical Care Guidelines in Progress

Interdisciplinary committees, including adults with CF and parents, are busy working on the following consensus statements:

**Enteral Nutrition Consensus Statement**

Sarah Jane Schwarzenberg and Amanda Leonard are chairing this committee. The committee finalized the consensus statement in September and the manuscript has been posted on PortCF for public comment.

**Colorectal Cancer Screening Consensus Statement**

Albert Lowenfels and Alexander Khoruts are chairing the colorectal cancer screening consensus statement committee. The statement is currently under development.

**Diagnosis Consensus Conference**

Philip Farrell, Patrick Sosnay and Clement Ren are chairing the diagnosis consensus conference. The committee met at the North American Cystic Fibrosis Conference to discuss these guidelines and develop consensus statements. The manuscript is in preparation.

For more information about the clinical practice guidelines, contact Sarah Hempstead at shempstead@cff.org.

Adult Peer-to-Peer Mentoring Program

The CF Foundation is developing a peer-to-peer mentorship program for adults living with CF. The program recognizes the knowledge of those living with the disease and their desire to share their experiences in order to help others in the CF adult community.

Phase two of the program development has been completed. The work group was expanded to include five people with CF, six clinicians, one parent and three Foundation staff who were charged with developing a roadmap for the program and the pilot design. The roadmap has been shared with Executive leadership as well as other CF Foundation staff, and we will now be moving to phase three, which includes developing and launching the pilot.

To learn more about the program and pilot phase, please email Aimee Jeffrey Stoian, community support manager, at astoian@cff.org.

**Orkambi™ White Paper Available**

The *Orkambi™* white paper summarizes the current body of evidence around the therapy. This paper and its content can be used to help explain the clinical efficacy, safety and likely benefit of *Orkambi™* to payors.

The CF Foundation will share future versions as research continues.
Co-Production of Care

Low-tech Prototype Testing of a “Co-production of Care” Dashboard

The Dartmouth Institute, in partnership with Ann & Robert H. Lurie Children’s Hospital of Chicago/Northwestern, University of Minnesota and Children’s Hospitals and Clinics of Minnesota, has initiated “low-tech” testing of a “co-production of care” dashboard to be used at the point of care. A rigorous design process included 25 clinicians, parents and individuals with CF from the CF Care Model Design Project, as well as feedback from members of the CF Foundation’s Adult and Family Advisory group. The Dartmouth team, leaders from the CF Foundation and the five participating programs have now “locked down” a version for testing.

This first version of the dashboard captures patient-generated health information and questions or requests for providers; a summary of current health including pulmonary function, nutritional health and overall well-being; and a summary of next steps following a clinic visit and barriers to sustaining daily care. By combining real-time, patient-reported data with clinical data to create the dashboard, providers and individuals with CF can focus on treatment decisions and support self-management. The CF Foundation also will use the dashboard data to enhance information in our Patient Registry.

Each site is currently testing the low-tech coproduction dashboard in the delivery of CF care, using questionnaires and spreadsheets. The Dartmouth team is collecting feedback from the providers and individuals with CF testing the dashboard — how it is used by clinicians and people with CF and their families, and if it is changing their interactions and the individual’s health and providing value. The Dartmouth team anticipates each program will test the dashboard during 20 to 25 clinical encounters and take the lessons and feedback into an IT-enabled prototype testing process in 2016.

Project partner Cincinnati Children’s Hospital Medical Center (CCHMC) continues testing a patient-facing platform for tracking patient-reported outcome measures (Orchestra) and sharing lessons and results with the five programs. The programs and CCHMC also are learning from an international network of programs in Sweden and the U.K. that are testing the coproduction concept.

To learn more about the coproduction project, contact Kathy Sabadosa, M.P.H., at kathryn.a.sabadosa@dartmouth.edu.

CF Adult and Family Advisors (AFA)

In late 2014, we introduced the CF Adult and Family Advisors (AFA), a group created to allow the Foundation and its partners to include more people with CF and their families in programs and initiatives that they are interested in. There are nearly 250 members in the CF Adult and Family Advisors group and we want to thank everyone for helping us grow this past year.

We are always accepting applications. If you know a person within the CF community who may be interested in providing his or her unique perspective about CF care, research and quality of life, please send them the following application link: afasignup.cff.org.

The members of the AFA have been a great source for feedback and knowledge on a variety of topics. We encourage you to utilize the AFA as a resource for different perspectives from adults with CF and their families, and to spread the word to others who may be able to use this group.

To view what the AFA has participated in this past year, please click here for the 2015 Annual Report.

For more information about utilizing the AFA and the recruitment process, please contact Danielle Lowe or Kelsey Fredkin at communitypartnerships@cff.org.
Supporting Patient Participation in Research

A huge thank you to all the care centers that are referring patients for clinical trials! Your time and energy toward this effort is helping move the pipeline forward despite the unprecedented number of studies currently enrolling.

To assist in this process, a document available on CFF.org, Clinical Trials Happening Now, lists all current and upcoming multi-center Cystic Fibrosis Foundation Therapeutics (CFFT)-approved clinical trials. By clicking on the available links, you will find each study’s description and contact information for participating sites.

To compensate care centers for the time involved in supporting referrals, the CFFT has implemented the Clinical Research Referral Support Program (CRRSP). The CRRSP program allows care centers to receive an additional $750 for each patient they referred to a research center who was then enrolled. To be considered “enrolled,” a patient must be randomized into a clinical trial or for an observational study in which he or she participated and provided information beyond the screening visit. To receive this small stipend to your center grant award, information regarding referrals from your care center must be submitted to Patty Burks at pburks@cff.org.

Both the Clinical Trials Happening Now document and the CRRSP program were made available to help people with CF who want to take part in research and give them the opportunity to do so, and to help care centers navigate the process.

For more information or questions about clinical trials, contact Patty Burks at pburks@cff.org.

Lessons from the CF Community to Improve Clinical Trial Enrollment

2015 was the busiest year for CF clinical trials and 2016 looks to be even busier. The Therapeutics Development Network’s projections for 2016 estimate a total of 45 studies with 21 new trials planned. Enrollment projections estimate that 3,500 individuals or about 11 percent of the population with CF will need to participate in studies for adequate enrollment.

With the need for more clinical trial participants in mind, the CF Foundation sponsored a large survey (N=760) in 2015 of adults with CF and parents of children with CF about their perceptions of clinical trials and participation in studies. The survey showed high interest from CF adults and parents in research. This survey, along with follow-up surveys of our CF Adult and Family Advisory group, have also identified ways to improve our clinical trial recruitment efforts.

The Foundation is taking several steps to address the barriers and concerns that emerged from this research. These steps include:

- Redesigning the clinical research tools on CFF.org
- Addressing concerns about safety
- Incorporating the patient voice more in the drug development process
- Supporting referrals with the Clinical Research Referral Support Program

Some steps to move research forward on the local level could include:

- Having the CF doctor be the first to introduce a trial
- Building relationships with nearby sites for referrals
- Talking with all patients about the current developments in research or direct them to CFF.org for more information

To see the full report from the survey or to share ideas about other ways you think the Foundation can support you in recruitment and referral, please contact Christina Román at croman@cff.org.
Update: A CF Collaborative Chronic Care Network

Care Model of the Future

Over the past year, experts from the CF community — people with CF, family members, clinicians, researchers and leadership at the CF Foundation — have been working together to design the CF Care Model of the Future. This care model is envisioned as a system that will make it easier for everyone in the community to work together at scale to improve health, care and costs for people with CF.

The project investigators at Cincinnati Children’s Hospital Medical Center — Michael Seid, Ph.D., Peter A. Margolis, M.D., Ph.D., and Raouf S. Amin, M.D. — have submitted a proposal to the CF Foundation to test the design for the care model in a subset of the CF community — a Pilot Learning Network (PLN). The expected outcomes for this three-year pilot are sufficient evidence, knowledge and know-how to continue sharing the care model with the rest of the CF community.

CF care centers participating in the PLN will partner with patients and families on these and other improvements. Participation in this ongoing improvement work will consist of monthly virtual meetings, regular sharing of experiences and tools via an online information exchange and participation at semiannual community conferences. Support for participating care centers will include leadership development, QI training and coaching, and travel support.

A structured set of processes will be used to advance innovations from conceptual design, to iterative testing, then on to implementation to ensure successful integration into the CF care system. It is expected that using this “innovation management” process within the PLN will result in the capacity to identify and test potentially transformative concepts that will improve processes, outcomes and costs of care.

For more information, contact c3ncf@cchmc.org or michael.seid@cchmc.org.

Great Strides

The 2016 Great Strides campaign is in motion with a new look! We welcome all care centers to join us by helping to lead the charge for people with cystic fibrosis. Lace Up with us today!

We’re thrilled to announce AbbVie as our inaugural National Elite Sponsor for Great Strides. With this renewed commitment, AbbVie will lead the way on walk day. In the meantime, be sure to check out their newly designed web page that provides a “one-stop” shop to access their free patient and clinician resources: CFChef, (nutritional support and recipe library), CFCareForward (includes patient financial resources and free vitamin and nutritional supplement program), AbbVie’s CYSTIC FIBROSIS Scholarship program and other valuable resources.

Together, we continue to make Great Strides for all people with cystic fibrosis!
Revisit NACFC 2015 & Mark Your Calendars for 2016

The 29th Annual North American Cystic Fibrosis Conference (NACFC) in Phoenix, Arizona was a great success! The CF Foundation would like to extend a special thank you to all 4,228 attendees who participated.

You can still access content and information from the 2015 NACFC:

- Complimentary access to session recordings of the 2015 NACFC plenaries, symposia and workshops is available for full registrants. Short course presentations are available for purchase.

- The 2015 NACFC mobile app is still live and fully accessible. All original content is still available, including abstracts, summaries, notes and more. The conference code is 2015NACFC. If you haven’t downloaded the app yet, visit the Apple App Store or Google Play Store and search for NACFC 2015.

- The Handout Hub is still live for select individual course participant lists, case summaries, abstracts and more!

- Couldn’t make it to Phoenix? View videos and slides from plenaries and watch the archived free live streams of the plenaries and select other sessions, such as the short course Advanced Cognitive Behavioral Strategies for Depression & Anxiety, which may be of interest to mental health coordinators.

- If you haven’t already processed your CMEs or CEUs, please do so as soon as possible via the NACFC CE Portal.

The 30th Annual North American Cystic Fibrosis Conference will be held Oct. 27-29, 2016, in Orlando, Fla.

Mark these dates on your calendar:

- Monday, April 11: Abstract submission opens; case submission for consultation clinics and physician grand rounds opens; education resources submission begins

- Monday, May 9: Deadline for abstract submission and case submission for consultation clinics and physician grand rounds; education resources submission closes

Thank you for your continued commitment to our mission to cure CF and to provide all people with the disease the opportunity to lead full, productive lives by funding research and drug development, promoting individualized treatment and ensuring access to high-quality, specialized care.