Discussing the challenges of sustaining daily treatments of cystic fibrosis can be difficult for many patients and their families, as well as for the multidisciplinary teams who care for them. To help patients, families and care teams have open, non-judgmental, problem-solving conversations about daily care, a pilot project at six adult care programs tested the use of five materials. These materials – posters, tent cards, magnets, sticky notes and ID badges – were used as conversation starters and were designed through a collaborative effort between care teams, adults with CF and members from the Partnerships for Sustaining Daily Care (PSDC) team.

Overall, 150 patients and 90 care team members offered feedback on these conversations through surveys, and interviews. The results showed that although these materials were helpful as conversation starters, with some teams reporting that they engaged patients who had never been engaged before, trusting relationships between patients and care teams were critical to supporting productive conversations over time in the care center setting.

As a result of this pilot project, the following are key questions care team members can ask themselves to promote productive conversations for sustaining daily care with their patients during care center visits:

1. **Judgment-free zone:** Patients reported that they are often anxious about being “judged” for being “non-adherent.” How can you address this anxiety in a non-judgmental way?

2. **Problem-solving:** Patients reported that they need help solving problems and overcoming barriers. How can you work with your patient to identify and address barriers?

3. **Structure of visit:** Patients and care teams reported that it is more helpful to have these conversations at the beginning of the visit. How can the clinic flow support having these conversations first thing?

4. **Busyness of clinic:** How can the pace of the clinic visit change to allow for these conversations?

Conversations around sustaining daily care offer critical opportunities for care teams to support their adult patients’ ability to balance daily CF care with the demands of life. The PSDC team will continue to partner with the CF community to support relationship-building conversations between members of the care team and their patients. For more information about the results of this pilot project, please contact psdcteam@cff.org.
COMMUNITY PARTNERSHIPS

WHAT WILL COMMUNITY PARTNERSHIPS DO THIS YEAR?

• Continue to strengthen the Adult Advisory Council (AAC), a rotating group of 12 adults with CF who are approved by the Cystic Fibrosis Foundation’s Board of Trustees. The AAC helps to ground the Foundation’s work by providing insights into the hopes, needs and aspirations of the CF adult community. To find out more about the AAC, click here.

• Expand the CF Adult and Family Advisors (AFA), a group of nearly 300 individuals with CF and their caregivers. AFA members participate in committees, help in the design of CF Foundation projects and work with the Community Partnerships department to increase community engagement.

If you know someone with CF or a family member who may be interested in providing their perspective about CF care, research and quality of life, please share the following application link with them: afasignup.cff.org.

We encourage you to spread the word about the AFA so that the perspectives informing our work are truly reflective of our rich and diverse patient community. To learn more, click here.

• Pilot the adult Peer-to-Peer Mentoring Program to enable adults with CF to share their experiences and support others living with the disease. We aim to create a program that can be expanded in 2017 to the entire country and include younger segments of the patient population, family members, spouses and partners.

• Host a virtual conference where the content will be designed for and delivered by adults with CF. Supported by project planning and enabled through technology provided by the Foundation, the conference will offer an interactive experience where people with CF can safely connect, learn and collaborate as an online community.

To learn more about Drucy Borowitz and the Community Partnerships department, view her recent blog post.

ENSURING ACCESS TO CARE: ORKAMBI® AUTHORIZATIONS

In concert with CF clinicians, the CF Foundation Policy Team engages with health insurers and other decision makers to provide information about the complexities of CF, promote the CF care model and support coverage and access to care and treatments.

Current priorities include ensuring appropriate coverage of Orkambi®, especially addressing challenging prior and reauthorization requirements. Overall, coverage aligns with the the Food and Drug Administration (FDA) label. However, certain managed care plans and Medicaid programs have restricted access based on lung function.

Please contact Stevie Parker on the Policy Team at stparker@cff.org to share experiences and challenges with prior or reauthorizations for CF therapies. For assistance with individual cases, contact CF Foundation Compass at compass@cff.org or 844-COMPASS.
PARTNERSHIPS BETWEEN CF CARE TEAMS ACROSS THE CF FOUNDATION CARE CENTER NETWORK

Patient Registry Data: CF by the Numbers

During 2014, 1,500 individuals (5 percent of the 28,676 individuals in the Registry) were seen at two or more CF care programs. Although this is not a large proportion of the population, it presents another avenue for collaboration and partnerships.

We examined the characteristics of program transfers in individuals who were seen at more than one program. Some individuals had multiple transfers for an actual total of 1,953. Many transfers (34 percent) occurred within programs at the same center, of which 68 percent were transfers from pediatric to adult programs. In contrast, for transfers to different centers, only 6 percent occurred from pediatric to adult programs. Among those that changed centers, 71 percent were to centers in different states. Two-thirds of transfers were to the same program type (pediatric, adult or affiliate). The mosaic figure below displays these distributions.

As the CF population ages, more and more infrastructure is being developed to support the transition process from pediatric to adult care. These data also indicate that frequently, individuals are being seen at other programs in the country. Whether this is due to relocation or temporarily being in another location cannot be determined by these data. Overall, this highlights an opportunity for partnerships between care teams across our CF Foundation Care Network.

If you have questions or are interested in obtaining aggregate or record-level data from the Foundation’s Patient Registry, please email datarequests@cff.org.

This year, the CF Foundation hosted advocacy days in New York, Massachusetts, and for the first time in Florida and Pennsylvania. Volunteers, CF Foundation staff and care center clinicians met with state lawmakers to advocate for robust health care program funding that helps provide access to care centers and treatments. CF care team members provided a unique perspective by speaking about the access issues providers and patients face every day and discussing the specialized, multidisciplinary care provided at CF care centers.

Dr. Joan K. DeCelie-Germana, center director at The Steven and Alexandra Cohen Children’s Medical Center of New York said, “The patients were very excited that we attended the New York Advocacy Day. The legislators and their staff were genuinely interested to hear about CF and talk with us. As a doctor and nurse caring for children with CF, the experience was extra meaningful for us as well as our audience.” Advocacy days strengthen relationships with state decision makers to affect future policy decisions impacting people with CF.

Advocate Peter Hodge meeting with Representative Cary Pigman (R-Fl.) and Dr. Deanna Green during the Florida State Advocacy Day.
Congratulations to Daina Kalnins MSc., RD, for receiving the 2016 CF Dietitian Achievement Award! Daina has served as a CF dietitian since 1983 and is the director of Clinical Dietetics at Hospital for Sick Children in Toronto. She has worked closely for many years with Peter Durie, M.D. Daina has multiple original publications on CF nutrition and GI-related topics, has published two books on pediatric nutrition, written book chapters on CF nutrition, presented internationally on CF nutrition and GI-related topics and is well-known for her expertise in pancreatic enzymes and absorption. Her presentation “Assessing Pancreatic Status” was very well received at this year’s consortium meeting.

This year, Susan Horkey, LCSW, was honored. She has been involved in many community groups, works to raise funds for the CF Foundation and serves on the Board of the Child Advocacy Center. Susan has been actively involved at the North American Cystic Fibrosis Conference (NACFC), has had several publications, and is a member of the Collaborative Chronic Care (C3N) project and co-leader of the Social Work mentoring program. Susan’s research has focused on health beliefs, patient satisfaction, provider-patient communication and adherence. Susan presented “Understanding the Lives of Teens with CF: The UF Video Intervention/Prevention Assessment Project” at the consortium.

For her commitment to CF care, Terri Schindler, MS, RDN, received the Lifetime Dedication Award, in front of a standing ovation of her peers. Terri has been involved with CF for 25 years and was recognized with the “Nurturing Award” for her impact on the development of other dietitians providing CF nutrition care through her role on the CF nutrition listserv, the CF Nutrition Mentoring Program and on the CF Nutrition and Social Work Consortium. Terri received this award in conjunction with the consortium celebrating its tenth anniversary in Annapolis, Md.

We congratulate Daina Kalnins, MSc., RD, Terri Schindler, MS, RDN and Susan Horkey, LCSW, as this year’s award recipients and thank them for their many years of dedication and for all they have done for the CF community.
**Clinical Care Guidelines Update**

**Clinical Care for Preschool Aged Children (2-5 yrs old)**
The Clinical Care for Preschool Aged Children (2-5 years old) manuscript has been published in the April issue of Pediatrics.


**Enteral Nutrition Consensus Statements**
Sarah Jane Schwarzenberg and Amanda Leonard are chairing this committee. The committee is finalizing the manuscript in preparation for submission to the Journal of Cystic Fibrosis.

**Colorectal Cancer Screening Consensus Statements**
Albert Lowenfels and Alexander Khoruts are chairing the colorectal cancer screening consensus statements. These statements are currently under development.

**Diagnosis Consensus Conference**
Philip Farrell, Patrick Sosnay and Clement Ren are chairing the diagnosis consensus conference. The committee is preparing the manuscript for public comment.

**Mental Health Advisory Committee**
A mental health advisory committee, chaired by Beth Smith has been established to assist in the implementation of the International Committee on Mental Health in Cystic Fibrosis: Cystic Fibrosis Foundation and European Cystic Fibrosis Society consensus statements for screening and treating depression and anxiety, and the Award for a Mental Health Coordinator. This committee met in April 2016 to develop their charter and scope of work.

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

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**CF FOUNDATION COMPASS IS HERE FOR YOU**

Compass has launched and is ready to help you and your patients with:

- Understanding and getting insurance coverage and benefits
- Finding resources to pay for therapies and medications
- Getting legal information on topics like disability and government benefits and employment or school issues
- Finding community resources for other concerns related to life with CF

Your care center should have received a box of Compass materials, including brochures, referral cards, pens, magnets, pill boxes, sticky notes, posters and table tents.

To order more materials or talk with us about an issue, call 844-COMPASS (266-7277) or compass@cff.org. Visit CFF.org/compass for more information.

**COMPASS™ CYSTIC FIBROSIS FOUNDATION**

WITH YOU through insurance, financial, legal and other issues
THANK YOU CARE CENTERS – YOU MAKE GREAT STRIDES EVERY DAY!

While there are still a handful of Great Strides Walk events left this year, most have occurred and were a tremendous success! Thanks to all of the care center teams who walked, raised money and volunteered. You rock! We could never make Great Strides in cystic fibrosis without you.

AbbVie – our national elite sponsor – has a new educational blog called “Through Thick and Thin”. It is an effort to educate and reinforce the importance of nutrition, digestion and taking enzymes among teenagers living with CF. This unbranded web resource provides education that aligns with the communication style of today’s teenager. You may wish to share this site with your patients as appropriate.

THE PATIENT AND FAMILY EXPERIENCE OF CARE SURVEY

The CF Patient and Family Experience of Care Survey results are available online via Quality Desktop.™ When a program has enough surveys to show results, the contact person will be notified via email by Quality Data Management (QDM) and invited to participate in a 45-minute online training webinar to learn how to access and interpret their care center’s survey results.

Training webinar sessions are held the second Thursday of each month at 3pm (ET), and the fourth Tuesday at noon (ET). Registration is required to reserve your spot in the training; space is limited. Additionally, a 25-minute training video is available on PortCF. You’ll find it in the “Patient and Family Experience of Care Survey” folder.

To access your results via Quality Desktop.™

1. Contact your CF program leader, and ask them to request an account username and password for you from QDM.

2. Register for a Training Webinar by contacting QDM Client Services at 1-877-QDM-SUPPort (1-877-736-7877) or clientservice@qdmnet.com. Provide your program site number, program name and the time and date you wish to attend. Your username and password will be provided via email after training.

If you have any questions, please contact QDM Client Services at 1-877-736-7877 or clientservice@qdmnet.com.
Over the span of a week in April, the 21 teams supported by quality coaches in the second OneCF Center Learning and Leadership Collaborative (LLC2) and in the Fundamentals LLC (FUN LLC) participated in a benchmarking site visit to Boston Children's Hospital. FUN LLC teams attended sessions and visited Boston Children's for two and a half days, closing their visit at a luncheon convened to exchange progress reports with the LLC2 teams who had also arrived to conduct a two and a half-day site visit and conclude their learning sessions. In addition to observing CF care, the teams heard from QI experts about partnering to produce health care services (coproduction) and innovation in health care. The FUN LLC teams will continue to focus on QI fundamentals and look to complete the collaborative in October 2016.

Participating teams from the Virtual Improvement Program Fundamentals asynchronous QI course, which kicked off at NACFC in 2015, joined the LLC2 teams in closing out the learning sessions by completing their program in May 2016.

More Learning and Leadership Collaborative opportunities will be offered. Look for announcements or email Margie Godfrey, Ph.D., at margiegodfrey@gmail.com for more information.

Congratulations to the LLC2 teams for their successful focus on improving transition and transfer between pediatric and adult programs:

- Boston Children’s Hospital/Brigham and Women’s Hospital
- Columbia University, New York City
- Nationwide Children’s Hospital/ Columbus, Ohio
- Rush University Medical Center, Chicago
- University of Missouri, Columbia
- University of North Carolina, Chapel Hill

Congratulations also go out to the VIP-F teams for their focus on QI fundamentals:

- Froedtert & Medical College of Wisconsin
- Cystic Fibrosis Center Pediatric Specialty Clinics Children’s Hospital of Illinois
- Kaiser Foundation Research Institute, a Division of Kaiser Foundation Hospitals Kaiser Permanente Medical Care Program (ADULT)
- Kaiser Foundation Research Institute, a Division of Kaiser Foundation Hospitals Kaiser Permanente Medical Care Program (PEDIATRIC)
- NYU School of Medicine Pediatric CF Center
- Seattle Children’s
- St. Luke’s CF Center of Idaho Boise
- The Respiratory Center for Children at Goryeb Children’s Hospital
- The University of Texas Health Science Center at Tyler
- University of Tennessee Cystic Fibrosis Care and Research Center
- Washington University School of Medicine, St Louis Children’s Hospital
NEW CLINICAL TRIAL TOOLS!

Having trouble keeping track of the 40+ clinical trials happening across the network?

We are excited to announce new clinical trial tools coming to CFF.org on July 27, 2016. These tools have been redesigned to help you and your patients track down studies that are happening across the country and find more information about the drugs currently in development.

The new “Clinical Trial Finder” will include the ability to search for clinical trials by zip code, genotype, age and FEV1. Users will be able to sign up for email alerts that will notify them of new trials in their region or when the results of studies become available. We are also building out educational content about important topics such as what is being done to protect patient safety.

For more information contact Christina Román at croman@cff.org.

In Memorium

We are proud to remember these two champions for CF for their many important contributions to the CF community and the tremendous difference they made in the lives of people with CF.

Carolyn Denning, M.D., passed away January 10, 2016. Dr. Denning was a protégé of Dr. Dorothy H. Andersen and the first woman to head the Cystic Fibrosis Foundation’s Medical Advisory Council. She established the Cystic Fibrosis Center at St. Vincent’s Hospital in 1977 and retired in 1995.

Warren J. Warwick, M.D., who died on February 15, 2016, had a profound and lasting impact on the Foundation through his scientific expertise and his longstanding commitment to his patients. In 1964, the Foundation asked him to gather data on every patient treated at any of the then 31 accredited care centers to identify the best treatments. From that project sprang the CF Foundation’s Patient Registry, which is at the very heart of our focus on continuous quality improvement.

NEW ON CFF.ORG: REPRODUCTIVE HEALTH AND FERTILITY

Informed by adults with CF and clinicians, the new section explains how CF affects the male and female reproductive systems, and covers puberty, contraception, sex and intimacy. The content also includes recommendations for how people with CF can approach these sensitive topics and foster more productive conversations with their CF care teams.

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.