Fresh Blooms in Care

SPRING 2026

We are now the CF Consortium

Advancing nutrition, psychological and interdisciplinary care in CF

Who *we are*

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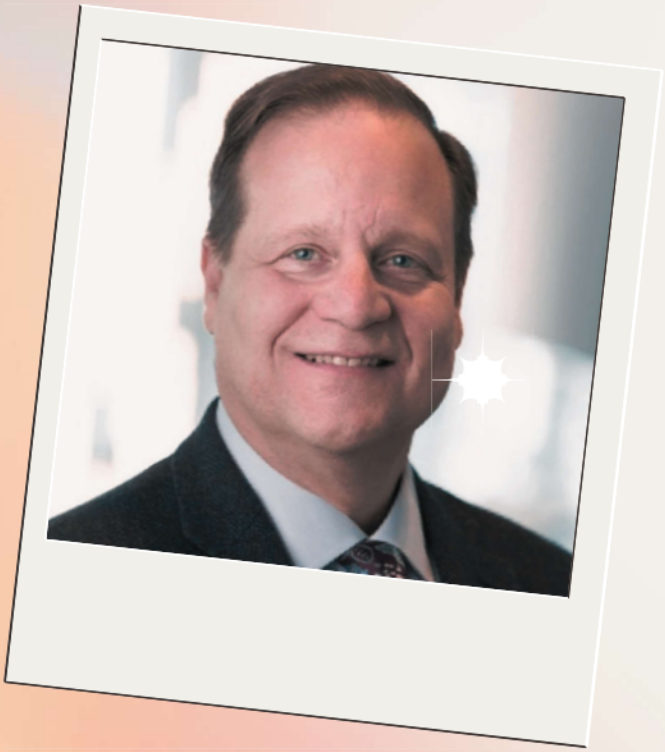
Welcome Bob Goodholm! Randee Luben is stepping down from the newsletter to pursue private practice and will be passing the torch to SW Bob Goodholm.



Congratulations to the SWs who received advanced credentials in March:

Elysia Burley : KY
Alison Kelly : VA
Leah Colsch : IA
Suzanne Muenzel : GA
Kate Devore : TX
Katherine Papia : NY
Stacey Gallegos : TX
Kay Pasquesi : OR
Kimberlee Garver : NY
Amy Plachta : NY
Bob Goodholm : FL
Amy Sangvai : NC
Dianna Greenland : TX
Ashley Severin : MO
Rebecca Headley : ID
Winsome Sewell : NY
Marci Johnson : OH
Kate Yablonsky : OH
Sunmee Joo : MO
Tamara Vance : MN

CF Support- Filotimo Foundation

I've been at my CF Center since January of 2020. I have tried to stay current and knowledgeable, especially about CF-specific resources. So I am a little embarrassed to say that I just learned about the Filotimo Foundation.I had the opportunity to meet with the President and Founder and want to share what I've learned.

Pete Proimos describes himself as "a 41-year-old guy with CF." I met with him this month and he's much more than that. Pete comes from a family of Greek immigrants, which is what led him to name his foundation, the Filotimo Foundation, using a Greek term that means "to give without expecting anything in return" (https://filotimofoundation.org).

The Filotimo Foundation was established in 2023 with a mission to provide "direct support to adults living with cystic fibrosis, helping cover essential living and medical needs and supporting family-building journeys." During our interview, Pete described a few of his experiences helping people with CF and noted that many times people experience a medical crisis that leads to a financial crisis. What I learned is that Pete is a natural listener and problem-solver and that by listening to people's stories he tries to give lasting rather than temporary relief.

Pete also recognizes that dramatic advancements such as highly effective modulator therapies have increased life expectancies for most people with CF but have also resulted in more anxiety as a larger proportion reach adulthood and the responsibilities and choices that come with adult life.

The Filotimo Foundation provides financial support for people who are experiencing hardship or want to start a family through fertility treatments or adoption. The application process is simple and starts with a brief form (https://www.filotimofoundationl.org). I think that one of the things that appears to distinguish the Filotimo Foundation from other charitable organizations for CF is the flexibility of the type of help that they provide. I encourage you to share this resource with your adult patients.

Have other resources you'd like to highlight? Let us know!

Bob Goodholm, LCSW

CF Support- Adding Tests to Annual Labs

Repeated blood draws are often viewed as routine in cystic fibrosis (CF) care, yet their cumulative impact on patients is frequently underestimated. For individuals living with CF—many of whom already experience a high treatment burden—unnecessary laboratory testing can contribute to both physical and psychological distress. Over time, repeated venipuncture may lead to heightened anxiety, procedural fatigue, and even avoidance of care. I know I have often gotten excited about adding a test into annual labs, thinking that "everyone should get this done" when in reality, it may not always be best for the patient.

Minimizing non-essential blood work is an important step toward trauma-informed, patient-centered care. Each lab order should be evaluated for its clinical necessity and potential to directly influence management decisions. When tests are unlikely to change treatment, deferring them can reduce harm without compromising outcomes.

Especially for our pediatric patients, every vial matters. Since the vials have to be drawn in a specific order, this may mean an additional stick to get to the "lavender tops" which include some of our vitamin labs which have to be drawn last.

Before adding to the annual labs, discuss what this would take with your nursing staff. They will help you know what that draw would look like before requesting it from the providers. Coordinating lab draws with other necessary procedures, using less invasive monitoring when possible, and extending intervals for stable patients are practical strategies that can make a meaningful difference.

Importantly, reducing unnecessary blood work may also improve adherence to care. Some patients delay or skip clinic visits due to fear of needles or prior negative experiences. By demonstrating thoughtful stewardship of testing, healthcare teams can build trust and create a more supportive clinical environment.

Dietitians and social workers play a key role in advocating for these approaches. By recognizing the emotional and behavioral consequences of repeated procedures, we can help shape care plans that balance medical necessity with quality of life. Thoughtful reduction of unnecessary blood draws is not about doing less—it is about doing what is most meaningful for the patient.

Carla Burke, RD

CF Scholarships

It's that time of year when our CF students are applying for financial aid, grants and scholarships.
Don't forget to connect them with the many CF Scholarships available

www.letsrockcf.org/bowman-brothers-trade-school-scholarship
www.everylifefoundation.org/rare-scholarship/
www.cfroundtable.com/scholarships
www.thesusannafoundation.org/scholarships/
www.vertexfoundation.org/healthy-families
www.patientadvocate.org/connect-with-services/apply-for-a-scholarship/
www.mandywagnerfoundation.org/apply-now
www.bgcf.org/scholarships/
www.elizabethandpatricknashfoundation.org/
www.dylansdream.org/apply-for-scholarship/
www.thebonnellfoundation.org/scholarships/
www.esiason.org/assistance/scholarships/bef-academic-scholarship/
www.cffamilyconnection.org/programs/andrew-w-eve-memorial-scholarship/
www.abbviecfscholarship.com/overview/

Socioeconomic Publications

Remotely addressing health-related social needs (ELICIT) in cystic fibrosis: design and implementation of a multicenter screening and intervention quality improvement project.

Bailey, Julianna ; Jennings, Deirdre ; Alao, Melissa ; Anderson, Justin D. ; Garcia, Bryan ; Gordon, Rachel ; Gravley, Katie ; Harrison, Moira ; Powers, Michael ; Prettiman, Stacie ; Salter, Nathan ; Sawicki, Gregory S. ; Albon, Dana. Therapeutic advances in respiratory disease, 2025-01, Vol.19, p.17534666251393088

Background:
Social determinants of health (SDOH) and health-related social needs (HRSN) drive disparities in lung function, nutrition, and survival in People with Cystic Fibrosis (PwCF). Addressing HRSN can improve access to care, yet standardized screening and intervention methods remain underutilized.
Objectives:
The aim of this project was to develop, test, and refine a remote HRSN screening and intervention model across multiple cystic fibrosis (CF) centers.
Design:
A multicenter, prospective Quality Improvement (QI) initiative
Methods:
Four CF centers, serving both pediatric and adult populations, piloted an electronic HRSN screening tool and a remote social need intervention strategy. Developed collaboratively with CF clinicians and patient and family partners (PFPs), the tool assesses nine HRSN domains. Multidisciplinary teams, including PwCF, held regular meetings to tailor implementation to each site's existing clinical workflow and staff structure. Over 1 year, each site conducted iterative Plan-Do-Study-Act (PDSA) cycles every 2 weeks to refine the screening process, sharing adaptations across centers.
Results:
All four CF centers successfully implemented the remote HRSN screening and intervention workflows, completing 26 iterative PDSA cycles to refine site-specific processes. Study site meetings were held with multidisciplinary attendance at 100% of meetings. The screening tool was integrated into pre-visit planning and telehealth workflows, allowing for social worker follow-up of identified needs. Multidisciplinary collaboration from all sites resulted in the generation of a comprehensive library of local and regional resources to support unmet needs identified during screening. Narrative patient testimonial highlighted the screening tool's effectiveness in facilitating discussions about social needs and connecting individuals to available resources from the perspective of PwCF.
Conclusion:
Our study has shown that HRSN screening and intervention are feasible, adaptable and acceptable to PwCF. Next steps include gathering comprehensive data on screening and intervention rates, domains of unmet social needs across regions, and sustainability interventions. Expanding HRSN screening and intervention to other CF Centers can provide data to support public policy and advocacy initiatives for reducing health disparities driven by SDOH.

Mental Health Publications

Development of the Cystic Fibrosis Stress Questionnaire: testing and validation.

Snell, Carolyn J ; Ryan, Morgan E ; Bailey, Isabel V ; Sandage, Danielle ; Ertman, Benjamin ; Dahlberg, Suzanne ; Alpern, Adrianne N ; Smith, Beth ; Garcia, Bryan ; Ito, Ethan ; Sawicki, Gregory ; Uluer, Ahmet.
BMJ open respiratory research, 2025-12, Vol.12 (1), p.e003322. Dec 2025, 12 (1). DOI:10.1136/bmjresp-2025-003322

Objective
Care guidelines for cystic fibrosis (CF) recommend annual screening for anxiety and depression using standardised measures, the Patient Health Questionnaire (PHQ-9) and the Generalised Anxiety Disorder Scale (GAD-7). Research in other chronic illness groups such as diabetes has demonstrated that illness-specific distress predicts daily functioning above and beyond depression alone. To address the need for a measure of illness-specific distress, we developed and validated the CF Stress Questionnaire (CFSQ), which could serve as a meaningful adjunct to mental health screening.
Methods
We developed a CF-specific measure of perceived stress with multiple phases of input from our patient population. We then conducted a multisite CFSQ validation study with 200 adults with CF across 3 geographically diverse CF centres, to examine the CFSQ's factor structure, internal consistency, convergent validity and test–retest reliability.
Results
Results of item and subscale-level analyses indicate that all but one subscale met the established internal consistency cut-off of >0.6. In terms of convergent validity, the CFSQ and its subscales were moderately to highly correlated with the PHQ-9 ($r=0.73$ for total score, $p<0.05$) and the GAD-7 ($r=0.66$ for total score, $p<0.05$) and moderately correlated with quality of life as measured by the Cystic Fibrosis Questionnaire Revised (CFQ-R) Social ($r=-0.59$ for total score, $p<0.05$) and Treatment Burden subscales ($r=-0.63$ for total score, $p<0.05$). Subscales of the CFSQ were moderately correlated with the CFQ-R Emotional or Physical Functioning subscales, and weakly correlated with forced expiratory volume in 1 s per cent predicted or body mass index.
Conclusions
The CFSQ is a valid and reliable measure in terms of internal consistency and convergent validity with existing measures of mental health and quality of life commonly used in CF care and research.

Mental Health Publications

Mental Health and Transplantation in Cystic Fibrosis

Georgiopoulos AM, Smith BA, Dellon EP, Hadjiliadis D, Colman R, Mullen TMD, Quittner AL, Sher YI.

Respir Med. 2025 Nov;248:108407. doi: 10.1016/j.rmed.2025.108407. Epub 2025 Oct 9. PMID: 41067290.

Background: People with cystic fibrosis (PWCF) and their caregivers may face the prospect of lung or liver transplantation as cystic fibrosis (CF) progresses. Despite the links between psychological distress, poor adherence and survival outcomes, their mental health needs may not be consistently addressed. Methods: We conducted a narrative review of mental health aspects of transplantation in PWCF, including health-related quality of life (HRQoL), pre-transplant psychosocial evaluation, neuropsychiatric complications, and psychosocial and psychopharmacologic interventions.

Results: Depression, anxiety and post-traumatic stress are common in this population, along with neuropsychiatric complications including cognitive impairment, delirium, side effects of immunosuppression, and drug-drug interactions. CF-specific guidelines recommend routine screening for depression, anxiety, and unmet palliative care needs for PWCF throughout the lifespan. Peri-transplantation, systematic monitoring can modify risk factors for and identify and treat delirium. Guidelines recommend screening, evaluation, and referral to care for depression, anxiety, and PTSD within 6 months post-transplant for PWCF and caregivers. Mental health intervention studies indicate there is potential to improve depression, anxiety, HRQoL, and medical outcomes.

Conclusions: As CF progresses, patients and caregivers require preparation for the psychosocial aspects of transplant evaluation, including the salience of social support, treatment adherence, and the importance of early interventions for mental health and substance use disorders. Specialists in mental health, palliative care, and pain management can be enlisted to improve symptoms and functioning in PWCF and caregivers at all stages of the transplant process. Psychological and psychopharmacologic interventions may require adaptation to target the specific needs of PWCF with advanced disease.

Mental Health Publications

Psychosocial and mental health in cystic fibrosis in the modern era of care: time to evolve

Harrigan M, Georgiopoulos AM, Quittner AL, Smith B, Douglas TA.
BMJ Open Respir Res. 2025 Feb 10;12(1):e002606. doi:
10.1136/bmjresp-2024-002606. PMID: 39929550; PMCID: PMC11815457.

Abstract:
Cystic fibrosis (CF) treatment has revolutionised care over the past three decades with major advances in survival. Despite these advances, CF continues to create psychological and social challenges for people with CF (PWCF) throughout their life and is associated with worse health outcomes and higher healthcare costs. Anxiety and depression screening and management protocols are widely implemented within CF care; however, a much broader scope of psychosocial challenges exist which lack a standardised screening and management approach. The advent of CF transmembrane conductance regulator modulator therapies is transforming the psychosocial landscape for PWCF with new challenges and evolving psychosocial needs.
What it means to have CF, the expectations, hopes and stressors are rapidly changing, and psychosocial care must keep pace if health outcomes are to be fully optimised. A symposium of international CF and psychosocial experts was convened in November 2022 to explore current and emerging issues in psychosocial health and identify opportunities and approaches to optimise psychosocial care. This state-of-the-art review summarises key symposium proceedings and highlights priorities for clinical practice and research in psychosocial health across the lifespan among PWCF. It also summarises state-of-the-art initiatives for screening and intervention to optimise CF psychosocial healthcare and patient outcomes.

Gastro-Intestinal Publications

Decoding liver injury in cystic fibrosis: How to tell drug-induced liver injury from cystic fibrosis liver disease

Junseo Lee

.World J Gastroenterol 2026 Mar 14;32(10):114946. doi: 10.3748/wjg.v32.i10.114946.
PMID: 41809454 PMCID: PMC12968613 (available on 2026-03-14 DOI: 10.3748/wjg.v32.i10.114946

Objective
Care guidelines for cystic fibrosis (CF) recommend annual screening for anxiety and depression using standardised measures, the Patient Health Questionnaire (PHQ-9) and the Generalised Anxiety Disorder Scale (GAD-7). Research in other chronic illness groups such as diabetes has demonstrated that illness-specific distress predicts daily functioning above and beyond depression alone. To address the need for a measure of illness-specific distress, we developed and validated the CF Stress Questionnaire (CFSQ), which could serve as a meaningful adjunct to mental health screening.
Methods
We developed a CF-specific measure of perceived stress with multiple phases of input from our patient population. We then conducted a multisite CFSQ validation study with 200 adults with CF across 3 geographically diverse CF centres, to examine the CFSQ's factor structure, internal consistency, convergent validity and test–retest reliability.
Results
Results of item and subscale-level analyses indicate that all but one subscale met the established internal consistency cut-off of >0.6. In terms of convergent validity, the CFSQ and its subscales were moderately to highly correlated with the PHQ-9 ($r=0.73$ for total score, $p<0.05$) and the GAD-7 ($r=0.66$ for total score, $p<0.05$) and moderately correlated with quality of life as measured by the Cystic Fibrosis Questionnaire Revised (CFQ-R) Social ($r=-0.59$ for total score, $p<0.05$) and Treatment Burden subscales ($r=-0.63$ for total score, $p<0.05$). Subscales of the CFSQ were moderately correlated with the CFQ-R Emotional or Physical Functioning subscales, and weakly correlated with forced expiratory volume in 1 s per cent predicted or body mass index.
Conclusions
The CFSQ is a valid and reliable measure in terms of internal consistency and convergent validity with existing measures of mental health and quality of life commonly used in CF care and research.

Gastro-Intestinal Publications

The Impact of Elexacaftor/Tezacaftor/Ivacaftor on Fat-Soluble Vitamin Status and Supplementation in a Pediatric Cystic Fibrosis Cohort

Fern Kimber, Darren Sills

.Pediatr Pulmonol 2026 Apr;61(4):e71596. doi: 10.1002/ppul.71596.

Abstract

Background: Children with Cystic Fibrosis (CF) are at risk of fat-soluble vitamin deficiencies, studies have shown Elexacaftor/Tezacaftor/Ivacaftor (ETI) therapy to substantially improve nutritional status. This study aimed to investigate the effect of ETI on fat-soluble vitamin levels A, D, and E, for children aged 6-16 years with CF.

Method: We performed a retrospective pre-post study of children with CF. Data collected included demographics, clinical characteristics, serum Vitamin A, D and E and vitamin supplementation dosages. Seven timepoints were decided for statistical analysis: T1-T3-pre-ETI and T4-T7-at 6 month intervals post-ETI. The significance of changes in vitamin levels and supplementation was assessed using a linear mixed-effects model. A p-value < 0.05 was used to indicate significance.

Results: Fifty-six children met the inclusion criteria, with 262, 257, and 252 complete observations for Vitamins A, D, and E, respectively. Median Vitamin D levels increased following ETI initiation ($p < 0.001$). There was no significant increase in median Vitamin A levels however post-ETI there was a significant association between supplementation dose and serum Vitamin A levels ($p = 0.008$). There were no significant changes in median Vitamin E. Over the timepoints there was an increase in the proportion of patients receiving no vitamin supplementation.

Conclusions: This study found following ETI initiation vitamin D levels increased, and the requirement for fat-soluble vitamin supplementation appeared to decrease. Whilst ETI was not associated with increased Vitamin A and E, the burden of supplementation decreased, and Vitamin A supplementation maybe more effective.

Health Markers Publications

Automated Insulin Delivery Systems in Cystic Fibrosis-Related Diabetes: A Systematic Review and Meta-Analysis

Bruno L Souza, Jessica Abramowitz, Sasan Mirfakhraee, Maria E C Tamega, Yosteline Costa, Gaspar R Chiappa, Marconi Abreu
Endocr Pract 2026 Mar 31:S1530-891X(26)00921-3. doi: 10.1016/j.eprac.2026.03.097

Objectives: To assess the effects of automated insulin delivery systems (AIDs) on glycemic control and selected metabolic and pulmonary outcomes in people with cystic fibrosis related diabetes (pwCFRD).

Methods: We searched MEDLINE (via PubMed), Embase, and Cochrane Library for studies of AIDs in pwCFRD. Eligible studies included at least 14 days of follow-up and reported continuous glucose monitoring outcomes. The primary outcome was time in range (TIR, 3.9-10.0 mmol/L or 70-180 mg/dL). Additional outcomes included time above range (TAR, >10.0 mmol/L or 180 mg/dL), time below range (TBR, <3.9 mmol/L or 70 mg/dL), average glucose, BMI, and FEV1. We performed single-arm meta-analyses using a random-effects model.

Results: 4 studies (n=69) met inclusion criteria. AIDs increased TIR by 9.55% (95% CI 1.49, 17.61; p=0.02) at short-term (14-30 days) and 11.55% (95% CI 5.61, 17.50; p<0.001) at long-term (⩾12 weeks) follow-up, respectively. TAR decreased by 8.41% (95% CI -15.59, -1.22; p=0.022) and 12.96% (95% CI -17.67, -8.26; p<0.001) at short- and long-term, respectively. Average glucose decreased by 1.01 mmol/L (18 mg/dL) (95% CI -1.98, -0.04; p=0.042) and 1.12 mmol/L (20 mg/dL) (95% CI -1.70, -0.54; p<0.001) at short- and long-term, respectively. AIDs did not change TBR, BMI, and FEV1.

Conclusions: AIDs improved glycemic control in pwCFRD without increasing hypoglycemia, with short-term benefits persisting over 12 weeks. Larger randomized trials are needed to confirm these findings.

Health Markers Publications

Changes to serum lipids, BMI and body composition in adults with cystic fibrosis on Elexacaftor/Tezacaftor/Ivacaftor (ETI): A scoping review

Anna Walsh, Clodagh Landers, Niamh Lucey, Oonagh Griffin, Suzanne Carter, Clare A Corish
J Cyst Fibros. 2026 Mar 20:S1569-1993(26)00044-5. doi: 10.1016/j.jcf.2026.02.015

Abstract

Elexacaftor-Tezacaftor-Ivacaftor (ETI) has substantially improved lung function and life expectancy for people with cystic fibrosis (pwCF). Emerging evidence suggests that overweight, obesity and dyslipidaemia are now developing in pwCF prescribed ETI. This scoping review, conducted adhering to PRISMA guidelines, aimed to provide an overview of the research currently available that investigated body mass index (BMI), body composition and serum lipid profiles in adults with CF treated with ETI. Peer-reviewed articles and conference abstracts were identified through database searches and conference proceedings. Studies reporting BMI, body composition (fat mass, fat-free mass) and serum lipid profiles in adults with CF following ETI initiation were included. Data were extracted and synthesised descriptively. Of 126 studies (60 peer-reviewed, 66 conference abstracts), 90% reported increased BMI after ETI initiation, with 61% indicating this was statistically significant. Fat and fat-free mass rose significantly in 5 of 8 and 4 of 7 studies, respectively. In the 18 studies (11 peer-reviewed publications, 7 conference abstracts) reporting serum lipids, significant increases were observed; for total cholesterol (72% of studies), LDL-C (80%), and HDL-C (56%), with increased triglycerides (31%), non-HDL cholesterol and HDL: Total Cholesterol ratio (22% for both) less frequently seen. Current evidence suggests that BMI, weight, and serum lipids increase in adults with CF following ETI initiation, with some studies also reporting increased fat- and fat-free mass. The majority of measurements remain within the recommended range. These findings highlight the importance of ongoing monitoring of nutritional status and cardiometabolic health in this population. Prospective research to better characterise long-term cardiometabolic health in pwCF is required.