

# Newsletter

## Topics:

- The changing care in the modulator era

- Parenthood experiences in CF

- The effects of gut biome on individuals with CF

- Tools for assessing caregiver challenges

- Food insecurity screening and local food access



Special Thanks to our  
Sponsors:

MVW Nutritionals  
Callion Pharma

Alcresta  
Nestle

# Board Members

**Please welcome new board members Aimee Goyette and Marci Johnson! Read about them on our website [CFRDSWCONSORTIUM.COM](http://CFRDSWCONSORTIUM.COM)**

Terri Schindler- [Terri.Schindler@UHhospitals.org](mailto:Terri.Schindler@UHhospitals.org)

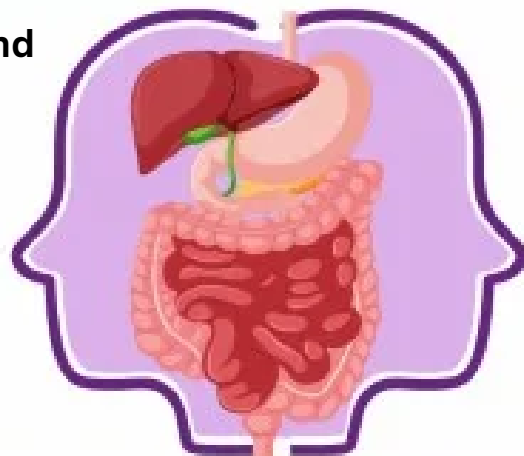
Kay Vavrina- [Kay.Vavrina@uhtx.com](mailto:Kay.Vavrina@uhtx.com)

Shayla Wilson- [Shayla@liberatecounseling.com](mailto:Shayla@liberatecounseling.com)

Kim Altman- [kiag007@nyp.org](mailto:kiag007@nyp.org)

Aimee Goyette- [Aimee.Goyette@atlantichhealth.org](mailto:Aimee.Goyette@atlantichhealth.org)

Marci Johnson- [Marci.Johnson@nationwidechildrens.org](mailto:Marci.Johnson@nationwidechildrens.org)



## Updates

**Free wellness program for adults and youth with CF:** Beam and BreatheStrong+ are offering a free a comprehensive, virtual wellness program to people with CF through September 2024. Your patients can [register online](#) using the "Get Started" button on the Beam home page. For questions, contact Whitney Brown at [awbrown@cff.org](mailto:awbrown@cff.org)  
Check out: <https://beamfeelgood.com>

## Upcoming Dates:

NACFC is coming up quick in Phoenix!! See you all there! Nov 1- Nov 5

The next Annual RD/SW CF Consortium will be in Portland, ME April 17-19.

Call for case presentations/QI opens Monday, Nov 17th (will be posted on RD/SW listservs)

Registration opens Monday, Jan 8th 2024

## Want to share?

If you have a CF related job opening at your center, a resource you want to share, articles you found helpful, or anything else you would like in the newsletter, let us know!

Email us at Carla, RD: [Carla.nowicki@prismahealth.org](mailto:Carla.nowicki@prismahealth.org) or Randee, LCSW; [randee@arizona.edu](mailto:randee@arizona.edu)

# Bites & Nibbles

## Upcoming CEUs and Resources



Be on the lookout for Upcoming CF Dietitian  
Coffee Talks!

Most Recent Oct 3rd @ 12pm EST Topic:  
Modulators

6 free tips to address trauma:  
From The Living Legacy of Trauma Card Deck, Janina  
Fisher, PhD

Halite  
Resources for seniors with CF and the aging CF  
patient

**Check on our website  
[CFRDSWCONSORTIUM.COM](http://CFRDSWCONSORTIUM.COM)**

**Special thanks to Clarissa Morency RD  
and Leah Colsch LMSW who are co-  
leading our social media platforms**

**f** CF Nutrition and Social Work Consortium

**@**@cfnutritionandsocialwork

# The Main Course

## The changing care in the modulator era

CF patient care and needs have changed since the advent of highly effective modulators, including nutrition therapy. Weights/BMIs are increasing and enzyme/vitamin requirements are also changing for a few. We need more focus on monitoring for chronic and age-related conditions such as GI cancers, pancreatitis, heart disease, bone disease and other potential complications related to normal weight obesity/obesity. Below are some recent publications on the changing trends in CF care.

Nutritional management of people living with cystic fibrosis throughout life and disease continuum: Changing times, new challenges.

Geneviève Mailhot et al. - J Hum Nutr Diet. Oct 2023

Evolving Nutritional Needs in Cystic Fibrosis

Theresa Frantzen et al. - Life (Basel) . Jun 2023

Spirometric and anthropometric improvements in response to elexacaftor/tezacaftor/ivacaftor depending on age and lung disease severity.

Katharina Schütz et al. - Front Pharmacol Jul 2023

Body mass index and nutritional intake following Elexacaftor/Tezacaftor/Ivacaftor modulator therapy in adults with cystic fibrosis

Laura Caley et al. - J Cyst Fibros Jul 2023

Changes in nutrition and growth status in young children in the first 12 weeks of ivacaftor therapy.

Alyssa Tindall et al. - J Cyst Fibros Jul 2023



# The Main Course

## Parenthood experiences in CF

### A Qualitative Exploration of Parenthood Experiences and Needs Among People with Cystic Fibrosis.

This study looked at qualitative interviews with 37 people with cystic fibrosis where parents discuss what it is like living with cystic fibrosis and having children. Five key themes were discovered among the participants: 1.) The responsibilities of parenthood and the responsibilities of CF care often conflict, 2.) Delegating tasks to partners or extended family can help, 3.) Patients with CF desire support/resources specific to parenting from their CF team, 4.) It is logistically and emotionally difficult to avoid illnesses transmitted from children, 5.) Parents with CF desire clinic-facilitated connections with other parents with CF for support.

#### **"Find ways to work parenting into cystic fibrosis": A PhotoVoice exploration of being a parent and having CF**

Olivia M. Stransky MPH, Savvy Benipal MD, Molly Pam BA, Jennifer L. Taylor-Cousar MD, MSCS, Patricia Documet MD, DrPh, Traci M. Kazmerski MD, MS

#### **Family-building and parenting considerations for people with cystic fibrosis.**

Kazmerski TM, West NE, Jain R, et al.

#### **Parenthood impacts short-term health outcomes in people with cystic fibrosis**

Traci M. Kazmerskia,b, Raksha Jainc, MinJae Leed, Jennifer L. Taylor-Cousare

# The Main Course

## Gut Biome In CF Patients

We know the CF gut microbiome and its relationship to outcomes is complex.

Perhaps education on dietary sources of pre- and pro-biotics can impact the gut and lung biome?

Or will it require probiotic supplements? If so, which one(s)?

Development of the intestinal microbiome in cystic fibrosis in early life

Courtney Price et al. - mSphere. Aug 2023

The association between gut microbiome and growth in infants with cystic fibrosis

Ashley Deschamp et al. - J Cyst Fibros. Aug 2023

An In Vitro Medium for Modeling Gut Dysbiosis Associated with Cystic Fibrosis

Kaitlyn Barrack et al. - bioRxivl Aug 2023

Epidemiology of small intestinal bacterial overgrowth

Irina Efremova et al. - World J Gastroenterol Jun 2023

# The Main Course

## Assessing Caregiving challenges, e-cigarettes, and employment disabilities.

### Development and Validation of a Short Form Psychometric Tool Assessing the Caregiving Challenge of Living with Cystic Fibrosis (CLCF-SF) in a

Child Doctors or caregivers will utilize a validated and shortened assessment tool named the Challenge of Living with Cystic Fibrosis in clinics to assess caregiving burden. Main themes assessed include parental well-being, markers of treatment burden, and disease severity.

### Perceptions and Use of E-cigarettes among Young Adults with Cystic Fibrosis: An Observational Study.

Rhoads S, Auth R, Chambers A, Blundin M, Mahoney L, McLaughlin S, Banerjee D.  
R I Med J (2013). 2023 Aug 3;106(7):58-63.

### How workplaces produce or reduce disability along the career paths of young people with cystic fibrosis.

Silvestri L, Issanchou D, Schuft L, Ferez S.  
Health (London). 2023 Jul 6::13634593231185265. [Epub ahead of print]  
PMID: 37409611 [PubMed - as supplied by publisher]

# The Main Course

## Food insecurity screening and local food access

Food insecurity (FI) continues to be a significant issue in the US, and families with an individual with CF are no different. Screening for and offering options for food insecurity is associated with improved nutrition outcomes, especially when screened using paper vs verbal screen.

This is especially vital when individuals live in a food desert. . My.CFF offers many tools for starting the process of screening for FI, as well as suggestions for interventions. COMPASS is another resource available for teams.

Check Out the Full Article:

[Food insecurity screening and local food access: Contributions to nutritional outcomes among children and adults with cystic fibrosis in the United States](#)

Julianna Bailey a, Elizabeth Baker a, Michael S. Schechter b, Keith J. Robinson c, Kate E. Powers d, Elliot Dasenbrook e, Monir Hossain a, Dixie Durham f, Georgia Brown g, Cristen Clemm h, Kim Reno h, Gabriela R. Oates

Journal Of Cystic Fibrosis 2023 Sept 4  
<https://doi.org/10.1016/j.jcf.2023.08.006>



# Additional Article Releases

**Evaluation of the Use of Appetite Stimulants in Pediatric Patients with Cystic Fibrosis.**

Kennedy K, Lee M, Sathe M, Ueng CS, Sharma P. , J Pediatr Gastroenterol Nutr. 2023 Jul 12

**Meconium ileus and pancreatic sufficiency with D1152H mutation: A case report and**

**review of the literature.** Kennedy K, Lee M, Sathe M, Ueng CS, Sharma P. J Cyst Fibros.

2023 Jul 7

**How workplaces produce or reduce disability along the career paths of young people with cystic fibrosis.**

Silvestri L, Issanchou D, Schuft L, Ferez S. Health (London). 2023 Jul 6

**Late Diagnosis in the Era of Universal Newborn Screening Negatively Effects Short- and**

**Long-Term Growth and Health Outcomes in Infants with Cystic Fibrosis.** Martiniano SL, Wu

R, Farrell PM, Ren CL, Sontag MK, Elbert A, McColley SA. J Pediatr. 2023 Jul 3

**Hyperbilirubinemia and Gilbert's syndrome in Cystic Fibrosis patients treated with**

**elexacaftor/tezacaftor/ivacaftor.** Terlizzi V, Timpano S, Salvi M, Tosco A, Castaldo A, Fevola

C, Leonetti G, Vitullo P, Sepe A, Badolato R, Salvatore D. J Cyst Fibros. 2023 Jul 1

**Changes in bone turnover after high-dose vitamin D supplementation during acute**

**pulmonary exacerbation in cystic fibrosis.** Wu M, Bhimavarapu A, Alvarez JJ, Hunt WR,

Tangpricha V. Bone. 2023 Jun 28

**Identifying the need for a UK colorectal cancer screening programme for patients with**

**cystic fibrosis (CF): 10-year retrospective review of colonoscopy and colorectal cancer**

**outcomes at a single CF centre.** Karuna Sapru, Peter Barry, Andrew Jones, John Walmsley,

Javaid Iqbal, Dipesh H Vasant BMJ Gastroenterol 2023 June 18

**Impact of intrinsic and extrinsic risk factors on early-onset lung disease in cystic fibrosis**

Leslie Huang, HuiChuan J. Lai, Jie Song, Zijie Zhao, Qiongshi Lu, Sangita G. Murali, Donna M.

Brown, Elizabeth A. Worthey, Philip M. Farrell Pediatric Pulmonology 2023 Jul 21