Dear Community Voice member,

Welcome to the July edition of the Monthly Results Updates!

New to Community Voice? Welcome! In these digests you will learn about recent opportunities that Community Voice members have participated in, the feedback, ideas, and insights we gathered, and the next steps or impact of each project. If you have any questions or feedback on how we can improve these digests, please contact us at communityvoice@cff.org.

Lung Transplant Referral Guidelines
Committee & Focus Groups

In 2016, the Foundation launched the Lung Transplant Initiative, a newly expanded $23.5 million multi-year effort to maximize transplant as a life-sustaining therapy and extend post-transplant survival. Development of guidelines and educational content are part of this initiative to improve the entire transplant journey. Community Voice members served on the Lung Transplant Referral Consensus Guidelines Committee and shared insights and feedback in focus groups and emails to help people with CF:

- Receive specialized care based on the latest research, medical evidence, and consultation from experts in transplantation through the publication of the Lung Transplant Referral for Individuals with Cystic Fibrosis: Cystic Fibrosis Foundation Consensus Guidelines
- Understand why it is worth talking about lung transplant early—especially before one is needed—by learning about what transplants look like today and accessing resources for how to plan accordingly, including a handout to help start these conversations with family and care teams.
Lung Transplant Initiative Webinar

If you would like to learn more about the Lung Transplant Initiative, a one-hour webinar will be held on Wednesday, August 21, 2019 at 5:30 p.m., ET featuring Albert Faro, MD, Senior Director of Clinical Affairs and Erin Tallarico, RN, BSN, Director of the Lung Transplant Initiative.

Register for the Webinar

Data Safety Monitoring Board

The Cystic Fibrosis Foundation and Therapeutics Development Network’s Data Safety Monitoring Board works to protect the safety and welfare of people enrolled in CFF/TDN-sanctioned clinical trials by reviewing the initial study protocol and proposed safety monitoring plan. Once the trial has started, study data is monitored in real time to ensure the safety and merit of the clinical trial. After carefully reviewing applications from Research Voice members and hosting interviews with top candidates, the committee leaders are excited to announce that four parents including Rebecca Murray, Rachel Cravens, Kerry-Doyle Shannon, and Julie Lazzara will be joining physicians, statisticians, ethicists, and six other community members to serve on this multidisciplinary committee.

From right to left: Rebecca Murray, Rachel Cravens, Kerry-Doyle Shannon, Julie Lazzara

PROMISE Study Focus Group

The PROMISE study is an observational research study led by CF researchers to better understand how treatment with a new CFTR modulator may affect people with CF and impact their future clinical care. To help inform people with CF about the study, an information sheet was created and shared with a Research Voice focus group to get their opinion on whether the sheet covered all key information a person would want to know when considering participation in this study. Members shared feedback on how to improve the resource, including adding more detail on the length of study visits, cost and compensation, the overall purpose and impact of the study, safety and risks, and specific study procedures. The resource is currently being revised to incorporate their feedback and will be available in a future update.
Infection Prevention & Control Passport Card

Community Voice members shared feedback about the need to reduce the risk of cross-infection in healthcare settings beyond CF care centers. Thanks this feedback along with other members from the community, a printable IPC Passport Card was created to help educate healthcare providers about how to reduce the risk of spreading germs and provide people with CF and families a way to help them better advocate for themselves.

2019 CF Health Insurance Study

Last year more than 2,500 members of the CF community responded to the CF Foundation’s CF Health Insurance survey. This survey, along with in-depth interviews with people with CF and parents of children with CF, shaped Compass programming and helped us advocate with decision-makers across the country.

The 2019 CF Health Insurance survey is now open for people with CF, parents, and caretakers. This 15-minute survey was designed with researchers at the George Washington University to help us better understand how people with CF navigate health insurance, access to care, and cost. Your voice is critical to help inform Foundation policy efforts and programming. For more information about the survey, please visit www.cff.org/CFHIS.

National Organization for Rare Disorders (NORD) 2019 Patient and Family Forum

Betsy Sullivan, an adult with CF, and her mom Mary had the opportunity to speak on a panel about their experience with transitioning from pediatric to adult CF care at the 2019 Living Rare, Living Stronger NORD Patient & Family Forum.
Writing for the CF Community Blog

Check out these recent blog posts by Community Voice members! Community Voice currently has 89 members who have written 206 posts since the CF Community Blog launched!

- **Jumping Over My Fear to Join a CF Clinical Trial** – Amyee Phinazee
- **Focusing on the Now Helped Us Survive Losing Our Daughter to CF** – Frank & Sue LaRosa
- **What Overnight Summer Camp Taught Me About CF** – Hogan Reed

Want to contribute to the CF Community Blog? Fill out this [questionnaire](#).

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Invite others to join Community Voice by sending them to [cff.org/CommunityVoice](http://cff.org/CommunityVoice).

For questions or concerns, please contact the CF Foundation's Community Partnerships department at [communityvoice@cff.org](mailto:communityvoice@cff.org).

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