

January 21, 2019

Dear Inova CF Community,

Happy New Year! We are excited to continue to partner with you as we enter a new year and wanted to take an opportunity to share our accomplishments for 2018 and our goals for 2019.

2018 can be summarized in one word: **GROWTH!** We experienced a 38% increase in patient numbers which brings us to about 90 total adults with cystic fibrosis cared for at Inova. With this growth, we have tried to take advantage of everything the CF Foundation (CFF) offers Care Centers in terms of resources and support:

- **CFF Mentoring Program**
 - Melissa Bowen (nurse coordinator), Lauren Marinak (nurse practitioner), and Quyen Duong (respiratory therapist) participated in this program geared at advancing their professional development in CF in their respective specialties
- **CF Fun to One Learning and Leadership Collaborative Program**
 - We were selected to participate in this fifteen month quality improvement program run by the Dartmouth Institute in conjunction with our colleagues at *The Pediatric Lung Center* and six other CF Care Centers around the country
 - Our focus area is communication, so be on the look-out for more from us on what's happening here at Inova and on the national level in CF
- **Therapeutic Development Network:** We applied for this program in November 2018. There was stiff competition and we were not selected, but we will try again in 2 years-time! We have a great interest in research and a strong track record of success in many pulmonary diseases, and will continue to offer and increase research opportunities in CF.
- **CF Physical Therapist and Pharmacist:** We applied for grants for these part-time positions for our CF program. We will find out in February if we will receive funding.
- We were fortunate to hire **Erin Lopynski, RD as our CF dietician** in October. I am confident that you will enjoy working with Erin if you have not yet had the chance!
- **CFF Great Strides:** members of the adult and pediatric teams participated in the Northern Virginia Great Strides Walks again this year. Our team name is *Airway Angels*
- **Charity Cycle Ride:** members of our CF team and community participated in a charity spin class. Everyone enjoyed themselves and burned calories at the same time ☺

Many of our team members had the opportunity to travel to Denver in October for the yearly North American Cystic Fibrosis Conference (NACFC) which is always a great time for team bonding, networking, and learning about the latest and greatest in CF from around the world. As a team, we learned a lot and for the first time, **we held a post-NACFC webinar** in December to share information that we learned with you. If you missed it, you can find a recorded version here: <https://youtu.be/uEBcRyJhKOM>.

- **Highlights from NACFC:**
 - We presented an abstract on our CF pulmonary rehabilitation program design in both an oral presentation and poster form
 - Several staff members attended for the first time, including Dr. Aryal, Lauren Marinak, NP, Dr. Katugaha (infectious disease doctor), and Maureen Myrvold, RN, a bedside nurse from the Acute Pulmonary (inpatient) unit

- **The big news in terms of new drug development was on the “TRIPLE” drug combination tezacaftor/ivacaftor and VX-659 or VX-445.** This triple drug combination (now in phase 3 studies) is designed for patients with 2 copies of the delta F508 mutation or 1 copy of the delta F508 mutation with another type of mutation. It appears that it may improve lung function as much as 10-12% for some people with CF and may be FDA approved and available by the end of 2019! See our webinar for more details☺.
- **Goals for 2019:**
 - **Improve communication** with our patients through more newsletters and webinars, and more feedback from you☺
 - **Create Post-Transplant Annual CF Appointments:** people with CF who have had a lung transplant will be seen by the CF Coordinator, dietitian, social worker and physician once a year to address CF specific needs, outside of lung transplant (like GI or sinuses)
 - **Create a Patient Family Advisory Board:** let Elizabeth Elizabeth.Davies2@inova.org know if you are interested in being a part of this group who will help us improve the CF care experience at Inova. We are likely to meet quarterly (virtual meetings) and a stipend for participation may be available. We need your input—both patients and caregivers!!
 - **Participate in the Patient and Family Experience of Care Survey.** This is a service provided by the CFF to get patient input thru a 30 question survey to help us improve our care experience. Survey will be sent twice a year after clinic visits
 - **Improve the hospital experience** through more training of staff on the inpatient unit and by developing a handout on what to expect when admitted to our hospital
 - **Consistently provide a CF respiratory therapist** in clinic for airway clearance issues
 - **Apply for additional grant opportunities** to get more dedicated staff for our program
 - **Continue to participate in Great Strides:** members of the team will participate in the Northern Virginia and Washington, D.C. If you are interested in joining our team, please contact Melissa at Melissa.Bowen@inova.org

As a reminder, we have a Facebook Page for our Inova Adult CF Program. It is a closed group and completely voluntary. If you're interested in joining, email Elizabeth at Elizabeth.Davies2@inova.org.

Mark your calendars for Wednesday, May 15th for our third annual CF Center Open House Event in the Physician Conference Center at the Inova Fairfax Medical Campus. This will be an opportunity for us to come together as a combined pediatric and adult CF community, in person for our CF supporters and caregivers, and remotely for CF patients (webinar). Each of our CF team members will provide an update on what's happening in CF and there will be a time for questions. We hope you will join us!

Thank you, as always, for your confidence in our program and your support of our community. It is truly a privilege to be involved in your care and in your lives.

Best wishes for 2019,

A. Whitney Brown, MD
 Adult Program Director
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We are dedicated to enhancing the lives of people with cystic fibrosis by delivering innovative and individualized care in collaboration with patients and their families.

THE INOVA ADULT CF TEAM



Pictured Left to Right: Chris King, MD; Kim Palczynski, RRT; Quyen Duong, RRT; Elizabeth Davies-Wellborn, SW; Lauren Marinak, NP; A. Whitney Brown, MD; Gerilynn Connors, RRT; Erin Lopynski, RD; Melissa Bowen, RN; Kareem Ahmad, MD

(Not pictured: Shambhu Aryal, MD; Oksana Shlobin, MD; Jessica Chun, NP; Meg Fregoso, NP; Rebecca Kopelen, RRT; Cheryl Russell, RRT; Michelle Schreffler, RN; Matthew Kott, RN)

THE INOVA ADULT CYSTIC FIBROSIS TEAM

CF Physicians

A. Whitney Brown, MD

Christopher King, MD

Shambhu Aryal, MD

Kareem Ahmad, MD

Oksana Shlobin, MD

Post Lung Transplant Nurse Practitioners

Jessica Chun, NP

Meg Fregoso, NP

Inpatient Nurse Practitioner

Lauren Marinak, NP

CF Program Coordinator

Melissa Bowen, RN, BSN, MPH

Pre-Transplant Nurse Coordinators

Michelle Schreffler, RN, BSN

Matt Kott, RN, BSN

CF Social Worker

Elizabeth Davies-Wellborn, MSW, LSW

CF Dietician

Erin Lopynski, RD

CF Lead Respiratory Therapist

Quyen Duong, RRT