

Summary: Voice of the Cystic Fibrosis Patient Report *Continued from page 3*

- The CF community is known for its enthusiastic participation in clinical trials; the majority of meeting attendees were clinical trial participants – either currently or in the past.
- Meeting participants expressed strong willingness to assume risks in participation with clinical trials, also indicating that distance, placebo, blood draws, missed work, and multiple clinic visits would not discourage their participation.
- The desire for enhanced research, drug development and trials for members of the CF community with nonsense and other rare mutations was passionately expressed.
- Attendees expressed the desire to participate in clinical trials not only for one’s own personal health, but with the hope that others might benefit in the future.
- Individuals with cystic fibrosis have a strong desire to participate

in trials, and are often frustrated when they are excluded due to their FEV1. A consistent theme was a desire for drug developers and the FDA to consider expansion of criteria for CF clinical trials beyond the current FEV1 limitations to include number of exacerbations, quality of life, weight, etc.

- N-of-1 studies were encouraged due to the number of rare mutations in the CF community.

The Externally-Led Patient-Focused Drug Development Meeting on Cystic Fibrosis was a powerful event in illuminating the voices of those impacted by CF. It is hoped that this facilitates an ongoing conversation between the FDA and the CF patient community so as to inform those who assess the value and efficacy of CF-related therapies. Every day without new therapies matters.

The recording of the meeting is available on CFRI’s YouTube channel: <https://tinyurl.com/y77jt99h>. To read the full report, go to cfri.org, and click on the “Advocacy” tab.

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fervent wish that our funding continues to expand to keep pace with the requests for research grants.

In his cover article, CFRI-funded researcher Lucas Hoffman, MD, PhD, provides a wonderful overview of his inspired work. As a member of CFRI’s community, you are a part of this innovative

research. Thank you for your ongoing support. With your help we will continue to move closer to a cure, while enhancing the lives of those living with cystic fibrosis.

Peace and good health,



Bill Hult | Board President

Five Feet Apart: Bringing the CF Experience to the Big Screen

By Siri Vaeth, MSW

The film *Five Feet Apart* tells the story of Stella and Will, two teenagers with cystic fibrosis (CF) who meet and fall in love while in the hospital. Stella is listed for transplant, yet Will is ineligible due to culturing *Burkholderia cepacia*. The need to stay six feet apart to prevent cross infection is initially obvious, but as their relationship develops, the lines become blurred.

Five Feet Apart has triggered tremendous discussion in the CF community. Some celebrate the portrayal of CF on the big screen as an awareness-raising opportunity. Others question the message conveyed to young people with CF in terms of adherence to infection control protocols. We are a diverse community, and no film will accurately portray us in our full complexity.

CFRI was honored to host an online “town hall discussion” on the film, with over 950 people participating via Zoom and Facebook Live. As moderator, I was inspired by everyone’s honesty and candor in sharing what resonated most, including the relationships

with the medical care team, the isolation, the depression, and the intense frustration with the physical limits of infection control.

When asked to share their favorite scenes in the film, few mentioned Stella’s stealing a foot from CF. Rather, many people appreciated when Stella and Will disrobe and stand before each other, showing their scars, G-tubes and CF war wounds, exhibiting simultaneous vulnerability and intense power. This inspired a frank discussion about the body shame experienced by many with CF, and underscored the strength of that scene.

Other scenes were “favorites” due to their significance, including when Poe shares that his fear of being a burden on others has led him to reject their love. This scene triggered an extremely meaningful conversation, as



others expressed this same fear. Touch is a human need, and the scene in which Poe mourns that he cannot comfort Stella with a hug – a gesture taken for granted by those without CF – was painful and accurate.

Five Feet Apart was created with the input of Claire Wineland, and from the opening scene it is impossible not to think of her as we watch Stella posting her videos online. Claire is deeply missed, and it was wonderful to feel her presence throughout.

CFRI looks forward to hosting future “town hall” discussions. We are a community that hungers for connection, and we want to keep the conversation going.