CFRI Advocacy and Awareness: About Copay Accumulator Programs

By Siri Vaeth, MSW

Through its Many Voices ~ One Voice Cystic Fibrosis Advocacy and Awareness Program, CFRI engages our community to raise awareness about the burdens of cystic fibrosis (CF), the impact of its rare disease status, the diversity of our community, the critical need for research funding, and barriers that impede access to therapies and care. One such barrier to care is the proliferation of copay accumulator programs that are embedded in nearly two-thirds of private insurance plans nationwide.

Copay accumulator programs impose significant financial hardship upon patients. Many CF community members use copay assistance from drug manufactures and charitable organizations to access their medications. Historically, these funds were applied toward a person's deductible and out-of-pocket expenses. Once the full value of the assistance was utilized, patients would usually have met their deductible and be able to afford their copay.

With a copay accumulator program, the payers accept the funds from the copay assistance, and, after the copay assistance is fully expended, force the patient to meet their deductible. In essence, the deductible is paid twice: once by the manufacturer or charity, and once by the patient.

Those who rely on specialty medications are most impacted by these policies. While some argue that copay assistance is a strategy by pharmaceutical companies to drive people to expensive name brand drugs instead of generics. The vast majority of copay assistance is used for prescriptions that have no generic equivalents. This is certainly true in the cystic fibrosis community.

Studies have shown that copay accumulator programs impede access to therapies and exacerbate health disparities. When out-of-pocket prescription costs reach $75 to $125, more than 40% of patients leave their medication at the counter. When these costs reach $250, over 70% of patients will forego their medications. This leads to greater risks of health decline and costly emergency room visits.

To date, 16 states and Puerto Rico have passed laws to make all copays count; another dozen states have legislation in the works. This includes California, where CFRI has joined the ALS Association, Hemophilia Council of California and the California Rheumatology Alliance to sponsor AB 874 to ensure all copays count. At the federal level, HB830 has been introduced to ban copay accumulator programs. This legislation has tremendous bipartisan support.

There are many ways to get involved with CFRI's advocacy and awareness efforts. We seek your engagement! Please email Stacie Reveles at sreveles@cfri.org for more information.

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CFRI Funds Innovative CF Research

At the core of CFRI's mission is to pursue a cure for cystic fibrosis through supporting innovative research. CFRI is committed to ensuring that research will continue toward a cure. We invest in the highest quality and most innovative scientific research that will increase understanding of the disease, broaden treatment options, improve quality of life, and expand the search for a cure. We seek to attract the next generation of researchers and foster a long-term thriving national CF research community, with an emphasis on outreach to ensure gender, race and ethnic diversity. We also seek to encourage research that will contribute toward therapies for those ineligible for CFTR modulators.

Members of CFRI's Research Advisory Committee (RAC) are currently in the process of reviewing and vetting a diverse range of high-quality research proposals. The RAC recommendations will guide CFRI's Board of Directors, which will vote on 2023 research grant awards, with awardees to be shared with our CF community in early May.

Current CFRI-funded researchers include:

Elizabeth Nash Memorial Fellowship Award:

- Suzanne Fleiszig, PhD, Principal Investigator; Naren Kumar, PhD, Post-Doctoral Fellow; UC Berkeley – *Characterizing the intracellular diversification of Pseudomonas aeruginosa in chronic lung infections.*
- Paul Bollyky, MD, PhD, Principal Investigator; Nina Pennetzdorfer, PhD, Postdoctoral Fellow; Stanford University – *Targeting Bacterial Resistance to Phage Therapy in Cystic Fibrosis.*

New Horizons Award

- Steven Aller, PhD, The University of Alabama at Birmingham – *Role of CFTR Arginine-933 in Folding, Gating and Potentiator Drug Binding.*
- Steven Jonas, MD, PhD; The Regents of the University of California, Los Angeles – *Developing Nanotechnology-Enabled Gene Therapy Solutions to Correct CFTR Mutations in Airway Stem Cells: Toward a One-Time Cure for Cystic Fibrosis.*
- Carlos Milla, MD, Principal Investigator; Stanford University – *Improving CF Airway Mucociliary Clearance: Toward Transition from Animals to Humans.*
- Kenichi Okuda, MD, PhD, Principal Investigator; University of North Carolina at Chapel Hill – *Pathways Maintaining Basal Mucin and CFTR-mediated Fluid Secretion in the Human Distal Airway.*
- Matthew Porteus, MD, PhD; Stanford University School of Medicine – *Identifying Biomaterials that Enable the Transplantation of Gene Corrected Airway Stem Cells to Treat Cystic Fibrosis.*
- Zachary Sellers, MD, PhD, Principal Investigator; Stanford University – *Targeting IRBIT to Correct Bicarbonate Secretory Defects in Cystic Fibrosis.*

The researchers above will present their work at CFRI's National Cystic Fibrosis Education Conference on Friday, July 28, at the Grand Bay Hotel San Francisco in Redwood City, CA.

These promising projects are made possible through generous contributions from the community. Thank you to all whose support is advancing innovative cystic fibrosis research.