

# Many Voices ~ One Voice: CFRI's Advocacy & Awareness Efforts on Behalf of the CF community

Through its Many Voices ~ One Voice Cystic Fibrosis Advocacy and Awareness Program, CFRI engages our CF community to raise awareness about the burdens and complications of the disease, including the lack of a cure, impact of its rare disease status, the need for CF research funding, and barriers faced by our community in accessing care.

Along with numerous patient advocacy groups, CFRI is involved in the movement to create Rare Disease Advisory Councils. There are 10,000 identified rare diseases (defined as one that impacts less than 200,000 Americans) including cystic fibrosis, and it is estimated that 1 in 10 Americans has a rare disease. State Rare Disease Advisory Councils (RDACs), provide the community with a formal platform and official voice to help advise state officials on policies and services that impact us. Currently, nearly 30 states in the U.S. have RDACs, and CFRI is a member of several coalitions working to advance these efforts. This includes in Calif-

ornia, where AB 2613 has been introduced to create an RDAC.

CFRI also participates with several coalitions to advance legislative bans on co-pay accumulator policies, which do not allow payments from drug manufacturer assistance programs to be applied toward a person's deductible and total out-of-pocket expenses. These policies are embedded in 64% of private insurance plans and create significant financial hardship for many members of our community. CFRI is working with others to support legislation mandating that all payments for prescriptions be applied toward one's deductible and annual out-of-pocket total. In California, CFRI is a cosponsor of AB 8130 which would ban these policies.

This type of legislation has already passed in a twenty states, Washington DC and Puerto Rico, with broad bipartisan support. On the federal level, bipartisan legislation has been introduced in the House and Senate



(H.R.830 and S.B.1375, the Help Ensure Lower Patient (HELP) Copays Act. If you would like to get involved, or need more information, please contact us at CFRI.

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## 2024 CF Summer Retreat: Created By and For Adults with CF July 28 – August 1, 2024

CFRI's Retreats for Adults with CF bring together community members from across the nation and globe. Our recent virtual Spring Retreat in March was attended by over 50 adults with CF as well as family members and friends. We are now gearing up for our annual CF Summer Retreat, which offers adults with CF a welcoming place to engage with their peers. The retreat will be held as a hybrid event. For those attending in person at Vallombrosa Retreat Center in Menlo Park, California, we will have our usual stringent cross-infection and COVID-19 protocols in place. For those unable to travel to California, many of the sessions will also be offered online.



**The retreat will provide health-related and psychosocial support programs and activities including:**

- Exercise activities tailored to individuals' unique capacities;
- Educational workshops with guest speakers from CF centers across the country, addressing such issues as transplant, GI challenges, hemoptysis, nutrition, and kidney disease;
- Rap sessions (support groups) to support positive mental health;
- Dedicated time to connect, network, and socialize with others.

Attendees consistently report that the retreat offers new information about CF therapies and treatments, dramatically improves psychosocial health, and provides resources and strategies for coping with the daily challenges of CF. While the retreat is geared toward adults with CF, attendees are able to invite adult family members and supportive peers. **Join us!** For more information, go to [www.cfri.org](http://www.cfri.org) or call Mary Convento at 650.665.7559.

*The CF Retreat is generously sponsored by Vertex Pharmaceuticals, AbbVie, and private donors, with special thanks to Devin Wakefield.*