ADVOCACY TOOLKIT

CFRI Cystic Fibrosis Research Institute

RESEARCH · EDUCATION · ADVOCACY · SUPPORT

About Cystic Fibrosis Research Institute & Advocacy

The Cystic Fibrosis Research Institute (CFRI) is a 501(c)(3) dedicated to enhancing quality of life for the cystic fibrosis (CF) community. CFRI's mission is to be a global resource for the CF community while pursuing a cure through research, education, advocacy, and support.

CFRI's advocacy efforts focus on educating and engaging those impacted by CF, their care providers, the general public, and lawmakers. We aim to broaden understanding of the challenges faced by the CF community and identify solutions to promote equity, access to therapies and care, and enhanced quality of life for all.

CFRI's advocacy and awareness programs aim to:

- Build and strengthen coalitions of national CF and rare disease agencies and community members
- Educate the CF community, their care providers, the general pubic, and lawmakers
- Track national and state legislation important to those with CF and CFRI as an organization
- Serve as a trusted resource to decision makers throughout the nation's federal and state legislative, executive, and administrative bodies

About This Resource

CFRI believes that everyone can be an advocate. Whether you prefer providing CF-related education and resources in one-on-one interactions with friends and family, or you enjoy speaking with elected officials to advance a specific initiative, your voice matters!

This toolkit provides an overview of how to engage in advocacy efforts, while also providing educational materials on specific CF-related topics that can be used for yourself, shared with those in your immediate circle, or offered to key decision makers.

For more information about CFRI's advocacy efforts, visit www.cfri.org/advocacy

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Engaging in Advocacy

ADVOCACY is any action or activity that aims to raise awareness, promote public involvement, or drive action related to a particular cause or issue. Advocacy can influence policy, public opinion, education, and/or change social practices.

Advocacy can include a broad range of activities including, but not limited to, having conversations with family and friends, posting your thoughts on social media, sharing your story related to a particular topic, signing petitions, attending a demonstration, or meeting with elected officials.

As member of the CF community, there is a lot one can speak up for or speak out against. Starting small can still end big. Effective advocacy happens at every level, often spurring a ripple effect of support that results in momentous change.

As you become more comfortable engaging in advocacy initiatives, you might consider meeting with elected representatives to advance or prevent specific legislation from passing into law.

This is a powerful step in taking action to protect the rights of people with CF and others living with a rare disease. As you meet with members of local, state, or federal government, remember that they are there to serve the best interests of their constituents. Do not be afraid to make your needs and wishes heard.

Forming Relationships

Before you can share your story and make an ask of your elected official, you need to introduce yourself and begin forming a relationship. The best practice is to first attempt reaching out via phone; if you can speak to someone directly you are more likely to garner their attention and make headway towards a meeting. However, often the offices of elected officials are busy, and email is the only way to make initial contact.

Use the template below, modifying it to suit your personal and professional style of communication, to contact your elected official's office.

Dear **[Elected official]**,

I am a constituent and a **[a person with cystic fibrosis / family member of someone with cystic fibrosis / member of the cystic fibrosis community]**. In following up with my phone message, I respectfully request a meeting with the office of **[elected official]** to seek support and hopefully champion our efforts to **[initiative e.g., broader newborn screening for rare genetic mutations in Mississippi]**. Specifically, I would like to discuss **[insert a specific focus for the topic]** .

We deeply appreciate **[elected official]** for their service and support of the cystic fibrosis community. For more information about cystic fibrosis, please explore the factsheet attached to this email.

We would like to meet with your office to discuss this further and we hope **[elected official]** is willing to support and consider championing this initiative. Please let me know the best staff member we can stay in communication with, and if there is any additional information we can provide. I look forward to setting up a meeting in the near future and appreciate your office's consideration of this request.

Sincerely,
[Name & organizational affiliation]

Sharing Your Story

Sharing your story can help shape your future. Use any or all of the tips below when speaking with key decision makers to broaden awareness, inspire empathy, advance access & improve quality of life for those within the CF community.

- **Find your hook:** Craft a powerful opening and identify your goal
- **Know your audience:** Research the person you will be speaking with and try to find common ground
- **Paint a picture:** Use descriptive, visual language; help the person envision your experience by using tangible examples
- **Use emotion:** Remember to remain professional, but don't be afraid to express sadness, anxiety, frustration, or appreciation in your voice
- **Be inclusive:** As you transition towards your conclusion, use fewer 'I' statements and include more 'we' statements to reflect the needs of the entire CF community
- **End strong:** Provide solutions, offer an ask, and/or seek commitment from the person you are speaking to

If possible:

- **Use research & data:** Underscore the importance of particular details by introducing compelling evidence & resources about the topic
- **Touch on vision:** Show that your vision is possible by referencing other regions, states, organizations, policies, or countries that have been successful

When you meet with key decision makers, you never know if you will have 5 or 50 minutes to speak with them. Always ask at the beginning of the meeting so that you know how to allocate the time. As a general rule of thumb, try to keep your personal story between two and three minutes.

Oral & Written Testimony

Public testimony provides individuals with an opportunity to participate in the legislative process by sharing with key decision makers why a proposed bill or policy should or should not be supported. Public testimony can be written and/or oral. The rules surrounding how to structure one's testimony may vary depending on state, legislative branch or body, and number of people planning on testifying. Despite these variables, one can expect that preparing testimony of 1-2 minutes in length—that includes a brief introduction and ask(s)—is appropriate.

Example Testimony:

Good afternoon,

Opening: I am writing to you as a 26 year old Cystic Fibrosis patient who has received a miracle in the form of a drug. Trikafta took me from full time oxygen, the need for a double lung transplant, hospitalizations every couple months and countless procedures to zero oxygen and transplant need and a full time teacher participating in all Colorado has to offer. Selecting Trikafta to review could potentially take this miracle out of our hands!

Ask #1: I am asking you to please exclude Trikafta and other rare disease medications from the PDAB considerations. Daily use of this drug is required to maintain the effects and it is the only breakthrough CF drug of its kind, not just masking symptoms but making the body function correctly. There are many copay assistance programs as well as non profits who help make this medication accessible to many CF patients! We want the companies to keep up this amazing research and keep fighting for a cure so that one day CF will stand for cure found! **Ask #2:** We would also ask to have public testimony at Mondays PDAAC meeting so that me and many others with Cystic Fibrosis can share our stories.

Closing: Please do not cost CF patients like me their lives! Thank you for your time and consideration.

Thank you,
Hannah Pfeiffer and all CF patients like me

Leveraging Social Media

Social media is a powerful tool for raising awareness, mobilizing supporters, and influencing change. With just one post, you can reach thousands of people, educate the public, and amplify the voices of those impacted by CF. Platforms make it easy to share personal stories, engage with key decision-makers, and inspire collective action. By leveraging social media, you can build a stronger, more informed community while pushing for meaningful legislative and policy changes.

Your voice has power—use social media to educate, inspire, and advocate for the CF community. Every post, comment, and share moves us closer to change.

Best Practices for Effective Advocacy on Social Media

- Make posts personal & relatable, use storytelling to make an emotional impact. Keep it clear, concise, and authentic.
- Use high-quality, eye catching visuals or use infographics to break down complex CF issues (avoid text heavy graphics).
- Add subtitles to videos for accessibility and broader reach.
- Encourage Engagement by ending with a question or call-to-action. Ask followers to comment, share, or tag a friend, and respond to comments to foster discussion and keep the post active.
- Be Respectful & Professional - advocacy should be compelling but remain constructive.
- Repost from trusted CF organizations like CFRI, advocacy groups, and medical professionals.
- Share Existing Content from other accounts, make sure to get permission if sharing personal stories and testimonials.
- Post during peak engagement times (morning, lunchtime, or evening).

Using Hashtags & Tagging Accounts

- Use a mix of broad (#CysticFibrosis) and niche (#CFAdvocacy) hashtags.
- Avoid using too many—stick to 3-5 per post for Instagram, 1-2 for Twitter.
- Tag legislators, advocacy groups, media outlets and CF organizations to increase visibility.
- Acknowledge community members to foster engagement.

Platform-Specific Tips for Advocacy

Facebook:

- Use & post in Facebook Groups to build engaged communities.
- Post longer-form content with links to petitions, news articles, or blog posts.
- Facebook Live is great for real-time advocacy discussions and Q&As.

Instagram:

- Stories and Reels drive higher engagement—use polls, Q&A stickers, and countdowns.
- Carousel posts (multiple images) boost visibility and encourage swiping.

LinkedIn:

- Share professional perspectives on CF advocacy and policy changes.
- Write or share articles that provide in-depth analysis on CF-related legislation.

TikTok & YouTube:

- Use short-form videos to explain key CF issues in a digestible way.
- Leverage trending sounds and challenges to increase reach.

X (Twitter), Threads & Bluesky:

- Keep posts concise and impactful—lead with strong, bold statements.
- Tag policymakers and use trending hashtags to get noticed.

Unsure of What to Write? Try These:

- “Did you know people with CF face daily challenges accessing life-saving medications? Let’s advocate for change! #CysticFibrosis #AdvocateForCF”
- “I support better healthcare access for those living with CF! Learn more about how you can help. #CFAwareness”
- “CF warriors need our voices! I’m sharing this to spread awareness. #CysticFibrosisAdvocacy”
- “Access to CF care shouldn’t be a fight! I’m using my voice to demand better policies for our community. Will you join me? #CFAwareness”
- “Behind this smile is a lifetime of hospital stays, medication struggles, and perseverance. CF is an invisible illness, but our fight for change should be visible. Let’s make our voices heard! #AdvocateForCF”
- “This is what CF looks like: 30+ pills a day, hours of breathing treatments, endless medical bills. We need better support and policies to ease these burdens. Let’s push for change! #CFPolicyMatters”

Cystic Fibrosis (CF) - The Basics

- CF is an **inherited chronic, life threatening disease** that impacts every organ system
- CF has been diagnosed in **approximately 40,000 people** in the United States & an estimated **105,000 people** worldwide
- CF impacts people of **every race & ethnicity**
- CF has **no known cure**

Causes

CF is a recessive genetic disorder, which occurs when a child inherits two abnormal genes from each parent. This gene is called the cystic fibrosis transmembrane conductance regulator (CFTR). When both parents are carriers of the mutated CFTR gene, there is a 25% chance the child will have CF.

There are approximately 2,000 mutations to the CFTR gene that have been identified to date,[2] with over 700 that are known to be disease causing. Not everyone with a CFTR mutation will have CF or significant adverse health impacts.

Symptoms

For those that do, the amount of salt that moves in and out of cells is impacted, which results in thick mucus production. This mucus can clog the small passageways of the respiratory, digestive, endocrine, and reproductive systems. This mucus can also trap harmful bacteria and cause infections.

Primary symptoms include:

- salty tasting skin
- persistent cough
- frequent lung infections
- frequent sinus infections
- nasal polyps
- poor growth
- difficulty gaining weight
- meconium ileus
- shortness of breath
- male infertility

Rare Disease Status

In the United States, a condition is considered a rare disease if it affects less than 200,000 people. Presently, over 10,000 rare diseases have been identified, which together impact more than 30 million Americans.[3]

Approximately 40,000 people have been diagnosed with CF in the United States, and that number continues to grow as more people—particularly those of diverse racial and ethnic backgrounds—receive testing.

CF is fortunate to have FDA approved therapies, however receiving a diagnosis of CF and accessing useful therapies often remains challenging. This is particularly true for people of color with CF, who are more likely to have rarer CF mutations, receive a late diagnosis, and be ineligible for current therapies.

Banding Together

RARE DISEASE ADVISORY COUNCILS

Rare Disease Advisory Councils (RDACs) are advisory bodies intended to give the rare disease community a stronger voice in state government. RDACs can offer strategic suggestions, conduct research, and inform elected officials and the general public about the needs of people with rare diseases. RDACS can help improve health outcomes and quality of life for people with rare diseases and their families by allowing people with lived experience to collaborate with legislators.

For more information about RDAC legislation, visit the National Organization for Rare Diseases (NORD): www.rarediseases.org

95%

Of rare diseases do not have FDA approved therapies.[4]

35%

Of deaths that occur within the first year of a child's life are due to a rare disease.[5]

6.3 yrs

Average length of time to receive a rare disease diagnosis.[6]

17 visits

On average to healthcare professionals before a diagnosis.[6]

$220,000

Cost, if not greater, of delayed diagnosis and healthcare encounters per person.[6]

Diversity & Inclusion

CF impacts people of all races and ethnicities.

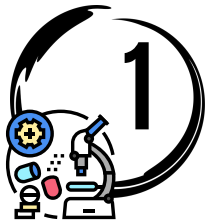
While more common among people of European descent, CF is found in every community. It is estimated that:

- 1 in 15,000 African Americans have CF [7]
- 1 in 10,000 people of Indian origin have CF [8]
- 1 in 9,200 Hispanic/Latinx people have CF [7]

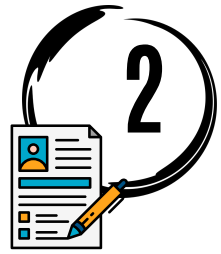
It is believed that exponentially more carriers of the gene that causes CF can be found across all racial and ethnic groups.

For those with CF who are not of European descent, there is often the sene of being rare within a rare community. CF is included on the newborn screening panel in every state, but these tests often fail to identify rare cystic fibrosis mutations more common in people who are not of European descent. Due to the misconception that CF is rare among people of color, physicians may miss the signs and fail to order testing for children who have symptoms of CF. Due to lack of awareness of CF among the general population, those whose loved ones have symptoms of the disease may not know to insist on testing to rule out CF. For those who receive a late diagnosis of CF, the probability of experiencing poorer health outcomes increases.

Drug Approval in the USA



Development & Research: The drug is developed and undergoes preclinical research. The drug then moves to clinical trials where it is tested on humans.



NDA Application: Every new drug must submit a New Drug Application (NDA) to the Food & Drug Administration (FDA) for review. This application includes data from the pre-clinical & clinical trials, as well as information about the drug's chemistry, pharmacology, etc.

FDA Review: The FDA reviews the submitted NDA, making sure to evaluate if the drug is safe, effective, and if the benefits outweigh the specified risks. If approved, the FDA inspects the facility where the drug will be manufactured.

Drug Access & Funding: Once the FDA approves a drug, it has been approved for use across the US. In general, people can access FDA-approved drugs through private insurance, Medicaid/Medicare, and/or co-pay assistance programs. However, access to an approved drug is not guaranteed. State Medicaid systems, private payers, and self-funded plans may not include all drugs on their approved formularies.

CFTR Modulator Therapies

"I was able to get early access to Trikafta in September of 2019 and within 4 weeks, my lung function went up 14%. I was able to get off full-time oxygen and gained a lot of strength. This changed the trajectory of my life."
- Young Adult With CF

What is a CFTR modulator?

- A Cystic Fibrosis Transmembrane Conductance Regulator (CFTR) modulator is a medication which attempts to improve the malfunctioning protein made by the abnormal CFTR gene
- The five CFTR modulators are: Alyftrek®, Trikafta®, Symdeko®, Orkambi® & Kalydeco®

How can CFTR modulators help people with CF?

- CFTR modulators help reduce the thick mucus found in the body of people with CF by correcting the CFTR protein that controls the flow of water and chloride in and out of cells
- Successful use of CFTR modulators often result in increased lung function, increased BMI, lower pulmonary exacerbations, etc.

Who can access CFTR modulators?

- Only people with specific CF mutations can use CFTR modulators in the United States
  - Alyftrek® has been approved for 208 CF mutations
  - Trikafta® has been approved for 177 CF mutations
  - Symdeko® has been approved for 154 CF mutations
  - Orkambi® has been approved for those who have two copies of the F508del CF mutation
  - Kalydeco® has been approved for 97 CF mutations

Who does this exclude?

- It is estimated that approximately 10% of people with CF cannot take CFTR modulators for various reasons. People of color with CF often have rarer mutations that are not responsive to modulators. Due to the high incidence of late or misdiagnosis of CF among racial & ethnic minorities, it is believed that far more than 10% are CFTR ineligible.

Rare Disease Research

The Department of Health and Human Services (HHS) is a federal entity that aims to enhance the health and wellbeing of Americans. Housed under the HHS are the National Institutes of Health, Food & Drug Administration, and Centers for Disease Control & Prevention.

These agencies are central to the development of biomedical research and public health solutions that directly impact the rare disease community. As members of the rare disease community, it is essential that policy makers and members of government understand the need for continued, robust funding of these agencies as vital ways to support the health and wellbeing of Americans.

National Institutes of Health (NIH)

- The NIH funds and conducts rare disease research, which broadens rare disease understanding and therapy options.
- There are 27 Institutes & Centers at the NIH, with the National Center for Advancing Translational Sciences (NCATS) being recognized as the epicenter of rare disease research.
- NCATS fast tracks development of rare disease treatments by focusing on scientific approaches that can address multiple diseases.

Food & Drug Administration (FDA)

- The FDA partners with rare disease researchers, patient communities, and product developers to advance and evaluate treatments.
- There are three FDA Centers that have a rare disease emphasis:
  - CDER
  - CBER
  - CDRH
- The FDA also houses the Office of Orphan Products Development, which implements the Orphan Drug Act and a grant program that has supported numerous FDA-approved therapies.

Centers for Disease Control & Prevention (CDC)

- The CDC conducts research, disseminates health information, and responds to dangers of public health.
- The CDC guides National newborn screening programs.
- ICD codes—which classify diseases—are maintained through the CDC, along with the system used to record medical conditions & symptoms.
- Many rare diseases have national epidemiology and surveillance programs maintained through the CDC.

Newborn Screening

Babies diagnosed through newborn screening benefit from early medical treatment, which improves health outcomes. Cystic fibrosis is included in every state's newborn screening panel. While newborn screening for CF is available across the nation, the methods and breadth of screening vary drastically.

How does newborn screening occur?

Shortly after a child is born, a healthcare provider will test for the presence of CF by pricking the baby's heel and gathering a blood sample. This sample is then placed on a Guthrie card, which shows the baby's personal information for identification purposes. This card is then mailed to a state laboratory where the blood sample is tested for a pancreas-made chemical called immunoreactive trypsinogen (IRT); people with CF tend to have high IRT levels. If the IRT test produces a high score, a DNA test to determine the presence of CF will occur.

How does newborn screening differ by state?

All 50 states across the US include CF on the newborn screening panel. Currently, there are approximately 40 different algorithms used across the country to screen for CF. Due to this variability, some states only test for a few mutations, while others have a much more comprehensive panel. For more information about newborn screening in a particular state, email publicpolicy@cff.org.

Key points when talking to decision makers:

1) Every individual and family deserves to be tested for CF in a timely and exhaustive manner no matter their geographic location. Timely diagnosis results in better health outcomes, less financial strain on the healthcare system and improved emotional wellbeing for patients and families.
2) People of diverse racial and ethnic backgrounds are more likely to have rarer CF mutations. Newborn screening should encompass testing for every known mutation, ensuring that race and ethnic-based health disparities are eliminated.
3) The more information known about the types and prevalence of various CF mutations, the more data that becomes available to study and work with to find a cure for this disease.

Pharmacy Benefit Managers

Function

A Pharmacy Benefit Manager (PBM) is a third-party intermediary between insurance providers and drug manufacturers. While claiming to help lower prescription costs, PBMs rarely pass savings on to patients. They purchase medications from manufacturers and wholesalers and sell them to pharmacies and health plans.

Scope

PBMs have grown to provide drugs to nearly all insured Americans. Only 3 PBMs - Express Scripts, CVS Caremark, and Optum Rx - control nearly 80% of the prescription drug marketplace,[9] meaning they are determining formularies and deciding what patients can access.

Impact

PBMs have increasingly taken advantage of their position as essential go-betweens to steer patients to higher-cost drugs and pharmacies, charge high administrative fees, and charge pharmacies more – sometimes much more – for drugs than they paid for them.

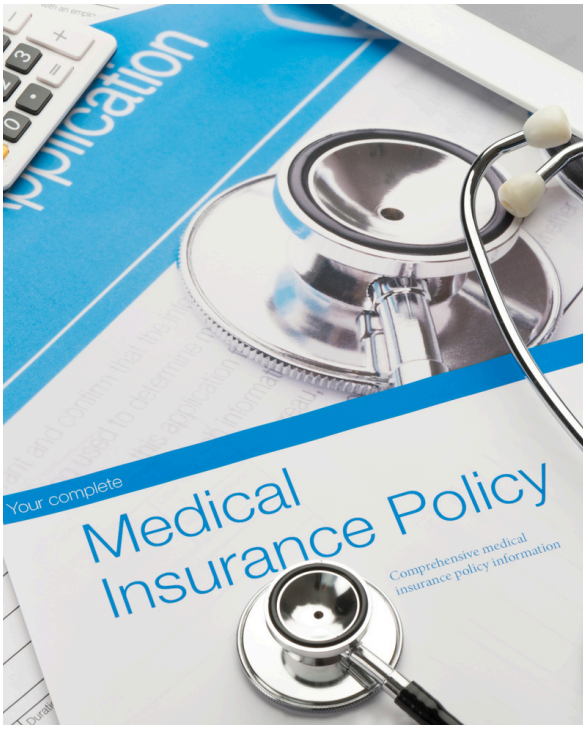
Key points when talking to decision makers:

1) Most PBMs lack transparency. Currently, PBMs have no obligation to share details with insurers about how they determine formulary placements, why some drugs in the formulary are more costly than others, and what proportion negotiated drug payments they keep.

2) PBMs have been known to overcharge for generic drugs. It has been estimated that CVS Caremark is able to charge prices for specialty generic drugs that are 24 times higher than what manufacturers charge.

3) Because there is little competition in the PBM industry, with just 3 companies controlling about 80% of the market, large PBMs can shape their services in ways that benefit them, often at the expense of patients and families.

Copay Accumulator Policies



Copay accumulator policies, enacted by insurance companies, prohibit financial assistance—whether from a private foundation, pharmaceutical manufacturer, or individual—from counting toward one's deductible or out-of-pocket maximum.

This means that although patients can use their copay assistance for initial cost savings, once the funds are expended they must still pay their annual deductible or out-of-pocket maximum.

Copay accumulator policies allow insurers and PBMs to receive two payments per prescription—first with the funds from patients' copay cards, and again with patients' funds once the copay card has been maximized.

Often, these policies are inserted in their insurance plan without informing patients. When patients become informed, many are forced to walk away without their lifesaving medication because they cannot afford the full price.

Key points when talking to decision makers:

1) Copay accumulator programs result in a patient's costs increasing, while insurers and PBMs double their profit.
2) Insurers and PBMs often argue that copay accumulator policies encourage the utilization of less expensive generic equivalents instead of name brand drugs. However, the majority of medications purchased using manufacturer copay cards have no generic equivalent.
3) Studies have shown that when out-of-pocket costs reach $75-$125, more than 40% of patients leave their prescriptions at the counter.[10] Delayed or missed treatments pose a risk to patients' health, putting strain on the patient, their family, and the healthcare system.

Prescription Drug Affordability Review Boards

Prescription Drug Affordability Review Boards (PDABs) were implemented by states with the intention of taking action against the rising costs of prescription drugs. PDABs primarily seek to reduce government and commercial spending on prescription drugs, and secondarily attempt to stabilize the price of medications for patients.

Affordability Reviews

There is no established definition of 'affordability' across states with PDABs. Common considerations include:

- Average copays & out-of-pocket expenses
- Assessment of assistance programs
- Availability & pricing of alternative therapies
- Review of PBM policies
- Input from affected patients & experts
- Use of cost assessment reports that utilize discriminatory metrics.

Impact on Patients

Manufacturers may find that upper payment limits make it economically unviable to offer certain medications, leaving patients without essential treatments.

This reduced access can have downstream impacts to a state's economy, placing financial burdens on medical institutions now facing an influx of patients with complex healthcare needs.

Key points when talking to decision makers:

1**)** PDAB review of rare disease medications could jeopardize patient access to life saving therapies by imposing upper payment limits. Other states across the nation have begun to implement PDAB policies that exempt rare disease & orphan drugs.
2) PDABs often use quality-adjusted life year (QALY) metrics to measure the efficacy of medications. QALYs fail to take a patient-focused perspective by imposing ableist values on an individual's life.
3) Patients and families should be able to weigh in on legislation that directly impacts their health and wellbeing without having to publicly disclose their identity. The public statement period in PDAB hearings often limits the number of voices decision makers hear from.

Step Therapy

Step therapy, also known as 'fail first' therapy, is a process by which insurers require patients to take alternative medications before they can access what was prescribed by their provider.

In other words, step therapy is a common cost-control strategy whereby insurance companies will approve lower-cost medications first. Step therapy is often applied with little regard for a patient's treatment history or medical situation, and can be detrimental to people with CF.

More than one dozen states currently have NO step therapy protections.

The Cost of Step-Therapy on Patients, Families & the Healthcare System:

- In the short-term, it may appear that step therapy saves state and federal programs money. However, studies show that agencies may end up paying more in the long-term once a patient has left the hospital (e.g., outpatient services).

- The United States spends more on administrative health costs per person compared to other similarly large and wealthy countries. Providers are known to spend significant amounts of time on administrative duties such as filing prior authorizations or fighting denied claims.

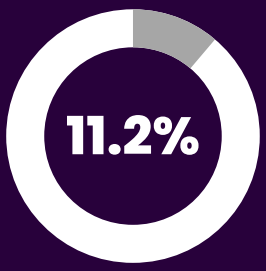
Federal Legislation: The Safe Step Act (S. 652)

Currently, there is proposed federal legislation to improve step therapy protocols and ensure patients are able to access optimal treatments. This legislation would require that insurers implement a clear and transparent process for a patient or physician to request an exception to a step therapy protocol. The bill outlines five exceptions that a group health plan must grant an applicant if they can demonstrate eligibility.

Step therapy protections help everyone in need of specialized healthcare treatments, not just those with CF.

CF & Cancer Awareness

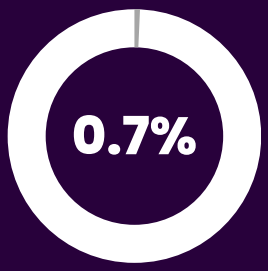
AS LIFE EXPECTANCY FOR THOSE WITH CYSTIC FIBROSIS (CF) INCREASES—LARGELY DUE TO HIGHLY EFFECTIVE MODULATOR THERAPIES—CANCER DIAGNOSES ARE BECOMING MORE COMMON. LEARN MORE ABOUT THE CONNECTION BETWEEN CF & VARIOUS CANCERS AT WWW.CFRI.ORG/CANCER-AND-CF



Cancer as the primary cause of CF-related deaths in 2023 [11]

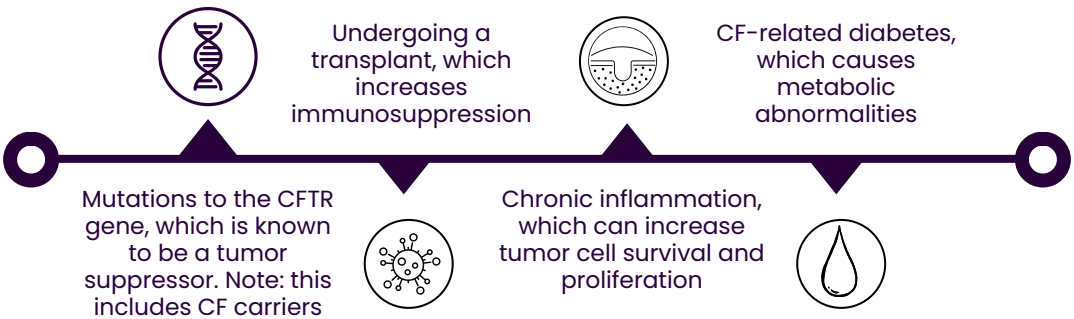
3.9 yrs

Median time between transplant & the first incidence of cancer [12]



Increase of cancer among non-transplanted people with CF between 2006-2017 [12]

RISK FACTORS



CANCERS THAT MAY BE MORE PREVALENT AMONG PEOPLE WITH CF

GASTROINTENSTINAL

Colorectal, pancreatic & liver cancers are particularly common.

People with CF are 5-10 times more likely to develop colon cancer than the general population. [13]

PANCREATIC

Studies show that people with CF have a five to ten times higher risk of developing pancreatic cancer than the general population. [14]

RESPIRATORY

Bronchial gland carcinoma is a lung cancer subtype more common among people with CF. Frequent infections from pseudomonas aeruginosa may contribute to this increase. [15]

CERVICAL

Individuals post-transplant are at a higher risk of developing HPV, which can progress into cervical cancer. A 10-fold higher risk in people post-transplant has been documented. [16]

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