



**WISHING YOU PEACE,
HAPPINESS & GOOD HEALTH THIS
HOLIDAY SEASON!**

HAPPY HOLIDAYS!

The year 2011 saw the founding of The Rose Foundation and Colleen's *Run for Roses* from The Arch to The Apple. And yet, many of you have been supporting our family, the Cystic Fibrosis Foundation and a cure for CF since 1997 when Katie was diagnosed with CF. Team *Katie's Klan, 2004*, preceded Team *Run for Roses/Katie's Klan, 2011*. We are humbled and blessed by your kindness and willingness to give what you can to fund research to make Katie's life and 30,000 others living with CF grow up and live the healthiest life! Over \$323,500.00 has been raised through Team Run for Roses, Ride for Roses, Trivia Nights, auctions, Wine & Paint nights, Whiskey & Wine Tastings, Dine-to-Donate, etc. Katie and others with CF have seen treatments progress from chest percussions to The Vest to a smaller mobile Vest; countless numbers of pills per day and inhaled medications per day to the newest of drugs, Trikafta, which has decreased one or two meds for some. This is why we can't and won't stop now. Colleen's Dream of *Run for Roses* became a reality as did many other teams of CF families.

Dream with us! Help us in whatever way you can. We can't do it alone for

need attendees at events, volunteers, raffle items, sponsors and donors.

Dream IT, then Make It Happen. Thank you for spreading awareness and bringing others to our events. Thank you for doubling your donations through you business MATCHING GIFTS PROGRAMS and nominating us for donations through you company's CHARITABLE PROGRAMS.

Every dollar raised and every new person joining our team pushes us to the FINISH LINE!

We won't stop 'til it's DONE!

*****MARK YOUR CALENDARS for Saturday, April 22, 2023 to attend our Run for Roses Trivia Night & Silent Auction!

*****READ BELOW AMAZING PROGRESS IN CFF RESEARCH

*****IMPORTANT INFO FROM VERTEX ON CO-PAY ASSISTANCE and PRESS RELEASE ON mRNA PROGRAM

Please keep following us on [Facebook](#) and sharing our information and our newsletters with your family and friends. We are grateful for any end of year donations made by clicking link: [GREAT STRIDES](#) or via VENMO: THEROSEFOUNDATION-CF. We absolutely need all of YOU to get us to the CURE for CF!!

As always, the Caul Family and The Rose Foundation Board are so thankful for all you do to help us spread awareness and raise funds for a cure!

Sláinte,

Linda & all the Cauls

Running 'til CF stands for Cure Found!



SAVE THE DATE**SATURDAY, APRIL 22, 2023**
More Details To Follow**CFF 2022 ACOMPLISHMENTS &
LATEST IN MODULATOR THERAPIES**

From Michael P. Boyle, MD, President and CEO

- For the first time, the median predicted life expectancy for a child born with CF today has reached 53 years, up 15 years from just a decade ago.
- We now have a drug development pipeline with more programs than ever before. The CF Foundation's collaborations with leading biotech and venture capital firms have resulted in 35 major industry research programs focused on genetic science, allowing us to boldly advance our Path to a Cure initiative.
- Several clinical trials for CF genetic therapies are underway or will begin in the coming year, including three promising mRNA therapies.
- We continue to study the effects of modulators, as well as pursue the next generation of modulator therapies and expand existing modulators to younger children.
- CF care teams offered highly specialized care through our extraordinary network of more than 130 CF care centers nationwide, which the Foundation helps fund.
- We reaffirmed our commitment to equity, racial justice, diversity, and inclusion, partnering with members of our community to better understand the health disparities that people of color with CF face. We are taking concrete steps to address these disparities, including establishing a newborn screening initiative to improve equity in diagnosis and ensuring that we have more diverse representation in CF clinical trials.
- To further fuel our mission, we officially launched the Milestones III: Driven by a Dream campaign this summer and have already raised \$110 million, which is more than halfway toward our goal.
- For the first time in nearly three years, we gathered again at hundreds of in-person events nationwide and held inspiring virtual events led by people with CF, such as BreatheCon and ROSE UP.
- Additionally, in July, we welcomed Steven Rowe, MD – a leader in the international CF research community – as our new Chief Scientific Officer.
- We also welcomed KC White as the first adult with CF to lead the Board of Trustees. KC will build on the legacy of our Immediate Past Chair, Cam McLoud, whose dedicated service helped transform CF over the past two decades.

Modulator Therapies:

Orkambi® for children with CF [ages 1 to 2 years](#) who have two F508del mutations

FDA scheduled to announce decision on whether to approve Trikafta® for children with CF ages 2 – 5 in 2023.

There is also progress on the development of new and potentially better [modulator therapies](#)

VERTEX UPDATES

Important Updates on Co-pay Assistance

Co-pay Assistance Information:

- Insurance providers have implemented co-pay adjustment programs as a way to shift costs onto patients by not counting co-pay assistance provided to patients by manufacturers like Vertex towards patients' annual deductibles and/or out-of-pocket maximums.
- The consequence of these insurance programs is that funds supplied in good faith by Vertex to patients are taken by the insurance provider, increasing costs for patients.
- We oppose any programs or initiatives that increase costs for patients by taking funds provided to patients as part of patient support programs. Vertex intends for any co-pay assistance to benefit patients. In response to these practices, Vertex GPS™: Guidance and Patient Support has been forced to make changes to its Co-pay Assistance Program in response to restrictive insurance practices that increase costs for patient.
- The maximum amount of co-pay assistance for eligible patients will be \$20,000 annually for 2023, which should provide more than enough assistance to cover the out-of-pocket costs of Vertex medicines for patients whose insurance plans adhere to the federal limits set by the Affordable Care Act for essential health benefits.
- Patients covered by traditional commercial insurance plans will not be impacted by these program changes and may pay as little as \$0 for their Vertex medicine in 2023.
- Patients whose insurance plan includes a co-pay adjustment program (such as an accumulator or maximizer) that applies to their Vertex medicine may face higher out-of-pocket costs in 2023 due to the restrictive design of their insurance program.
- *Vertex is working with all patients to ensure continued affordable access and will offer direct support to any eligible patient that faces financial hardship.*
- *Vertex is committed to ensuring that no patient will discontinue their Vertex medicine due to these program changes.*
- *There will likely be legislation in several states and at the federal level in 2023 to ban some copay accumulator and copay maximizer programs. Interested stakeholders are currently organized through the All Copays Count Coalition (allcopayscount.org).*

IMPORTANT: make sure you reach out to GPS to check in <https://www.vertexgps.com/> (Vertex GPS™: Guidance and Patient Support is committed to helping all enrolled patients maintain access to their Vertex medicine through the January 2023 Co-pay Assistance Program changes. If you have questions or need support, call or text a GPS Support Specialist ([1-877-752-5933](tel:1-877-752-5933), option 2 when calling).)

If you receive any questions regarding this press release, please contact your healthcare professional.

ADVOCACY FOR CF

Beginning in January, following the 2022 Midterm elections, our advocacy journey with the cystic fibrosis community continues.

The CF community is small but powerful. Volunteer advocates drive our legislative and regulatory agenda forward at every level of government. It only takes seconds to respond to a call for action!

PLEASE join NOW. Text "FIGHTCF" to 96387 to join a list of volunteer advocates.

Next, discover new ways to advocate and learn about the issues we care about on cff.org.

Thank you for taking the first step. We need you!

Help Fight Superbugs by Passing the PASTEUR Act Now

"The CF Foundation is advocating for the PASTEUR Act, a bipartisan piece of legislation that would help to build a sustainable pipeline for antibiotic development. Now is the time to pressure Congress to act. Urge your member(s) of Congress to pass the PASTEUR Act without delay."

Tell Your Members of Congress: Act Now on PASTEUR

'The Pioneering Antimicrobial Subscriptions to End Upsurging Resistance (PASTEUR) Act is picking up momentum in Congress. Since its introduction last summer, this bipartisan, bicameral bill has gained dozens of Congressional cosponsors and ignited conversations about the importance of addressing antimicrobial resistance.

It's time for Congress to turn interest into action.

Call on your members of Congress today to urge them to pass the PASTEUR Act to jump-start the development of desperately needed new antibiotics for people with cystic fibrosis and all Americans affected by antimicrobial resistance."

[Call now »](#)

GIFTS with your business so you can **DOUBLE** your donation! Here is a [link](#) on the CFF website that you can search by company. Just click and scroll to the bottom and search for your company.ny'same. **THANK YOU!**



WE NEED YOU!

*Please SPREAD AWARENESS for CF!

*Share our newsletter

*'LIKE' us on facebook: [Run for Roses](#)

*Join our board - call Linda 314-952-7944

*Volunteer at our events

*Check your business for matching dollars - Here is a [link](#) that you can search by company

*Nominate The Rose Foundation for your business' charitable giving program

*Secure auction and raffle items for events

Contact Linda at 314-952-7944 or caullinda@hotmail.com

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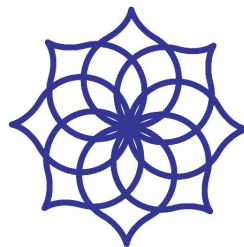
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