



# HAPPY THANKSGIVING

We are so grateful for YOU!

"These people need your help. And (we) need your help. This is the perfect season for us to stop thinking about ourselves and start thinking about others."

~Christmas Angel

For the last 10 years we have met so many wonderfully generous people on this journey of spreading awareness, sharing stories and raising funds for a CURE for CF. I think I can speak for all of the CF families in expressing the love and gratitude we have for our growing CF community of friends and supporters.

Since Colleen's *Run for Roses*, we have 4 FDA-approved therapies and more than 25 potential new meds in the pipeline! Researchers are working to find a drug for the remaining (less than 10%) CF population who do not have a treatment as yet. In just the past 2 years during the pandemic:

\*Trikafta was approved for 6 - 11 year-olds

\*15% of those with CF required hospitalization during COVID

\*17% of adults with CF required IV antibiotics, down from 40% over the past decade

\*pregnancies tripled in women

The CFF *Path to a Cure* recently announced the First-of-Its-Kind Deal, to collaborate <u>with Pioneering Medicines</u>, <u>an initiative of Flagship Pioneering</u> and to invest up to \$100 million to accelerate the development of genetic-based therapies for CF.

WE WON'T STOP 'TIL IT'S DONE!

# **MIRACLE FOR ROSES**

The Rose Foundation was invited to participate in *Tablescapes* at Old St. Ferdinand Shrine in Florissant.

Please join in the Family Fun during any of the dates listed and **VOTE** for our table: Miracle for Roses.

Also, on Nov. 27 from 2-9pm, enjoy the activities from St. Francois St. To St. Ferdinand Shrine:

2pm: Jingle Run for Kids

2:30-4:30pm: Pictures with Santa

2-6pm: Pony Rides, Sweet Reads & Crafts

5:30pm: Tree Lighting 6:15pm: Golf Cart Parade Download flyer <u>HERE</u>







OLD ST. FERDINAND Purchase tickets at the door at time of the event SHRINE 1 Rue St. Francois St. Florissant, MO 63031

# **CF STORIES from Glennon Gram**

Read how your support improves the lives of so many living with CF! Posted on SSM Health Cardinal Glennon Children's Foundation Glennon Gram:

### Meet Mike and Jack - Cystic Fibrosis Patients

#### Meet Mike!

Mike is a 51-year-old Cystic Fibrosis patient- who was treated at SSM Health Cardinal Glennon until he was 22 years old. He is an avid cyclist, marathoner, Ironman, triathlete, author and executive and personal life coach.

"Cardinal Glennon set me up for up for every wonderful thing that I have been able to do, and live decades beyond my life expectancy. They emphasized the importance of daily habits, which were vital to long-term success, but also allowed treatment to align with my personal life and goals," says Mike. Despite Mike's determination and efforts to stay healthy, he suffered for decades from a challenging daily experience, shortness of breath with athletic exertion, prolonged lung and muscle recovery from exertion, and worries over life expectancy with each passing year. "In 2018, I struggled to cycle at all. I maxed out at 40 miles and simply couldn't get beyond that. Every ride was short of breath," says Mike.

altered the outlook for longevity and quality of life. I don't know how to encapsulate the fact a lifelong cough COMPLETELY disappeared within 4 days of taking the first dose. I have mental clarity and mental stamina because my brain is getting more oxygen than it has received in 20 years. My athletic performance has had an exponentially positive increase. I can ride faster, further and recover faster from exertion. Both my lungs and muscles recover from a hard effort better than in the past 20 years. I can ride 60, 70 and 80 miles, maintaining a faster speed, with full breaths. The best thing, though? My body feels like it could live to a normal life expectancy. At 48 years old I was simply trying to get to 50. Now at 51, I'm under the assumption 60 and beyond will happen like other 'normal-bodied' people," says Mike.

Because of the remarkable promise shown with both adult and pediatric patients, SSM Health Cardinal Glennon initiated therapy with Trikafta in all eligible patients as soon as it was approved, and our nurse coordinators, pharmacy staff and physicians are working hard to get the drug approved by third party payors. Blake Noyes, MD – SSM Health Cardinal Glennon Division Director of Pulmonology says, "Most patients have had marked improvements in wellbeing, lung health and pulmonary function studies along with marked improvements in nutrition. As a result, we are seeing a considerable drop in how many patients require hospitalization for IV antibiotics and aggressive airway clearance.

Prior to Trikafta, it was not unusual to have 3-5 Cystic Fibrosis patients in the hospital at once. With this new therapy, we now have no more than 1 maybe 2 patients at a time. "The dramatic improvement in quality of life has been overwhelming," says Noyes.

#### Meet Jack!

Twelve year-old Cardinal Glennon patient, Jack, has been on Trikafta for 15 months. "His quality of life has completely changed," says Dee, his mom. "He has energy like every other 12 year old and rarely ever coughs anymore. He was able to go a year and a half without a hospitalization, which is huge for him. He is going to play basketball this winter, and he is so excited to be part of a team with his friends!"

#### Cardinal Glennon kid Jack

The nationally-recognized SSM Health Cardinal Glennon Cystic Fibrosis Center has been named a Therapeutics Development Network (TDN) team by the Cystic Fibrosis Foundation. The Cystic Fibrosis TDN is the largest CF clinical trials network in the world, bringing together experts from across the country to evaluate the safety and effectiveness of new CF therapies through clinical studies.

Because of our partnership with Saint Louis University Hospital, we are blessed to be able to transition patients as they grow (like Mike... and eventually Jack) from SSM Health Cardinal Glennon to Saint Louis University Hospital across the street.

We are involved actively in clinical research to improve cystic fibrosis therapies and, thanks to



If you have a few dollars to spare at the end of the year, please consider a donation for a CURE on our website: <a href="mailto:runforroses.com">runforroses.com</a>

#### **RF UPDATES:**

**October 16 Silent Auction:** 

A HUGE THANK YOU to all of our participants, sponsors, donors, board members and volunteers who made our October event a huge success! Together with our April auction we raised over \$18,200!!! With donations throughout the year, we have raised over \$24,500 for a CURE FOR CF!!!

Thank you for putting others first and giving those with CF a fighting chance to live and breathe as we do! We are humbled and grateful for all of you!

Congrats to our 50/50 Balloon Raffle winner: Karen and Joe Buehler!!

- \* Save the Date: Whiskey Tasting: Jan 21, 2022
- \* Save the Date: Run for Roses Trivia Night / Silent Auction: April 30, 2022 at TASK

All of us wish you and your family a healthy and happy Thanksgiving!! The Caul Family continues to share our GRATITUDE for all of you!

Thank you for your gift of BREATH and HOPE!

With Love...

Slainte,

Please follow us on our Run for Roses Facebook page and if you have any dollars to spare, donations can be made online at The Rose Foundation.

# 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

\*Become a sponsor for Trivia

\*Check your business for matching dollars - Here is a link that you can search by company: <a href="https://ww2.matchinggifts.com/cff">https://ww2.matchinggifts.com/cff</a>

\*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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