

#Breathe Rasier

OUR MISSION

The Cystic Fibrosis Association exists to help people with CF to breathe easier — physically, financially and emotionally.

RUNNING FOR MY LIFE

By Sophia Backlund

"Failure to Thrive" were the words written on my medical document as the reason to receive diagnostic testing for Cystic Fibrosis.

I was one year old at the time and could not imagine the roller coaster this disease would take me on throughout the trajectory of my life. The mindset of my CF Team, family, and eventually myself once I was able to fully comprehend the severity of the illness was to simply prevent progression.

With the best efforts possible, I was able to confront Cystic Fibrosis head-on and gain strength and hope from the baby victories. With every hospitalization, exacerbation, and infection, I made a point to remain optimistic and grateful for the health I had.

In 2019, I was fortunate to start a genetically modifying drug called Trikafta. For the first time in my life, I saw a positive trajectory in my health. My cough disappeared, my hospitalizations decreased, and my energy skyrocketed. I never knew what being healthy felt like until this point.

There were moments in my illness when I promised myself that if the opportunity ever arose to take my life back, I would not hesitate to act. With this newfound feeling of health, I threw myself into my body's abilities and took up a new hobby: running.

I started slowly, knowing the scarring in my lungs would prevent any immediate success. Gradually, breathing

became easier and my distance lengthened. I found inspiration in my father who completed the Abbott Six World Marathon Majors in my honor, and signed up for my first half marathon.

I was able to train and complete the LifeTime Chicago Half Marathon in September with my dad by my side, beating my goal time in the process.

I was able to surpass the limitations that used to hinder me and discover the joy of taking my life back. By refusing to let my Cystic Fibrosis diagnosis impede me, I have made an entirely new definition of "running for my life" and can happily say I no longer meet the requirements of "Failure to Thrive"





CHARITABLE DONATIONS

We extend our sincere gratitude to our friends for their recent gifts. Each gift received directly contributes to the programs and services that are offered to CFA members. Every gift, no matter its size, makes a difference!

Kyllo Trucking

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Anonymous

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Lavina Benkendorf

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Nilson Farms

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KAREN COSSETTE'S STORY



At the November Cystic Fibrosis Association Board of Directors meeting, outgoing board member Karen Cossette was awarded the "Caught in the Act of Caring Award" in appreciation for her 28 years of board service.

Karen has spent much of her adult life serving as a volunteer and board member for CFA, and we

greatly appreciate all the work she has done on behalf of CFA.

Karen was born with Cystic Fibrosis and is living out a hope filled future thanks to advances such as the CFTR modulator, Trikafta, Karen recently shared that due to taking Trikafta since 2020, her care team has determined that she no longer needs twice daily breathing treatments which frees us a significant time in



her schedule. You can read more about the study that led to this decision here: https://on.cff.org/46Ystf7

We rejoice with Karen, and many other CFA members who have a greatly increased quality of life thanks to Trikafta. Your continued support of CFA makes this possible!

FARMERS UNION INSURANCE DONATION

Courtney Schauer with Farmers Union Insurance dropped by the CFA office with a generous \$1000 donation to help our friends with Cystic Fibrosis to #BreatheEasier. Thanks to this generous gift, we are able to say "yes" to more people who need our help to pay for medications, or for travel to medical appointments. We are thankful for the continued support of Courtney and Farmers Union Insurance.



2023 VIRTUAL SONIA WALK A SUCCESS

The Balliet Family chose September 2 for the date of the annual Virtual Walk in memory of Sonia Balliet-Heidenreich. Family and friends gathered across the state and across the country to honor Sonia's memory, as well as to raise funds for CFA.



This event has raised \$7,000 in 2023, and the giving window for this year's event is still open. You may give online at: https://ddock.co/2c01f757 or mail a gift to the Cystic Fibrosis Association with a notation that it is earmarked for the Sonia walk

We thank the following people for their generosity:

Paul Balliet Betty Jo Balliet Paula Balliet Douglas Balliet Donovan Balliet Laura Bearfield Wesley Belter Bridget Belter Lynda Belter Maureen Birchem Kelli Burgad Stacey Cokeley Les Covey William Davidson Sandra Deboer James Decosse Rebecca Finch Betty Goroski Nancy Hagen Diane Halvorson Daniel Hartley Lori Hawk Susan Heidenreich Deborah Hentges Elizabeth Hermes Brian Jacob Shirley Jahner Kelly Jahner Julie Jenkins Carla Job Marianne Kalin Keith Kallberg Melanie Kalvoda Carrie Keener Mary Kelsch Marilyn Kelsch

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HOPE FOR CYSTIC FIBROSIS

As we look forward to Christmas, I once again, am reflecting on the Hope of the season, and the hope within the cystic fibrosis community.

I am rounding out my eleventh year of working for the Cystic Fibrosis Association of North Dakota, which feels like both an exceptionally long and a noticeably fleeting time.

I am not going to lie, when I first came to CFA, I was not sure how long I would work here. I was new to the world of fundraising and absolutely new to the world of Cystic Fibrosis. The CF landscape in 2013 was quite different than it is today.

I witnessed our members enduring hospitalization after hospitalization. I sat and listened to grieving mothers whose children fought CF bravely. I had come to accept that for many, an eventual lung transplant may be many of our people's only hope.

It was challenging work. I often felt unable to help these people that I grew to care for as if they were my own family members

The tide began to turn as researchers were able to create CFTR modulators which have been nothing short of lifechanging! The optimism and hope that many of our members have is nothing short of miraculous.

If you have time for an engrossing and informative read this winter, I highly recommend the book, Breath from Salt by Bijal P. Trivedi. This 500-page book traces the narrative of the CF community 1935 to 2020, and I guarantee that it will have you cheering at the end.

The same passion and enthusiasm that has helped to improve the lives of people with CF all over the world is also present right here in North Dakota with families that keep pushing for more and better, and health care teams that continue to show up for and fight for their patients.

In this coming year, I challenge you to dream big for the CF community. I know that our little team here in the CFA office sure does!

Thank you for your support in the past year, and I ask that you continue to support us in the new year as we strive to help all our members live out their hope-filled futures!

Pam Thompson



MEMORIALS AND HONORARIUMS

Giving memorials and honorariums are special ways of remembering and honoring someone who has made a difference in your life. The idea of helping someone else by honoring these individuals extends the positive impact of their lives in our world. Our thanks to those who remember, and to those they remembered. Thank you to all who have donated!

In Memory of Sylvia and Jan Fatland Dean Fatland

Ryan Pritchett

Bob and Meredyth Pritchett Whitney Brothers

Carley Buchanan

Terry and Cindy Thomas Kav Suko Michael Lehn

Donald Olson

Dean and Sandy Swenson

Paul Christianson

Dean and Sandy Swenson

James Thompson

Dean and Sandy Swenson

Tom Schmid

Dean and Sandy Swenson

Neil Buringrud

Tom and Sandra Payne

Duane Buzick

Tom and Sandra Payne

Darrell Belka

Tom and Sandra Payne

Marsha Bergman

Tom and Sandra Payne

James Swank

Tom and Sandra Payne

Geneva Miranowski

Dan and Phyllis Lien

Jack Weise

Debby Barth

Bill Gackle

Cindy Gackle

Mavis Seim

Erhart Hehr

Karen Lindgren

Brent Meidema

Linda McIonie

Pat Zimmerman

Arnie Nyhusmoen

Dean and Sandy Swenson

Don Erickson

Dean and Sandy Swenson

Shawna Gackle

Jill Denning Gackle

Family of Ray Busch Family of William Gackle

Dan Alexander

Jeff Hafner

Clint Danielson

Susan Fischer

Marcy Weight

Dean and Sandy Swenson

Judy Siggerud

Pam Wohlwend

Norman Rost

Norma Rost

Joe Eversvick

Dean and Sandy Swenson

Tom Mattern

Marjorie Johnson

Al Jaeger

Codie Eldridge

Jerry and Candace Eldridge

Hannah Kramer Braaten

Sue Kramer

Brent Winkelman

Merry K Johnson

Pam Wohlwend

In Honor of

Chelsey Haukos

C Arlene Haukos





BIRTHDAYS

Included are those members who have passed. In keeping with the reality that though they are not here with us now, they are never forgotten.

September

Vicki Zacher 9-6

Dillan Helbling 9-8

Shayne Haustviet 9-19

Adalynn King 9-19

Michael Crawford 9-20 †

Erik Swenson 9-20

Neveah White 9-21

Mason Kline 9-23

Richard Eddleston 9-26

Daviney McKay 9-27

Ty Mills 9-28

October

Logan Hahn 10-4

Gunnar Bruce 10-8

Joseph Bettenhausen 10-11

Angela Schmidt 10-12

Monte Deis 10-14

Weston Bohner 10-15

Tom Mattern 10-18 †

Ashlee Nilson 10-19

Khloe Schmidt 10-28

November

Rebecca Dahl-Dwyer 11-1 †

Kevin Thom 11-3 †

Andrew Jahnke 11-6

Ellen Voegeli 11-7

Morgan Johnson 11-9 †

Hannah Kramer-Braaten 11-11 †

Denice Vetter 11-24 †

Thalia Lanz 11-26 †

Robert Schank 11-27

Rita Rott 11-29

December

Mandy Anderson 12-4

Caleb Dorich 12-7

Nicole Schwartz 12-13

Kenna Brockpahler 12-16

Seth Brown 12-16

Jesse Hehr 12-20

Sonia Balliet-Heidenreich 12-21 †

Silas Sundby 12-31

SUNNY SKIES FOR THE 34TH ANNUAL TURKEY TROT

Mild November weather allowed for a record number of 1900 Turkey Trot registrations. The Turkey Trot continues to be the biggest fundraiser of the year for the Cystic Fibrosis Association of North Dakota. The community of Bismarck Mandan continues to come together for this Thanksgiving morning tradition.



We are grateful to all who came out to run, walk, trot, and shuffle! We have been adding to the festive environment inside the Elks before and during the race. This year we were joined by KZ Photo Booth, Feil Orthodontics with delicious bananas, Make a Wish handed out granola bars as well as information about wishes for children with CF. Dr. Jacob Retzer with Unbound Physical Therapy offered free athletic assessments. In the parking lot 3andMe served up coffee and treats and AlphaLit Bismarck set up a fun TROT23 display. If you have not participated in the Turkey Trot—make plans to join us next November 28 in Bismarck! Thank you to our sponsors who made our event possible and profitable.







GIVING HEARTS DAY

Once again, the Cystic Fibrosis Association of North Dakota will be participating in Giving Hearts Day on February 8, 2024.



On this one day online giving event, we hope to raise \$25,000 for the Cystic Fibrosis Association of North Dakota.

Giving is easy! Simply go to **GivingHeartsday.org** on February 8 and donate to the Cystic Fibrosis Association of North Dakota, or mail a check to CFA, 107 W Main Ave. #150 dated February 8 with "Giving Hearts Day" on the memo line.

We hope to use funds raised this Giving Hearts Day to help better serve some of our members who not only live with CF, but also face food insecurity—which is a very real problem in our current economy.

So, mark your calendars and get ready to make a difference in the life of someone living with CF!

P.S. - We are always looking for generous donors or businesses who desire to offer matching funds for Giving Hearts Day. Your generous gift can help double someone's donation. Contact Pam at pthompson@cfand.org to help.





Mike Zimmerman
President
Pam Thompson
Development Director
Newsletter Editor







taco john's

2023 NACHOS NAVIDAD

A big spicy thank you to Taco John's for once again donating to the Cystic Fibrosis Association of North Dakota with the Nachos Navidad promotion. A portion of each Nachos Navidad sold at select Taco John's locations will be donated to CFA. What a tasty reason to grab a delicious lunch!

UPCOMING EVENT

GIVING HEARTS DAY

February 8, 2024

Mark your calendars!



The CFA Newsletter is also posted on our website: CFAND.org

If you would like to stop receiving a paper copy in the mail, please let us know by emailing Pam at pthompson@cfand.org or call 701-222-3998 or toll free: 1-800-767-3593.