Breathe Easier **Cystic Fibrosis** ssociation

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OUR MISSION

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

Progress and Promise: How Your Support is Changing Lives for People with Cystic Fibrosis

Each year, the Cystic Fibrosis Foundation releases its Patient Registry Highlights, offering a snapshot of how people with cystic fibrosis (CF) are living, growing, and thriving. The 2024 Patient Registry tells an encouraging story, it is one of progress, resilience, and the real, measurable impact of donor-supported services like the ones we provide here at the Cystic Fibrosis Association of North Dakota (CFAND).

Lives Are Getting Longer

One of the most uplifting trends in the 2024 report is the continued increase in life expectancy for people with CF. Thanks to advances in treatment, especially CFTR modulators that target the root cause of the disease such as Trikafta, individuals with CF are now living longer, fuller lives than ever before. This is not just a national statistic; it's a reality for children, teens, and adults right here in North Dakota. They are planning for the future, pursuing careers, starting families, and living with hope.

Fewer Lung Transplants, More Quality Years

For years, lung transplants were often the final option for people with CF. Now, the need for lung transplants is decreasing nationwide. Highly effective therapies are helping preserve lung function and reduce the number of people progressing to advanced lung disease. This means more families are spared the uncertainty and hardship of transplant surgeries. It's another sign that the fight against CF is changing, but the need for support remains as urgent as ever.

Bridging the Gaps: Where Your Donations Go

While treatments are improving, the financial burden of living with CF can still be overwhelming. That's where your generosity makes a life-changing difference. The Patient Registry data emphasizes that access to these breakthrough medications and specialized care is not always within reach. Many families face steep out-ofpocket costs, challenging travel to CF care centers, and ongoing financial strain.

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Your donations to the Cystic Fibrosis Association of North Dakota directly support:

- Medication Cost and Co-Pay Assistance: Even with insurance, life-saving medications can be unaffordable. We help cover co-pays and medication costs, so families don't have to make impossible choices.
- Travel Assistance: In a rural state like North Dakota, distance can be a barrier to care. With only two CF clinics in the state, some families drive hundreds of miles for treatment. Our travel grants help ensure they can keep crucial appointments without financial hardship.
- College Scholarships: As more people with CF live into adulthood, they are dreaming bigger and aiming higher. Our scholarship program empowers students with CF to pursue their educational goals, thanks to the extended lifespans your support helps make possible.

Your Impact: Hope and a Future

The 2024 Patient Registry is a powerful reminder that progress in research and treatment must be matched with local support. Improved survival rates and fewer lung transplants are incredible milestones, but these milestones only matter if people can access and afford the care they need.

When you support CFAND, you're not just funding programs. You're walking alongside North Dakota families, helping them breathe easier, travel further, and build a brighter future.

Thank you for making this life-changing work possible.

You can read more about the 2024 Patient registry data at: https://www.cff.org/medical-professionals/ patient-registry

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 Honor of

Travis Skuza Elaine Brown

Logan Hahn Chris and Nikki Hahn ♥ Carolyn Wright ♥ Marcie Vessey ♥ Cynthia Belohlavek ♥ Lani and Adam Wahler ♥ Tonya Giermann ♥ Linda Fleischer ♥

Ben and Sarah Lien Dan and Phyllis Lien ♥ Laura and Tony Wolf ♥

Maria and Jack Wharham Linda Johnston ♥ Brad Clemenson ♥

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Cooper Paulson Maurice Adair ♥ Erin Paulson ♥

David and Nancy Liffrig David and Sheila Hoffman ♥

Daviney McKay Judy Keller ♥

Ada Lynn Smith Timothy Smith ♥

Silas Sundby Lori Krause ♥

In Memory of

Marcia (Klucos) Moes Anonymous ♥ Teri Wiles ♥

Sonia Balliet-Heidenreich Katherine Hadland ♥ Bridget Belter ♥ Melanie Kalvoda ♥ Gena And Ella Blaine ♥

Shawna Gackle Anonymous ♥

David Goroski Suanne Goroski ♥ Ryan Pritchett Whitney Brothers ♥ Nancy Bolte

Jamie Rumple Haupt Kathy Rumple ♥

Jamie Kirchmeier Melissa Benson 🔻

Donna Hollar Kate Barone ♥

Dan Alexander Jeff Hafner ♥

Morgan Taylor Johnson Amber Gathman ♥ Krista Estenson ♥

Clarice O'Grady Esther Burns ♥

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David Dockter Audrey Duppong Naida Feland Valerie and Rob Messmer Jody and Michelle Sommer Pastor Philip David Leer

Jim Melcher Pam Wholwend

Marilyn Shannon Pam Wholwend

Sandy Bulik Pam Wholwend

Sharon Johnson Pam Wholwend

Kyle Hardy Andrew Hafner Arne Boyum Cheryl Lindner

Carol Berger Dean and Sandy Swenson

Melvin Such Dean and Sandy Swenson

Keaton Nelson Douglas Krueger

Giving Hearts Day Donation

In Memory of Kyle Hardy

We were saddened to learn of the passing of long time CFA Member, Kyle hardy. His obituary is as follows:

April 26, 1988 - May 7, 2025

Kyle John Hardy, age 37, passed away peacefully on May 7, 2025, surrounded by his family. He met a sudden and severe illness with unbelievable courage and grace, and was well cared for at the University of Minnesota Medical Center.

From the day he was born in Rolla, Kyle brought his characteristic easygoing attitude and mischievous nature to the world. He graduated as a Rolla Bulldog in 2006, then attended Bismarck State College, and went on to graduate from Valley City State University. He returned to the Turtle Mountains and taught Social Studies/History, first in Dunseith for two years and then Belcourt, where he was recently honored with a 10-year award. Like his dad, Kyle loved the sport of wrestling and was a dedicated coach. Kyle took pride in being involved in his school, serving as advisor of the Student Council and a track coach. He felt strongly about his students having "roots and wings;" he loved learning about Ojibwe culture and also shared his own wanderlust, facilitating trips for students to places like Bismarck, Atlanta, Orlando, and Washington, D.C.

In September 2019, Kyle triumphed over the disease that disrupted but never defined his life, when he received a double lung transplant. He lived life with a renewed sense of purpose in the 2071 days afterward; the enormity of the gift of life from his donor was never lost on Kyle.

Kyle carried immense gratitude throughout his life for everyone who helped him along his way. He paid things forward by volunteering at the Able Games and Special Olympics, serving his beloved community on the Rolla City Council, and providing encouragement and guidance to those in his lung transplant support group.

He loved wrestling, football (go Bison), taunting Vikings fans (especially his brother and sister), hunting, watching movies, learning war hero stories, tape (it's hard to explain), gummy snacks, Mountain Dew, playing cards, collecting, traveling, and confusing people with spontaneous renditions of obscure songs like "76 Trombones" and "I Love (Little Baby Ducks)." He was humble, brave, resilient, sweet, generous, kind, thoughtful, patient, reliable (on his own timeline), stubborn, and so funny. His friends were incredibly important to him. More than anything, Kyle loved to see the people he cared about happy. He loved to make people laugh and could turn just about anything into a joke that you then shared with him for life.

Kyle was happiest in the last year of his life, after meeting Alise, the woman he planned to marry and spend life with. He traveled so frequently to Canada to see her that the border patrol knew him by name. Kyle became a beloved and devoted stepfather to Lena and Rhys.



This was a role he cherished, bringing him so much joy and providing Lena and Rhys with exciting adventures and laughs, countless movie nights and snuggles, unending love, kindness and support.

Welcoming Kyle into Heaven were his grandparents, Bennie and LaVonne Carlson, and Lyle and JoAnn Hardy; and his uncle, Donald Murray.

Kyle will live on in the hearts of his parents John and Becky, brother Cordell (Sabyl), niece Tateleigh, sister Tatia, and the love of his life, Alise, and their children Lena and Rhys. Kyle will also be dearly missed by a close extended family of aunts, uncles, and cousins, and many friends. And we can't forget about his gentle, loyal dog Rocco, who Kyle loved immensely.

For those who wish to honor Kyle, memorials may be sent to the Hardy family to be distributed to meaningful organizations in his name.

A Celebration of Life will be held on Tuesday, May 13, 2025 at 7:00 PM at The Derrick Dixon Event Center, Belcourt, ND with visitation beginning at 5:00 PM. A Mass of Christian Burial will be held at 11:00 AM on Wednesday, May 14, 2025 at The Derrick Dixon Event Center, Belcourt, ND. Father Richard Fineo presiding. A meal will be held immediately following the funeral mass at the event center. Burial will take place at St. Ellen's Catholic Cemetery, Cavalier, ND at 4:00 PM on Wednesday, May 14, 2025.

Giving Hearts Day

The Cystic Fibrosis Association of North Dakota once again participated in Giving Hearts Day, a one day online fundraising day in February. Over \$22,000 was raises to help our friends with CF to #BreatheEasier.

Thank you to the following individuals and businesses who helped make this day a success. (Some gave in honor or in memory of individuals-they will be listed on the Honor/memorial listing with a red heart by their name.)

Eide Bailly LLP Impact Foundation Kyllo Trucking Maurice Adair Charles and Tracey Allen Brenda Anderson Shawn and Jennifer Anderson Ted & April Anderson Anonymous Pat Baker Kate Barone Debby Barth Jeremy Barth Matt and Lacie Baumgartner Kayla Beauchamp Mary Beauclair Chris Becker Kelsie Becker Burton and Patricia Belknap Cynthia Belohlavek Bridget and Mark Belter Dave and Jennifer Bender Misty Benske Melissa Benson Lorraine Berg Joel Bird Standing Rock Lutheran Church WELCA Gena Blaine Mr. and Mrs. William Bobby Priscilla Boman Rvan Botner Whitney Brothers Lacy Brousseau Esther Burns Michael and Debbie Chappo Steve and Bonnie Chase Brad Clemenson Dean and Ardella Deis Michael and Shawn Deisz John and Cassie Dorich Mary Erman Krista Estenson Emilie Fischer Susan Fischer Barbabra Flint Roger and Nadine Florhaug

Solli Frank Dr. Sandee Funk Dave and Carol Gackle John Garske Amber Gathman Tonya and Dean Giermann Angela and Rodney Glass Lesley Gorby Suanne Goroski Meredith and Joe Gross Renee and Dale Grosz Katherine Hadland Jeff Hafner John and Gayle Hafner Chris and Nikki Hahn Dan Halvorson Logan Handyside Chelsey Haukos Erhart Hehr Susan Heidenreich David and Sheila Hoffman Nancy Huber Tim and Naomi Hurtt Michael Jablon Jim Jackson Al Jaeger Sharon James Jeffrey Japel Ken and Kathy Johnson Linda Johnston Marianne Kalin Melanie and Mark Kalvoda Joe Kambeitz Carrie Keener Judith Keller Shelley Killen Rodney Kjellberg **Rivers Edge Plumbing** and Heating, Inc. Emily Kossan Sue Kramer Lori Krause Cody and Jen Kritzberger Patricia Kropp John Krueger Lois Kutschinske Terry and Bonnie Landenberger Bob and Karen Landman Robert and Gayle Lee Dan and Phyllis Lien Benito and Kay Dawn Mar Richard and Seng Marohl Jeannette Mausehund Dennis McCoy Terry and Kathy McKay Michelle Mielke Roberta Modin Merri Mooridian Bill and Kathy Muhs Heather Nelson Bill and Marna Nelson Tiffany Ness Cynthia Neubauer Ryan and Ashlee Nilson Katie Nilson Gary and Joy Ochsner Camie O'Connor Kim O'Neil Brian and Erin Paulson Scott and Becky Payne Thomas Payne Raychel Perman Jerry and Mary Petersen Dan and Annette Peterson David Pladson Lillian Pladson James Quirk Karen Retzlaff Kathy Richards Bruce and Roxane Romanick Christine Rosenberg WIlliam Rothman Frank and Gail Rothschiller Kay Rotvold Scott and Diann Rudolf Kathy and Jim Rumple Jesse Sailer Kevin and Cheryl Sailer Kelly Sand Blair and Nicole Sandy Kraig and Gerri Sarsten Lance and Judy Sateren Ron Schneider

City of Minot Employee **Donations Committee** Kirsten Schumacher Robin and Carlotta Schwartz Wes Schwartz Nancy Sheridan Jolyne Sigvaldssen Jackie Sirjord Duane Smith **Timothy Smith** Todd Stockert Michelle Such Dean and Sandra Swenson Erik Swenson Stacey Thomas-Pahlke Stephen and Mae Tinguely Dakota Medical Foundation Marcie Vessey Joe Vetter Lani Wahler Joyce Waldock Jeff Walkinshaw Twila Weis Karen Wettels Beth Wharam **Emily Wilcox** Teri Wiles Don Willey Laura and Tony Wolf Jamie Wolle Wilbur and Carolyn Wright Servant WSI Holly Zahn Joel Zenker **Dennis** Zimdars Mike and Jessica Zimmerman Stan Zimmerman



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.

June

Donna Hollar 6-5 **†** Chase Miller 6-6 **†** Cooper Paulson 6-9 Terry Dockter 6-14 **†** Preston Helbling 6-21 Maria Wharam 6-24 Rexella Evitt 6-25 Gaylen Marzolf 6-26 **†** Marchell Phillips 6-26 Jamie Haupt 6-30 **†**

July

Jordan Peterson 7-4 Codette Eldridge 7-6 **†** Christina Vasquez 7-9 Benjamin Lien 7-14 Jaken Kasper 7-16 Declan Lee 7-16

August

Tom Meagher 8-2 † Carly Buchannan 8-10 † Christian Worth 8-10 Jack Bollinger 8-11 Chelsey Haukos 8-11 Raeann Germain Broste 8-13 † Dennis Wilkie, Jr. 8-15 † Cody Mills 8-16 David Goroski 8-18 † Daniel Alexander 8-20 † Katie Wangler 8-20 Michael Barth 8-21 Ryan Begger 8-23 † Lily Stroup 8-26 Cierra Strom 8-27

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!

Robert and Paula Bachmeier Donovan and Amy Balliet Mary Bergeron Mr. and Mrs. William Bobby Elaine Brown Andy and Kariann Buntrock Monte and Kaylin Deis Richard Eddleston Linda Fleischer Dale Heinert Janelle Henninger James and Beth Hughes Leela & Lavender Douglas Krueger Apex Physical Therapy and Wellness Brady Pelton Preferred Restaurant Group Daniel and Linda Schwartz Don Schwehr Marcus Stalboerger Ethan Stockham Erik Swenson Michelle Wiedrich Flasher American Legion Scranton Public School Student Council Leela and Lavender Paypal Giving Fund Taco Johns Thrivent Choice

Every effort has been made to ensure the accuracy of the gift reporting. If an error has been made in your giving history please contact us at (701)222-3998. *Thank you!*

"Take a Swing at CF" Golf Scramble

Fore! Are you ready to hit the greens for a great cause? We're excited to announce our upcoming "Take a Swing at CF" Golf Scramble, scheduled for August 12 at Tom O'Leary Golf Course in Bismarck.

This Event is not just about great golf; it is an opportunity to come together as a community to support the Cystic Fibrosis Association of ND in our mission to help people living with CF to breathe easier.

Whether you are an avid golfer or just looking to enjoy a day outdoors, this scramble promises fun, friendship, and a lot of excitement! Gather your friends, family, or coworkers and form a team, or sign up as an individual and we will pair you up with fellow golf enthusiasts.

Participants will enjoy 18 holes of golf, a delicious lunch, and the chance to win some great prizes! Plus, you will e helping to raise valuable funds that directly support those living with CF in our community.

Don't miss out on this fantastic day of golf and camaraderie. Sign up today and help us make a difference for people with CF. To register, visit CFAND>org or contact Pam at 701.222.3998.

Thank you for your support, and we can't wait to see you on the course!

Together, let's take a swing at CF!

Event Details:

- August 12, 2025
- Tom O'Leary Golf Course
- Registration 11, shotgun start at noon
- \$150 per golfer



Mike Zimmerman President Pam Thompson Development Director Newsletter Editor



UPCOMING EVENTS

TAKE A SWING AT CF GOLF SCRAMBLE August 12, 2025

36TH ANNUAL TURKEY TROT November 27, 2025



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