Dear Friends,

I often find myself thinking about the hopes and dreams of CF families, and just how far we have come in our search for a cure. This community has funded breakthroughs and met milestones because we are willing to push the boundaries of what is possible.

In the 1980s, CF Foundation-funded scientists made history when they discovered the CF gene — years before the human genome had been mapped. The research community was doubtful that we would find small molecules that would alter how the defective CFTR protein functions, but we made believers out of skeptics. When we began the Milestones campaign, fundraising industry advisors said it would be impossible for a health care nonprofit to raise $175 million in a major gifts campaign. But together, we achieved that goal as well.

The possibility of a cure is closer to us today than it has ever been, and it is the mission of the Milestones II: Accelerating the Search for a Cure campaign to fuel the development of additional therapies that will lead us to a cure for all people with CF. To date, we have raised $56 million total towards our $75 million goal.

None of this would be possible without caring and generous donors who are committed to ending this disease. Our community rose to the occasion and met the $1.4 million-match at the end of 2013, providing a strong finish to a very successful year in advancing our mission. While we have wisely created opportunities through our venture philanthropy model to receive royalties that refresh and re-fund ongoing research, these funds only scratch the surface of what is needed to accelerate vital research initiatives and accomplish our ultimate goal.

If our achievements have taught me anything, it is to believe that even the loftiest goals are possible. Inspired by our progress so far, we have set an even more aggressive campaign goal to raise $75 million by the end of 2014. By closing the campaign ahead of schedule, we aim to fund additional therapies that will eventually lead to better treatment options for all people with CF. But we cannot do this alone. We need you by our side.

The tenacity of this community has shown that we will challenge what is possible in our search for a cure. It is my hope that the momentum we’ve created continues to fuel many wonderful things, including the power of possibility.

Sincerely,

Joe O’Donnell
Chair, Milestones II
Longtime Friends Increase Their Support to Help Fuel Further CF Research and Drug Discovery

Businessman Bill Luzum has been a longtime friend and supporter of the Cystic Fibrosis Foundation. The gene responsible for the disease runs in Bill's family, and over the years, Bill has made small, personal donations to help support the search for a cure.

When Bill’s granddaughter, Sophia, was diagnosed with the disease in 2012, he knew he needed to do more. He turned to Hazel Bowen, the daughter of his longtime friend and colleague, Ivan Bowen, for help and support.

Hazel is the president of the Ivan Bowen Family Foundation, a charitable organization established in her father’s name. When Ivan passed away in 2012, he left Hazel with the task of growing and running a much larger family foundation.

During his lifetime, Ivan had many passions, including supporting medical research. As president of the family foundation, Hazel is dedicated to continuing her father’s legacy.

“We were in the midst of constructing a mission and direction for the family foundation when Bill came to me and asked if we could support the Cystic Fibrosis Foundation. I immediately said yes to an initial Milesnones campaign gift,” Hazel said.

That initial gift to the Milestones II campaign in February 2013 was followed more recently by a much larger commitment to be spread over five years.

“Our support of the Cystic Fibrosis Foundation feels to be a worthy investment in so many ways,” Hazel said. “I know this money will be well spent, and I am honored to be able to do something for Bill and his family — this man who had been so important to my father. Supporting the search for a cure is a marvelous way to carry on my father’s legacy.”

For more than 50 years, Martha Atherton has supported the mission of the Cystic Fibrosis Foundation through volunteerism and financial gifts.

She and her late husband, Bob, first got involved with the Foundation in 1959 after their first child, Robert David, passed away from CF when he was just 4 months old. Martha and Bob went on to have two more children, John Curry and Richard Hillary. Richard was diagnosed with CF shortly after birth and passed away at age 13.

“Being part of something that was bigger than ourselves helped us manage our grief. By supporting the mission of the CF Foundation, we felt we were helping to make a difference,” Martha said.

Martha continues to help make a difference today. She recently visited the laboratory of Dr. William Skach, Ph.D., at Oregon Health and Science University and felt inspired to further her support of the search for a cure. Martha became a member of the Chairman’s Circle with an additional significant gift to the Milestones II: Accelerating the Search for a Cure campaign.

She hopes her contributions will make it so another family never has to lose a child to CF again.

“We know just how devastating this disease is, and that led us to doing all we could to support the mission of the Foundation,” Martha said. “The Foundation takes a very entrepreneurial and innovative approach to fighting this disease, and it’s working. I have hope because the CF Foundation has created a pathway to a cure.”
Springing Into Action: Paul Motenko Fights CF From Every Angle

Paul Motenko made a commitment to help find a cure for cystic fibrosis when his daughter, Stacy, was born 27 years ago. Stacy, who has two copies of a rare mutation, was not expected to live to see adulthood.

“From the moment we received the diagnosis, I sprang into action. I wanted to do whatever I could to provide a better future for my child,” Paul recalls. “That’s how I got involved with the Cystic Fibrosis Foundation.”

Now president of the board of directors of the Orange County Office - Southern California Chapter, Paul has helped raise millions of dollars over two decades to support the search for a cure.

Paul embraces all areas of giving. He engages donors by matching programs, fundraisers and events to their interests. One of the most unique programs Paul helped found attracts surfers to the CF cause.

Pipeline to a Cure events celebrate the development of hypertonic saline and the role that surfers played in identifying the therapeutic effects of saltwater on people who have cystic fibrosis. Since 2007, Pipeline to a Cure galas have raised more than $3 million to help support the mission of the Foundation.

This year Debbie and Paul’s support included conducting an annual fund letter-writing initiative and becoming first-time members of the Milestones Club.

“My family and I are so proud to be members of the Milestones Club, and part of a community that is so dedicated to ending cystic fibrosis,” Paul said. “Every gala that we host, every new contact we make, every dollar we raise brings us closer to finding a cure for CF — and when the day comes that all people with CF are free of the disease, we can say we were a part of the cure.”

Until that day comes, Paul and his family remain strongly committed to supporting the CF Foundation, the search for a cure and CF families everywhere.

“The CF Foundation is doing everything it can to help my daughter Stacy, and all people with CF, regardless of their mutation,” Paul said. “My wife Debbie and I want to match that commitment. We want to do all that we can to help end this disease.”

Anonymous (3)
Craig & Sue Arnold and John & Kris Arnold
John Barlow
Base Productions Inc.
Arnold and Mabel Beckman Foundation
Janice Bell
Britton and Vahna Benedict
William Benz
Bimbo Bakeries USA, Inc.
BioMed Realty L.P.
BlueCross BlueShield of South Carolina
Bernice Bollig
Kathie and Jon Bruno
Peter Busch
Caesars Palace
The CF Smackdown
Church of Jesus Christ Latter Day Saints
Marilyn Cressler
Dugas Family Foundation
Peter Dunkel
Elevation Church
The Ernst & Gertrude Ticho Charitable Foundation
Debra Fox
Gantz Family Foundation
Gilead Sciences, Inc.
Joe and Emily Gillespie
Bill and Ethel Gofen
Alan and Vicki Goldenberg
Horner and Martha Gudelsky Family Foundation
The Gratis Foundation
Haun Welding Supply
The Hawks Foundation
Mary and Jim Hawkins
Jim Heyser
Bryan and Anna Hunt
Jeffrey Hurt
International Aero Engines
The Ivan Bowen Family Foundation
Robert and Pamela Jackson
Joseph Jacovini
Wayne & Carla Jensen, great grandparents of Maddie McCamville
John & Monica Judge
Galin Karpisek and Joyce Fledderman
John and Grazia Kaufman
Debbie Kirk
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Ladish Company Foundation
The Lanterman Foundation
Legum Foundation Inc.
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Anixter Family Foundation
Charles and Eva Lipman
Jack and Lynn Lunden
The Massman Foundation
Jake and Beth McCarthy
Jim and Linda McCoy
Arthur McFadden
James Meiss
Meltzer Family Philanthropic Fund of The Associated Jewish Community Federation of Baltimore
Merit Medical
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Barbara Rapp
The Rite Aid Foundation
Karen and Scott Rittenbaum
Mark Rittenbaum
Rock CF Foundation
Cassandra Russell
Sacks Family Foundation
John and Virginia Sall
Saxena Family Foundation
Bob & Jennifer Sawyer, In Honor of Henry Freeman
Sequenom
The Sheba Foundation
Sheehy Ford Lincoln
Jonathan and Amy Slenski
Fred Smith
South Carolina Physicians Care Charity
Jon and Andrea Sprole
Frank P. Stansberry
Leslie Stemleib
The Trey Ricketts Sites Fund of The Dallas Foundation
Thomas J. Regan Jr. Fund
Joan Timberlake
Townsend Family Foundation
Triangle Community Foundation
Dennis and Julie Walsh
Jeff and Natalia Walsworth
Wheeler Foundation
The Wish for Wendy Foundation, Inc.
Wishes and Dreams for Cystic Fibrosis
Mrs. Anita Zucker

www.CFF.org
Milestones Donors Gather at Events across the Country

Sara Martin and Patricia Agnew at NACFC

Bob Beall with Casey and Jackie Magner and their children Patrick, John, Matthew and Annie in Chicago

Rich Mattingly and Mike Asher at NACFC

Cam McLoud and Bill Benz at NACFC

John McKenna and Preston Campbell in New York

Rich Mattingly, Cyndi Troop, Gayle Greenberg and Bob Troop in Westlake, Ohio

Clay Hagler, Bob Beall, Bobby Plott and John Abernethy in Mountain Brook, Ala.

Paul Negulescu with Maggie and Paul Delaney in Anaheim, Calif.

www.CFF.org
Milestones Donors Fuel New Discovery and Development Efforts to Find Treatments for All People with CF

Using lessons learned from Kalydeco™ (generic form: ivacaftor) and other therapies currently in development that target the underlying cause of cystic fibrosis, the Cystic Fibrosis Foundation is moving forward with efforts to speed discovery and development of new lifesaving therapies for all people with the disease.

Honing In on Nonsense Mutations

Through new and expanded alliances with leading pharmaceutical companies and academic researchers, the Foundation is pursuing opportunities to find therapies to treat those with rare CF mutations, including “nonsense” mutations. About 10 percent of people with CF have nonsense mutations, which interrupt the production of a full length CFTR protein — the key protein in CF — preventing it from functioning normally.

A drug discovery collaboration between the CF Foundation Therapeutics Laboratory in Boston and researchers at the University of Alabama at Birmingham and Southern Research is focused on screening drugs already approved by the U.S. Food and Drug Administration (FDA) and other clinically available compounds to determine whether they can help the production of a full-length CFTR protein in people with nonsense mutations of CF.

Program researchers have screened more than half of the FDA-approved library of 1,600 compounds. Because these compounds are already approved as safe for humans, any that appear to be effective in lab tests could potentially move more quickly into clinical studies.

Trials to Expand the Use of Ivacaftor

Two large Phase 3 trials have begun studying ivacaftor combined with the potential therapy VX-809 in people with two copies of the most common CF mutation, Delta F508. Results from these important studies, which enrolled more than 1,000 people in record time, are expected in summer 2014. Additionally, a Phase 2 study is evaluating the combination therapy in people with one copy of the Delta F508 mutation.

The U.S. Food and Drug Administration approved Kalydeco to treat people ages 6 and older who have one of eight additional cystic fibrosis mutations. Kalydeco is now approved for people with the following mutations: G551D, G178R, S549N, S549R, G551S, G1244E, S1251N, S1255P and G1349D.

Ongoing Study Shows Long-term Benefits

Results from the ongoing G551D Observational (GOAL) Study of people with the G551D mutation of CF ages 6 and older who are now taking Kalydeco showed significant improvements in several key areas — including mucus clearance, and lung infections caused by the bacteria Pseudomonas aeruginosa.
“I am able to breathe easier knowing the CF Foundation is working to find a cure for Gus and all people with CF.”

Marianne Kohlhaas, mother of Gus, age 6