

Milestones Update

News from the Cystic Fibrosis Foundation's Major Giving Campaign

FALL 2009



Milestones to a Cure
Campaign Chair
Joe O'Donnell

Dear Friends,

Five years ago, the Cystic Fibrosis Foundation embarked on its largest major giving campaign, *Milestones to a Cure*. Thanks to the tireless dedication of volunteers and donors around the country, the *Milestones* campaign has continued to grow and fund the essential development of new treatments for those with CF. Currently, donors have committed more than \$144 million to the campaign, and we are revving our engines to reach our \$175 million goal.

To discuss our next steps, a group of devoted *Milestones* campaign leaders took part in a wonderful exchange of ideas at a meeting this June in Rye Brook, New York. I was inspired by the thoughtfulness, energy and generosity of this group and am sure that we have what it takes to power the campaign to new heights.

At this meeting, I proudly announced a \$6 million challenge match and an opportunity for us to double the generosity of campaign gifts. Until the end of this year, every major gift given to the CF Foundation will be matched. I hope each of you will invite others to give at this time and allow us to expand the campaign and its ability to support continued progress in research and drug development.

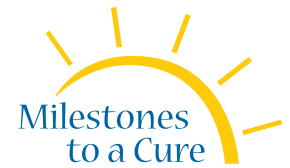
The Foundation continues to make extraordinary progress in these areas because of your ongoing support. Last year's promising development of potential therapies dedicated to treating the basic defect would not have been possible without the support of *Milestones* donors. This year, several key compounds are advancing in clinical trials, including VX-770, which entered Phase 3 trials this summer across the country.

As we advance the Foundation's mission and face the unique challenges presented by the current economic environment, we need your help more than ever.

Thank you for your continued dedication. I know with your help and this match opportunity, we will reach our ultimate goal and cure CF.

Sincerely,

Joe O'Donnell
Chair, *Milestones to a Cure*



"With the support of the *Milestones* campaign, our drug development pipeline continues to flourish, advancing our search for a cure every day."

Robert J. Beall, Ph.D.
President and CEO,
Cystic Fibrosis
Foundation



| Adding *tomorrows* every day.

Challenge Match

Milestones campaign chair **Joe O'Donnell** is excited to announce that two families, who have devoted more than three decades to fighting CF, have made **\$6 million available for major gift matches through the end of 2009.**

Now through December 31, 2009, major gift donations of \$10,000 or more paid in one calendar year will be matched. Multi-year pledges at the Milestones Club levels (\$50,000 or \$100,000) or more paid in one calendar year will be matched.

With the support of the *Milestones* campaign, the Foundation continues to make remarkable progress in CF research. And, for the first time, patients are taking drugs in clinical trials that address the basic genetic defect in CF, not just its symptoms.

Double Your Donation Today!

Be a part of the largest matching gifts initiative in CF Foundation history. To make a matching donation, please contact John Lehr, Vice President of Major and Planned Giving at 301.907.2594 or jlehr@cff.org.

Jennifer and son Casey, age 7

Leaders in Giving



Pat Perotti

Pat Perotti is a man with a mission. When he saw millions of dollars going unused in legal settlement cases, he found a way to put the funds toward a good cause—and he knew just the right one.

A class action attorney, Pat realized that millions of dollars in class action settlements were going unclaimed. From law school, he remembered an obscure doctrine called *cy pres*, which allows the court to donate unclaimed funds to charities. Recently, Pat's organization, Ohio Lawyers Give Back (OLGB), donated \$170,000 to the Cystic Fibrosis Foundation. Pat is now working with the CF Foundation and other lawyers to spread awareness of CF and the *cy pres* doctrine.

At the **Northern Ohio Chapter's Chefs Gala** last March, following a moving *Bid for a Cure* by ten-year-old Brooke Guthrie and her 14-year-old brother, Brandon, Pat announced his generous donation. "Brooke walked right across the stage to me and said, 'Mister, you're going to let me live longer,'" Pat recalls. "I was moved to tears...she stole my heart," he says.

"The CF Foundation is not only skilled at helping patients get the care they need, but also at running an incredibly smart and effective business operation," he says. "They're winning the fight to find a cure, and I like backing a winner."



Randy and Julie Ridenour

When **Randy** and **Julie Ridenour** became devoted fans of the Pittsburgh Penguins, they had no idea this dynamic hockey team would lead them to become number one fans of the CF Foundation and its search for a cure for cystic fibrosis.

"As season ticketholders, Julie and I were invited each year to the **Western Pennsylvania Chapter's Penguins at Your Service** event to benefit the CF Foundation," says Randy. "At this event, we learned more and more about the disease, and we got to meet many children with CF and their families. We were compelled and concerned right from the start."

To support the Foundation's mission, the Ridenours arranged to give the Foundation \$60,000 per year for a period of 20 years through the Ridenour Charitable Trust. "My wife and I had become very involved in chapter events. We knew children who one year were just fine, and by the next had lost their lives to CF. We wanted to change that," Randy says.

Since then, the Ridenours have helped spread awareness about CF and are encouraged by the advances the Foundation has made in CF research and technology. "The life expectancy for people with CF is so much higher now," says Randy. "Before, I never believed people with CF would live to go to college and have careers and children of their own. But now I do." He adds, "Thanks to the Foundation, I truly believe there may be a cure in our lifetime."

Industry Impact



Oil and Gas Industry Fuels Foundation's Mission

When four leaders from the oil and gas industry gathered around a table in Houston, it wasn't their concern about the fluctuating gas prices or changing economy that brought them together, but their shared drive to cure a disease. The three fathers and one grandfather each have a personal connection to CF—three children and one grandchild living with the disease.

The devoted volunteers put their hearts and heads together to launch a new initiative by strategically leveraging their relationships within the oil and gas industry. At the end of the evening, these leaders pooled their personal resources and committed \$1 million to the *Milestones* campaign.

Under the leadership of **Mike Beatty** from the **Colorado Chapter** and **Ralph O'Connor** from the **Texas Gulf Coast Chapter**, the committee agreed to raise \$3.5 million, seeking contributions from industry representatives.

“We have **great hope** that our collective effort will lead to strong support for the Foundation's mission and **a cure for this disease.**”

Mike Beatty, Major Gifts Chair, Colorado Chapter



Ralph O'Connor



Mike Beatty

Investments into Action

The *Milestones to a Cure* campaign continues to fuel the Foundation's robust Therapeutics Development Program. With more than 30 potential drugs in the therapeutics pipeline, the Foundation continues to achieve significant progress.



In collaboration with the Foundation, Vertex Pharmaceuticals has developed two compounds designed to treat the underlying cause of CF.

In 2008, Vertex announced positive results from Phase 2 clinical trials of VX-770 in CF patients who have the G551D mutation of the CF gene. Participants who received the treatment had improved lung function and a decrease in the salt content of their sweat. **Based on the positive data, Vertex launched pivotal Phase 3 clinical trials of VX-770 earlier this year to determine if the drug is safe, effective and acceptable for approval by the Food and Drug Administration (FDA).**

Vertex's second drug candidate, VX-809, which would affect patients with the most common mutation ($\Delta F508$), continues to advance through the drug development process. Last year, Vertex tested VX-809 in healthy volunteers to determine its safety. **In March, Vertex announced the initiation of a Phase 2a clinical study of VX-809 in individuals with CF.**



The Foundation expanded its collaboration with Transave, Inc. for the continued development of ARIKACE™ (liposomal

amikacin for inhalation), an antibiotic that aims to treat *Pseudomonas* lung infections in cystic fibrosis patients. Results from the first Phase 2 clinical trial were positive. **Transave will receive up to \$2.2 million in Foundation support upon achievement of scientific milestones.**

In the News

- In a speech before the American Medical Association in June, **President Obama** highlighted the success of a CF Foundation-accredited care center in Ohio to illustrate how a reformed health care system could provide better health outcomes for all Americans.
- The CF Foundation's drug development efforts were featured by best-selling author Dr. Jerome Groopman in ***The New Yorker***. The article—"Open Channels"—focuses exclusively on drugs in the Foundation's pipeline that show promise in treating the underlying defect in cystic fibrosis.
- The **Harvard Business School** issued a second case study that features the CF Foundation entitled "Bob Beall at the Cystic Fibrosis Foundation." It focuses on the elements of leadership at the Foundation, the history of the organization as well as drug discovery efforts, access to care, advocacy and plans for the future.
- ***The New York Times*** featured online stories of people with CF and their family members, who describe their experience of living with CF through audio interviews and photographs in a series called "Patient Voices."

| Adding *tomorrow's* every day.

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“I know **the
CF Foundation
is working hard**
so I can look
forward
to a longer,
healthier life.”

Mary-Leigh, age 26