

Milestones Update

News from the Cystic Fibrosis Foundation's Major Giving Campaign

VOL I, NO.2 OCTOBER 2006



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

Dear Friends,

Just one year ago, we kicked off the public phase of the *Milestones to a Cure* campaign, the largest major gifts fund-raising initiative in CF Foundation history. Since then, a dedicated group of volunteers and donors have stepped up to contribute to the campaign and rally others to offer critical support for the development of essential new therapies for cystic fibrosis.

Currently, we have nearly \$90 million in commitments towards our \$175 million goal. This support directly funds the Therapeutics Development Program, and never has there been more activity on this front. There are now 30 potential therapies in the CF Foundation's drug discovery and development pipeline. These include projects at the earliest stages of laboratory study, as well as those entering Phase 3 clinical trials, the last phase of testing before final FDA approval.

Our projects show tremendous promise, but to keep the pipeline well stocked with therapies, we need to build stronger support for the campaign. Among many efforts underway, we have been working hard to establish campaign steering committees at Foundation chapters across the nation. Many of these, including the Tennessee Chapter, have already begun to achieve success. In addition, on September 12, a small group of campaign leaders gathered at the Canadian Embassy in Washington, D.C. to review our progress and strategize how to keep the momentum growing. In a wonderful exchange of ideas, leaders agreed that we need to continue to translate the tremendous enthusiasm for the campaign into action plans that will bring significant results.

As we dedicate ourselves to building strong support for the *Milestones* campaign and continuing vital efforts to *add more tomorrows every day* to the lives of those with CF, I am deeply grateful for your help and your generosity.

Sincerely,

A handwritten signature in black ink that reads "Joe O'Donnell". The signature is fluid and cursive, with the first and last letters of the first and last names being capitalized.

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



**“With the
*Milestones to a
Cure* campaign,
we can better
keep pace with
the increasing
opportunities
before us in CF
research and drug
development.”**

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



Building for the Future

CF Foundation Friends Expand the Campaign

Stephen Karp, chairman and chief executive officer of New England Development, and his wife, Jill, have long known of the CF Foundation's mission as a cause dear to their friends Joe and Kathy O'Donnell. Recently, in the spirit of friendship, the Karps expanded their support of the Foundation, giving a generous \$1 million gift through the Karp Family Foundation to help fuel vital new CF therapeutics development. "My wife and I, our son Douglass and daughter Jana have been very lucky in our lives. Our family is healthy, and we are in a position to give to others, especially children, who may face daunting challenges," Karp recently said. "The CF Foundation has made tremendous progress in recent years in developing new treatments and advancing the search for a cure, and our family is proud to offer our support to the *Milestones* campaign."



Stephen and Jill Karp with their children Douglass and Jana

The **Tennessee Chapter's** local efforts on behalf of the *Milestones to a Cure* campaign are fast approaching an impressive goal: \$1 million in major gifts raised by the end of 2006. Leading the chapter's efforts is Major Gifts Chair **John Burch, Jr.**, a long-time volunteer and devoted CF father.



John "Jack" Burch and John Burch, Jr.

Determined to fight the disease since two of his children, John and Melanie, were first diagnosed, Burch and his family have grown ever more active. Spearheading the Tennessee Chapter's campaign effort seemed a natural role for Burch who is known for his warmth and optimism. Already he has rallied significant support in the local tight-knit CF community. CF grandfathers Wilbur Sensing and John "Jack" Burch, Sr. enthusiastically agreed to join the campaign as steering committee members and generously donated leadership gifts.

To date, the chapter has raised more than \$850,000, thanks to the outstanding support of members of the chapter's Board, Life Trustees and CF families. "The Tennessee Chapter's Major Gifts Committee is determined to reach our goal," Burch, Jr., noted recently. "We embrace the mission of *Milestones to a Cure*, and are 100 percent committed to supporting new CF research."

Hoping to spark interest in the CF cause throughout his local community, **Bart Murphy**, a CF father of two from Wheaton, Ill., began volunteering with the Greater Illinois Chapter more than 13 years ago. Since then, he has served as president of the Greater Illinois Chapter and has co-chaired the chapter's premier *Casino Fling* fund-raiser, while actively seeking to increase awareness about the disease and support therapeutics development.



Bart Murphy

Murphy is a partner in a Chicago law firm, Wildman Harrold Allen & Dixon LLP and recently, through his work with **Fujifilm USA**, he was able to secure a substantial contribution from Fujifilm to the *Milestones to a Cure* campaign. Fujifilm is proud that its support of the major giving campaign will fund research that will help people with cystic fibrosis live longer, healthier lives. "My wife, Lilly, and I are constantly amazed at the generosity of people and companies, such as Fujifilm, who are not directly impacted by CF and yet help in the quest for a cure by donating to the CF Foundation," Murphy said.

Looking Ahead

Milestones Leaders Gather at Canadian Embassy

On September 12, 2006, *Milestones* Campaign Chair Joe O'Donnell, CF Foundation President and Chief Executive Officer Robert J. Beall, Ph.D., CF Foundation Board Chair Cam McLoud and a small group of campaign leaders gathered in Washington, D.C. to strategize new ways to expand the campaign. A highlight of this meeting was a special reception and dinner at the Canadian Embassy overlooking the U.S. Capitol. Joining CF Foundation friends and leaders for this occasion was the Honorable Michael Wilson, Canadian ambassador to the United States, who kindly offered his hospitality.



Dr. Robert Beall, Ambassador Michael Wilson



Gary Sabin, Joe O'Donnell, J. Crandall



Meg and Brent Pratt



Mary Stone, Pat Hitchcock O'Connell, Tere Carrubba



Bob and Cam McLoud

MilestonesUpdate



Mimi Beall, Doris Tulcin, Dr. Robert Beall



Rich Gray, Ralph O'Connor

PHOTOS: BECKY HALE



Joe O'Donnell, Bob Niehaus



Joe O'Donnell, Amy and John Weinberg

“What touches me is that so many caring people have signed on to this battle simply out of the goodness of their hearts. I always stand in the shadow of their nobility, in the greatest of gratitude, because we families who have been cursed with CF cannot win this fight alone.”

-Frank Deford, chairman emeritus of the CF Foundation

Investments into Action

Science Highlights

Milestones to a Cure, the largest major gifts campaign in the CF Foundation's history, continues to invest money directly in our Therapeutics Development Program. Because of your major donor support, we are able to work collaboratively with companies poised to help accelerate cystic fibrosis research. CF Foundation projects continue to achieve vital progress:



Denufosal, developed by **Inspire Pharmaceuticals**, moved into Phase 3 clinical trials. Denufosal is being studied as a possible early intervention therapy to improve mucus clearance.



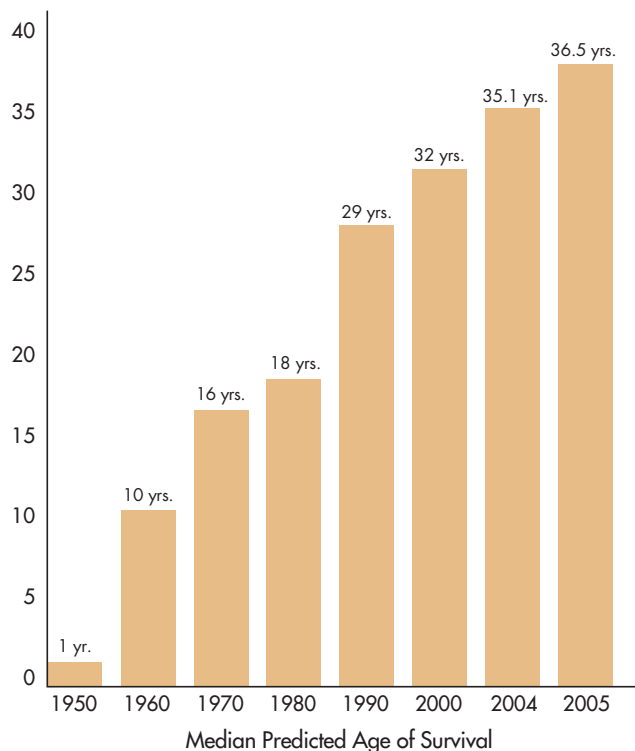
ALTU-135, a new version of pancreatic enzymes developed by **Altus Pharmaceuticals** to improve nutrition absorption, is currently being prepared for Phase 3 testing.



VX-770, the first compound to enter clinical development from the Foundation's collaboration with **Vertex Pharmaceuticals**, is being evaluated in healthy volunteers and CF patients as part of a Phase 1 clinical trial.



Cystic Fibrosis Foundation Therapeutics, Inc. recently awarded **CombinatoRx, Inc.** up to \$13.8 million to discover novel drug combinations for the treatment of CF.



In 2005, the Cystic Fibrosis Foundation reported another increase in the median predicted age of survival for people with CF to 36.5 years of age, up from 35.1 in 2004.

In the News

CF Foundation Gets Noticed

In the past four months, the CF Foundation has been recognized by major publications such as, *Forbes*, *The New York Times*, *Nature* and *US News & World Report*, for its innovative business model and aggressive approach to funding research for an orphan disease.

The New York Times called the CF Foundation "one of the most active in drug development," spending "more than \$100 million in the last few years screening chemicals to see if they would make drugs, helping to run clinical trials and giving grants to biotechnology companies."

In the September 25, 2006 issue of *US News & World Report*, Vertex President Joshua Boger noted the Foundation's critical role in ensuring the advancement of CF treatments. "If the CF Foundation was not willing to step up and support early-stage development, I am positive we wouldn't have prioritized work," Boger noted.

Milestones to a Cure... building a portfolio of progress

6931 Arlington Road
Bethesda, MD 20814
...adding tomorrows every day.
Cystic Fibrosis Foundation



“My husband, Marc, and I are grateful to volunteers across the nation who are helping to make a difference and change the future of our children.”

-Margarate Cassalina, CF mother of Eric and Jena (above)


Milestones
to a Cure
building a portfolio
of progress