



Cystic Fibrosis Lifestyle Foundation

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Cycling for Cystic Fibrosis Canada – Key West 2006

Brian Callanan is a 30 year old with cystic fibrosis living in Burlington, VT. He is currently director of Joseph's House Parish Outreach Center in Burlington, but has also formed the Cystic Fibrosis Lifestyle Foundation in 2003 to help build healthy attitudes and lifestyles for adolescents and young adults with CF. The reason Brian has endeavored on this project is to address the psychological and social needs of people with CF in exceptionally difficult periods of life. He has learned through having cystic fibrosis the importance of psychological, social and emotional health in relation to physiological health. The vision of CFLF is to help children with CF learn to become responsible and positive adults in order to live stronger and longer lives.

Cystic fibrosis is a fatal genetic disorder that affects over 30,000 Americans, usually the most vulnerable being children. This terrible disease is marked by chronic infections, clogged airways and reproductive problems. Thirty years ago, children struck by the disease were not expected to reach their 8th birthday. Today, thanks to incredible developments in treatments and medicine, many people with CF now live into their 30s and beyond, enjoying fuller more comfortable lives. Transitioning from childhood care to self-care is a critical stage of development for the growing adult CF population. Social and emotional challenges for this age group can be compounded by effects of isolation, mortality, anger, denial, depression and resentment. Effective management of CF requires treatment of the whole person through creating responsibility and a healthy lifestyle of an individual. Although scientists are beginning to explore various avenues for a cure, the quality of life for individuals at this crucial stage of transition from childhood to adulthood must not be neglected.

Brian started CFLF in 2003 with the intent of providing individualized recreational programs for people age 13-24 with cystic fibrosis. The difficult challenge with this condition is that peers are not allowed to directly interact because of infection control. This caused camps for children to be closed, and became the national CF Foundation policy to isolate the spread of bacteria in the lungs of people with CF. The lack of direct peer support is a unique limitation for people with cystic fibrosis in comparison with other chronic and terminal conditions. CFLF is working to start providing access to activities promoting fun, success, self-esteem and peer advocacy for this population in January 2007.

Currently, Brian Callanan and a friend, Stephen Trull, are readying for a ride from Canada to Key West to raise awareness and funds for CFLF. Their trip will cover 2650 miles over 40 days, and 13 states. While CFLF has raised over \$20,000 since April 2006, the financial target for this bike ride is to raise \$50,000 through individual and corporate sponsorship. They will be starting the trip leaving Burlington on July 28th and arriving in Key West in the beginning of September. The itinerary and maps are available on www.cflf.org and the site will be updated with pictures, stories and health condition along the way.

Please contact Brian at the above information with questions or to schedule an interview.

CFLF-Living Stronger! Living Longer!

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