



## ***Cystic Fibrosis Scholarship Foundation***

*Helping young adults with CF pursue their dreams*

***FALL 2015***

### ***From the President:***

As 2015 comes to a close, it is a good time to review the past year. In July 2015, the Food and Drug Administration approved Orkambi, a major advance in the fight to find a cure for cystic fibrosis. This drug helps restore the functions of the defective protein in the gene. Orkambi is targeted to those patients with CF that have two copies of the most common mutation. This represents half of the CF population and its impact is expected to be far reaching. The future is looking brighter for all of those affected by CF. Currently, 50% of the CF population is 18 years of age or older and the median life expectancy is now more than 40. The young adults with CF will continue to need CFSF to be a source of support in their pursuit of a college or vocational degree.

As a parent of an adult with cystic fibrosis who celebrated his 33rd birthday in June and his first wedding anniversary in July, I am more committed than ever to helping these young people. Thirty three years ago when our son was three months old on the fateful night that our doctor gave us the diagnosis, he explained that life expectancy at the time was the late teens, but he encouraged us to be hopeful as medical advances were being made every day. Our mission was to keep him as healthy as possible so that he could benefit from the medical advances. The medical community has provided these young people the means to live a longer life and CFSF's mission is to help them fulfill their dreams if it includes a college education. Many of the new drugs which have been developed and approved are very expensive and will continue to drain a family's financial resources even if the family has medical insurance.

Although we at the Foundation are appreciative of the generous support of our donors, it is the students who best can express the personal impact the donors have on their lives. Please take a minute to read some of their letters on pages 2 and 3. Our support of these young people will not only help them individually but in the long run will help all of us as they make their impact on society in their chosen profession.

We wish everyone a happy and healthy holiday season and thank all of our donors for their help in impacting the lives of our young adults with cystic fibrosis.

***Mary Kay Bottorff***

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## 2015-2016 Scholarship Recipients

Dear Friends of CFSF:

I would like to extend my sincerest appreciation for providing me with this amazing opportunity to memorialize and honor Jill Balboni's name. This scholarship could not be made possible without Ms. Balboni or you, and I would like to thank you with all my heart for your generosity and compassion. Cystic fibrosis is a disease that I know has impacted both of our lives in



a great way, for it has brought both good times and bad times. This disease has shaped me into the young man I am today because it is through the challenges that cystic fibrosis throws at me that I grow stronger. While letting cystic fibrosis cripple me may seem like an easy way out, simply surviving is not enough. I want to live, and I do this by seizing every day for what it has to offer. Your contribution to my higher education means the world both to me and my family. With a large amount of our family's income being used up for medications and treatments, we sometimes become worried as to how my college education will be funded. However, with your philanthropic contribution to my family, we can now worry less about our future and enjoy the present. I will be attending the Georgia Institute of Technology beginning in August. I am majoring in Nuclear and Radiological Engineering, and plan to go on to study Medical Physics.

I would just like to thank you once more because I cannot put into words how grateful I am to have received the Jill Balboni Memorial Scholarship. She was such an inspiring woman, and I am blessed that I get to honor her name through my community service and through my hard work in school. I will be sending follow up letters concerning my school and community service activities. Thank you Ms. Bridge!

Sincerely, *Andrew*

Dear Friend of CFSF:

I am writing to express my gratitude to you for the generous scholarship that was awarded me last month. I know that this scholarship will help me advance my education to a level that would be unattainable without it. I plan to use the money you have bestowed unto me to pursue an advanced education in musical instruction, with a specialty in choral education.

Choir has been my absolute passion and love for many years, and I've known that I want to make it my life's profession for the past three years. There's a certain rush I can feel from standing in front of a choir and leading them in a beautifully arranged piece of music. My choir teacher at Red Mountain high school gives all of the seniors an opportunity to conduct a song of their choice at the last concert of the year, and I took that opportunity. Based upon that experience, I now have no shadow of a doubt that I want to be a choir teacher. It is simply what makes me happy, and I know that life is too short to be spent on something that you don't love.

Out of all people who understand mortality, kids with CF are at the forefront of that group, and I'm no exception. I want to spend as much of my life doing what I love with the people I love so I can look on my accomplishments in life and be proud.



Living with CF has been a significant challenge in my life, but I don't let it define me. In my mind, I am a regular 17 year old kid who likes girls and hanging out with friends; CF takes a seat on the end of the bench in my mind. Although I am somewhat limited in my physical abilities, I don't let CF get in the way of what I want to achieve in my life.

I am truly honored to be recognized and sponsored by the Kevin Tidwell Foundation. Kevin's life is a true inspiration to me, and I hope that I can emulate his example every day as I strive to achieve my goals. Thank you so much for your donation to my life; I promise you I will use these funds to further my education and honor Kevin's life and legacy.

Sincerely, *Marcus*

Dear Friends of CFSF:

My name is Sarina and you have helped me reach my dream of a college education through the CFSF. I recently graduated from North Dakota State University on May 16 and I wanted to personally thank you for



your contribution to making my dream come true. I have always loved learning and despite Cystic Fibrosis I now have two bachelors' degrees in Public History and History.

I am proud of the accomplishments I have worked toward in the past three years and I look forward to creating a life that I adore and making a difference in the world. I have had incredible experiences at NDSU, such as designing and creating a museum exhibition, writing and creating documentaries and working on the Cuplomacy project ([www.cuplomacy.com](http://www.cuplomacy.com)). I recently received a job as an intern at the Emily Reynolds Historic Costume Collection at NDSU for the summer and look forward to learning about collections management.

I am excited about the next steps in my life as I plan to move to Minneapolis, MN in September and pursue a career there. I am also am considering graduate school in the future and hope to work around the country on interactive and participatory museum elements. I absolutely love to travel and hope to integrate travel into my life in a big way. I hope all is well with you and again that you for everything.

### *Sarina*

Dear Friends of CFSF:

I am writing to you at this time to inform you of how well this semester went at Washington State Community College, as well as brag about my future plans that I am looking forward to. I graduated from WSCC this May with a 3.1 GPA, which was low for me. I had a hard time in one class so it brought my GPA



down a bit, BUT I GRADUATED! I am so proud to say I graduated with a General Science Transfer degree and Liberal Arts degree. I will be attending Bradford Veterinary Technology program at Bradford Vet Tech Institute this July. I am so very excited to move onto a different school and begin my career path. I have a long love for pets and animals in general, so I am very sure that I will love my major. I want to thank all of you for every bit of help I have received from this scholarship. It is such a blessing to be able to say that I graduated with 2 degrees with no debt because of the scholarships I

received, one of which, from CFSF. I have been so fortunate to have good health along the way to keep my strength high and continue to be a great student. My doctors, family, friends, etc., have been so encouraging for both my schooling and my health. I thank each and every one of you for the support and the help through this scholarship, as it will continue to help while at Vet Tech School. No matter what my health puts me through, I will continue to strive for good grades and become a Veterinary Technician one day, thanks to all of the help and support that I have received.

Once again, thank you so much for your generous scholarship. It has been such a blessing to both me and my family!

### *Madison*

Dear Friends of CFSF:

Thank you for the CF Scholarship that has helped support my college education for another semester. This past semester was tough in terms of staying in good health while maintaining good grades. I was hospitalized in May for two weeks for a CF "clean-out" but I managed to still get all A's and B's at school! I'm in much better health now and looking forward to starting the next semester. I've learned so much and can't believe I'm already half way through with college! Thank you for helping make this dream possible for me. I appreciate it so much.

### *Stephanie*

## ***12th Annual Tim and Ritch Dangel Memorial Golf Scramble***

On Saturday, September 26, 2015, more than 100 golfers hit the links at the Circling Hills Golf Course in Harrison, Ohio. The day could not have been more perfect with the temperatures in the high 70's and the sun shining brightly. Dinner, the raffle and auction were held at the club following golf. The tournament is held in memory of Tim and Ritch Dangel, brothers who both fought their battle against CF. A great time was had by all and



\$8000 was raised in memory of Tim and Ritch. The tournament is organized by Rick Niklas, uncle of Tim and Ritch. The proceeds from the event will be awarded in the spring of all the wonderful family of Tim support as well as all the supported the event.

fund a multi-year CFSF scholarship 2016. Thanks to Rick Niklas and and Ritch for their hard work and sponsors and companies that



## ***Upcoming Wine Tasting Event – Chicago***

The annual Chicago wine tasting to benefit CFSF is planned for the Sunday afternoon of January 31, 2016 at The Chicago History Museum. This year we will travel to Europe and enjoy wines and foods from Southern Italy. The afternoon will include a silent auction as well as a raffle and our fun Buy A Cork. We are seeking corporate sponsors for the event. Sponsorship levels are \$2,500, \$5,000 and \$10,000. If you know of any companies who might be interested in this opportunity to help our young adults with CF, please contact the office.



If you are interested in working on the committee to help promote the event or wish to purchase tickets, please contact us at 847-328-0127.

## ***Honor Someone You Love – Remember Someone You Miss***

Searching for a special gift to commemorate a birthday, anniversary, the holidays or wedding? Looking for a meaningful way to remember a loved one? This may be the right time for you or someone you know to help our young adults with CF pursue their dreams. It is easy to do. Fill out the enclosed envelope and send it to CFSF. We will promptly send the recipient notification of your donation.

## ***Amazon Smile***

Do you do holiday shopping at Amazon? If you purchase items from Amazon please sign up for Amazon Smile. A percentage of each of your purchases is then contributed to CFSF. It is a simple way to help us provide more young adults with CF a college education. Sign-up today at [smile.amazon.com](http://smile.amazon.com), and select the Cystic Fibrosis Scholarship Foundation, and leave the rest to Amazon!

## ***2016-2017 Scholarship Applications***

Applications for the 2016-2017 school year will be available on the website, [cfscholarship.org](http://cfscholarship.org) by the end of November. Applications will be accepted starting in mid-January. Students are notified by the third week of April of the Committee's decision.