



Cystic Fibrosis Scholarship Foundation

Helping young adults with CF pursue their dreams

FALL 2016

From the President:

As 2016 comes to a close, it is a good time to look back and take time to understand cystic fibrosis, the disease. We are all committed to help our young adults who live with this disease every day of their lives but I think it is worthwhile to understand what cystic fibrosis is and the impact it has on a person's life. The simple definition of CF is that it is a progressive, genetic disease that causes persistent lung infections and diminishes the ability to breathe over time. The defective gene causes a thick, buildup of mucus in the lungs, pancreas and other organs. The mucus buildup in the lungs clogs the airways and traps bacteria which leads to recurrent lung infections and extensive lung damage. In the pancreas, the mucus prevents the release of digestive enzymes that allow the body to break down food and absorb the nutrients.

There are more than 30,000 people in the US living with CF (70,000 worldwide). Approximately 1,000 new cases of CF are diagnosed each year with more than 75% of them diagnosed before age 2. The reason our work at CFSF is so important is that more than 50% of the population with CF is over the age of 18. Breakthrough treatments have added years to the lives of people with CF. The median survival age is close to 40 years of age. In the 1950's a child with CF rarely lived long enough to attend grammar school. Because of the advancements in research and patient care, many people with CF are living long enough to realize their dreams of attending college, pursuing careers, getting married and having children. While great strides have been made, there is still no cure and too many lives are cut short before all their dreams can be realized. Our mission at CFSF is to help make the dream of a further education a reality for those who wish to pursue this goal.

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 the following pages. 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.

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2016-2017 Scholarship Recipients

Dear Friends of CFSF:

2016 is halfway through and it is time to start the fall semester again. Sadly, this is the last letter you will be receiving from me. I've enjoyed sharing a bit of my life with you each semester. I will be graduating this coming April and shortly after I will be taking the national board exam to become a Certified Occupational Therapist Assistant. It is a dream come true for me to have come this far.

Winter semester was less overwhelming for me than fall was. I'm not sure if the curriculum was straightforward or if the instructors were less harsh on me when it came to grading. I do regret not focusing harder on my schoolwork because my final grades in each class were just under an A.

When I wrote last, I was still adjusting to the new baby and all of the changes he went through in his first year. Now he is walking and talking; it's hard to imagine how our family was before he was born. We have bonded so much this summer, my kids are acting like actual siblings and they constantly bicker with one another.

My CF is different from others my age. They struggle to put on weight and I am technically obese. This summer, I decided to make a change in my life. It started when my son started eating solid food. He always wanted to eat what I was eating which honestly was not healthy nor nutritious. As a family, we started eating healthier by adding more fruits and vegetables in our meals. In Michigan, we seldom have great weather so when summer came I put a lot of effort into getting the kids active again.

I've lost twenty-five pounds since May and I am determined to continue. When I started exercising this summer, something was different. I suppose it was because I didn't just want to lose weight, I needed to. I couldn't keep up with my kids and felt exhausted all the time. My breathing has even felt easier for me, especially after a run, which is a love/hate relationship.

For now, I look forward to finishing my classes and of course, graduating! Additionally, I'm eager to use the skills I've learned into helping others. For the first time ever I will be self-sufficient and stable enough to provide for my kids. I want to acknowledge that you have been a great part in this process and for that I genuinely thank you and appreciate what you have given me and the foundation.

With gratitude, *Kelly*

Dear Friends of CFSF:

I would like to give you an update about my last semester in Vet Tech School. It was a tremendous one, at that! We finished up our Surgical term, which gave us an opportunity to watch cat and dog surgeries, as well as participate in the important roles in surgery: anesthesia, IV



catheter placement, recovering the patient, etc. We also began our large animal theory classes, which means in a few weeks, we will be attending farms to work on large animals, which isn't possible at school. I only have 2 terms (4 months) left in this program and I am so blessed it is going the way I planned. In October, I will be going on my externship and spending 2 months in a real Veterinary Clinic, where I will work and learn to be in the environment. In December, I will graduate with an Associate's degree as a Veterinarian Technician, which I have worked so hard for. I love this career and my health would never have stopped me from completing this program. As for my health, I am very lucky that nothing has gotten in the way of my schooling. I try my best to keep up with my treatments, as well as medications and doctor appointments... I cannot express how thankful I am for this opportunity and without this scholarship it may not have been possible, due to income. Again, I want to thank you for letting me have this scholarship.

Sincerely, *Madison*

Dear Friends of CFSF:

Hi, my name is Jacob Weinstein, and I am an upcoming sophomore at USF. I am writing this letter to give an update on my current state of affairs, along with my education and health statuses. First, I would like to give a big thank you to every single supporter and donor of the Cystic Fibrosis Scholarship Foundation. I am very sincere when I say that I would have a much harder time attending school without this scholarship. This money goes towards creating a better future for me, and every day, I consciously make an effort to enact the same kindness that is expressed toward me onto anyone who can use it. I feel so glad knowing that there are people in the world that will volunteer time and money to others in need, and for that I am very thankful. That's one of the great things about having CF; I understand at a young age how much care actually goes into decisions that are made by people because I am the RECEIVER of those decisions, those acts of kindness that take much more apathy to happen, and that is something that I have been blessed with.

In regards to my health, I am doing pretty great! I recently (more like 3 months...wow time flies!) started taking Orkambi, a drug that treats the underlying cause of CF in people with two copies of the Delta F508 gene. I have had a stronger appetite, more energy, more dedication to my goals (I am willing to bet that this is related), and honestly a better outlook on my future. I have lived in fear of dying since I was little (Imagine knowing how much longer you have to live. CF feels kind of like that, and it's frightening), and recently I have started taking steps to change that. I am less afraid to take risks and I am more open to change. Because of Orkambi, I can honestly say that I am excited for what the future will bring.

In other great news...school is great! During my last semester at USF I got almost all A's and B's (damn you precalculus...C+) and I am going to start classes for my major this year! I am very excited to go back to school. I will be getting an apartment off campus with one of my best friends that I just happened to meet at USF, along with two other people. I have high hopes that I will achieve more this year than I ever have.

To Summarize, thank you, school's great, health is great, let's keep it up. (Seriously, thank you all again for the generosity that you show towards little old me. It will not go unrewarded, even if the reward is just the good feeling that you get ... and this letter.)

THANKS AGAIN! *Jacob*

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, and select the Cystic Fibrosis Scholarship Foundation, and leave the rest to Amazon!

13th Annual Tim and Ritch Dangel Memorial Golf Scramble

On Saturday, September 24, 2016 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 70's and the sun shining brightly. Dinner, the raffle and auction were held at the club following



golf. A live auction was held for a 5 nights stay at a 2-bedroom condo in Nuevo Vallarta, Mexico. 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 over \$9000 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 fund a multi-year CFSF

scholarship to be awarded in the spring of 2017. Thanks to Rick Niklas and all the wonderful family of Tim and Ritch for their hard work and support as well as all the sponsors and companies that supported the event.

Upcoming Wine Tasting Event – Chicago

The annual Chicago wine tasting to benefit CFSF is planned for the Sunday afternoon of January 29, 2017 at The Chicago History Museum. This year we will travel to the Eastern



Mediterranean and enjoy wines and foods from this special region. 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 and include tickets to the event. 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, please contact us at 847-328-0127. For tickets and more detailed information on the event visit cfsf.ticketleap.com/wine .

Dear Friends of CFSF:

It is mid-summer now and the fall semester is approaching along with the proper time for me to reflect on the spring semester. This was by far the most difficult semester of my college career and I have a feeling that it will only get more difficult. However, that does not discourage me from achieving my goals. Despite not being able to make an A in my accounting class I still learned so much from it. I enjoyed what I learned and I am very enthusiastic to learn more. This upcoming semester I will be taking two accounting classes: Intermediate 1 and Accounting Information Systems. After speaking to other students who are a few steps ahead of me, I now know that these classes will be a challenge, but I welcome it.

Throughout the long and difficult spring semester I contemplated quitting my job at Chase to focus more on my classes. I am still considering this because I don't want my school to come second to work, but I also know that spending so much time away from home was hindering my health. I hate the idea of quitting my job not because of the loss of income, but the skills I've learned, the people I meet, and the opportunities that come from working at the bank are invaluable. I believe I really need to find the right balance between work, school, and my health to have a successful semester.

Lastly, I applied for the school's PPA program, which is an accounting program that helps students who intend on taking the CPA exam get on a fast track towards that, prepare them for internships, and meet successful business people that will provide the students guidance through their college career. It is really a great program and I am excited to hear if I will be accepted into it. I should hear back by August as to whether I am accepted so wish me luck and I'll update you in December. Best regards, *Tyler*