

2/7/14

Dear CF Patients and Friends,

My name is Kevin D'Agostino and I am a fellow 27-year old CF adult diagnosed at birth. I am writing to offer some support in the way of exercise and conditioning. I won't get into a long-winded story but I just wanted to tell you a bit about how exercise has impacted my life with CF. To make it quick. I was always a pretty sick kid growing up, hospitalized 2-3x a year and home IVs maybe another 1x a year. PFTs slowly declined as I made my way through high school and into college as my interest in caring for myself quickly decreased as my desire to "party" increased. That didn't go so well for me as I became sicker and sicker through my college years and post college years. I rarely did my prescribed treatments and never used the "vest" but did "work out" a bit. I was 90 lbs when I went to college. Had a gtube but never used it.

My FEV1 on my PFTs hit their lowest probably early in my 20s when my FEV1 was 22%. Coughing and spitting up crap overwhelmed me and I barely could finish sentences I coughed so much. Things have since changed.....

Okay, long story short. I took up working out and am religious about it. I work out about 5x a week and pump protein shakes into my gtube post workout. I don't do any other meds except zithromax orally, and albuterol and symbicort inhaler. Exercise is solely responsible for my health. It allows me to cough up all that crap in my lungs while getting a body and cardio workout. IT HAS CHANGED MY LIFE!! I am not a solid 130lbs and I think in pretty good shape. I have done 3 small triathlons and do Crossfit workouts at the gym and keep up with a lot of the other members. My last FEV1 was 46% and I probably feel the best I've ever felt in my life. I still get tune-ups about once a year but literally never cough. I used to get the "are you smoker?" every single day. Now, I work without anyone knowing anything is wrong with me. I fit in. I am NOT "tooting my own horn" nor do I hope you think I am. I'm just a believer in exercise and results are a testament to its power; it's not a fluke. Exercise will do this for everyone.

You must know that I am NOT involved in the CF community at all. I don't go on blogs, have zero CF friends, don't go to charity events anymore, am not involved with foundation (the latter are probably bad things) but I find that if I don't surround myself with things related to CF, the less I feel I have CF. I guess this is my "coming out" into the CF community moment. My mom told me the other day after she saw me breathless sucking on 5L of oxygen post-workout "Kevin, you have to reach other people with CF and truly stress the importance of exercising and show them what it has done for you." She made a great point. It's very hard for CF patients who have trouble walking up the stairs without complete exhaustion to watch or hear healthy athletes tell them how to work out. It's demoralizing and depressing. Basically I want to help you all get healthy and realize that you can have CF and be in great shape but you have to work at it. I also must stress that I am not a "spaz exerciser" that loves to workout. In fact, I dread it everyday. I hate it but I know that 15 minutes a day will make me feel amazing...mentally and physically. If I am preaching to choir and whoever received this email exercises a lot, GREAT!! If not, I want to help. I've seen what inactivity can do to people with CF. My sister is on the list for

her second lung transplant...shes 21. She definitely got dealt a worse hand of CF than me but she wasn't nearly as active and I believe it played a huge role in her prognosis.

Anyway, I wrote more than I should've.....I just wanted to let you guys/girls out there know that I am here for you if you need a kick in the ass or want to work out together. I'd love to start a weekly training session....free of charge. We all work out together.....I haven't quite figured out the kinks with cross-contamination yet but that will be a bridge to cross when we arrive. In the meantime, I want this email to spark some motivation, spark some desire to get healthy and stay healthy. I would love some feedback. Also, if you are on 2L of oxygen and can barely walk up the stairs....DO NOT let that stop you from emailing me back and participating. While one person does sprints, the other walks in place. Its a stepping stone.

I'll call this

OPERATION: KICK ASS!!.

Working alone sucks. We need to support each other, especially with exercise. I need a kick in the ass some days and I am here to kick you in the ass. Love to hear back from anyone. Stay healthy, god bless and keep up the good fight

Sincerely,

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Feel free to text, call or email. i'd love any type of communication.