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Everything Respiratory

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Jan Petersen Esq.

We so admire Jan Petersen for all of the work he's done through the Alpha-1 Foundation. His excellent leadership skills and caring personality makes him more than deserving of the moniker "Respiratory Hero". Jan Petersen has been the city attorney for the City of St. Cloud Minnesota since 1979. Since Petersen's diagnosis of Alpha-1 nearly twelve years ago he has been advocating on the behalf of Alpha-1 patients through the Alpha-1 Association. He currently serves on the Alpha-1 Association's Board of Directors. If Petersen's story doesn't inspire you to advocate for patient's rights, nothing will.



Stephen Gaudet RRT

When we first found out about Stephen Gaudet (Or "Breathin Stephen" as his blog followers know him as) we knew we had to get him into our magazine. Stephen Gaudet used to be a respiratory therapist until 2005, when he was forced to retire because of his refractory asthma. Since his retirement Gaudet has run several marathons, and was the first person with severe asthma to compete in and complete the Boston marathon. Gaudet now spends his free time blogging, exercising, and participating in various asthma advocacy groups. Maybe Stephen's story will inspire some our readers with asthma to get more active!



Trey Schwab

Trey Schwab's story is an inspiration to transplant patients everywhere. Trey Schwab was an assistant coach and scout for the Minnesota Timberwolves from 1993 to 2000. After beginning a coaching job at Marquette University he was diagnosed with Idiopathic Pulmonary Fibrosis, he also found out that he would need a double lung transplant to survive. He received his life saving transplant in 2004, and since then he's focused on counseling and helping other people in need of transplants. We hope you'll enjoy his story of courage and perseverance in this issue.

William Houck

We first met William through his mother who called for questions about oxygen related products for her son. William has BOOP, and requires oxygen twenty-

The not so glamorous side of being a severely asthmatic walker

Stephen Gaudet is a 56 year old who has lived with severe asthma since his early childhood. He has a form of the disease called refractory asthma; a type of asthma that is severe and difficult to treat. In 2005 Gaudet was getting sick so often that he had to retire from his career as a respiratory therapist and went on permanent disability. Later that year he decided to follow the advice he had been giving his respiratory patients for years and began to exercise. He started walking short distances each day regardless of if he was short of breath or not. Once he got into the habit of exercising regularly he set his sights on completing half of a marathon. After 6 months he was able to complete his goal, and he soon resolved to finish an entire marathon. Gaudet finished his first marathon at the 2006 Portland Marathon. Gaudet went on to participate in other marathons, but his dream came true in 2009 when the Boston Athletic Association formally recognized his disability and was accepted into the 2009 Boston Marathon. Gaudet completed the Boston Marathon without receiving special privileges (Gaudet crossed the finish line with Mike Mc Bride, the first person with Emphysema to complete the Boston Marathon).



Stephen with Mike McBride, ???, and ???
at the 2009 Boston Marathon

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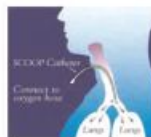
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Gaudet is set apart from most people who have severe lung disease is that he has a very high tolerance for respiratory discomfort, which can be viewed as both a positive and negative thing. His FEV1 (Forced Expiratory Volume) at the time of the last Boston marathon he ran was 35% (to put this in perspective, the average FEV for adults is 75%-80%), which is very difficult to do while walking fast for 26 miles. He's lived much longer than people thought he would, and

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he's convinced that without all of the exercise he's done over the past five years that he would have been dead long ago. Gaudet has been invited to the 2011 Boston Marathon, but may not be able to participate because of his lung function has declined. Gaudet is being evaluated for lung transplant surgery again, and has yet to decide if he wants to pursue the transplant option. In the meantime he still walks as much as possible and is involved in various asthma advocacy groups. Below is a post from Gaudet's personal blog, *Breathin Stephen*.

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Breathin' Stephen



Left to right, Tom Chromy (Caire Oxygen systems) Mike Mc Bride, Me, Peter LaBerge, Brett Townsend also from Caire Inc. Celebratory dinner after the 2010 Boston marathon.

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Yeah, I made it to Boston. I've walked the Rome and Portland marathons a couple times, and yeah I've been written up in lots of walk magazines and medical journals, but I think a lot of people who hear about me or read my blog, assume that because I've done all these things, that I lead an exciting life and that my asthma is well controlled and more of a nuisance than anything else. What they don't see, and what I rarely write about unless I'm really sick, is the hell I go through on a daily basis when I'm not doing all those "fun" things.

Most days start out pretty good with my best breathing occurring during the morning hours. That effect however, rarely extends into the afternoon. Generally, as the day progresses, so does my breathlessness. If I eat even a small meal for lunch or dinner, the bloating that

results, only adds to my breathing discomfort. By early evening I'm usually so short of breath that I will have to take neb treatments every hour or two until bedtime. On most evenings I have to take Ativan or a strong opiate to quell my Dyspnea enough to where I can nod off. When it's time to go to bed I pre-medicate with a neb treatment, 2 Motrins and a half a Vicodin.

If I'm able to sleep at all, it's usually for no more than 2 hours at a time and then I wake up gasping for air. Sometimes I'm so physically exhausted that I will lay there in a semi-awake state feeling myself suffocating...it's

an awful feeling. After about 5 minutes of that, I have to sit up to catch my breath and then get up and take a breathing treatment. By the time I finish with the breathing treatment, I'm unable to fall back asleep and will lay in bed wide-awake until the sun rises. By 4 am my shoulder muscles are hurting so bad from shrugging them all night long that I'm forced to get out of bed just to relieve the pain. Finally by 6am when the 9 pills and the 3 different inhalers I took finally kick in, I'll usually start to feel pretty good again. After that, if all goes well, I have about an 8-hour window of decent breathing, in which to get my daily

chores done, walk, and get my daily exercise and/or training in.

Keep in mind that the above scenario only plays out when I'm having a relatively GOOD breathing day. On the not-so-

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good breathing days, you can skip the exercise part all together...or anything physical for that matter. If my asthma gets out of hand, then I have to deal with the uncertainty of just how bad it will get and the added stress of possibly being admitted to the hospital...or worse. Then there's the burden that these things place on the people who care about me.

So yeah, I've done some pretty amazing things and I hope to continue doing more, but at the end of the day I'm just a regular dude with really bad asthma and a tremendous will, dealing with this disease the best I can.

If you want to hear more stories from our amazing asthmatic walker, visit his blog at: <http://breathinstephen.com/>



Left to right Peter LaBerge, Mike Mc Bride, Me, Lis Sheppard