



From the desk of Ian Alexander

“Pulmonary Fibrosis (PF) is a lung disorder characterized by a progressive scarring known as fibrosis and deterioration of the lungs, which slowly robs its victims of their ability to breathe. Approximately 128,000 Americans suffer from PF, and there is currently no known cure or cause. An estimated 48,000 new cases are diagnosed each year. PF is difficult to diagnose and an estimated two-thirds of patients die within five years of diagnosis. Sometimes PF can be linked to a particular cause, such as certain environmental exposures, chemotherapy or radiation therapy, residual infection, or autoimmune diseases such as scleroderma or rheumatoid arthritis. However, on many instances, no known cause can be established. When this is the case, it is called idiopathic pulmonary fibrosis.”

Being asthmatic since birth I had regular check-ups annually with specialists to keep my condition in line which included random x-rays. About six years ago my physician advised me that there seemed to be a few suspicious spots that they needed to investigate and recommended a CT Exam. Upon verification the pathologist suspected a form of autoimmune disease “scleroderma” or IPF. I was monitored for a period of four years on a regular basis at the Montreal Chest Institute as the disease remained dormant and then in 2007 my physician indicated to me that from the previous CT exam that there had been new activity and it was time to organize an internal biopsy for conclusive evidence. The results came back positive for the disease and I was put on a form of cortisone and anti-suppressants to see if they could curb the progression. After significant lobbying with the Dr’s at the Montreal Chest Institute I obtained a letter of recommendation to Hospital Notre Dame Transplant Centre to qualify for the lung transplant program.

Unfortunately, once the disease became active in my system it took less than a year from requiring minor amounts of oxygen to the maximum amount I could get 24 hours a day. There were so many trips in/out of hospital for care and treatment-loss of weight/appetite and the ability to get around. As the Canadian lung Association states – “When you can’t breathe nothing else seems to matter”!

As my disease developed rapidly I tried desperately searching in and outside of Canada to find a hospital that could service my requirements for new lungs for life since this becomes the only option and thanks to what I call a miracle the Toronto General Hospital came through for me and my family. I was listed with “Quebec Transplant” however my condition with regards to the waiting period was not going to be available in time for my survival.

For those offering/educating others regarding defending oneself for the opportunity to transplant once diagnosed with PF/IPF, I certainly recommend the following:

1. Obtain a biopsy as soon as a suspicion of the disease has been diagnosed.
2. Obtain a reference from your physician to complete all necessary tests at a Transplant Centre to qualify for the Transplant Program. Wait times are expensive especially when the disease progresses quickly and there are only so many opportunities available. There is no priority list available in Quebec in other words no matter one’s condition it becomes first come first served depending on the size



and tissue matches of the organs. For some reason Quebec is the only territory in North America that doesn't offer a priority list.

3. Look into other options/locations for transplant because time certainly becomes a factor when the disease starts to spread!

Since the transplant I have had good success and have had the best treatment and follow-up from both Hospital Notre Dame and the Toronto General. After transplant there is a significant rehab and recovery with many peaks and valleys. It is so important to stick with the physio program, attend all clinic days, take all medications on time and keep the hands clean because germs spread rapidly and the immune system is always on the low side because of the anti-suppressants.

I couldn't imagine going through life after this experience without trying to help others fight this disease so our family has set up a foundation-TAFF (The Alexander Family Foundation). By organizing charity events to raise funds to help other individuals stricken with this disease and eventually hope to find some corporate sponsors that will help us donate much financial assistance towards research-educating the public-lobbying the government so the suffering will end. Services must be extended to save more lives and other solutions made available for survival! One major point I must continue to re-enforce as I do almost daily is "Sign your driver's license regarding donation of organs – as well your "Power of Attorney" if you have one!

We all must work together to fight this silent killer that is spreading rapidly around the world and yet still unknown to most Canadians. We need to accelerate the efforts to research to find a leading cure for "Pulmonary Fibrosis", while educating, supporting, and advocating for the community of patients, families, and medical professionals fighting this disease.

God bless you!

Ian Alexander

*CPF is the largest nonprofit organization in the US dedicated to advocating for those with PF. For more information please visit <http://www.coalitionforpf.org>