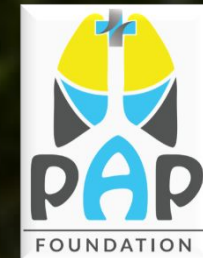


STEVE PARK

PAP Patient Education Day



A Patient's Perspective on Living with PAP





A Little Bit About My PAP Background

- Shortness of breath started in 2000 after a severe respiratory infection.
- Diagnosed by CT scan and bronchoscopy in October 2001 at the age of 44.
- Initially treated with daily 250 mcg gmcsf injections. Stopped after 10 months.
- My PAP was very aggressive. I had 44 lung lavages all performed by Dr. James Ellis of National Jewish Hospital in Denver. My first lavage was August 2002 and my last lavage was May 2006. They averaged about 6 1/2 weeks apart, with the shortest time being 3 1/2 weeks.
- I was on continuous oxygen 24/7 for 4 years, 2 months, and 13 hours, needing anywhere from 1L to 15+L.
- I had multiple infections of MAC and MAI complexes and Norcardiosis and in April 2004 I had a collapsed left lung as a complication of a 2nd bronchoscopy.
- High dose (1300 mcg) gmcsf injections followed by low dose gmcsf inhalations resulted in being symptom free in 2006. I stopped all gmcsf inhalations in 2010.
- I was symptom free for 10 years and 5 months when a series of infections resulted in new PAP symptoms reappearing in fall of 2016. Restarted inhaled gmcsf in January 2017. Currently, I'm symptom free with no limitations.





PAP PROGRESSION



For some patients PAP progression is very slow and gradual. These patients may only notice being slightly out of breath upon mild exertion. They may go years between lavages and may never need supplemental oxygen. They are able to work and go about their lives.

For other patients PAP progression is very rapid and aggressive. These patients may always be short of breath and any physical exertion may lead to them almost passing out. They may need frequent lavages and continuous supplemental oxygen. They may no longer be able to work and their lives are significantly impacted.



PAP AND QUALITY OF LIFE



Quality of life expectation varies from one patient to another, depending on how impacted they are by PAP.

One patient may be content to just be healthy enough to be able to walk the dog and climb stairs without getting out of breath.

While another patient expects to be able to run marathons, ride their bike, or climb mountains.

How patients react to PAP also varies. Some patients may spiral into deep depression and just kind of give up. Others accept their illness and get on with their lives the best they can. Most experience all the emotions from depression, anxiety, frustration, anger, and feelings of hopelessness and isolation.



Tips for Living with PAP and Maintaining your Quality of Life



- Support system of family, friends, coworkers, pastors, doctors, and other patients.
- Facebook – PAP- Pulmonary Alveolar Proteinosis Patients & Caregivers page
- Find the right doctor. Make sure they are experienced in treating PAP.
- Stay informed and be proactive in your care and treatment. Be your own best advocate!
- Monitor your progress with a pulse oximeter – record SATs, resting, 5 minute step test.
- Consider getting the aPAP blood test annually to track your numbers.
- Stay active, exercise – use supplemental oxygen to help you stay active.
- Overcome your vanity and use your oxygen.
- Get the right O2 equipment and nebulizer that suits your lifestyle. Running on Air <https://runningonair.net/> is an excellent guide/source for everything Oxygen.
- Attitude and Perspective – Get Busy Living.



STAY STRONG. STAY POSITIVE

THERE IS LIGHT AT THE END OF THE TUNNEL

