

Patient Advocate Vldy Rozenbaum, PhD, Shares His Long Journey with Lung Disease

Rozenbaum's patient advocacy group, COPD-ALERT, is impacting patients internationally.

Lung disease has been a lifelong companion of Vldy Rozenbaum, PhD, but he hasn't let his condition stop him from pursuing better health, not only for himself, but for millions of others like him. His patient advocacy group, COPD-ALERT (www.copd-alert.com), provides much-needed networking and information for patients all over the world, and his growing relationship with the AARC is bringing the strength of the Association to bear on his primary goals and objectives.

AARC Times: When were you first diagnosed with COPD, and how long have you had the condition?

Dr. Rozenbaum: I have had lung problems all my life. In 1952 I had a lobectomy for bronchiectasis. My first encounter with COPD was about 1980, when my primary physician grew very concerned about my lung function — my FEV₁ was around 50% — and immediately put me on prednisone. I did not fully understand his concern because I did not feel any major physical limitations.

AARC Times: How has your condition progressed over the years, and what steps have you taken to help control it?

Dr. Rozenbaum: For many years I was doing OK. I was not physically limited in any major way. My pulmonologist prescribed albuterol and a high dose of theophylline for me and sent me to a pulmonary rehabilitation program. However, in the late 1990s I began experiencing episodes of dyspnea with activity. My FEV₁ dropped below 40%. I did not sleep well. After a nocturnal spirometry test I was put on oxygen at night. Later, a sleep study established that I have sleep apnea, so I began to use CPAP. The bronchodilators and rehab were not doing enough for me. I started getting out of breath while exercising, so one of the physical therapists suggested that I use oxygen, and that was a great help.

In 1999 I had a series of episodes that had the appearance of heart attacks. I was in and out of the emergency room. Neither my pulmonologist nor cardiologist could explain them or do anything about them. I also had a few episodes of syncope, which none of the specialists I consulted could diagnose. One time at work my legs gave out, and I could not walk. I developed very severe chest pains, and I could doze off only for a little bit while sitting up. Pain medications did not help. I was afraid to fall asleep; I thought that I would not wake up.

I was hospitalized for two consecutive weeks at a local hospital and at Johns Hopkins. Doctors could not explain my symptoms nor come up with a remedy, but they told me to stop taking theophylline. I had no choice but to retire on disability. My syncope was diagnosed as bradycardia shortly thereafter, and I was fitted with a pacemaker. I experienced another severe chest pain because of that.

None of the doctors I consulted could offer any explanation or remedy. I tried acupuncture for pain, but it was as ineffective as pain medication. With my FEV₁ around 30% by then, I was prescribed oxygen to use with activity. I was frantically searching the Internet for answers, but they were not available.

AARC Times: What did you do then, and how are you doing with your condition today?

Dr. Rozenbaum: I finally spotted some COPD patient-support groups online. Some of them had extensive archives that contained experiences of many patients as well as personal comments on symptoms, medications, and self-management tips. I joined one of the groups and found interactions with other patients very helpful. These interactions provided me with some practical tips and information about various organizations and government agencies that provided me with access to more information and to experts in the field.

I read a lot and interacted with other patients and, increasingly, with medical professionals as well. This allowed me to better understand my symptoms and develop effective self-management. I purchased an oximeter to regularly monitor my oxygenation. I made sure that I had competent and open-minded doctors with whom I could have meaningful discussions about

my therapy, and I switched to more effective medications.

On occasion, I purchased proven medications abroad before they were available in this country, such as Spiriva and Symbicort. I began to attend various educational seminars and conferences for medical professionals and patients. This gave me access to the top experts in the field and to the newest clinical findings. I made sure that my group, COPD-ALERT, included pulmonologists, respiratory therapists, nurses, pulmonary researchers, and equipment experts. This allowed me and the group members to benefit from their explanations and comments. To improve my breathing techniques, I acquired a special software, *Breathing Trainer*, developed by Deane Hillsman, MD, a pulmonologist and a member of my group.

Today, my condition is stable. I maintain an FEV₁ at 25% and continue with my medications, long-term oxygen therapy, and pulmonary rehabilitation. I am active in

various organizations, attend conferences — even abroad — and pursue my non-medical hobbies as well.

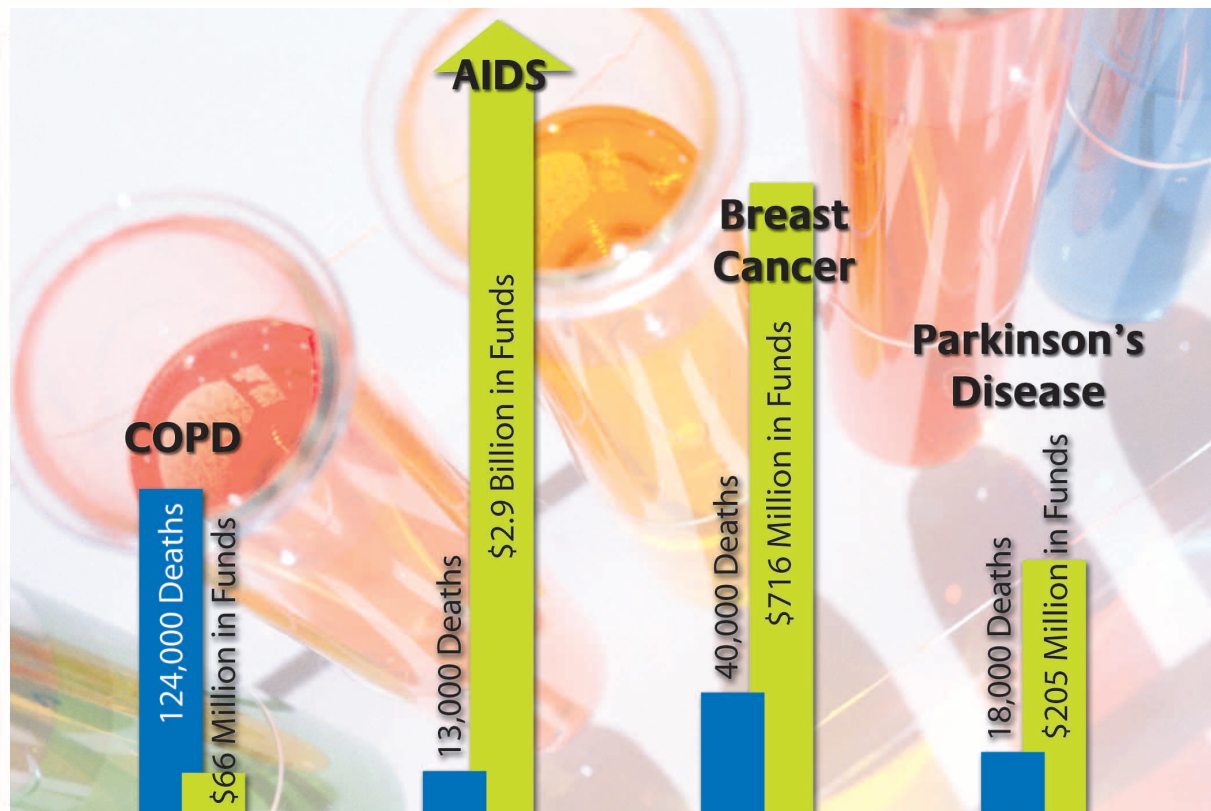
AARC Times: What led you to establish COPD-ALERT?

Dr. Rozenbaum: My initial involvement was precipitated by my own need to learn from other patients, as I was not getting enough information from my doctors. My experiences with other groups prompted me to create my own. I did not like their management style and wanted to do more in COPD advocacy.

AARC Times: How do you believe COPD-ALERT is helping to raise awareness of COPD and promote increased funding for research into new treatments?

Dr. Rozenbaum: COPD-ALERT is networking with many organizations and government agencies to voice the concerns of the COPD patient community. These include local community organizations, professional associa-

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SOURCES: COPD-ALERT web site, www.copd-alert.com/CA-FACTN.pdf; Centers for Disease Control and Prevention web site, www.cdc.gov/nchs/fastats and www.cdc.gov/nchs/data/hestat/preliminarydeaths04_tables.pdf#2; National Cancer Institute web site, <http://seer.cancer.gov/statfacts/html/breast.html>; National Institutes of Health web site, www.nih.gov/news/fundingresearchareas.htm; National Heart, Lung, and Blood Institute web site: www.nhlbi.nih.gov/health/public/lung/copd/campaign-materials/pub/speakers-guide-with-pp-inserted.pdf

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– Vlady Rozenbaum, PhD

tions, government agencies, and elected officials on the local, state, and national levels. Furthermore, our members in various states are key players in the American Lung Association-affiliated organizations and programs. We participate in letter-writing campaigns, provide comments to drafts of regulations under consideration by various agencies or bills in Congress, and contact the media on COPD-related matters. We distribute e-mail alerts on COPD issues requiring immediate attention. All these activities are very important, because even the main players are sometimes too busy to follow important issues such as the continuous disproportionate underfunding of COPD research.

AARC Times: How did you first learn about the AARC, and what led you to get involved with our organization?

Dr. Rozenbaum: I learned about the AARC at the annual National Heart, Lung, and Blood Institute Public Interest Organizations meeting in 2001. I found the leaders of the AARC engaging and very serious about COPD advocacy.

AARC Times: You have supported the AARC through your appearances at our annual Capitol Hill Lobby Days and other efforts. How do you believe AARC support for COPD patients is making a difference?

Dr. Rozenbaum: The importance of AARC support for COPD patients cannot be exaggerated. AARC members understand COPD patients’ needs very well, and they are among the best allies COPD patients can count on.

AARC Times: If you had to list the top five patient concerns regarding COPD today, what would they be?

Dr. Rozenbaum: No. 1, more funding for COPD research. No. 2, federal support for pulmonary rehabilitation. No. 3, repealing the 36-month cap on oxygen reimbursement. No. 4, approval of portable oxygen units — compressed and liquid — on a plane. And No. 5, competitive bidding.

AARC Times: What would you say to respiratory therapists about these concerns, and why do you think it is important for them to come for-

ward and join with their COPD patients to support the causes that are most important to patients?

Dr. Rozenbaum: No. 1, COPD research has been continually disproportionately underfunded. Despite 124,000 deaths annually, only \$66 million is allocated by the National Institutes of Health for COPD research. Compare that with AIDS — 13,000 deaths and \$2.9 billion; breast cancer — 40,000 deaths and \$716 million; and Parkinson’s disease — 18,000 deaths and \$205 million. COPD is the fourth leading cause of death and the second major cause of disability in this country. The death rate is going up and so are the enormous health care costs, and it is estimated that by 2020 COPD will move to third place among the major causes of death (see chart).

No. 2, pulmonary rehabilitation is essential for slowing down the progression of COPD and for effective management of the disease.

No. 3, the cap on oxygen reimbursement will put an undue burden on the patient to whom the ownership will be transferred. It will create problems with deliveries, maintenance, monitoring, and access to new technology. We support the Home Oxygen Patient Protection Act reintroduced in the House and introduced in the Senate this year.

No. 4, the Federal Aviation Administration’s approval of five portable concentrators for air travel is highly inadequate. The concentrators are too heavy, they require extra batteries because the airlines do not allow the use of electric outlets — which are available only on some planes anyway — and these concentrators are only allowed on the plane at the discretion of the airline. Patients must be allowed to use the same portable equipment on the plane that they use on the ground.

No. 5, there is a serious danger that smaller oxygen providers, particularly in rural communities, will be out of business due to competitive bidding. This will have a negative impact on the quality of service, and it will increase the costs of oxygen delivery. ■