

## Patient Promotes Respiratory Awareness

by Edna Fiore

**Note:** This month's column is written by Edna Fiore, a pulmonary patient from Colorado and a tireless advocate for those who suffer from respiratory illnesses. Recognizing the critical, clinical, and quality-of-life importance respiratory therapists provide to those who suffer from pulmonary disease, Fiore has devoted endless hours and expended great energy in not only raising public awareness of COPD and the respiratory therapy profession but has become an active voice to policymakers both in Colorado and in Washington, DC.

### My introduction to the respiratory profession

Thanks to pioneering work in the field of portable oxygen therapy and pulmonary rehabilitation spearheaded by Thomas L. Petty, MD, FAARC, and Louise Nett, RN, RRT, FAARC, Colorado has been a leader and innovator for COPD awareness and advocacy since the 1960s.

In 2003, Dr. Petty brought together patients, professionals, members of the Colorado Society for Respiratory Care (CSRC), and providers including representatives from hospitals, home care suppliers, physicians, educators, and members of the American Lung Association of Colorado in order to organize and present an educational COPD conference. This was the starting point for networking and interaction by both patients and clinical professionals. The focus of this first Moving Mountains Lung Health Conference was awareness and education. Attendees reached a consensus to keep the momentum going by organizing the newly named Colorado COPD Connection. This initiative was spearheaded by Patty Koff, RRT-NPS, from the University of Colorado; Mary Gilmartin, RN, RRT, from National Jewish Health; and Brenda Crowe, CRT, from Exempla Lutheran Health.

At a subsequent conference in 2010, we honored Dr. Petty by calling this conference the Thomas L. Petty, MD, Moving Mountains Lung Health Conference. We also renamed our Colorado COPD Connection to the more encompassing Colorado Lung Health Connection (CLHC). Both the CSRC and the CLHC coordinate their work in public outreach, awareness programs, as well as political advocacy efforts.

### A number of opportunities to be heard

How did I become involved and active? As a patient I had participated in COPD studies since 1996 and participated in the pulmonary rehabilitation program at Exempla Lutheran Health. I joined the online COPD support group EFFORTS (Emphysema Foundation For Our Right To Survive) in 2001 and became aware of the vital importance of political advocacy.

In 2007 the CSRC sponsored the first Respiratory Society Patient Chapter, which is dedicated to supporting, educating, and sharing information with respiratory patients throughout the state of Colorado. I was privileged to be the first patient AARC member as a member of the CSRC Patient Chapter.

I took my involvement with the CSRC and patient advocacy efforts even further. As many of you know, for the last 14 years the AARC, partnering with the state respiratory societies, has been sending RTs to Washington, DC, every year to advocate to members of Congress the respiratory legislative agenda. I became the first patient to become an active and official PACT (Political Advocacy Contact Team) representative.

On Advocacy Day 2009, veteran CSRC PACT representatives Allen Wentworth, RRT, and Leigh Otto, MEd, RRT,

### about the author...



Edna Fiore has been an FDA Pulmonary-Allergy Drugs Advisory Committee patient representative since 2007 and also serves as a stakeholder representative for the Patient-Centered Research Outcomes Institute.

put me in a wheelchair with my AirSep FreeStyle portable oxygen concentrator and off we flew to DC. We then spent an entire day making the “rounds” of all seven Colorado House members and both of our senators. The three of us were able to impress upon the legislators’ staff members the important role of RTs in the management of COPD and other respiratory issues.

Since I first attended the AARC Congressional Hill Day event, patient participation in this important event has increased. In 2011, the COPD Foundation, Alpha-1 Association, and Alpha-1 Foundation sent patient advocates along with RTs to the AARC Hill Day. And in March 2012 we had over 350 congressional appointments — and we were joined by patients from the Pulmonary Hypertension Association. We had a total of 32 patient representatives going to the Hill. The COPD Foundation generously provided funding to help cover the costs of many of the patient advocates.

Participation in the AARC PACT — whether it is the Washington, DC, Hill Day or state- and local-based events — has really afforded me clear insight into and understanding of the legislative process. The opportunity to meet and interact with the legislators’ staffs in Washington, DC, to make the case for pulmonary patients and the importance of the respiratory therapy profession has provided me with a solid basis for presenting the perti-

nent issues to others in the respiratory community, both in Colorado and on the online support groups.

I continue to work closely with both the Colorado Society for Respiratory Care and the Colorado Lung Health Connection. Both organizations coordinate with each other to schedule frequent visits to the local offices of our congressional legislators. We have recruited Rep. Diana DeGette and Sen. Michael Bennet to be members of the Congressional COPD Caucus. Both organizations take an active role in the AARC “Take Action” and Virtual Lobby Week campaigns via email.

### **Reach out to the patient community**

I urge all of the AARC members to reach out to the patient community by speaking about advocacy at Better Breathers Clubs and by participating in online support groups such as EFFORTS and COPD-ALERT. There are many patients who would become involved in advocacy and awareness if they were directly approached by the representatives of the respiratory therapy community. I feel that it is really imperative that the patient voice be heard as the implementation of the Affordable Care Act progresses and the role of respiratory therapists under it becomes more and more important in the efficient and effective delivery of care. ■