An RT at the New River Health Center in West Virginia keeps a close eye on patients as they take advantage of some of the equipment donated by the Dorney Koppel Family Charitable Foundation.

Creating Strength in the Broken Places

Grace Anne Dorney Koppel's mission to bring pulmonary rehabilitation to underserved areas is mending lives as well as lungs

When Grace Anne Dorney Koppel was first diagnosed with COPD in 2001, her physicians told her she would not survive more than 3–5 years. Never one to accept such news at face value, she went on the offensive. After learning more about the condition, she enrolled in pulmonary rehabilitation, markedly improved her lung function, began advocating for other patients just like her, and in 2010 got what she calls "the best gift I have ever received" when her husband, former "Nightline" anchor Ted Koppel, presented her with the first Grace Anne Dorney Pulmonary & Cardiac Rehabilitation Center in Leonardtown, MD.

Dorney Koppel outlined those experiences and more during her keynote address at AARC Congress 2011 in Tampa, FL. Now she brings us current on what she's been up to since then in this Q&A.

Q ***AARC Times:*** When you addressed our Congress back in 2011, you were doing quite well with your own COPD. How are you doing today?

A **Grace Anne Dorney Koppel:** Remarkably, from my low point (26% of predicted) when I was diagnosed with COPD in September of 2001, a couple of weeks ago at my regular six-month checkup for 2014, I am holding solid at 50% of predicted. For a few years, after the upper lobe of my right lung was removed in 2005 since I had lung cancer, I had a boost in my lung function, similar to what is seen in lung reduction surgery, and achieved the heights of 65% of predicted. Today, at 1 liter FEV_1 and 50% predicted, I can do all that I want to do. In the last year I've traveled extensively both throughout the United States and to Asia and Africa and always managed to hit the ground running. The only time that I need supplemental oxygen is on flights longer than two hours at altitudes over 35,000 feet.

Q ***AARC Times:*** That is remarkable. To what do you attribute your continued ability to accomplish so much despite having COPD?

A **Grace Anne Dorney Koppel:** Climbing Everest was never on my "bucket list." I am able to do everything that I want to do, perhaps at a slower pace than others, but I know how to pace myself. I take my inhaled medicines exactly as prescribed, get flu vaccines yearly, read all the current research on COPD, and fortunately, have not had an exacerbation since 2006. My hand sanitizer is always in my pocket; and if family members or friends have a respiratory infection, they know to stay clear of me.

I continue to work 10–12 hours a day but always manage to squeeze in 2–3 miles of aerobic activity so that I can maintain my very active schedule. COPD is my major health problem; my lung cancer has not returned, and I am a cancer survivor nine years after surgery. I do not have heart disease or another serious comorbidity.

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>
> – Grace Anne Dorney Koppel

Pulmonary rehabilitation 13 years ago was what saved me. Continuing exercise and fitness training on a daily basis is what turned my life around. Realizing that millions of others have not had the opportunity to learn about our common disease (COPD) has motivated me to reach out as an advocate so that more and more of us can learn to live well with COPD.

Q ***AARC Times:*** You opened the first Grace Anne Dorney Pulmonary & Cardiac Rehabilitation Center at St. Mary's Hospital in Leonardtown, MD, in 2010. How many programs have you opened since then, and where are they located?

A **Grace Anne Dorney Koppel:** There are four Grace Anne Dorney (GAD) Pulmonary Rehabilitation Centers: St. Mary's Hospital, Leonardtown, MD (2010); New River Health Association, Scarbro, WV (2013); Boone Memorial Hospital, Madison, WV (2013); Cabin Creek Health Center, Dawes, WV (2013). This fall, another two Grace Anne Dorney Pulmonary Rehabilitation Centers are scheduled to open in West Virginia at the Lincoln Primary Care Centers in Hamlin and Man. We are in discussions with several other foundations in other states and are hopeful that in the years to come we will have many more GAD Pulmonary Rehab Centers in areas with the highest incidence of COPD and no rehab facilities.

Q ***AARC Times:*** How do you decide which hospitals and which communities you are going to work with to open new pulmonary rehab centers carrying your name, and how are these centers funded?

A **Grace Anne Dorney Koppel:** We search out locations both on our own and through our partners. The requirements are a high incidence of COPD in the community plus no pulmonary rehab facilities. Outside the urban centers, in rural areas, there is a severe shortage of pulmonary rehab centers. Our partners are those who already support rural health centers and special access hospitals. Federal agencies and state agencies have also generously lent their expertise and support.

We provide funding for the "hard costs" — construction, exercise machines, monitoring equipment, etc. — and the community or a foundation willing to participate must match our funding. My husband wisely believed that without "skin in the game," the community would not be involved. We have been fortunate in that we have been able to find willing, dedicated partners — the St. Mary's Hospital Foundation, the Benedum Foundation

Grace Anne Dorney Koppel, center, visits with graduates of the St. Mary's Hospital program at an annual anniversary party.

of Pittsburgh, PA, private donors, the United Mine Workers of America. Without partners, our work and mission could not be achieved.

Q ***AARC Times:*** What goes into opening a new center, and how are respiratory therapists usually involved in the process?

A **Grace Anne Dorney Koppel:** There is no formula. Each case is unique. Finding a partner, usually a foundation that will work with us, is the first step. In some instances, an existing room is equipped and dedicated to pulmonary rehab, with minor construction. In other instances, a wing is added to a building already in place. In rural communities, construction costs are lower than in urban areas. Needs and circumstances vary greatly. A budget is approved by our partner and by our foundation — the Dorney Koppel Family Charitable Foundation.

Yes, a respiratory therapist is part of the planning, as is a pulmonologist. Johns Hopkins has assisted us in assuring that the program planned is of the highest and best quality. It is part of our contract that each of the GAD facilities assists the next ones selected for funding. Our West Virginia clinic managers and respiratory therapists travelled to Maryland and spent a couple of days at St. Mary's observing and learning what worked best and what didn't. Beyond the first year, each of the clinics is self-supporting through insurance reimbursements. They are not profit centers, but they are not operating in the red either.

Q ***AARC Times:*** Do you have any patient outcomes to report from the GAD centers up and running today?

A **Grace Anne Dorney Koppel:** Feedback is very positive. At graduation in West Virginia for example, each patient gives a testimonial of what they are able to do that they were not able to do before. One man can now walk to and from his mailbox to get his mail and no longer feels housebound. In southern Maryland, at the two-year anniversary celebration, a woman who needed a lung transplant spoke. She graduated from pulmonary rehab and was strong enough to undergo the transplant surgery. She has "new lungs" and no longer has COPD.

Q ***AARC Times:*** Despite the fact that Medicare now covers pulmonary rehab, many places still find it difficult to open these programs. Do you think the Oct. 1 addition of COPD to the Hospital Readmissions Reduction Program is going to change that situation for the better?

A **Grace Anne Dorney Koppel:** We are hopeful that more pulmonary rehab facilities will become available so that all who have COPD will be empowered to take control of their breath and their lives. It is logical that pulmonary rehab programs bridge the gap between hospital and home — I still can't understand why pulmonary rehab is not reimbursed at the same payment level as cardiac rehab. We have the evidence that pulmonary rehab reduces hospital admissions, reduces mortality, and improves quality of life for stable COPD patients. It is a safe and effective intervention in COPD patients. It is a cornerstone in the management of patients with stable COPD. Emerging evidence suggests that pulmonary rehab is an effective intervention for COPD patients both in the stable and acute setting (post exacerbation). Unfortunately, only a very small number of patients who have stable COPD have the opportunity to get the benefits of pulmonary rehabilitation, since there are so few centers.

Q ***AARC Times:*** We know you've also been active in the National Heart, Lung, and Blood Institute's "Learn More, Breathe Better" campaign and other efforts to promote greater awareness of COPD. Tell us a little about what you've been doing with other groups and organizations to improve the care and treatment of people with COPD over the past couple of years.

W. Virginia AARC member Chuck Menders, BA, RRT, AE-C (far left), attended a W. Virginia rehabilitation clinic grand opening with Grace Anne Dorney Koppel and her husband Ted (far right).

A **Grace Anne Dorney Koppel:** I am a member of the board of directors of the COPD Foundation; active on the board of governors of the Patient Powered Research Network (for COPD) funded by PCORI (Patient-Centered Outcomes Research Institute). Lately, almost all of my time has been consumed with either speaking out to raise awareness of COPD, serving on various committees of the COPD Foundation, or working for the Dorney-Koppel Family Charitable Foundation, locating partners and bringing pulmonary rehab facilities to communities in need.

Q ***AARC Times:*** What does the future hold for the Grace Anne Dorney centers and your own personal advocacy on behalf of COPD patients?

A **Grace Anne Dorney Koppel:** One day, we will be able to identify the various phenotypes of COPD. We now know, for example, some who have COPD have frequent exacerbations and multiple hospitalizations yearly. An antibiotic taken several times a week can make all the difference for these individuals. We are making progress through research, but new medications and research are slow. We will not likely have a cure that is "one size fits all" any time soon. There is no "magic bullet" for COPD on the horizon. Approximately 15 million have been diagnosed with COPD; another 12–15 million remain undiagnosed and untreated. Each of us must become an evangelist and spread the message that COPD is treatable and most of us can lead long, useful, and productive lives if we get treatment. Early diagnosis and treatment is important.

Since that is the case, I feel passionately that learning how to manage, how to live a full and challenging life with COPD, is the answer for the foreseeable future. My husband and I and our daughters will continue establishing pulmonary rehab centers throughout the United States for as long as they are needed. My COPD diagnosis gave my life new meaning and ultimately enriched my life. The 3–5 year life expectancy I was given when diagnosed was wrong. I'm going strong 13 years later. Everyone should be able to have the chance for change that I was given.

Q ***AARC Times:*** What message would you like to send to COPD patients such as yourself and the respiratory therapists and other clinicians who care for them?

A **Grace Anne Dorney Koppel:** I want everyone who suffers from breathlessness, cough, muscle wasting, anxiety about where the next breath is coming from, to feel that they are able to contribute, to work, to teach life lessons to their family, to be useful and powerful people who are in control of their own lives.

I want all who have COPD to become "strong in the broken places." Pulmonary rehab is the most powerful tool in our arsenal for treating COPD, but only a small percentage of patients are able to access it since it is unavailable outside of large urban areas. This must change. Yes, I and 15 million other Americans have a disease that is not curable. It is, however, highly treatable. Let's emphasize the treatable aspect of the disease and see the results. Pulmonary rehabilitation can transform. ■