

## Understanding Chronic Obstructive Pulmonary Disease (COPD): Part I

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*A growing number of people worldwide are being diagnosed with chronic obstructive pulmonary disease (COPD), which, like asthma and cystic fibrosis, is an obstructive lung disease that makes it difficult to exhale all the air in the lungs. Ventilator-Assisted Living has largely focused on restrictive lung disease – mainly neuromuscular conditions such as post-polio, muscular dystrophy and ALS – that causes difficulty in fully expanding the lungs with air and often requires the use of mechanical ventilation. Now, noninvasive ventilation is also being prescribed for some people with COPD. In a series of articles, we will explore what COPD is, how it is treated and where it fits in the overall respiratory health care picture.*

Today's health care climate is focused on two things:

1. Improve the quality of patient care
2. Drive down health care costs

Be it the patient in need of care, the physician who treats them, or the payer, every stakeholder is feeling the pressure to do more with less. Within this equation, chronic respiratory disease occupies a disproportionately large amount of the burden. While chronic disease accounts for roughly 75 percent of U.S. health care spending, chronic respiratory disease is the second highest cause of hospital admission cases, accounting for nearly 16 percent of the cost of care.

In the United States alone, there are approximately 12 million people living with COPD. And, according to The National Heart, Lung and Blood Institute, another 12 million haven't even been diagnosed yet, or are still developing the disease. Globally, COPD has become one of the top three leading causes of death. There is no disputing COPD as one of the single largest threats to both human health and the rising cost of care internationally.

As organizations, advocacy groups and others look for solutions to this mounting problem, many are discovering that an accurate understanding of COPD is lacking. They are largely unfamiliar with the disease, what causes it and how to properly address it. This lack of understanding only reinforces existing challenges. Identifying the signs and symptoms early will go a long way to enhance global health and keep costs in check.

### What exactly is COPD?

COPD is a term used to describe two primary disease types: chronic bronchitis and emphysema. Each of these disease types has distinct characteristics and related symptoms, but many people can have a combination of the two.

### Chronic Bronchitis

Chronic bronchitis is defined as a chronic productive cough, lasting for a minimum of three months at a time, occurring in two consecutive years. The diagnosis must be for a patient in whom other causes of a productive chronic cough, e.g., pneumonia, have been excluded. Pneumonia can have a productive cough for a short period. However, once the pneumonia is resolved, the cough would go away. Chronic bronchitis is most often caused by smoking and is very similar to acute bronchitis, combining airway

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## From Around the Network

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*International Ventilator Users Network's mission is to enhance the lives and independence of home mechanical ventilator users and polio survivors through education, advocacy, research and networking.*

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## New Products

**Respireo mask series** from Air Liquide Medical Systems SA includes Respireo Primo N, a nasal mask; Respireo Primo F, a full face mask; and Respireo Primo B, an oral mouthseal. Available outside the USA. [www.airliquidemedicalsystems.com/en/ventilation/non-invasive-ventilation/respireo.html](http://www.airliquidemedicalsystems.com/en/ventilation/non-invasive-ventilation/respireo.html)

**Aloha™ nasal pillow system** from DeVilbiss Healthcare has a feature enabling vent users to adjust the angle and depth of the pillows. Available worldwide. [www.devilbisshealthcare.com/products/sleep-therapy/interfaces-and-masks/nasal-pillow-interfaces/aloha-nasal-pillow-system](http://www.devilbisshealthcare.com/products/sleep-therapy/interfaces-and-masks/nasal-pillow-interfaces/aloha-nasal-pillow-system)

**Cuirass shells** for use with Dima Italia's **Pegaso** negative pressure ventilator come in eight sizes for adults and two for infants. Available outside the USA. [www.dimaitalia.com/english/documenti/pegasov/BROCHURECORAZZEEN.pdf](http://www.dimaitalia.com/english/documenti/pegasov/BROCHURECORAZZEEN.pdf)

**Multilevel ST30V and ST40V** are new bilevels in Dima Italia's Multilevel series. The ST30V sets a target volume and guarantees a minimum volume; maximum inspiratory pressure is 30 cm H<sub>2</sub>O. The ST40V model provides inspiratory pressure up to 40 cm H<sub>2</sub>O. Available outside the USA. [www.dimaitalia.com](http://www.dimaitalia.com)

## Centers for Medicare and Medicaid Services (CMS)

**Medicaid waivers.** For a listing of all Home and Community-Based Services Waivers (HCBS) 1915 (c) that enable people to live in their own homes instead of institutions, go to [www.medicaid.gov](http://www.medicaid.gov). Click on Medicaid and CHIP Program Information, then click on Waivers. [www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/](http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/)

**Money Follows the Person.** For more information on how the Affordable Care Act of 2010 strengthens and expands the "Money Follows the Person" Program to more states, go to [www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Balancing/Money-Follows-the-Person.html](http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Balancing/Money-Follows-the-Person.html)

**Competitive Bidding Program (CBP) update.** The GAO (Government Accountability Office) released a *Review of the First Year of CMS's Durable Medical Equipment Competitive Bidding Program's Round 1 Rebid*. In commenting on a draft of this report, HHS noted that the CBP round 1 rebid resulted in savings of more than \$200 million in its first year. HHS also cited the results of CMS's monitoring of beneficiaries' access to DME in CBP areas as evidence that the CBP did **not** affect beneficiaries adversely. The full report, released in May 2012, is available online: [www.gao.gov/assets/600/590712.pdf](http://www.gao.gov/assets/600/590712.pdf).

For more on competitive bidding's effects on home health care companies, go to the American Association for Home Care's website: [www.aahomecare.org/associations/3208/files/MPP\\_Testimony\\_House\\_Ways\\_and\\_Means\\_Health\\_Subcommittee\\_050912.pdf](http://www.aahomecare.org/associations/3208/files/MPP_Testimony_House_Ways_and_Means_Health_Subcommittee_050912.pdf)

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## Mary Katherine “Katie” Beckett

1978 – 2012



Her name may not be a household word, but thanks to Katie Beckett and her mother, more than a half million American children with disabilities have been able to live in their own homes and participate in their communities.

Shortly after her birth, Katie contracted viral encephalitis, leaving her partly paralyzed, unable to swallow and barely able to breathe. Under the Medicaid law at that time, Katie could only receive care through Medicaid if she remained in the hospital even though her family could care for her at home with a ventilator.

Her mother, Julie, began lobbying politicians and bureaucrats including an Iowa Congressman who convinced the Reagan Administration that the system should be changed to allow states to provide Medicaid to children receiving care in their homes. Ultimately President Reagan intervened, citing the case as an example of “hidebound regulations” and marking a shift in policy toward government support for home health care. Shortly after, Congress passed the *Tax Equity and Fiscal Responsibility Act of 1982*, often called the Katie Beckett Waiver, under which Medicaid pays for home care for disabled children.

On May 18, 2012, Katie Beckett died in the same Cedar Rapids, Iowa, hospital where she was born 34 years ago. The cause was a digestive disorder not related to her respiratory disability. According to her wishes, her body was donated to the University of Iowa.

“I think she just wore out,” her mother said. “Katie was doing a lot of public speaking – she loved the banter of questions and answers. She had found her niche. She did more in her 34 years than most people do in a lifetime.”

Katie was trached and used a ventilator 16 to 18 hours a day when she finally moved home from the hospital as a toddler. Gradually she was able to breathe

on her own and only required the ventilator at night.

She traveled to Washington numerous times to testify before Congressional committees and to serve on national disability policy panels. She graduated from Mount Mercy College in 2001 with a bachelor’s degree in English and a creative writing minor. She was working on a novel and had completed 10 chapters. “I found it on a flash drive when I was closing her apartment,” Julie Beckett said. “I haven’t read it, but I know the heroine had a disability, although that isn’t the focus of the book.”

Her disability was not the focus of Katie’s life either: Advocacy was. As she wrote about herself at age 22, “It was not my choice but rather a path chosen for me. Whatever and wherever my career takes me, I know that I will always be an advocate for people with disabilities. You can count on that.”

Katie was the first co-chair of Kids As Self-Advocates (KASA), a project of Family Voices, the organization co-founded by her mother that aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. KASA is a national, grassroots organization created by youth with disabilities that encourages teens and young adults with disabilities to speak out, make choices and advocate for themselves.

“Katie was remarkable,” Julie said. “She didn’t mince words. She understood her situation and her ability to change minds. We had so much fun together; I feel like she’s still here. I will keep on going. That’s what we planned to do.” ▲

irritation and a continuous cough. In chronic bronchitis, the small airways (bronchioles) in the lungs become swollen and inflamed, and produce large amounts of mucus causing a chronic productive cough.

### Emphysema

Emphysema is the abnormal, permanent enlargement and damage of air sacs (alveoli) and small airways (bronchioles) in the lungs. Similar to chronic bronchitis, emphysema is often caused by smoking. However, it can also be caused by a genetic disposition to the disease or occupational pollutants. With the deterioration of the alveoli comes a loss of elasticity or recoil effect of the lungs.

Emphysema also causes airways to collapse and is commonly described in layman's terms as floppy lung disease. It is significantly easier to understand how emphysema plagues a patient if one can understand the basic physiological principles of respiration.

Normal breathing takes place in three phases: inspiratory phase, expiratory phase and pause or rest phase.

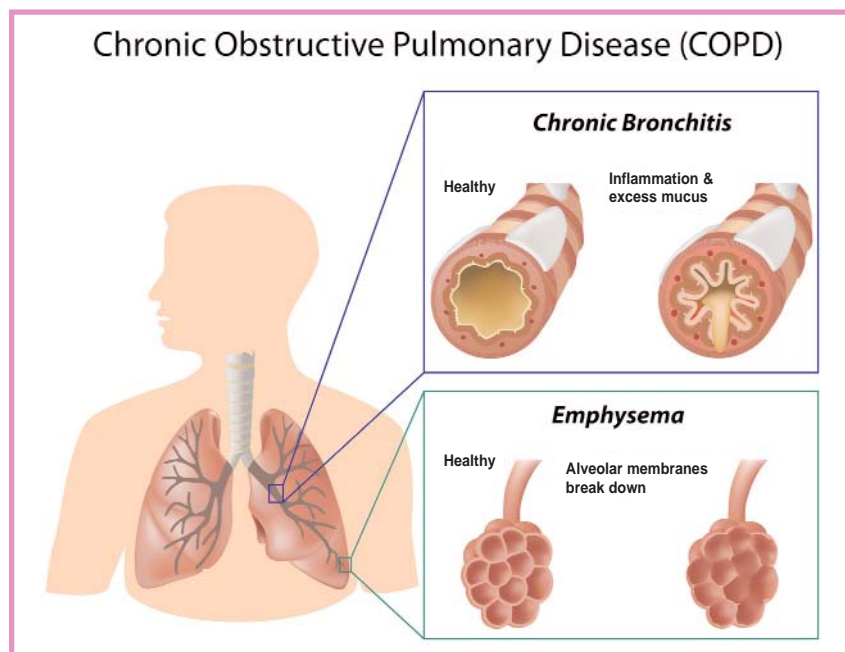
The inspiratory phase is an active motion in which the diaphragm muscle contracts and flattens to expand the chest and in turn expands the lungs. The intercostal muscles, located between the ribs, contract to elevate one's ribs, causing further expansion of the chest wall. Combined, these motions cause a negative pressure in the chest, resulting in ambient air filling the lungs.

The expiratory phase is normally a passive motion. When the diaphragm and intercostal muscles relax, positive pressure is created in the lungs. This positive pressure pushes air out of the lungs rather effortlessly.

For those living with emphysema, this basic body function is interrupted by the loss of elasticity (or recoil) and the destruction of the airways. This causes "air trapping." When air trapping occurs, the small amount of positive pressure applied to the lungs when the diaphragm and intercostal muscles relax for exhalation can no longer expel air from the lungs. Patients are forced to use additional (accessory) muscles to exhale any waste product, such as carbon dioxide (CO<sub>2</sub>), from the lungs.

As the disease progresses, so does the damage to the lungs. Exhaling trapped air, or CO<sub>2</sub>, becomes more and more difficult for the body. It now requires a forceful contraction and more energy expenditure. The result is an increased shortness of breath, impacting basic daily functions, such as eating. With increased muscle use, combined with a decrease in caloric intake, rapid weight loss often follows. The overall health of the patient becomes compromised.

The pause, or rest phase, occurs when exhalation is completed, and there is a short break before the next breath. Most COPD patients fail to experience



a rest phase, as they have to forcefully push in order to remove any air trapped in their lungs. These patients are unable to completely exhale all the trapped air, eventually developing what is referred to as a “barrel chest.”

COPD is commonly referred to as a progressive disease, getting worse and worse over time. The progression of the disease is best diagnosed by spirometry (the measuring of breath). Spirometry will identify how obstructed the patient’s airways are from airway secretions and can show roughly which part of the airways are being obstructed. It can also help the treating physician determine the stage of the disease. COPD has four stages:

**Stage 1 (Mild):** Commonly identified by minimal shortness of breath, with or without the onset of a cough and/or sputum.

**Stage 2 (Moderate):** Commonly identified by a noticeable shortness of breath, typically brought on by physical activity, with or without a cough or sputum. This is often the stage where medical attention is sought.

**Stage 3 (Severe):** Commonly identified by a shortness of breath, which inhibits the ability to perform normal daily activities. The patient’s quality of life may become diminished by a reduced exercise capacity, possible hospitalizations and/or require oxygen therapy.

**Stage 4 (Very Severe):** Commonly identified by a largely impaired quality of life, resulting from a dramatically reduced capacity to breathe. The patient usually experiences frequent exacerbations or flare-ups, resulting in hospitalizations.

As the disease progresses, it becomes harder for patients living with COPD to exchange oxygen and carbon dioxide. Eventually, exacerbations become life threatening and are referred to

**Zach Gantt, RRT**, has nearly 20 years of respiratory care experience in health care, specializing in disease management, outcomes-based services and patient-centered care. He maintains a thriving health care education consulting business and serves as a respiratory instructor at Roane State Community College and is a board member and chapter president for the Tennessee Society for Respiratory Care.



**Greg Williams, CRT**, has some 20 years of patient-centered care and respiratory therapy experience in health care for a wide range of patient populations, from neonatal to geriatric. His work and commitment to patient-centered care has received various awards and recognitions, including Community Health Systems 2003 employee of the year and the award for clinical manager of the year in 2005 and 2007.

as respiratory failure. If exacerbations persist over time, the patient becomes classified as having chronic respiratory failure (CRF). At this point, the patient is likely living with the latter stages of COPD, that is stage 3 or stage 4.

## COPD and the Health Care Landscape

The increase in prevalence of chronic conditions like COPD has been largely to blame for the global health care crisis. Over the past several decades, health care reached a tipping point. Simply put, the global economy cannot financially afford the cost of care as it stands. In order to drive down costs, the health care system, and those within it, must change.

Patients must be equipped with the tools and information to live better and healthier, and providers must be more proactive about caring for their patients. Historically medicine has been reactive – treating patients once they’ve already become sick. This reactive approach rapidly drives up the cost of care and does little to promote healthy living habits or preventing chronic conditions.

Though the current state of health care is commonly considered a “crisis,” it has sparked a positive

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change in perspective. Many are thinking differently and creatively about how to encourage healthy living and improve patient care. Some providers are developing what are known as disease management programs, working with patients in the early stages of COPD and trying to reverse the course of this difficult disease. Others are pioneering tech-

nological innovations, developing medical devices that enable quality care to take place in the home, rather than the hospital.

Unfortunately there is no cure for COPD. Reducing the incidence of this disease and making a quality of life difference for those living with it will require a shift in how we approach health, as patients and as clinicians. Proposed treatments and solutions will come in many forms. And in all likelihood, there will be no silver-bullet solution.

In the next issue of *Ventilator-Assisted Living*, we will discuss how high-touch clinical care and high-technology are coming together to play a significant role in the care and treatment of COPD. ▲

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Centers for Disease Control and Prevention. Chronic Disease Overview: Costs of Chronic Disease. Centers for Disease Control and Prevention Web site. Available at [www.cdc.gov/nccdphp/overview.htm](http://www.cdc.gov/nccdphp/overview.htm). Accessed July 24, 2007.

National Institutes of Health, "Estimates of Funding for Various Diseases, Conditions, Research Areas," March 8, 2005, at [www.nih.gov/news/fundingresearchareas.htm](http://www.nih.gov/news/fundingresearchareas.htm). Also, Cary P. Gross, MD, Gerard F. Anderson, PhD, and Neil R. Powe, MD, MPH, MBA, "The Relation Between Funding by the National Institutes of Health and the Burden of Disease," *N Engl J Med* 1999;340:1881-1887 at <http://tinyurl.com/ddb2y>.

## From Around the Network

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### Canadian Study on Prolonged and Long-Term Mechanical Ventilation

Currently there is no national strategy in Canada for the management of individuals at risk for or requiring prolonged and long-term mechanical ventilation (PMV/LTMV). Due to the lack of a national or provincial database to inform policy development, a study has been designed to collect the information needed to establish a national PMV/LTMV network of health care providers. The study will also describe health service provisions and promote the delivery of safe, high quality care to this population in different health care settings, including the home.

The study is being coordinated by the Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, and the Survey Research Unit, Centre for Research on Inner City Health, St. Michael's Hospital, Toronto. For more information, contact the Principal Investigator, Louise Rose ([louise.rose@utoronto.ca](mailto:louise.rose@utoronto.ca)). [www.stmichaelshospital.com/crich/sru/ventilation.php](http://www.stmichaelshospital.com/crich/sru/ventilation.php).

### Families of Children with Special Health Care Needs

The Department of Health and Human Services (HHS) has announced \$4.9 million in Affordable Care Act funding to support Family-to-Family Health Information Centers. The Centers are run by and for families with children with special health care needs. They provide information, education, training and outreach for families of children and youth with disabilities and the professionals who serve them. [www.familyvoices.com](http://www.familyvoices.com) ▲

## IVUN Announces Educational Conference Calls

Responding to a request from long-time users of home mechanical ventilation, IVUN will offer a series of hour-long educational sessions via the telephone starting in early fall.

Long-time vent users, who are aging, many times are isolated in their communities without real-time contact with experts and other users.

You are invited to suggest topics you would like explored to assist you and your family in making decisions about home mechanical ventilation.

**Is there an expert you'd like to hear?** Send your ideas to Joan L. Headley at [info@ventusers.org](mailto:info@ventusers.org) by August 1, 2012.

The date, time and topic of each call will be announced in *Ventilator-Assisted Living*, *IVUN Membership Memo*, on [www.ventusers.org](http://www.ventusers.org) and on IVUN's Facebook page. The call is free, but reservations will be required, and available space will be first-come, first-served. *To participate, all you need is a telephone.*

These educational sessions are supported by the March of Dimes.



### Calendar

**JUNE 21-24. FSMA Family and Professionals Annual Conference.** Bloomington, Minnesota. [www.fsma.org](http://www.fsma.org)

**JUNE 28-JULY 1. Parent Project Muscular Dystrophy 2012 Connect Conference.** Ft. Lauderdale, Florida. [www.parentprojectmd.org](http://www.parentprojectmd.org)

**JUNE 30-JULY 1. Facioscapulohumeral Society International Patient and Researcher Network Meeting.** Atlanta, Georgia. [www.fshsociety.org/2012Meeting](http://www.fshsociety.org/2012Meeting)

## Join IVUN!

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The eight-page newsletter will be sent electronically in February, April, June, August, October and December. (IVUN Members without email access may request print copies by contacting IVUN). Members will also receive an electronic *IVUN Membership Memo* in alternate months. To become a Member, complete this form.

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