

Annie Costello and Dee Wilson Costello

OXYGEN THERAPY



“The scars on my body and feet make it tricky to put on socks, and my mom gets frustrated when we change them a lot before the bus gets here. But I’m thankful to be alive.”

If you had asked me ten years ago if I thought that we had any hope of having a healthy child, my answer would have been “No way.” But thanks to God, a great medical team of pulmonologists and neonatologists, and support from the world’s finest clinicians and researchers, here we are!

During my pregnancy I developed severe HELLP (Hemolysis; Elevated Liver enzymes; Low Platelet count) syndrome, and Annie was born at 26 weeks gestation, weighing 750 grams. In the delivery room, she received assisted ventilation, surfactant, chest compressions, and resuscitation medications.

I was a neonatal doctor before Annie’s birth, but when I saw her for the first time, I fainted. I felt like all my hopes and dreams evaporated that day, and life was over. When Annie was four weeks old, she nearly died of an infection that caused a huge pneumatocele in her lung. As Annie worsened, debate raged about whether to remove the lung and wean her from ventilation. I recall the sad Christmas Eve when she was on maximal support. All I could think of was, soon everyone will be going home to their families, and my child is going to die, and I’ll be all alone. The low point was when a pediatric pulmonologist named Carolyn Kersmar came in, sat with me, cried with me, then pulled up her sleeves and said, “We’re not gonna touch that lung. We’re gonna do some creative management, get this kid off the vent, and this kid’s gonna make it.” And come Christmas morning, we were all still there! We were on the ventilator for several more months, failed six planned extubations, and spent an eternity in CPAP.

Four months later, we went home with oxygen, feeding tubes, monitors, and more questions than answers. I broke the oxygen tanks on the first night. I was desperate when

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Children with lung disease can have low levels of oxygen in their bodies and some need to use extra (supplemental) oxygen in order to bring their oxygen levels up to a healthier level. Children with lung diseases such as bronchopulmonary dysplasia (BPD) or cystic fibrosis (CF) may require oxygen therapy. Extra oxygen protects their bodies from the effects of low oxygen levels, helps them to function better, and allows them to stay more active.

- Oxygen is a medical treatment. Use oxygen exactly as prescribed by your child’s health care provider.
- If your child has any of these symptoms: shortness of breath, morning headache, or seems more tired or drowsy, contact your child’s health care provider.
- Oxygen used properly is safe. Do not smoke near oxygen, or keep oxygen near open flames, or other sources of heat or flames.

Learn more: ATS Patient Information Series. “Oxygen Therapy for Children” New York, NY: American Thoracic Society, 2008. thoracic.org/patients/patient-resources/resources/oxygen-therapy-children-2008.pdf

seven attempts to wean to room air failed. Although you hate the equipment, you bond to it. When we finally did get off of oxygen, I was afraid to leave home because it was too far from the tanks and monitors.

Due to severe bronchopulmonary dysplasia and steroids, Annie had several motor delays. We were terrified of germs. Then one day, after nearly two years of captivity, we went crazy and went to Disneyworld. On the plane, Annie was fascinated with the other children. She had never seen any before.

The road to today has been hard, but Annie is now a vibrant ten-year-old who loves school and life. I'd like to share a few of her words with you:

“My name is Annie. I struggle with small things, like shortness of breath when I run fast, or wheezing when I get respiratory viruses, like I had last week. Every time these things happen, my mom gets scared and relives the NICU all over again. We spend a lot of time working on motor skills, doing activities like riding horses and chasing chickens. It's paying off. I'm getting faster. The scars on my body and feet make it tricky to put on socks, and my mom gets frustrated when we change them a lot before the bus gets here. But I'm thankful to be alive. A lot of people helped save me and my family.”