



By Nicole DeCosta ✉

The West Linn Tidings, Mar 1, 2007



Molly Bell

Lucy Bell, 5, and her father Patrick Bell, center, of West Linn spent time with Gov. Ted Kulongoski in February as he signed a proclamation declaring it Congenital Heart Defect Awareness Week. Before age 2, Lucy had 17 heart surgeries and procedures.

An advertisement for Schuck's Auto Supply. The top part features the company logo with a star and the text 'SCHUCK'S AUTO SUPPLY'. Below this, it says 'Winter Deals for SNOW & SUN'. The 'SNOW' section shows a snowbrush and a bottle of snow melt. The 'SUN' section shows a bottle of car wax and a car air freshener. At the bottom, it says 'Store Pickup or Free Shipping'.

Even though February was American Heart Month, heart conditions are prevalent year round, and many of these heart irregularities are formed before birth. Five-year-old Lucy Bell of West Linn received 17 heart surgeries and procedures before age 2 to repair her damaged heart.

Bright-eyed and smiley, Lucy spent time Feb. 12 with a dozen other children with heart defects formed before birth, while at Gov. Ted Kulongoski's office in Salem. That day the governor declared it Congenital Heart Defect Awareness Week in Oregon – marked by a coalition of families, non profit organizations, support groups and health professionals dedicated to increasing public awareness of congenital heart defects.

“The heart is the first organ that’s formed. Her heart and its defect was formed probably before I knew I was pregnant,” said Molly Bell, Lucy’s mother. “She’s our little miracle baby.”

Lucy was born with Tetralogy of Fallot, said Bell. Her defects formed during the development of her heart. These include less blood flow to the lungs, low levels of oxygen in the blood and the mixing oxygen-rich blood cells with oxygen poor blue blood cells inside the heart. With Lucy, these complications caused cyanosis, a condition when a child becomes a “blue baby” with skin, fingertips and lips of a bluish tint.

At Lucy's two-week checkup her pediatrician noticed a heart murmur. It was undetected through ultrasounds throughout Molly's pregnancy. Lucy was in surgery a week later to establish blood flow to her left lung.

When a ductus – a passageway from her heart to her lung – closed, Lucy went into cardiac arrest and her cardiologist manually pumped her heart for her for 30 minutes, said Bell.

The Bells describe the next month as “touch and go” – Lucy was on life support, her lungs and kidneys were monitored closely, she used dialysis and received nourishment from a feeding tube. At one point a priest read her last rites.

But now at home with her younger brother and sister, Lucy runs about the kitchen and giggles. Her weekly check-ups and physical therapy sessions are replaced by yearly visits with a cardiologist. Her parents say that cognitively she is doing fine, but is a bit behind physically. Her heart complications have taught the family much about patience, the value of research and the meaning of family.

“We've learned to not sweat the small stuff,” said Bell. “We don't take a runny nose too seriously.”

Bell is a part of a support group called Northwest Families with Heart, and organizes local events through the Children's Heart Foundation. According to the Oregon chapter of the foundation, nearly twice as many children die from congenital heart defects each year in the U.S. than from all forms of cancer and yet pediatric cancer research receives five times the funding.

The non profit state chapter was started in 1996, and has raised more than \$1.9 million and funded 24 research projects, according to its Web site, www.chforegon.org.

Bell said she encourages fund-raising efforts to research heart defects and speaks highly of Pulsoximetry tests, in which small sensors clip to your fingers to test oxygen saturation which could indicate heart trouble.

She said she hopes Congenital Heart Defect Awareness Week soon becomes a yearly tradition in Oregon.

“We've learned to enjoy every minute we can (with our kids). It really was an eye opener how quickly life can change. In an instant your whole life can change,” said Patrick Bell, Lucy's father. “We hope she can someday maintain physical activity along with her classmates. And become president of the United States, of course.”

In the meantime, what did Lucy say she'll never forget about meeting the governor?

“One second,” she said, smiling and running to grab something across the room. “Just one second.”

Soon, Lucy paraded in a huge balloon that read “A Day for Hearts” – a remembrance of her health triumphs and a reminder that so many others are in need of support.

For more information about the Children's Heart Foundation, visit www.chil

drensheartfoundation.org.

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