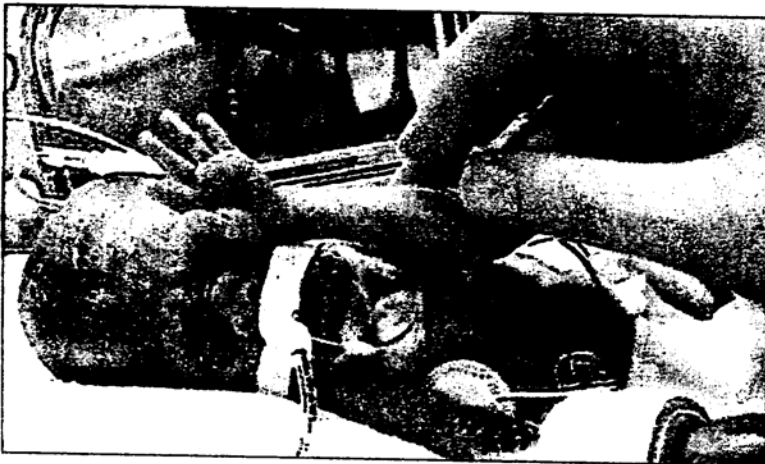


Sophia Louise Tocco was born at 23 weeks, below, as a nurse's hand shows how small she was. Sophia wasn't expected to be able to walk or talk. But at 3 years old, at right, she's made amazing progress, getting therapy at Pediatric Health Choice — a pediatric day care — in Daytona Beach.



News-Journal/PAM LOCKEY



Tocco family photo

Toddler struggles to thrive; young father struggles to live

By ANNE GEGGIS
STAFF WRITER

Seventeen weeks ahead of her scheduled delivery date, Christina Tocco hadn't even thought of a name for her daughter when the labor contractions started — and couldn't be stopped.

At just 23 weeks' gestation, Tocco's baby faced the twin threats of premature births: death or lifelong disability.

"They asked me, 'If she doesn't make it, do you want to hold her as she passes?'" Tocco, 30, of Holly Hill recalled. "I couldn't believe it. Right then I was coming to the realization I was going to lose my daughter."

Premature birth is the leading cause of U.S. babies' deaths before their first birthday, and the problem is growing. Premature births are up by more than one-third since the 1980s and account for 12 percent of U.S. births.

Yet the point at which medical

SEE BORN, PAGE 3B

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Beating the Odds

The March of Dimes ranked Florida the 10th-worst state in its national report card on premature births. Smoking, drinking and taking other drugs during pregnancy can increase the risk, as does young motherhood, or older motherhood. Black women, those who have taken infertility drugs, or those pregnant with multiple children also face higher odds of delivering infants too soon. But no one really knows what can cause a healthy pregnancy to take a wrong turn. What there's no doubt about is that the longer a baby stays in utero, the better the chances for survival, particularly for those who make it past 24 weeks' gestation. The rate at which these infants die before their first birthday has improved about 2 to 4 percent for each category in the past 10 years.

Gestational age	Mortality rate*	Gestational age	Mortality rate*
23 weeks	64.3 percent	32 weeks	2 percent
24 weeks	41 percent	33 weeks	1.5 percent
25 weeks	27.2 percent	34 weeks	1.1 percent
26 weeks	18.4 percent	35 weeks	0.8 percent
27 weeks	13.4 percent	36 weeks	0.6 percent
28 weeks	8 percent	37 weeks	0.4 percent
29 weeks	5.3 percent	38 weeks	0.3 percent
30 weeks	3.9 percent	39 weeks	0.2 percent
31 weeks	3.1 percent	40 weeks	0.2 percent

* rate at which they die before their first birthday

SOURCE: March of Dimes

■ **MORE ONLINE:** Follow the links to more facts about premature births: news-journalonline.com

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CONTINUED FROM PAGE 1B

intervention can save these babies has remained the same for 30 years, according to Dr. Alan de Klerk, recently hired as the first neonatologist at Florida Hospital Ormond Memorial, the hospital where Tocco was admitted.

Some improvements have been made so medical treatment for "preemies" doesn't have to mean lifelong disabilities. But extremely premature babies, like Tocco's, are in what de Klerk calls a "gray area" at which it's not clear whether extraordinary medical measures should be taken to save the baby's life.

"There's a respectable survival rate," de Klerk said, but also a good chance of things like cerebral palsy and other problems that could follow a premature infant for life.

If Sophia Louise Tocco had come into the world just a week earlier, her chances would have been "extraordinarily" small, de Klerk said, adding, "Those very small few that may survive have devastating complications and lifelong disabilities that make the quality of life very, very poor."

LIVING WITH THE EFFECTS

The reason 23 weeks is such a magic number with premature births is it takes that long for lungs to develop the ability to exchange the gases that maintain life — an act technology can't mimic, holding back medical science's ability to treat infants born earlier than that, according to Florida Hospital's de Klerk.

What has advanced significantly, however, is how oxygen is given to premature babies so it doesn't harm them.

"One of the problems with mechanical ventilation is that you can damage the lungs while doing that," de Klerk said. "They've made very, very big strides over the last three decades. . . . Ventilators are much, much more sophisticated" and there's also been a strong move to avoid ventilation and instead use a continuous positive air pressure machine often used to treat sleep apnea.

Those advances came too late to help 32-year-old Randy Silcox of South Daytona. Though born just six weeks early, he's dealt with the effects of his premature birth all his life.

At 5 feet tall, Silcox is smaller

Helping Hand

■ A fund has been set up to help the Silcox family as they try and save \$5,000 needed to get him on the transplant list at Shands Hospital in Gainesville.

■ Donations to the Silcox Lung Transplant and Family Assistance Fund can be made at any Bank of America branch.

than his peers, a fact probably attributable to the 6 feet of intestines he lost at birth. But that pales in comparison to his breathing problems. At age 15, the 1996 graduate of Atlantic High School was diagnosed with a disease usually associated with lifelong smoking, chronic obstructive pulmonary disease, according to medical records.

"He was put in an incubator (at birth) and that's what started it," said his wife, Kim Silcox. "His lungs were burned from the inside."

Now the father of three needs a double lung transplant.

Instead of saving for a down payment on a house, the family — including Nolan, 9, Owen, 2, and Isabella, 12 months — is racing to raise the \$5,000 they need so he can get on the waiting list for two donated lungs. It's a tough mission for the couple, living on her \$7.42-an-hour job at a Head Start program and his \$1,200-a-month disability as they cope with stacks of medical bills that are not paid for by the Medicaid program he's on.

But it's an urgent situation, according to his doctor.

"Basically the only way he's going to survive is if he gets new lungs," said Dr. Michael Diamond, a pulmonologist who's been treating Silcox for four years.

After they raise the money, they could face years of waiting for compatible lungs. In the meantime, he's savoring each moment as a stay-at-home-dad and trying not to think about the fatal diagnosis. He's just started teaching Nolan how to play the blues on his electric guitar.

"It's definitely not what I thought my life would be like," he said.

SMALL STEPS

As the minutes ticked on after Sophia Louise entered the world — and she kept breathing — the decision was made that all 1 pound, 6 ounces of her be airlifted to Florida Hospital Orlando. There, the worst kind of brain hemorrhage was discovered. And so began a medical

odyssey that's been a marathon of doctor appointments, therapies and tests. And, at first, there was little hope.

"With the brain hemorrhage, they told me she would never walk, she would never talk," Tocco said. Added to that, Sophia's biological father walked out on mother and child shortly after the birth, which Tocco attributes to the disabilities they faced.

The seizures that Sophia Louise endured were the scariest. And none of her body's most basic functions — swallowing food, for instance — could be taken for granted. Her inability to drink still requires she take fluids through a feeding tube.

Still, Sophia gave her mother big smiles when she came home from the hospital after five months, even if the succeeding years have been filled with EVAC ambulance rides to the hospital, spiking fevers and digestion problems.

That's why being on the brink of watching her daughter take her first step at 3 years old brings tears to Tocco's eyes. And joy to her new dad, Tocco's fiancé, Dan Pelz.

"The doctor told me, 'Everything I've ever told you about her so far has been wrong,'" she said. "Sophia's her own book and we just need to figure out what chapter she's on."

Laurie Hass, administrator at Pediatric Health Choice, has been a witness to Sophia's progress since she started at the medical day care center at 6 months old, when it was uncertain whether Sophia would show purposeful functioning. Now it looks like Sophia will no longer qualify for the state's health insurance to pay for her time at the medical day care, as her needs have decreased. It's a graduation, of sorts.

"It gives me chills," Hass said.

With three building blocks in front of her, Sophia faces up to the challenge of stacking them.

In her focusing eyes beneath a fringe of golden curls, you can see the concentration forming. Even if the first try doesn't work.

"Uh-oh," she said as one plopped over.

Cheryl Fountain, the occupational therapy assistant working with her, was thrilled.

"She's saying, 'Uh-oh,'" Fountain enthused to Sophia's grandfather, Marshall Tocco, standing behind her. "When did she start saying that?"

Sophia's face lit up.