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PCH opens Down Syndrome Clinic

Nearly six years ago, Lynda Christel gave birth to Colten, who has an extra chromosome.

At first, she didn't want to accept that her newborn son had Down syndrome.

"It was this dark cloud that was over me," she said. "I didn't celebrate; I didn't do birth announcements. I was in a different place, quite frankly."

Christel, director of physicians relations at Phoenix Children's Hospital, went through the five stages of grief, mourning the loss of a healthy baby — even hoping the hospital had made a mistake and switched her newborn with someone else's.

On a different level, it was a slow, painful process learning how to navigate the health care system to provide care for Colten, who also was born with atrial septal defect, a genetic flaw that can be fixed only with open-heart surgery.

He was 4 when he underwent the surgery, and that's when Christel prayed to

God to let him live.

"My life has changed — so much so that I feel like my adult life is just beginning," she said. "There are so many more things to do and so many more things to learn."

This firsthand experience led her to convince the PCH administration and physicians that the hospital needed a clinic to provide comprehensive care to children with Down syndrome.

The Down Syndrome Clinic opened March 21 to mark Trisomy 21, which reflects that one in 800 babies are born with an extra copy of chromosome 21, leading to three copies: one from dad, one from mom, plus one extra. This causes problems in body and brain development.

"Some people say it's an extra chromosome because God gave them an extra love chromosome," Christel said.

Bursting with pride at the new center, Christel noted that about 160 babies were born in Arizona with Down syndrome



Lynda Christel with her son, Colten, and the clinic's medical director, Dr. Robin Blitz.

last year, and more than 900 children with the disorder have been treated at PCH during the past five years.

Because of the syndrome's complexity, a slew of specialists will work collaboratively on pediatric cases at the center.

Dr. Robin Blitz, director of developmental pediatrics for Barrow Neurological Institute at PCH, is medical director of the clinic.

"The goal of the clinic is to provide multidisciplinary evaluations and interventions for children with Down syndrome from birth to 18 years within one center, so families spend less time pursuing services through multiple agencies and professionals," said Blitz. "We want to become a one-stop shop for families in Arizona."

HOSPITAL EXPANSION

DOWN SYNDROME

161

The average number of babies born with Down syndrome each year in Arizona

80%

The percentage of children with Down syndrome born to women under the age of 35

60

The life expectancy for people with Down syndrome, up from 25 in 1983



Attorney views changes in federal health care law

Kristen Rosati, who will become president of the American Health Lawyers Association in July, has joined Polsinelli, leading the big data initiative at the Phoenix firm.

With experience in electronic health records, health information exchange, data sharing for research and clinical integration and accountable care organizations, Rosati is part of the law firm's health care team.

I had a chance to catch up with Rosati to get her thoughts on the rapidly changing health information industry.

What are the challenges of electronic health records? Using EHRs for the first time requires big changes in the way physicians and hospital personnel document the care they provide to patients. Plus, communication between EHRs doesn't work very well yet. To address the last challenge, most states are developing "health information exchanges" to handle electronic communications between physicians. In Arizona, our health information exchange is called the Health Information Network of Arizona.

What are some of the biggest regulation changes coming to the Health Insurance Portability and Accountability Act this year? One of the changes that will have a big impact on the health care industry is that HIPAA will now apply to people and organizations (called "business associates") that receive health information from health care providers and health plans. That will require many of these business associates to get new policies and procedures in place to ensure that they are adequately protecting any health information they receive.

What are the biggest issues facing health care lawyers today? Health care law evolves very quickly. Health care reform is just the most recent change in an ever-changing landscape of federal and state statutes and regulations, but it signals a significant shift in how the industry will be organizing how it provides and pays for health care.

Medicaid plan called crucial to behavioral health

There's been a lot of controversy regarding Gov. Jan Brewer's Medicaid expansion proposal, which would allow 300,000 more people to qualify for health benefits under the Arizona Health Care Cost Containment System.

But what you may not have heard is how behavioral health will be impacted — typical, since mental health appears to be the forgotten stepchild of health care.

Dr. Richard Clarke, CEO of Magellan of Arizona, which has a state contract to provide behavioral health services, said the gov-

MEDICAID EXPANSION

ernor's Medicaid expansion is crucial to people with behavioral health issues.

"Around 60,000 newly eligible members, including childless adults, would most likely access behavioral health services through the new Medicaid benefit package," he said.

This will provide expansion opportunities for Magellan and other organizations that have Regional Behavioral Health Authority contracts with the Arizona Department of Health Services.

The Medicaid expansion also meshes with the Patient Protection and AF-

fordable Care Act, which states mental health and substance abuse services must be provided in benefits packages.

Clarke was hoping to win the new RBHA contract for the Valley, but ADHS announced this week that the winning bidder was Mercy Maricopa Integrated Care. Magellan and Vanguard Health Systems Inc. had submitted a joint bid.

ADHS Director Will Humble said Mercy will expand from four co-located delivery sites to 20 integrated sites.

"Mercy Maricopa Integrated Care provided the department with the best example of integration and recovery oriented services through an extensive community-based approach," he said.



Clarke



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