The Power of One

USC's Chloe Kondrich serves as an inspiration and advocate for those affected by Down syndrome.

BY TRACY FEDKOE

Meet Chloe Kondrich, a typical 11-year-old sixth grader at Boyce Middle School. She plays Frisbee, loves ice cream and pop music, and knows her way around an iPad better than any adult. She's a "Daddy's girl," a princess, and sometimes a little bit stubborn, just like so many other girls her age. Chloe has met countless politicians, professional athletes and musicians, and most recently has had a law named in her honor. By the way — Chloe has Down syndrome, the most common genetic disorder that results in mild to moderate developmental delays due to having an extra 21st chromosome. But that's not stopping her, or her family. With her unabated kindness, kindred spirit, and zest for life, Chloe has touched the lives of everyone who knows her and now she will be able to reach so many more.

On July 18, 2014, Governor Tom Corbett signed a bill entitled the Down Syndrome Prenatal Education Act, or "Chloe's Law," requiring health care practitioners to provide parents with accurate educational information after a prenatal Down syndrome diagnosis. Her father, Kurt Kondrich, had been a city police officer but was so inspired by his daughter he shifted his entire career and life to became an early intervention specialist and advocate extraordinaire for his daughter and so many others with little voice. His dedication working with many organizations and legislators led to the quick development and passing of the bill last year.

The reason behind this legislation is that an alarming percentage of pregnancies with a confirmed Down syndrome diagnosis are terminated. It has been estimated that as much as 90 percent of all women who receive a prenatal diagnosis of Down syndrome choose to terminate their pregnancies, according to a collection of research reviewed by Dr. Brian Skotko, a pediatric geneticist at Children's Hospital Boston.

The Kondrich family feels that part of the reason for early termination is improper education and information at the time of diagnosis. When Margie Kondrich went into labor and gave birth to Chloe, it seemed like the only thing the doctor had to say was that Chloe displayed characteristics of Down syndrome. The staff didn't say she was breathing fine, she had all 10 toes and fingers, or anything positive. A nurse provided some out-of-date information to the shocked parents and they were on their way. Despite several sonograms where none of the typical markers showed up, had Kurt and Margie known, they wouldn't have changed a thing.

"I still knew that was my daughter and I loved her," said Margie.

It wasn't until Early Intervention Services became involved with Chloe that they started hearing positive news. They learned about all of the great things that Chloe would be able to do growing up such as playing games and sports, learning to read, going to school, and how early intervention would be critical to her development. Kurt and Margie decided to learn all they could in order to help their daughter have as many opportunities as possible. Kurt began working with adults with disabilities and attended support and educational groups, where he met a

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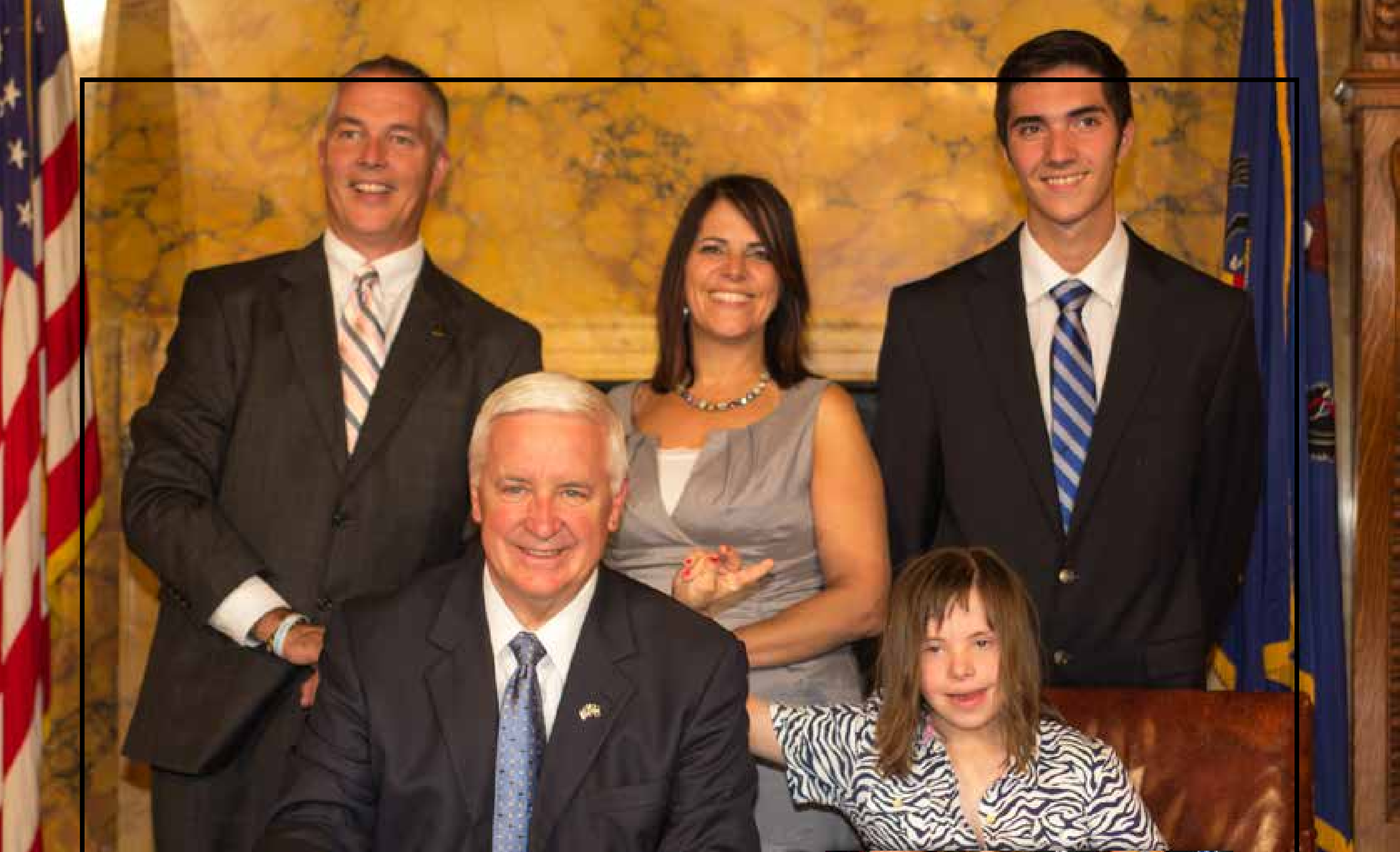

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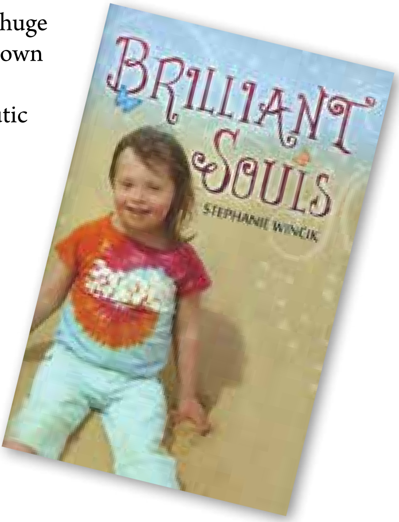
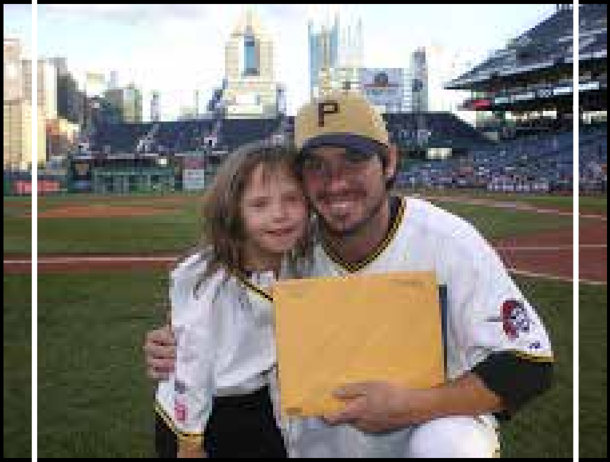
professor who saw his eagerness to get involved and encouraged him to apply to a master's program at Pitt. He took a "leap of faith" and completed his master's degree in 2006.

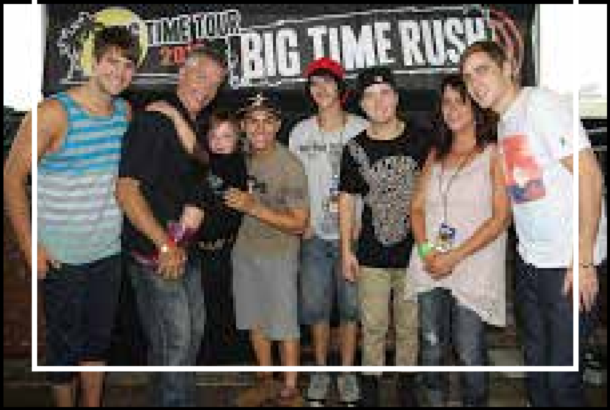
With Chloe's progress as his inspiration, Kurt started making connections in the local, city, and state government and talked to anyone who would hear his story. He visited the state capitol often and would take Chloe with him. "I didn't ask for money; I just asked them to get to know our kids," said Kondrich. With her adorable smile, wit, and happy disposition, Chloe provided a walking example of everything that Kurt was trying to accomplish.

Working with a friend he met from the Lejeune Foundation, he discovered that two other states had laws requiring accurate information be provided upon a Down syndrome diagnosis. Starting just last summer, Kurt worked with PA State Senator Randy Vulakovich and Representative Jim Marshall of the 14th District (Beaver County), who sponsored the bill. Kondrich continued doing the legwork of visiting the state legislators and gaining support. He was able to secure 30 sponsors in the Senate and 80 in the House "because of me going there, and the fact that they got to know Chloe." He called it divine intervention that got the bill out for a vote so quickly where it passed 50/0 in the Senate and 196/4 in the House, and remarkably brought both parties together in a unified stance. Chloe actually got to sign the bill with her friends Alex and Gov. Tom Corbett, whom she had met several times. It was a small signature on paper, but a huge impact for the future of those with Down syndrome.

Kondrich now works for Therapeutic Early Intervention Services (TEIS) as a developmental therapist, and is still pursuing his advocacy efforts throughout the state and country. Several other states have contacted him in their efforts to get similar laws passed including South Dakota, Vermont and California to name a few. He continues to be a voice for those with disabilities because he wants to make sure that early intervention continues







to be funded as he knows personally the value of that service, especially since the owner of TEIS, Julie Hudak, was Chloe's early intervention physical therapist from birth to three. "I want to continue to present the message that these kids are a blessing and so fun to be around," he said. Kondrich serves as a valuable resource to families with Down syndrome children as well as a volunteer for the Crisis Pregnancy Center to help those who have received a positive diagnosis make educated decisions. He has been very successful, because of Chloe.

In fact, Chloe has become somewhat of a political celebrity, getting to meet Sarah Palin, John McCain, and Tim Murphy, and was taken down to the floor of the U.S. House of Representatives when it was in session by Cathy McMorris Rodgers of Washington state.

Despite her celebrity status in government circles, Chloe is an active member of her class at Boyce Middle School. Her family moved to Upper St. Clair when she started kindergarten because of the excellent school system and atmosphere of inclusion.

"One of the things of which I am most proud about USC is that the students accept everyone," said Christine Finnegan, Chloe's teacher. Chloe has a modified and adjusted curriculum where she can work up to her full potential at her own pace.

"I love school. They like me," said Chloe to her mother.

"The area where Chloe shines the most is [her] amazing interpersonal skills. She really responds to being with her peers," said Finnegan.

Chloe is equally adored by her older brother, Nolan, a high school freshman. Kurt and Margie believe that Chloe has inspired Nolan to be a more compassionate, understanding person. He was the one to teach her to read, even before she entered kindergarten. Nolan plays volleyball for USC and his teammates also welcomed her and made her the team mascot.

The Kondrichs have gotten to meet a few celebrities because of Chloe such as NBA players Kevin Durant and Kyrie Irving, Clint Hurdle, Andy LaRoche, Sean Casey, Andrew McCutchen, and others. Chloe herself has a much longer list of celebrity encounters, topped by receiving a guitar pick and a hug from Carlos Pena of the band Big Time Rush. She's been on the big screen in Times Square three times for the National Down Syndrome Society and has even had the honor of being on the cover of a book, Brilliant Souls, by Stephanie Wincik, which candidly presents a strong case for the advocacy of those with Down syndrome.

Chloe looks forward to participating in Miracle League baseball and taking acting classes at the Center for Theater Arts this year and has made friends at the South Hills Bible Chapel Special Needs Ministry activities. Margie is in the process of organizing a social group for tweens and young teens with disabilities in the South Hills area to bring children and families together.

Despite many misconceptions, the Kondrichs are facing the same challenges as other families raising two children. "Down syndrome used to be big, but now it's such a small part of Chloe," said Margie. They choose to focus on her abilities, not disabilities, and encourage others to adopt the same perspective. Chloe gets access to the best doctors and therapists, and has a great life.

"She's not suffering. She's a happy, healthy child," said Kurt. Like Chloe, 99% of people living with Down syndrome reported they were happy with their lives and 97% liked who they are, according to a study published by the American Journal of Medical Genetics.

"Since we've had Chloe, we've been inspired to help so many people and want to continue to do so," said Kurt. "We're just basic people and we're blessed. Anyone can make an impact if you just set your heart to it." ■