

# Before Their Time

If you've ever wondered what would happen if you gave pancakes to a pig, Seth Cook has the answers you need.

"First, he'd want syrup to put on them," the 12-year-old explains. "But then he'd get all sticky, so he'd want to take a bath, a bath with bubbles, of course. Then, you'd have to find him a rubber ducky to play with."

Now, it's not as if Seth feeds breakfast food to animals that ultimately become breakfast food. These lessons come from a book he reads to a kindergarten class near his home in what his parents, Patti and Kyle, call "a logging town in the wilderness" of Washington state.

But as his parents and friends sit around the table laughing, he quietly concedes he also shares a more-important lesson with his youthful charges. Talking to the kindergartners, he says bashfully, in a high-pitched voice, "gives me a chance to talk about my disease." That disease being Hutchinson-Gilford Progeria Syndrome, the rapid-aging affliction that claims its victims before they leave their teenage years, the genetic-based malady that has this 12-year-old already suffering from arthritis and commonly brings

heart disease, diabetes and strokes by the age of 10.

Affecting one in every eight million kids, the disease is so rare that its closest victim lives near Chicago, and its sufferers often feel isolated. But Monday night, Seth was anything but alone in the hospitality suite at the Center City Marriott. He shared the room with a dozen of the 32 known progeria sufferers worldwide — the guest list resembles a World Cup grouping — and the mother of a 13th who'd recently passed away just days from his 18th birthday in Argentina.



**COMFORT IN NUMBERS:** The progeria reunion lets kids like Karlita Montaner, 8, know they're not alone.

Such losses are part of the harsh reality at these annual reunions, this being the 24th held by the Sunshine Foundation, a

nonprofit that's made some 31,000 wishes come true for kids suffering from debilitating diseases.

"We lose two, we find three [new cases]. We find three, then we lose two more children," explains Bill Sample, a far-too-modest retired Philly cop who launched the foundation in 1976 after having his heart wrenched too many times walking the beat near St. Christopher's. "So why not give them what we can, while we can give it to them?"

As we discuss how it's downright pathetic that they can't find big-ticket patrons in Big Pharma land — potential donors, the reunion cost 150 large — Sample says the reunion isn't about the lack of research and fundraising. It's about bringing the kids together so they know they're not alone. And it's about bringing their families together, so they know the same thing.

In many ways, progeria is the organization's most important focus; when doctors can't figure out what's wrong, their parents are referred to the foundation, which often diagnoses the cases and gives the families the hard-to-find information they need to go on from there. Such was the case with Seth, who showed tell-tale signs at 18 months. When a children's hospital near home had no clue, Sunshine invited Patti, Kyle and Seth to

the next reunion.

"The first day was a shock," recalls Patti. "We thought we'd get there and notice the difference between Seth and the other children. We didn't. After the second and third day, we knew it was something we'd have to come back to."

They've been back to swap parenting tips just about every year since, a trip that helps them attain some semblance of normalcy, which is important considering years ago, one parent took his life after seeing his child's future before his own eyes.

But really, how normal can it be for a 12-year-old kid to know people turn and whisper when he walks by, and that when other kids are heading off to college, his parents will be mourning him? Making sure Seth was absorbed in his PSP, I asked Patti how her quick-with-a-quip homeschooled kid who loves fishing, throwing the mini-Nerf football around the house and his rat terrier/shih tzu named Bullet, deals with the mortality issue. (The disease, after all, doesn't affect his mental capacity.)

"Well," she said, sighing the sigh of a mother who realizes she'll bury her son, "it's not something he fears. He believes in God. He believes in heaven. And he knows he's going there."

And just like that, she left me with a line that'll stop me from ever bitching about how tiring life can be. So next time I whine that my 33-year-old bones ache like they're 70, I'm going to think about pigs and pancakes. Next time, I'm going to think about Seth.

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