



Staff photos by Chris Harubin

Seven-year-old Sarah Rodler from Austria plays with other kids in the lobby of the Adams Mark Hotel in Philadelphia after ending a gathering of children with progeria on Friday.

Progeria

(Continued from Page A-1)

Dakota.

"It's my family. Michaela lives for this week," Elizabeth McAvoy said. "She knows she's different. I haven't told her why. But here, she can be with people who look like her."

Michaela, 6, suffers from progeria, a rare genetic condition characterized by an appearance of accelerated aging in children. It affects one in 4-8 million newborns. Diagnosis usually occurs around age 2 and, at that time, symptoms that resemble the regular aging process being to develop. Skin becomes wrinkled and dry, hair falls out, circulatory and respiratory diseases can develop. Progeria patients have difficulty taking on muscle mass, and their bones are often brittle. Each year can have the effects of seven.

For the McAvoy's, the past week provided a break of sorts — a chance for Michaela to be herself, be comfortable.

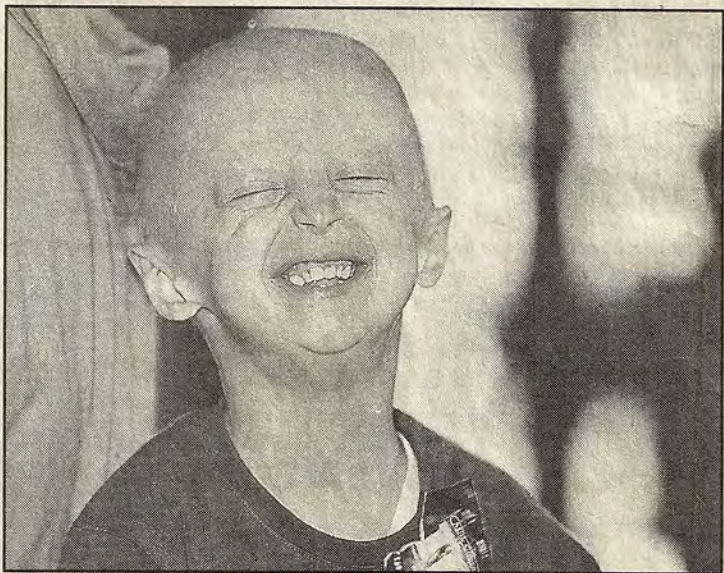
It's not always that easy.

Children are generally accepting, but adults are the worst, McAvoy said. Some point and laugh, most stare. Some call her names — like Pirate — for the bandana she wears on her head.

But the week with the Sunshine Foundation is special.

This year, the reunion brought together 35 of the 43 children known to suffer from progeria in the world, South Jersey Director Christine Condi said, spending \$250,000 to cover airfare, hotel costs, activities, and two daily meals for the families.

During the week, children



Sammy Basso, 6, from Italy, laughs after eating M&Ms before leaving for home Friday.

and their parents attended parties, field trips to beaches and zoos and information sessions. They took in a Phillies game — and met the players afterward — and got to ride on the backs of Harley Davidsons when a senior citizen motor cycle club came to visit, a highlight for Mark Okines and Kerry Button's 3-year-old daughter Hayley.

It was their second year attending, and a very different year from the first, Button said.

"I almost didn't come last year because I didn't want to see what kids older than Hayley looked like," she said. "I thought when I first got here that it was going to be sad. It's not like that at all."

When Hayley was first diagnosed, the family felt very isolated, Button said, due largely to the rareness of progeria.

So they decided "to go public." They appeared on talk shows and in newspapers, did Internet chats, talked to people about the condition.

Now practically everybody knows them — and understands progeria — in their Southeast England hometown. That lends the family support, Button explained.

Still, when they venture out to visit family and friends, people do take to staring.

"People are people," she said. "I used to do it, used to look at children in wheelchairs ... But these are all fantastic kids. I don't think I've seen one of them cry. They're all very special."

For more information on the Sunshine Foundation, call (609) 953-2141 or visit www.sunshinefoundation.org/southjersey.

— Barbara Green can be reached by e-mail at bgreen@sjnewsco.com.