



PHOTOS BY HILDA M. PEREZ/ORLANDO SENTINEL

The moment. Sammy, 6, and Laura Bass-Lucein (above) from Italy share the joy of just playing Sunday at the Sunshine Foundation's 20th Annual Progeria Reunion at the Marriott Renaissance in Orlando. Below, Sarah Rodler from Austria relaxes poolside. The rare disease ages children's bodies 8 to 10 years per year.

CHILDREN PUT THOUGHTS OF ILLNESS ASIDE JUST FOR NOW

By JON STEINMAN

SENTINEL STAFF WRITER

It is a crippling disease that heaps a decade of infirmity onto its young victims for every year they age. It is a rare disease afflicting one child out of every 8 million children worldwide.

And it's always fatal, striking down most victims soon after they become teenagers.

But for the children who suffer from the genetic disease progeria — whose victims endure arthritis, brittle bones and worse while others their age are mastering a bicycle — the moment, the living here and now, is what matters. So even with Sunday's grim news that one of the 32 children and young adults attending the Sunshine Foundation's 20th annual progeria reunion in Orlando had died, the others kept on.

"We're all together, united here," said Megane Durel, 9, from Normandy, France.

Children from 17

nations are attending the reunion that ends its five-day run Wednesday. "We're here to have fun."

Like the others, Megane doesn't hide from the cruel and rare fate dealt to her. She isn't quiet and morose. She won't ignore the grim news, like that delivered on Sunday. But for her, life is exceptionally short, and the days given over to having fun and not standing out from the crowd are shorter still.

That's why beside the Marriott Renaissance Hotel pool beneath scattered clouds and rain,

Megane practiced her belly dancing — a talent she will display during Tuesday night's talent show and dance. She frolicked in the pool and teased her mom while others swam past. But the fourth-grader whose teachers describe as gifted did not open her diary. She didn't even



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