

A Beautiful Life

A teen with a rare genetic disease sends a YouTube message to her idol and inspires millions around the world.

*"No matter what's your outside
Get it with your inside
Open your eyes; you deserve the spotlight."*

Those lyrics from the hit pop song, "Spotlight," are just some of the dozens of Selena Gomez lyrics that 14-year-old Hana Hwang has meticulously copied down into her diary.

"Her songs connect with me; that's why I like them," says Hana, whose diary is filled almost entirely with Gomez lyrics. "I don't really have any secrets," she explains with a shy smile. "I just write her songs in there."

She never expected to actually meet Selena Gomez, though. And she certainly never expected to be thrust into the spotlight herself.

The high school freshman was born with an extremely rare genetic syndrome called progeria, which causes certain organs to age eight to 10 times faster than normal. The disorder, which occurs in one in 8 million births, results from a genetic mutation and is not inherited.

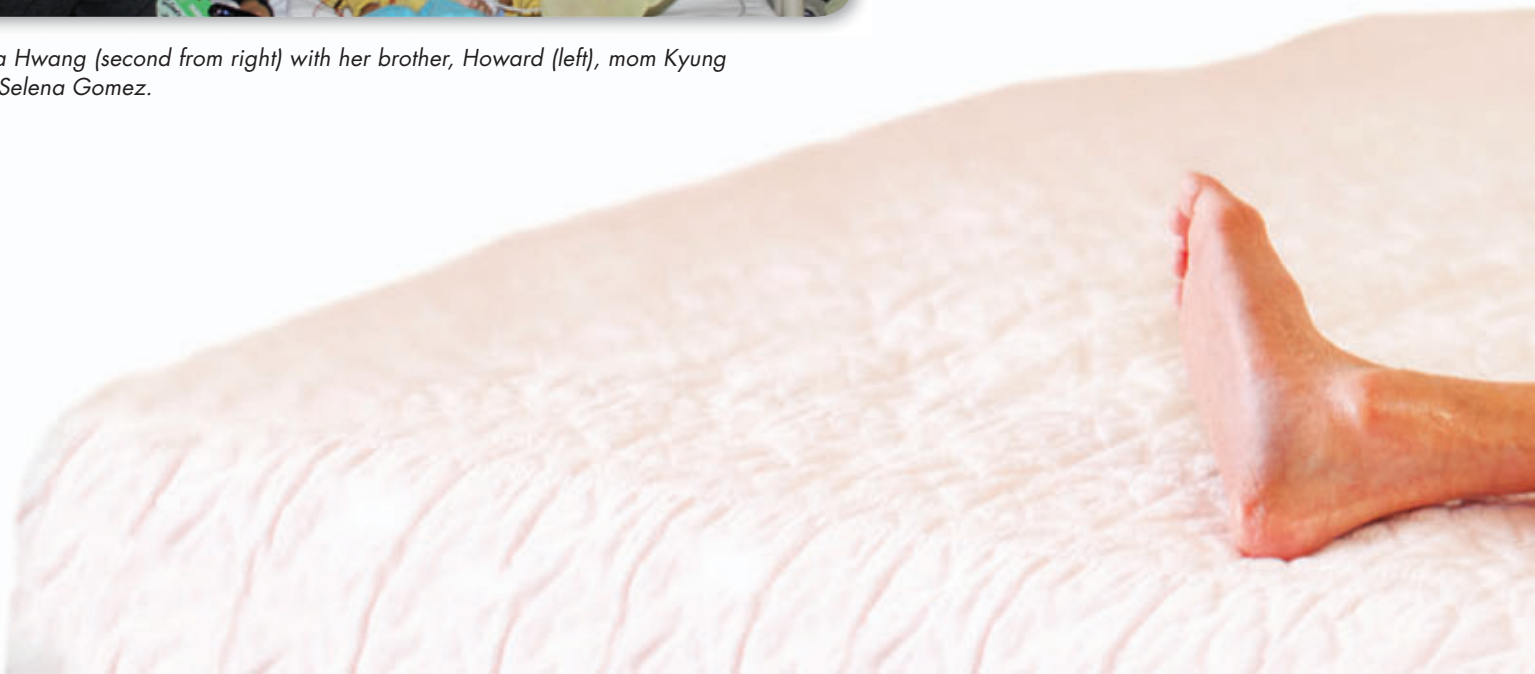
At 14, Hana has the heart of a 90-year-old. Progeria also severely stunts growth and causes patients to lose their hair and body fat. She stands just 3 feet tall and weighs less than 25 pounds.

But, like Gomez sings, that's just the outside.

"Intelligence and emotional development are not affected by progeria," stresses Linda Randolph, MD, head of Medical Genetics at Children's Hospital Los Angeles.



Hana Hwang (second from right) with her brother, Howard (left), mom Kyung and Selena Gomez.





Hana visits with a volunteer from the hospital's Amerman Family Foundation Dog Therapy Program.

Explains Hana: "On the outside, I can't do a lot of things that other kids can do. But on the inside, I'm a normal girl."

A Video Goes Viral

When Gomez walked into Hana's room at Children's Hospital, Hana reacted like any other girl: she was speechless.

It was Dec. 13, 2011, and Hana was in the hospital with pneumonia. Unbeknownst to her, her tutor had called radio station KIIS-FM to enter Hana in a contest. But when Ryan Seacrest learned Hana's story, he contacted Gomez, who made a special trip to Children's Hospital.

Touched that the superstar would visit her, Hana decided to make her a bracelet to thank her, and her tutor took a short, impromptu video.

"Hi Selena! I made this bracelet for you!" Hana says cheerfully to the camera. She holds up the colorful beaded bracelet and goes on to say that Gomez is her hero.

Two weeks later, Hana went home to the Koreatown neighborhood of Los Angeles, where she lives with her mom, Kyung Hwang, and her brother, Howard. That's when she learned that her video on the Children's Hospital YouTube channel had 1 million views.

Over the next few months, her video garnered more than 3 million views. An online rumor even spread that she had died—so she made a second video refuting it.

Although some viewers posted cruel comments, thousands of others rushed to her defense. Many of them were children and teens inspired by Hana's courage and positive attitude. To her delight, they posted their own videos supporting her.

"That was kind of funny," she says, with a typical teen giggle.

Hana, age 14



A Beautiful Life (continued)

Since then, Hana has been featured on FOX 11 News, been backstage at *American Idol* and attended a Gomez concert, where she gave her the bracelet. Gomez later tweeted a photo of herself wearing Hana's gift.

But Hana hasn't let her sudden fame go to her head. She still prefers a quiet teen life—going to school, drawing, making bracelets and listening to music.

Her YouTube stardom has had a positive effect, though. Speaking through a hospital interpreter, Hana's mom, who speaks Korean, explains:

"Before, whenever she went anywhere, people would think she was a baby. She hated that. With that video, people recognized that Hana is like any other teenager, with the same aspirations and the same interests."



Hana with her fan mail



Hana hugs her cardiologist, Jondavid Mentee, MD.

Big Plans

There's no cure for progeria. The average life expectancy is 13, although some progeria patients have lived into their early 20s. Hana has severe cardiovascular disease and suffered a mild heart attack in early 2011.

Currently, she's doing well and her condition is stable. She understands the seriousness of progeria, but she still has big plans—to finish high school and start her own jewelry line or become a computer animator.

In everything she does, her positive, happy nature shines through.

"She's super friendly; she gives everyone hugs and smiles," says her cardiologist, Jondavid Mentee, MD, director of the Heart Failure Program at Children's Hospital. "What's special about Hana is not her rare disease, but that she's a remarkable, beautiful person."

It's just like the lyrics from another Gomez hit, "Who Says":

*"I'm no beauty queen
I'm just beautiful me
You've got every right
to a beautiful life."* ■