

Recognizing the Signs of Pediatric Growth Hormone Deficiency

How Early Recognition and Advocacy Helped One Family Find Answers

FAMILY FEATURES

Our concerns about Alex's growth began around the age of 7," said his mother, Diane Benke.

Though Alex measured around the 50th percentile for weight, his height consistently hovered around the 20th percentile. Benke's instincts told her something wasn't quite right.

"I kept asking our pediatrician if this could mean something more," she said. "Each time, I was reassured that everything was fine. After all, I'm only 5 feet tall myself."

At first, Benke tried setting her worries aside. Alex was one of the youngest in his class, and she wondered if he could simply be a "late bloomer."

However, as Alex progressed through elementary school, particularly in the 4th and 6th grades, his height percentile dropped into the single digits. The height difference between Alex and his peers became impossible to ignore.

Despite Benke's growing concerns, their pediatrician continued to assure them Alex was fine.

"We were told as long as he was making some progress on the growth chart, there was no need to worry," she said, "but we were never actually shown the charts."

It wasn't until one of Benke's friends confided that her own daughter had recently been diagnosed with Pediatric Growth Hormone Deficiency (PGHD) that she decided to seek an endocrinologist.

"Although it took several months to get an appointment," Benke said, "we were determined to get more answers."

Navigating the Diagnosis Process

Getting a diagnosis for many medical conditions can be a long journey. However, early detection and diagnosis of PGHD is important. It can help minimize the impact on overall health and support optimal growth.

Once Alex was seen by a pediatric endocrinologist, he underwent a series of evaluations, including bloodwork, a bone age X-ray to compare his chronological age with his skeletal age and a growth hormone stimulation test, which measures the body's ability to produce growth hormone. He also had a brain MRI to rule out the potential of any pituitary abnormalities.

The results of these tests confirmed the diagnosis of PGHD, a rare condition that occurs when the pituitary

gland does not produce enough growth hormone. PGHD affects an estimated 1 in 4,000-10,000 children.

Some common signs parents might notice include: their child being significantly shorter than other kids their age, slower growth rate over time, delayed puberty, reduced muscle strength or lower energy levels, slower bone development and delayed physical milestones.

"Receiving Alex's diagnosis was a relief," Benke said. "It provided clarity and a path forward."

Moving Forward with Treatment

"While the diagnosis process was exhausting, starting treatment made the process worthwhile," Benke said.

For decades, daily injections of a drug called somatropin, which is similar to the growth hormone your body produces, have been the standard of care for PGHD. It wasn't until 2015 that the Growth Hormone Research Society recognized the need for a long-acting growth hormone (LAGH), offering once-weekly dosing as an alternative to daily injections.

Benke explained navigating the insurance approval process was another challenge.

"Our insurance required us to try a daily medication before approving a weekly option," she said.

Alex spent three months on daily medication, often missing doses, before he was approved to switch to a weekly treatment option.

"The weekly option made such a positive impact," Benke said. "We now have minimal disruptions to our daily routine and Alex hasn't missed a single dose since."

Beyond a more convenient dosing option, the change gave Benke peace of mind.

"We could focus more on being a family again, without the daily worries of his next dose," she said.

If you're concerned about your child's growth, talk to their doctor as soon as possible. Early diagnosis is important, as treatment becomes less effective once a child's bones stop growing.

Benke's advice to other parents: "Trust your instincts. If something feels wrong, seek out a specialist and push for answers and don't give up, even when faced with hurdles... Stay hopeful and persistent – it's a journey worth fighting for."

Visit GHDinKids.com to download a doctor discussion guide to help prepare for your next appointment.

