

Growth Hormone—How Much Is Too Much?

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We know that growth hormone treatment is one of the best things that ever happened to improve the quality of life for children and adults with Prader-Willi syndrome (PWS). But, due to the enthusiasm of parents, and the lack of knowledge of some physicians ordering the growth hormone, we think it is important that you have a better understanding of the consequences of too much growth hormone (GH). In the past we have published information by Dr. Jennifer Miller on high IGF-I levels which can be a warning that the person is on too much growth hormone. Here I would like to focus on how a physician (and parents) can calculate appropriate dosage. I recently received a call from a mother who found out that her eight-year-old has been on a growth hormone dose that was probably almost double what it should have been, which in turn has created significant gigantism/acromegaly. (Too much IGF-I can cause abnormal growth of your soft tissues and skeleton creating excessive overgrowth of facial features. Gigantism is GH excess in children and acromegaly is in adults) This mom said she trusted that the physician knew the proper dosage and she did not have any concept of what would be an appropriate dose, so I'd like to give some of the guidelines from PWS experts that you can share when necessary.

From the second edition of our PWSA (USA) growth hormone booklet:

For infants with Prader-Willi syndrome, the dosing is based on body surface area. The typical starting dose is 1 mg/m² per day. In older children, beginning doses are typically calculated based on weight alone, or ideal body weight if the child is significantly overweight. Most endocrinologists adjust doses in older children after monitoring growth velocity, weight and IGF-1 (Insulin-like Growth Factor-1) level. The largest dosage is given at the time of puberty, when children normally have their last big growth spurt. For adults, there are standardized dosing regimens for beginning GH treatments. The adult dosage then is subsequently titrated based on IGF-1 levels.

From Dr. Sue Myers, an endocrinologist on our PWSA (USA) Scientific & Clinical Advisory Boards

Although the official recommended Genotropin dose for pediatric patients with PWS is 0.24 mg/kg/wk (for example, 1.5 mg daily for a 100 lb child), I would add several caveats. First, many people with PWS are very sensitive to the effects of GH. In my experience, they may need significantly less than this recommended dose to achieve IGF-1 levels in the upper half of the normal range, sometimes half as much or occasionally even less. Second, overweight children's doses should be calculated based on their ideal body weight for height.

Dr. Barbara Whitman and I did a dosing study many years ago with Drs. Allen and Carrell. We found the positive effects of GH on growth and body composition to be dose-dependent, but the side effects will likely be as well. Following IGF-1 levels at least annually is critical to avoiding overtreatment as described above.

From Dr. Moris Angulo, an endocrinologist on our PWSA (USA) Clinical Advisory Board

Children with PWS seem to be a little bit more sensitive to standard doses of growth hormone (GH). The dose should be considered on ideal weight and monitor clinically features of excessive GH such as rapid growth, unusual enlargement of hands, feet and jaw as well as advanced bone age. Having at least 3 visits per year to a pediatric endocrinologist could help to identify early signs of under & over GH treatment.

That all being said, Dr. Jennifer Miller, and endocrinologists on our PWSA (USA) Clinical Advisory Board, cautions:

It is important for you to know that GH dosing needs to be adjusted for each individual and not only based on standardized dosing.