

Thyroid Issues in PWS

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One of the most commonly prescribed drugs in the USA is thyroid hormone (levothyroxine) to treat an underactive thyroid gland (hypothyroidism). That small gland, located on the neck, produces hormones that are essential to all parts of the body. Weight gain, tiredness, slow growth, and feeling cold are common complaints when the thyroid gland does not work. Thyroid deficiency is not the best explanation of these symptoms in PWS – but low thyroid levels can occur, and regular testing is important.

Primary hypothyroidism is the most common type of thyroid problem. When the gland itself does not work, thyroid deficiency is fairly easy to diagnose. There are symptoms such as weight gain, fatigue, slow reflexes, and low blood pressure and heart rate. Newborn babies are all tested for a severe type of hypothyroidism soon after birth. These problems are no more common in PWS than in the rest of the population. Primary hypothyroidism can be from an autoimmune process, which does run in families, so some people are just more likely to have this diagnosis.

In PWS, we are more likely to see a different type of low thyroid function – related to low thyroid stimulating hormone (TSH) which is from the pituitary. This is called **secondary hypothyroidism** or **TSH deficiency**. In this case, the thyroid gland itself is just fine – but it does not get the signal from the pituitary to make ideal amounts of thyroid hormone. This is an unusual reason for low thyroid hormones, but may be more common in PWS than in the general population. This type of “pituitary hypothyroidism” is easier to manage and is not as severe as primary hypothyroidism.

While most thyroid problems (primary and secondary hypothyroidism) are permanent lifelong conditions, there can be **mild TSH deficiency** when a child is taking growth hormone. It seems that sometimes the TSH production that was enough for slow growth and slow metabolism is simply not enough when growth hormone treatment kicks the body into a higher gear. Sometimes this condition returns to normal when the child is fully grown, and the thyroid supplement may not be needed when growth is completed.

Talk with your provider to understand which type of thyroid problem is being treated. Because **secondary hypothyroidism** is very rare, and primary hypothyroidism is very common, some healthcare providers may assume any patient taking thyroid pills has primary hypothyroidism. For example, emergency room doctors may want to draw a TSH, in case it is the thyroid dose that is causing symptoms – so be prepared to advocate by knowing which thyroid problem has been diagnosed. A very low TSH blood level in primary hypothyroidism would mean the person was taking TOO MUCH thyroid medication. In secondary hypothyroidism or TSH deficiency, a T4 or free T4 is a better test – because the TSH will always be low.

Ask your healthcare provider for advice about how and when to give the pills – usually on an empty stomach, which is hard to do with small children, and never in combination

with any food that contains soy. These pills taste sweet, but should not be chewed. They can be crushed. Thyroid pills are slow acting and stay in the body longer than most medications. Sometimes a missed dose should not be doubled up the following day – ask your provider.

Interested in knowing more about hormones? The Endocrine Society has a superb patient education website filled with detailed hormone information and explanations – www.hormone.org. It does not currently include information about PWS or TSH deficiency, the type of thyroid problem which is more likely in PWS and others with pituitary dysfunction.

Reviewed by Jennifer Miller, MD