Because of a medical crisis where a young person with PWS ended up in intensive care with a possible diagnosis of water intoxication, I e-mailed our medical boards about the situation. The following responses are from physicians with experience regarding PWS and water toxicity. We’re sharing their thoughts here to make the PWS community aware of this potential medical condition ~ Janalee Heinemann, Executive Director

Water intoxication is well known to occur in children and adults with eating disorders regardless of mental abilities, and also in individuals who are severely retarded. This is not a new phenomenon. I am frankly surprised that it doesn’t occur more often in PWS.

We have seen this type of situation several times. In my opinion, anyone who drinks 72 oz. (9 x 8 oz.) is drinking too much water, unless he or she is in a situation such as intense exercise and/or in a hot climate where there is a high rate of water loss. We have been trying to restrict intake to 1-1/2 quarts per day. I would think that even some “normal” people who drink that much water daily would be at risk for hyponatremia [water intoxication].

We have had several of our patients with PWS worked up by adult endocrinologists with no specific findings, except one who might be mildly deficient in anti-diuretic hormone (ADH), and most of the time he does not take his DDAVP and keeps a normal sodium with a restricted fluid intake. I think that this case is probably water intoxication, such as happens in many major cities, usually in babies who have parents who do not know better than to feed water to an infant.

The problem of water intoxication is a difficult one and may be related to two different physiological mechanisms: some of the patients we have seen have compulsive water drinking and often need to be restricted and/or monitored in order to keep their electrolytes in balance; this seems to be a problem related to the PWS itself.

On the other hand, there is a syndrome called SIADH, which is related to a problem the kidney has in filtering out the excretions, and in this case the kidney absorbs too much water. This problem may be related to medications, may occur with other psychiatric maladies and may occur unrelated to all of these. The latter situation is much more likely to throw the electrolytes out of order, as the body usually seems designed to handle fluids without throwing electrolytes off. However, for the person with PWS this may be more complicated because of right heart failure and decidedly needs to be reviewed and handled by a pediatrician/internist.

This person needs to be fluid restricted, but much more importantly, this person needs to be evaluated by a good endocrinologist (and perhaps a neurologist as well). It may be SIADH, but several tests are needed before a diagnosis and treatment plan are made. Water toxicity can be very dangerous.

I would be skeptical about water intoxication. What you haven’t said is what medications the individual was on or if there were other medical issues. It is possible that this may be a case of SIADH that can have a host of causes. In SIADH, there is an inappropriate release of anti-diuretic hormone that causes water retention and can cause this severe hyponatremia. Also when you said the kidneys were normal, what studies were used? Without more information, this is all speculation, but the amount of water we are told was consumed should be adequately handled by normally functioning kidneys as long as there is not an underlying problem like SIADH.

There are two issues: first, identifying individuals at risk and situations in which risk is increased for all individuals; second, protection and treatment.

Individuals at risk are those who consume large amounts of fluids daily where the majority of fluid consumed is water. Specific high-risk situations occur when fluids such as sweat, diarrhea, etc. — that is, fluids containing salt — are lost and then replaced with water, which obviously contains no salt. Certain medications and medical conditions also have a likelihood of causing SIADH that others have referred to.

For those few individuals at risk, prevention is first the identification to ensure that they don’t have unlimited access to water; individuals who sweat a lot in the summer, etc., need to properly replace lost fluid with fluids such as Gatorade. Providers and families also need to understand the potential seriousness of the problem.