

## In-Patient Psychiatric Treatment and Weight Gain: Breaking the Cycle!

By: Janalee Heinemann MSW

The following is an email I received from a mother. The situation is typical.

Hello Janalee,

*I had talked to you over a month ago about my son who was admitted to the psych ward. I had told you how unhealthy and fattening the food was. It was a real struggle to get them to feed him less food, let alone anything healthy. He gained 9lbs in approx 10 days and that was with me calling them everyday begging them to give him a healthier choice and monitoring his food access. I ended up calling the hospital administrator to intervene and explained that my son has a life threatening condition. I then had you fax over a letter on PWS and you told them it was life threatening. If you hadn't have done that I don't think they would have taken it seriously. It was still difficult as most of the staff hadn't read the fax and didn't seem to want to be bothered. It was one of the more horrifying experiences I have gone through. My son would tell me about the food he was given. One time it was potato chips for an afternoon snack. He told them he would prefer an apple. He was freely given brownies and lots of snack foods you would never give someone with PWS. He would have probably gained way more weight if we had not continuously intervened.*

*The staff was rude to me and would hang the phone up on me because I was always asking them to take away food. In the afternoon they had rest time. This is when you go in your room and sit. One of the staff had told him to go to bed. This is after sitting all day with no exercise. This whole experience was such a nightmare. It will probably happen again. We've already been through this three times. There has to be a better way to do this.*

Thank You for all your help, Nancy

**For several years we crisis counselors at PWSA (USA) have been frustrated with the dramatic amount of weight our people who have Prader-Willi syndrome gain when admitted to psychiatric units – in spite of how much information we give the hospital staff and forewarn them of the seriousness of weight gain for PWS.** (It also happens during general hospitalizations but not as often or as dramatic.) In this last year, in spite of my position at PWSA (USA) and my 14+ years of working with the syndrome professionally, plus providing information and meeting personally with hospital staff, it even happened with my own son who gained a dramatic amount of weight in the two weeks that he was admitted to a psychiatric unit – weight that his supportive living staff is still trying to get off of him. All such situations are difficult and the weight gain is dangerous for our people with PWS, which was exemplified in a call I received from a mom who had an adult daughter with PWS who died from a stomach perforation presumably due to being allowed too much access to food in the psychiatric unit. Of course now the hospital is being sued. What is it going to take for

hospitals to take the dangers of food access and overfeeding with PWS seriously?

To add to the problem of the actual weight gain is the reality that when our people with PWS are in this situation and get much more food than typically allowed, they are then motivated to try to get back into the psychiatric unit!

So how can we begin to break this destructive cycle? The following are suggestions from our crisis counselor, Evan Farrar:

- **With information.** Go to our web site at [www.pwsausa.org](http://www.pwsausa.org) and in the medical section, get the article, "Medical Alert for Inpatient Care". Also, have some extra copies of the PWSA Medical Alert book set aside to share with staff at the facility.
- **With advocacy.** Advocate yourself but also enlist the support of others. Talk to your child's medical provider(s) in advance to make sure they understand you will need them to contact the facility directly if your child is admitted. This type of doctor to doctor communication can make a big difference in breaking through the wall of resistance some facilities present. Also, are there others who could advocate for your child's needs? A counselor? A Chaplain? A Case Manager? The more voices expressing concern about food security and other PWS related issues the more likely it is the message cannot be ignored. The key is to have these folks ready to advocate as soon as you need them and that requires advance planning.
- **With training.** Do some research to find out where it is likely your child might be taken in the event of a psychiatric emergency in your area. Find out who is in charge! Make sure to get them information about PWS and offer an in-service training for staff. PWSA (USA) can help you with resources to use such as the DVD "Food, Behavior and Beyond". This will help you to build relationships you can utilize if your child becomes a patient of the facility. If this task seems daunting to take on yourself maybe your local chapter can work together to educate and train facilities in your area.
- **With PWSA (USA) Support.** Remember to call us if your child is admitted to a psychiatric facility. We can fax or e-mail helpful information directly to the unit so that information about food security and behavior is delivered promptly. We find facility staff are often more willing to listen to parent concerns when they know that an outside agency like PWSA (USA) expresses concern and monitors the situation.
- **With perseverance.** We can't give up on this important issue. This is a hard cycle to break but, working together, we can make a difference facility by facility which – in the end – will help people with PWS across the country who find themselves needing psychiatric care at an in-patient facility.