

Information on Summer Camps for the Camper with Prader-Willi Syndrome.



For many parents and caregivers, sending a child with Prader-Willi syndrome away to camp can be filled with mixed emotions. There may be excitement that their son, daughter or resident will be able to participate in an activity that allows them some fun and friendship opportunities. There may be some fears – will they be safe; will their medical needs be met? And there may be worries– will they be successful and not have any major behavior challenges; will their dietary and food seeking needs be met? Most want to know if this is the right camp for their child or adult with Prader-Willi syndrome.

There are many camps across the country that serve children and adults with disabilities. There are camps that operate day or week programs. Some offer a variety of different experiences and others may be more specialized. Some have experience in working with persons with Prader-Willi syndrome – others do not. For some, they will readily make accommodations for diet and behavior – others will not. Often, parents begin the search in the early months of the year. Some camps have a limited number of slots or have special weeks for certain ages or disabilities. It is never too early to begin the research.

The staff at PWSA (USA) relies on parents and caregivers to share camp resources. When they do not have resources, they do their best to locate some special needs camps in your area that the parent or caregiver can contact. Each year, there may be new counselors and/or new leadership at a camp that may affect the campers' experience. One camp may be a wonderful experience for one person with Prader-Willi syndrome and a not-so-nice experience for another camper. In all cases, it is up to the parents and caregivers to research and determine if the camp we may suggest is the right match for your son, daughter or resident. The staff at PWSA (USA) is not responsible for any actions that do or do not take place at a camp.

We would like to suggest asking questions or taking note on some areas when researching a camp:

1. Knowledge and Experience with Campers who Have Prader-Willi Syndrome: Have they served campers with Prader-Willi syndrome? Do they understand or are they willing to learn more about PWS? Are you willing to teach and assist in this learning?
2. Health Services – Do they have a nurse on duty? Who is responsible for administering medications? If a person becomes ill, what is done? Are they willing to learn about the unique health issues that may face persons with Prader-Willi syndrome?
3. Diet and Meal-Serving Style – Do they accommodate special diets? How are meals served? Do campers serve themselves or are portions served to them and monitored? Do they have a camp store or food opportunities that the person with PWS could access food? How much is food a part of their camp experience?
4. Behavior Management – Some have very strict rules about taking campers with behavior problems – you will want to know this in advance. Do counselors receive special training on behavior management? What sort of approaches or consequences do they use?

Make sure to share information about Prader-Willi syndrome and the camper with PWS with camp staff. Include suggestions on how to avoid food and behavior issues; make sure to list any strategies that you know will help the camper; and don't forget to include a health brochure so they will be sure to be aware and understand some of the unique health issues that can face this camper.

We all want the camper with Prader-Willi syndrome to have a positive, healthy experience. If you have had successful camp experiences, please share this with us.