

Prader-Willi
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**Written Testimony Prepared for Delivery by
Craig Polhemus, Executive Director, Prader-Willi Syndrome Association (USA)
at the November 5, 2007, Hearing of the Social Security Administration
on the Advisability and Possible Methods of Identifying and Implementing
Compassionate Allowances for Children and Adults with Rare Diseases**

On behalf of the tens of thousands of families containing individuals with Prader-Willi Syndrome (which though a rare disease is nonetheless the leading genetic cause of life-threatening obesity), I thank you for the opportunity to present this testimony.

Founded in 1975, PWSA (USA) is the national membership organization dedicated to helping children and adults with PWS and their families through every stage of life. One of our most critical programs is our Crisis Intervention Counseling program which assists families with legal, medical, behavioral, educational, housing, and other crises. Difficulty in obtaining timely approval for SSI is the most critical financial issue faced by these families on behalf of those individuals with PWS who attain the age of 18, about the same time that behavioral and other issues often require them to enter specialized group homes. Our Crisis Intervention Counselors deal with this issue on a daily basis, and their experience is reflected in this testimony.

I address each of your five questions in turn:

Question One

Because Prader-Willi Syndrome is not on SSA's List of Impairments and most people know little if anything about it, disability determinations are generally extremely slow and protracted. As a result, the experience of people with Prader-Willi Syndrome and their families or guardians when applying for SSI is one of great frustration. Because PWS is not a listed impairment, a person with PWS must be determined disabled based on other health conditions related to PWS. Most often, this involves qualifying as developmentally disabled.

In such cases, usually the first attempt for benefits is denied, especially if a person with PWS has an IQ over 70 though IQ is irrelevant to his or her inability to live or work independently. If an appeal is filed, it can take 6 months or a year before a decision is made. If that level of appeal is denied, which is frequently the case, then the final appeal with an Administrative Law Judge can take up to a year to complete. Some families have reported to us that the final appeal process took over three years. The Administrative Law Judge level is where many approvals for PWS take place because a face-to-face hearing gives the judge an opportunity to see the level of disability present in a person with PWS. This face-to-face evaluation is especially persuasive for someone unfamiliar with PWS because it is a complex disability that can involve many features including both physical and developmental disabilities.

During the waiting period, the individual with PWS is at serious risk. Due to lack of funds, young adults may be waiting for placement in a facility that specializes in the care of people with PWS. If they are severely or morbidly obese, they may be waiting for admission to the Children's Institute in Pittsburgh, PA. The Children's Institute – which serves both adults and children – provides the world's only specialized rehabilitation treatment program for people

still hungry for a cure.

with Prader-Willi Syndrome. We know of several people with PWS who have died before they could get SSI and Medicaid to help cover the costs of this life-saving service of the Children's Institute.

Yet all or virtually all the applicants whose representatives pursue all available hearings and appeals are ultimately found eligible because individuals with PWS are unable to work in an unsupervised setting due to their uncontrollable hunger which requires that food access be controlled 24 hours a day, 7 days a week, on a lifelong basis, along with other biologically driven behavioral issues incompatible with an unsupervised work setting.

Question Two

The omission of PWS from the List of Impairments is the primary reason for delay when a person with PWS applies for SSI. PWS is rare and relatively unknown, so SSA evaluators and even many members of the medical community are too often unaware of the specifics of PWS. Prader-Willi Syndrome is a life long, life threatening condition. An individual with PWS must be closely supervised all his or her life particularly because the issue of food management is so critical to the health of a person with PWS. Some people with PWS have tried to live independently in the community but to our knowledge those efforts have been unsuccessful and in some cases led to death. While we support the goal of independent living, we believe it must be in the context of a safe and healthful living environment for a person with PWS. This means, whether in a supervised apartment or residential facility setting, having constant supervision by people familiar with the syndrome. In addition, appropriate medical care is required on a regular basis to deal with the myriad of health challenges PWS creates. Trying to demonstrate and prove these needs on a case-by-case basis wastes SSA's administrative resources, complicates and prolongs the eligibility determination process, and risks both health and lives. If PWS were recognized as a qualifying impairment from the start, then the process would be greatly simplified to the benefit of our constituents and with consequent administrative savings for SSA.

Question Three

The TERI process is irrelevant to those with PWS because it is not classed as a terminal illness. Presumptive disability is not currently available because PWS is not on the List of Impairments. We strongly endorse the presumptive disability process and urge that PWS be immediately added to the list of qualifying conditions. This should eliminate the long wait time, allow people with PWS to more immediately access needed benefits, and save SSA much currently wasted administrative effort and cost.

Question Four

Because virtually every individual with PWS whose case is pursued through all available hearings and appeals is found to be eligible (in fact we are unaware of any contrary cases), there is little point for SSA's adjudicators to individually consider the impact in each specific case. The objective medical evidence required to definitively establish PWS is genetic testing, and a finding of PWS should suffice to establish eligibility.

Question Five

Although we welcome the opportunity to offer additional suggestions and will do so when space is not limited to two pages, by far the most important suggestions we can make are (1) to have PWS added to the List of Impairments and (2) for qualifying disability to be based solely on genetic testing establishing that an individual has PWS. Every day our association supports people with PWS, and their families, who are trying to create a stable and healthy life in the face of an incredibly debilitating disability. PWS affects every aspect of a person's life. For our families to have to spend time and precious energy proving a disability that is so obvious to them, and everyone around them, in their everyday life is both frustrating and demoralizing – especially when SSA's own experience establishes that these individuals do indeed qualify as disabled if they pursue all available hearings and appeals. We believe that placing PWS on the List of Impairments would be the swiftest and most effective step SSA could take to reduce unnecessary administrative expenditures and to remedy this enormous problem in the lives of people with PWS.