PRADER-WILLI SYNDROME ASSOCIATION Still hungry for a cure.

Prader-Willi Syndrome and the Federal Definition of Developmental Disability

At this time, a person with a PWS diagnosis is not automatically approved for SSI. Instead, a person with PWS usually is often approved based on the federal definition for a developmental disability found in the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C. §6000 et seq. and) which states:

"The term "developmental disability means a severe, chronic disability of an individual 5 years of age or older that –

- (A) is attributable to mental or physical impairment or a combination of mental and physical impairments:
- (B) is manifested before the individual attains age 22;
- (C) is likely to continue indefinitely;
- (D) results in substantial functional limitations in <u>three or more</u> of the following areas of major life activity
 - (i) self care;
 - (ii) receptive and expressed language;
 - (iii) learning:
 - (iv) mobility;
 - (v) self-direction:
 - (vi) capacity for independent living; and
 - (vii) economic self-sufficiency; and
- (E) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated, except that such term, when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided."