Prader Willi Syndrome Association (USA)

National Database of People with Prader Willi Syndrome

Over the years information about someone with Prader Willi Syndrome was collected by the Association on an informal basis with little attempt to verify its accuracy or to organize the information in a useful format. The information varied from virtually nothing to reasonably accurate data on a particular person. In the end the information gathered over the long history of the Association was ineffective for use in scientific or advocacy programs.

Recognizing the need for accurate prevalence data for research and advocacy activities and to help the scientific community contact potential research project participants, the Association began a program to establish an accurate database of people with PWS in the U.S. Key factors in designing the program were; simple survey design to ensure high return rates and accurate information; use of the internet; customized, yet simple, software for data input and maintenance; handling the pertinent HIPPA regulations and trend analysis.

Starting with a simple one page survey which asked for basic medical and contact information, the Association publicized the new database project in its bi-monthly newsletter, on its internet site and at its annual family conference.

In 2003, a group of independent universities won a grant from NIH to study certain rare diseases, one of which was PWS. As a side benefit of having begun work on its database, the Association was able to help the research team establish their database protocol and PWS will get a significant jump start on the overall research project.

Through September 2005, over 1,400 records were established. The first analysis of the data and trends was presented to 75 scientists at the scientific session of the annual conference in July 2005.

Finally, several countries have inquired about using the U.S. model for the development of their own database systems and scientists have requested the data to perform trend analysis.

While in its infancy the database project has already yielded benefits to people with PWS and promises to continue to be a factor in the Association's research and advocacy work.

Contact: www.PWSAUSA.org