



PARENTS AND SIBLINGS



HELP US FIND OUT HOW PWS AFFECTS FAMILIES LIKE YOURS

Researchers from the Pacific Graduate School of Psychology are conducting a study to learn about the impact on families with a child diagnosed with Prader-Willi Syndrome (PWS). The investigators are Mary Mazaheri, MS, and Raazhan Rae-Seebach, MS. They are requesting participation from adult parents and siblings (13 to 21 years of age) of individuals diagnosed with PWS. It is their hope that information that is learned will help identify needs of parents and siblings of children with PWS. It is also hoped that results of the study will facilitate communication and build stronger relationships between family members, as well as assist health practitioners in providing comprehensive care for these families. In this work, the researchers are collaborating with other health care providers including, Suzanne Cassidy, MD from the University of California, San Francisco.

If you choose to participate, you and your undiagnosed child will be asked to complete a series of questionnaires asking about resources, adjustment and perceived stress as it relates to the PWS diagnosis. The questions are designed to help us better understand your family's experiences of coping with a chronic medical condition, and to hear your suggestions for how care in this area can be improved. Your individual responses will be kept completely confidential. Total participation in this study will take approximately 3 hours.

If you are interested in participating in this study please email:

PWSresearchers@gmail.com

