



GUIDELINES OF CARE IN PRADER-WILLI SYNDROME MULTI-DISCIPLINARY CLINICS

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Introduction/Background: Prader-Willi syndrome (PWS) is a complex, multi-system disorder affecting approximately 1/15,000-1/30,000 individuals. The complexity of the disorder along with the numerous medical needs of individuals with PWS entails the implementation of a multidisciplinary approach for the care of these individuals. We hypothesize that a set of guidelines, if used by most multispecialty clinics, would provide optimal care for individuals with PWS. The main research aim of our study is to assess the practical implementation of care for multispecialty PWS clinics, and document impeding challenges. We started this process by assessing the use of guidelines in multi-disciplinary clinics affiliated with Prader-Willi Syndrome Association-USA (PWSA-USA).

Methods: We contacted PWSA-USA and received the contact list of clinics specializing in PWS, most recently updated in March of 2017. We called each of the phone numbers provided to determine if the clinic fit the multi-disciplinary classification. When contact was made with an established clinic, we requested an email address. From those contacts, we asked for age-dependent guidelines of care, invited the contact to share the guidelines, and requested comments on the specific utility of the guidelines.

Results/Discussion: Out of the 30 clinics that we attempted to contact by phone number provided by PWSA-USA, 16 lead to a successful communication (six of the phone numbers provided were out of service). We found 9 multispecialty clinics with a care coordinator and email address to follow up with an email invitation to share information. The rest of the contacts reported no established clinic, or no guidelines used. After a ten-day response period, 5 of the contacts gave the requested information. We determined that each of the responding clinics use different guidelines: 3 utilize published guidelines (Duis et al, 2018; AAP Health Supervision for Children with Prader-Willi Syndrome, 2011; IPWSO Website, 2019), and 2 use independent specialty-specific guidelines. The guidelines range from 2011 to 2019 in publishing date. One of five clinics responded with comments on utility of the guidelines for care that they use.

Conclusions: The multispecialty PWS clinics throughout the United States generally use independent guidelines to direct the care of individuals with PWS. We propose that regular discussion sessions surrounding specific standards of care at the PWS National Conference, and collaboration through online portals will facilitate a community of care.

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<https://www.ipwso.org/medical-professionals>