Advocating for Rare Diseases Through UHC

IPWSO
International
Prader-Willi Syndrome
Organisation

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The Case of Prader-Willi Syndrome (PWS)

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Using UHC framework/policies	Barriers to advocacy for PWS	Challenges with using UHC	Major advocacy wins	#UHC4RareDiseases campaign materials
Provide a coherent means of campaigning for equity for people with rare diseases.	Small numbers of people with PWS. Geographically dispersed. Cultural factors.	Relatively low awareness of the UHC campaign among rare disease organisations.	Growth Hormone Therapy is provided as a treatment for PWS in many countries.	Materials sent to the 37 national PWS associations that comprise IPWSO's membership.
Facilitate a shared campaign bringing together different countries and rare disease groups.	Advocacy priorities may differ in different parts of the world.	Some organisations may have already committed their limited resources to other initiatives.	PWS-specific social services are now provided in some countries.	#UHC4RareDiseases posts on IPWSO's own social media channels.
A vision for how people with rare diseases can be integrated into health and social services.	Self-advocacy by people with PWS is often difficult & caregivers may also struggle to fulfil an advocacy role.	Difficulty getting key decision-makers to take an interest in rare diseases.		