

Patient Journeys are info-graphical overviews that visualize patients' needs in the care of their rare disease. Because Patient Journeys are designed from the patient's perspective, they allow clinicians to effectively address the needs of rare disease patients.

For more information, please visit:

<https://www.ern-rnd.eu/patient-journey-hereditary-spastic-paraplegias-hsps/>






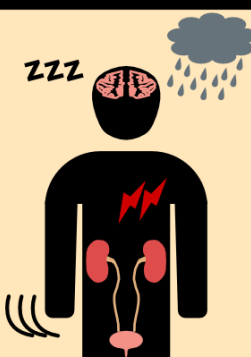
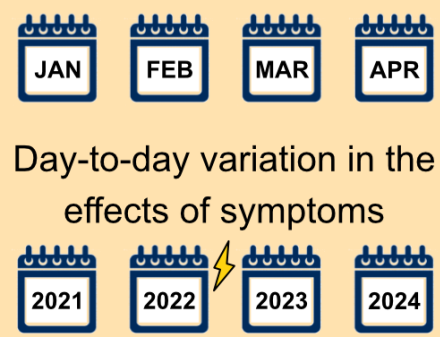




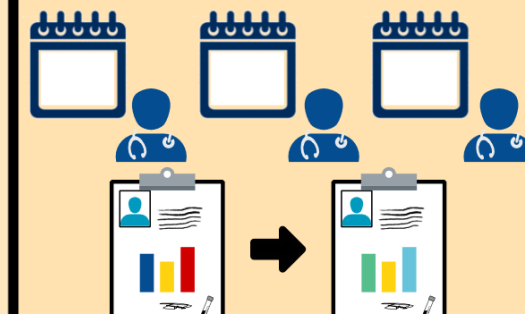
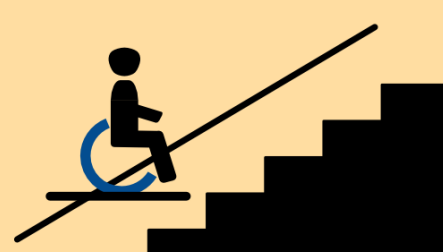

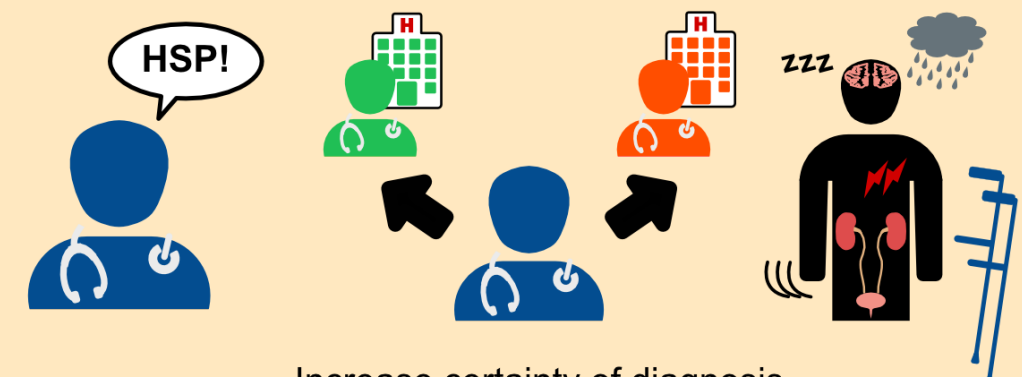





Hereditary Spastic Paraplegias

The patient journey



A visual description of what patients need and how clinicians can address them



	First symptoms	Diagnosis	Treatment	Monitoring	
Disease	<div><p>Childhood</p></div> <div><p>Age 30 - 50</p></div> <p>Early symptoms are often unspecific</p>	<div></div> <p>90+ different disease types. Misdiagnosis is common</p>	<div></div> <p>Possible symptoms: fatigue, urinary issues, pain, depression, spasms, cognitive problems</p>	<div></div> <p>Day-to-day variation in the effects of symptoms</p> <p>Slow progression of symptoms. New symptoms can develop</p>	<div></div> <p>Understand how to accept life with HSP</p>
Clinic	<div></div> <p>Early symptoms in people with HSP can include balance issues and tripping</p>	<div></div> <p>Clinical diagnosis after excluding other conditions</p>	<div></div> <p>Genetic diagnosis might be inconclusive</p>	<div></div> <p>Regular follow-up. Personalized plan changes over time with progression</p>	<div></div> <p>Plan to consider: future generations; changes at work; modifications at home</p>
Challenges	<div></div> <p>Knowledge of HSP is low in many healthcare professionals</p>	<div></div> <p>- Increase certainty of diagnosis - Referral of people with HSP to different expert centres - Awareness and prediction of all HSP-aspects</p>	<div></div> <p>No cure for HSP, only symptomatic treatment available. Research & clinical trials needed</p>	<div></div> <p>Not all people with HSP want to plan. Need for personalized support</p>	
Goals	<div></div> <p>- Clinicians should be able diagnose HSP and know experts to refer people with HSP to - Support for people with HSP after diagnosis, including physiotherapy and stretching - Providing people with HSP with information and treatment options</p>	<div></div> <p>Get people with HSP to maintain a routine with physical activity. Best quality of life possible.</p>	<div></div> <p>Providing information about support networks; current research work; patient registries</p>		

