PATIENT JOURNEY OF HUNTINGTON'S DISEASE

PATHWAY OF HUNTINGTON'S DISEASE

Huntington's disease (HD) is an autosomal dominant neurodegenerative disorder with a 50% chance of inheritance, affecting both men and women. Symptoms include motor, cognitive, and behavioral changes, usually emerging in middle adulthood. Juvenile HD, with onset before 21 years, progresses rapidly. Understanding the patient journey is crucial due to the lack of available treatments, making the late stage burdensome for patients and caregivers.

PATIENT JOURNEY

The HD patient journey begins with pre-manifestation, characterized by non-specific clinical signs and progresses gradually to late stages marked by functional losses.

Family history of HD

Predictive Testing – Only a small minority choose to access genetic testing, and for some, this process can take several years.

No known family history of HD

Access Healthcare – Experiencing unknown symptoms – access genetic testing and counselling for diagnosis

Potential Misdiagnosis – Initial symptoms may not be immediately recognized

Clinical Pathway | Challenges

As treatments are only available to manage symptoms, it maybe suitable to participate in clinical trials.

Pre-manifestation	First Symptoms	Diagnosis	Treatment	Monitoring
▪ Pre-manifest HD shows non-specific clinical signs, e.g., subtle cognitive or behavioral changes. ▪ HD runs in families and most people with HD witness it developing in close relatives.	▪ The transition from pre-manifest to manifest HD is gradual, with early symptoms resembling other disorders, complicating diagnosis. ▪ A conventional onset is marked by motor abnormalities as well as cognitive and behavioral issues.	▪ Diagnosis includes neurological examination and genetic testing. ▪ Disclosing genetic status is complex, influencing crucial life decisions for patients and families. ▪ Predictive testing is not recommended for asymptomatic children and adolescents.	▪ There are currently no available effective disease modifying therapies. ▪ Symptoms are mapped and managed based on functional relevance, with repurposed drugs addressing motor and behavioral symptoms.	▪ The main goal is to sustain function and autonomy. ▪ Key areas to monitor for an improved quality of life are physical activity, psychological well-being, and nutrition. ▪ Late-stage patients require full-time care and assistance.
▪ People at risk of HD and those with pre-manifest HD fear the disease onset. ▪ Suppressing and attempting to ignore symptoms are common coping strategies. ▪ Healthcare professionals are often unaware of the subtle alterations that can affect well-being and daily function.	▪ No two HD patients are alike, and because changes are gradual, it may take years to establish the disease onset. HD being a rare disease, healthcare professionals often struggle with diagnosis and miss relevant questions about family history.	▪ The intricate symptoms of HD often lead to misdiagnosis. ▪ Limited collaboration among genetic units, clinical practice, and research centers hampers smooth patient transitions from diagnosis to follow-up treatment.	▪ Patients under emotional stress and experiencing cognitive changes may overlook symptoms, straining familiy members. ▪ Treatment plans, adjusted for symptom fluctuation, often prioritize monotherapy ▪ However, adjuvant therapy, such as antidepressants, is frequently needed for managing other disorders.	▪ HD has a relentless progression, so patients and families strive to adjust to increasing challenges and adverse outcomes. ▪ Families and healthcare professionals struggle to keep patients active and motivated while dealing with gradual functional losses.

UNMET NEEDS

Category	Key Unmet Needs
Barriers in Life with Disease	Restrictions in social life
	Limitations in favorite activities
	Acceptance of limitations arising from the disease
	Acceptance of limitations resulting from the disease
	Negative emotions
Barriers in Accessing Professional Help	Lack of information about the disease and prognosis
	Control of symptoms
	Removing barriers
	Insufficient equipment
	Challenges when providing care
	Maintaining human dignity
	Securing optimum interventions at the end of life

Right from understanding key issues to advising you through the right set of insights and recommendations, Aranca Research, consolidation, and insightful analysis to aid in-depth understanding of therapy and effective decision-making

HOW CAN ARANCA HELP?

01 **Patient Journey Mapping:** Pre- and post-diagnosis, field stories, and burdensome part of disease from patient and caregiver perspective

02 **Disease Progression Modeling:** Parameters used in disease progression, disease and symptom progression

03 **Patient Breakpoint Analysis:** Understanding key pain points in the patient journey from patient and caregiver perspective

04 **Unmet Needs Mapping and QoL:** Disease progression, symptoms impacting QoL, daily activity impairment

05 **Economic Burden and Unmet Need Analysis:** Impact of disease on patient's economic well-being and unmet needs analysis

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info@aranca.com

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