

Navigating the Unknown

Understanding Rare Neuroimmune Disorders



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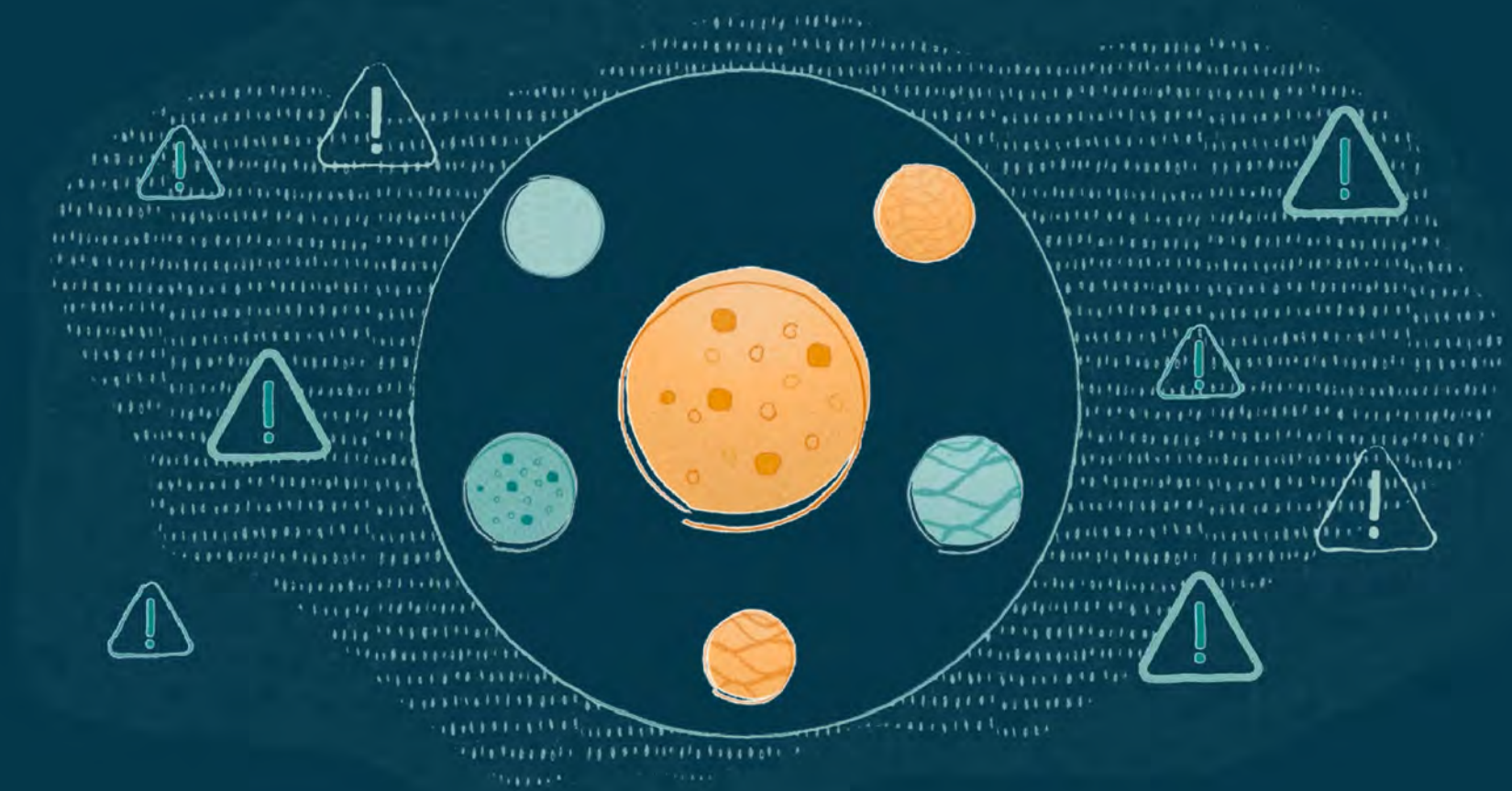
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Rare neuroimmune disorders are a group of conditions that affect the nervous system, particularly the brain, spinal cord, and optic nerves.



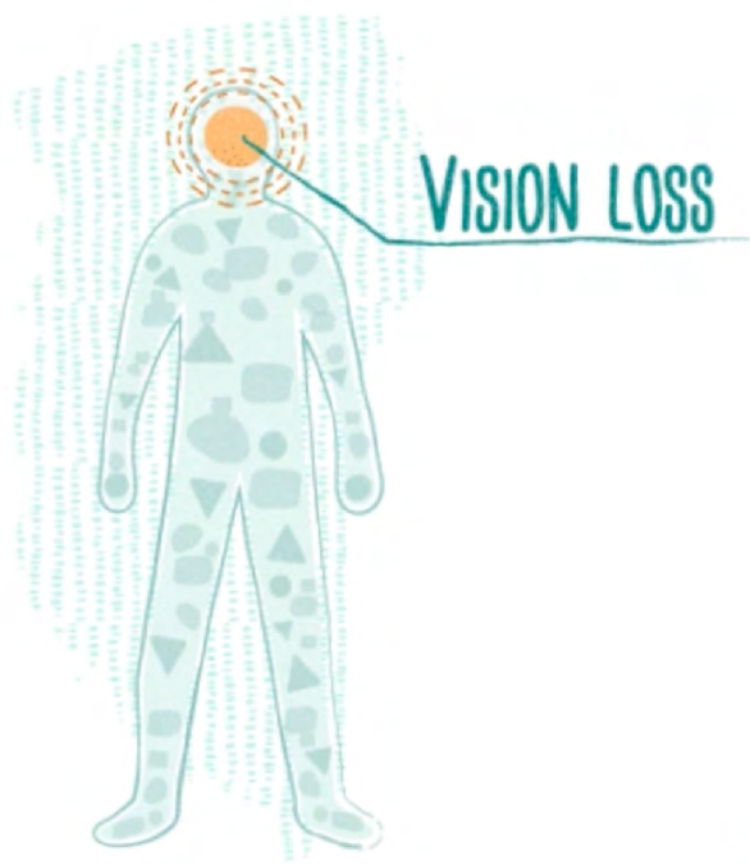
They include diseases like acute disseminated encephalomyelitis (ADEM), acute flaccid myelitis (AFM), MOG antibody disease (MOGAD), neuromyelitis optica spectrum disorder (NMOSD), optic neuritis (ON) and transverse myelitis (TM).



Damage to the central nervous system from these conditions has lifelong, and often permanent and devastating impacts.

Individuals often experience rapid and sudden onset of symptoms, leading to severe outcomes, from significant mobility issues, blindness, paralysis, loss of sensation, and bowel and bladder dysfunction to life-threatening complications requiring ICU care.

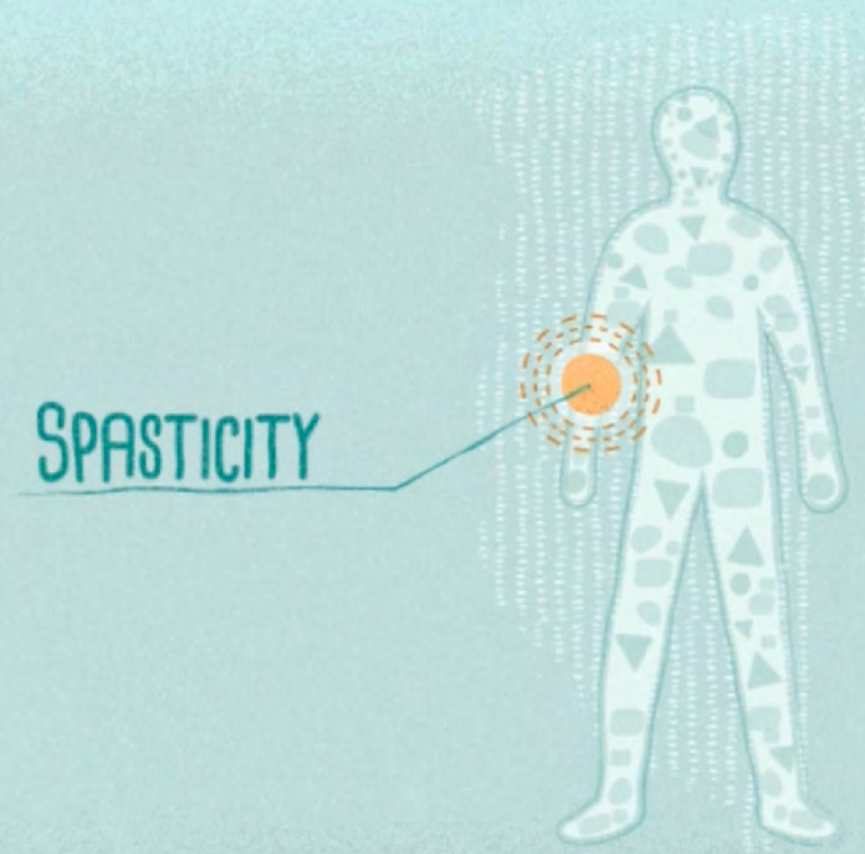
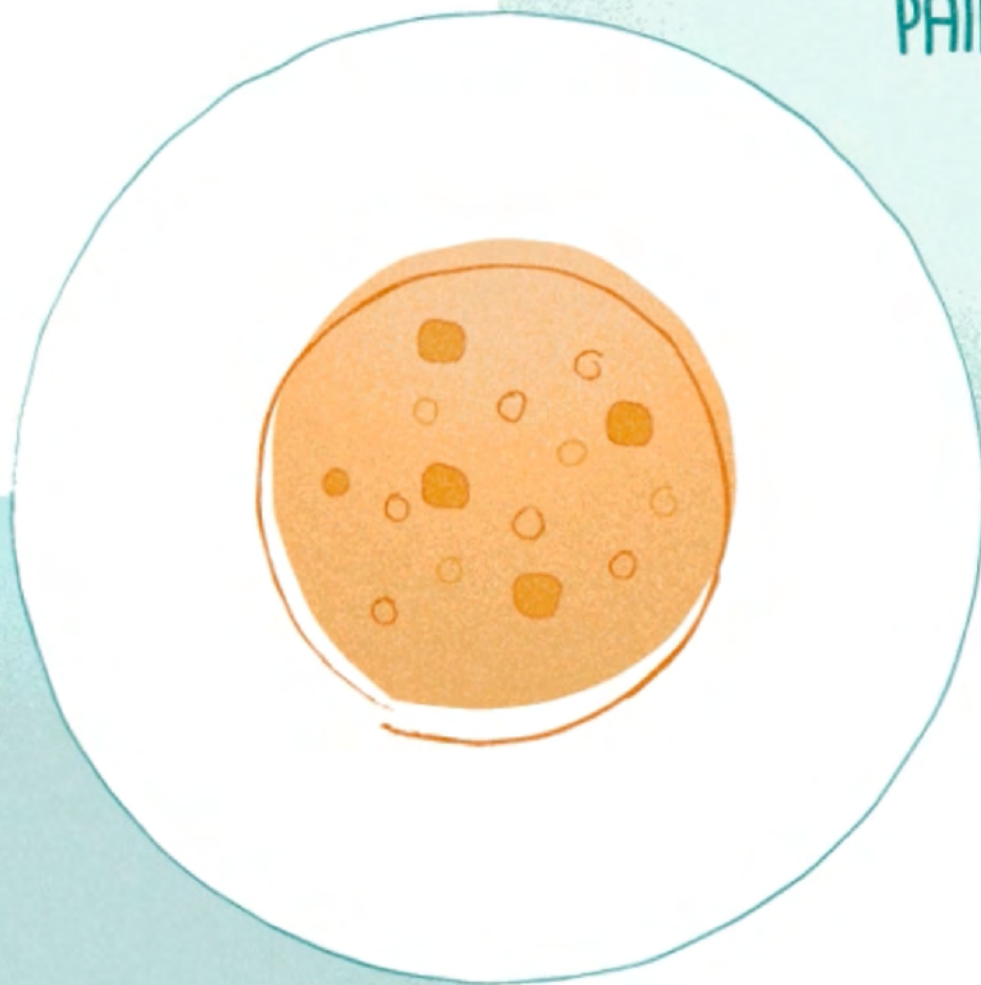




VISION LOSS



NEUROPATHIC PAIN



SPASTICITY



PARALYSIS

The data on the prevalence and incidence of these rare neuroimmune disorders is largely underestimated due to misdiagnosis and underdiagnosis. In total, these disorders have a conservative estimated incidence of 1 to 64 per million per year, depending on the disorder.



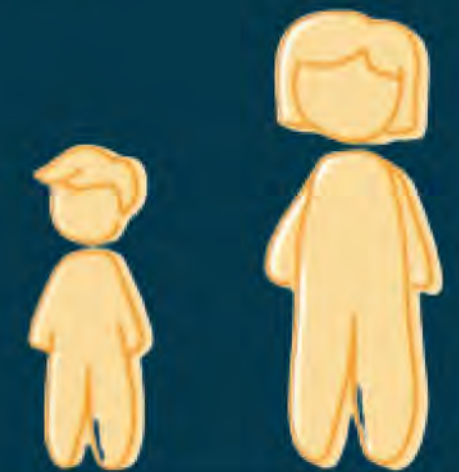
**Conservative estimates indicate that 83,000
Americans have some type of disability
caused by a rare neuroimmune disorder.**



They can strike anyone, from as young as 6 months old, often manifesting suddenly.



25% of cases affect children. The early onset of these conditions means children and families must confront these challenges from a young age, shaping their experiences and interactions with the world.



The exact causes of rare neuroimmune disorders remain largely unknown, adding a layer of fear and concern for patients and researchers alike. This uncertainty complicates both diagnosis and treatment strategies.





While some treatments exist to manage symptoms or slow progression, there is currently no cure for these disorders.

The path to a correct diagnosis is often long and complex, hindered by the rarity of these conditions and symptoms that can mimic other diseases.



Misdiagnosis, delayed diagnosis, and delayed treatments are common due to a lack of knowledge regarding symptoms, testing, and appropriate medical interventions in those providing front-line medical care.

Some of these conditions are relapsing, meaning individuals can experience periods of remission followed by flare-ups. This unpredictability can cause significant stress and anxiety, impacting mental health and overall well-being.





Adapting to a rare neuroimmune diagnosis involves navigating healthcare systems, advocating for one's care, and coping with the emotional toll through these uncertain times.



Many individuals face these challenges with limited support due to a general lack of awareness about their condition.

Some symptoms like fatigue, pain, and cognitive issues may not be visible, leading to a lack of recognition and understanding from society, including sometimes from friends and family, exacerbating feelings of isolation.



The built environment often does not accommodate the needs of those living with disabilities, presenting significant challenges in accessibility and inclusivity. This adds an additional layer of difficulty to daily life for those affected by rare neuroimmune disorders.





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