**SUPPLEMENTARY METHODS**

*Data Collection and Statistical Analysis:* Primary caregivers of 64 patients with genetically-confirmed AP-4-HSP were asked to complete the CPCHILD**©** questionnaire in their primary language 1-4. The questionnaire consists of 37 items in 6 sections covering the following domains: Activities of Daily Living/Personal Care (9 items); Positioning, Transferring & Mobility (8 items); Comfort & Emotions (9 items); Communication & Social Interaction (7 items); Health (3 items); and Overall Quality of Life (1 item). Sections 1-6 assess the degree of difficulty with accomplishing a task or activity. Section 7 rates the importance of each item to overall quality of life using a 6-point ordinal scale. Scores for each section and the total score are standardized and range from 0 to 100. On average, the questionnaire took 35.5±34.8 (SD) minutes to complete. Clinical severity was assessed using the Spastic Paraplegia Rating Scale (SPRS) 5. The spasticity subscore was calculated by summarizing items 7-10 scoring spasticity of hip adductor muscles, weakness of hip abduction, spasticity of knee flexion and weakness of foot dorsiflexion 6. To assess mobility, a four-stage functional mobility scale (4FMS) 7 was used: (I) walking without aid; (II) walking without aid but unable to run; (III) walking with aid; and (IV) wheelchair-dependent.

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