



Annual Health Maintenance Checklist for Hunter Syndrome (Neuronopathic and Non-Neuronopathic)

Recurring Lab Tests

Item	Notes / Comments
Urine GAGs – periodic, based on MPS specialist recommendation	
I2S antibody testing – periodic, start after 3 months / 12 infusions of ERT or as indicated	
I2S leukocyte enzyme level – for those post-HSCT, as recommended by transplant specialist	

Recurring Radiology / Imaging / Studies

Item	Notes / Comments
MRI brain/spine – every 1–3 years (monitor for hydrocephalus, spinal cord compression)	
Cervical spine flexion/extension x-rays – monitor for atlantoaxial instability	
Orthopedic x-rays – monitor for kyphosis, hip dysplasia, or other orthopedic issues	
ECG and echocardiogram – every 1–3 years (evaluate heart valves and function)	
EMG / Nerve conduction – every 1–3 years (evaluate carpal/tarsal tunnel syndrome)	
Audiology exam – every 6–12 months (assess hearing, adjust hearing aids if needed)	
Sleep study – every 1–3 years (evaluate for obstructive sleep apnea)	
Pulmonary function testing – every 1–3 years after age 5–6 (if able to participate)	
EEG – as needed (evaluate for seizures)	

Recurring Medical Specialty Visits

Item	Notes / Comments
Audiologist – every 6–12 months, adjust hearing aids, consider ABR under anesthesia if needed	
Bone Marrow Transplant Specialist – for HSCT patients, monitor follow-up labs and complications	

Cardiologist – every 1–3 years, interpret ECG and echo results	
Developmental-Behavioral Pediatrician – manage behavior and sleep concerns	
Endocrinologist – consult around age 8–9 (pre-puberty) to assess growth and bone age	
Gastroenterologist – as needed; manage reflux, nutrition, or G-tube needs	
Hand Surgeon – as needed for EMG-confirmed carpal tunnel syndrome	
MPS Specialist / Geneticist – every 6–12 months; review labs, radiology, treatment options, and clinical trials	
Neurologist – every 12 months; monitor hydrocephalus, seizures, nerve studies	
Neurosurgeon – as needed; monitor spinal compression or hydrocephalus	
Neuropsychologist – annually or per specialist; conduct cognitive testing and behavioral assessment	
Ophthalmologist – annually; assess visual acuity and retinal changes	
Orthopedist – annually or as needed for genu valgum, hip dysplasia, etc.	
ENT – annually; check tonsils, adenoids, airway, consider T&A; or tubes	
Pediatrician – every 6–12 months for vaccines, growth, and general health	
Pediatric Dentist – every 6 months; routine dental care (common issues: delayed eruption, enamel defects)	
Physiatrist / Rehab Medicine – as needed; adaptive equipment, orthotics, therapy modifications	
Pulmonologist – annually or per symptoms; interpret sleep studies and function tests	

Recurring Therapies

Item	Notes / Comments
Speech Therapy – typically 1–2 times weekly; consider augmentative communication evaluation	
Occupational Therapy – 1–2 times weekly; focus on adaptive equipment and self-help skills	
Physical Therapy – 1–2 times weekly; maintain mobility and function	

Behavioral Therapy (e.g., ABA) – as recommended by neuropsychologist or MPS specialist	
Other therapies to consider: hippotherapy, aqua therapy, art therapy, music therapy	

Educational / Developmental Services

Item	Notes / Comments
Early intervention (ages 0–3)	
School-based services (ages 3+) with IEP or Section 504 plan	
Engage local agencies supporting special needs (medical, developmental, educational)	

Additional Considerations

Item	Notes / Comments
Identify palliative and respite care resources	
Apply for state-based waiver programs (Medicaid, Katie Beckett, HCBS)	
Connect with home healthcare providers	
Maintain updated medical information (e.g., Backpack Health profile)	
Follow clinicaltrials.gov for ongoing studies	
Attend Project Alive community events to engage with experts and families	

These guidelines are based on consensus from MPS II experts and families and are intended as a reference for discussion with your medical team. Individual needs may vary. For updates, visit clinicaltrials.gov or attend Project Alive community events. Last updated: October 2025.

