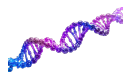




## Kids and Teens with HSP

Hereditary Spastic Paraplegia (HSP) affects the nervous system pathways that control walking and movement. Many children with HSP grow up to lead active, successful, and independent lives. With the right support, kids with HSP can thrive in: school, friendships, sports and activities, college and careers.



## What is HSP?

HSP is a group of rare, genetic neurodegenerative disorders that primarily affect the long motor pathways in the spinal cord. While HSP primarily affects movement, some students may also experience differences in learning, processing, or attention.

- The hallmark feature is progressive lower extremity spasticity and weakness.
- HSP is not a single condition. More than 90 gene types (SPG types) have been identified.
- Each gene impacts cellular function differently, resulting in wide variability in symptoms and progression.
- Even individuals with the same gene type present differently.
- HSP is best understood as a spectrum condition rather than a single clinical picture.
- Symptoms may evolve over time and vary significantly between individuals.

*Note: Supports should be individualized—as needs vary significantly from student to student and can vary day to day.*



### Possible Motor features:

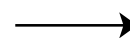
- Lower extremity spasticity
- Gait abnormalities / toe walking
- Muscle stiffness & weakness
- Fatigue & balance challenges
- Bladder and bowel dysfunction



### Possible complex features:

- Speech & fine motor challenges
- Learning or processing differences
- Behaviour regulation when fatigued
- Vision or hearing differences

Visit the SPF website for Kids & Teens



## Mobility can Vary. Students may:

 Walk independently  Use orthotics.  Use mobility devices.

*Although learning pathways may vary with the right accommodations students can access the curriculum and thrive*

*Please, be sensitive to diagnostic disclosure wishes*



## Respect, Understand, Include

- Be sensitive to diagnostic disclosure wishes.
- Focus on individual symptoms, not labels.
- Distinguish motor challenges from cognitive ability
- Promote school-wide social inclusion education.



## Common Challenges in School



### Mobility & Energy

- Walking long distances
- Fatigue impacting processing
- Physical education impact
- Bathroom readiness



### Other Challenges

- Social bias & stereotypes
- Carrying materials
- Fluctuating symptoms
- Time for tasks & transitions

*Fatigue can impact processing time as well as movement. Outputs may not reflect understanding. Processing time can vary.*



## Support Strategies That Help

- Extra time between classes
- Elevator access & rest breaks
- Typing instead of handwriting
- Extra time on tests
- 504 Plan / IEP / EHCP
- Multiple response formats
- Adaptions to PE to enable inclusion
- Flexible deadlines
- AAC technology where there are significant speech and language challenges.
- Seating for accessibility and to maximise participation including peer to peer collaboration

## Activities teens with HSP might enjoy



### Creative

Art  
Music  
Theatre  
Film making



### Technology

Robotics  
Coding  
Gaming  
App design



### Strategy & Thinking

Chess  
Debate  
Quiz bowl



### Adaptive Sports

Swimming  
Adaptive skiing  
Wheelchair basketball  
Rowing

### ♥ Helping Kids Build Confidence

Encourage strengths, independence, and connection with others. Students with HSP pursue a wide range of paths — including careers in science, technology, the arts, advocacy, and more.



**Childhood-Onset HSP 2025 Survey Report -use the QR code**

Visit [childhoodonsethsp.org](http://childhoodonsethsp.org) for the handbook and resources.

Contact us at: [kids\\_and\\_teens\\_committee@sp-foundation.org](mailto:kids_and_teens_committee@sp-foundation.org)

*Different pathways, limitless potential.*