SUPPORTING STUDENTS WITH PHTS

PTEN Hamartoma Tumour Syndrome (PHTS) is a rare genetic condition that causes an increased risk for certain cancers, benign growths, and neurodevelopmental conditions.



Executive Functioning

Students with PHTS have difficulty planning and organizing information. This includes:

- Sequencing multiple steps, and
- Remembering when to do things. For example,
 - scheduling appointments or responsibilities,
 - completing homework,
 - and planning activities or tasks.

Processing Speed

Students with PHTS process information differently and show slower processing speed. Including the following:

• Slower processing of speech, language, reading, and visual information.

Intervention

Students with PHTS can improve their planning and organizational skills with the following steps:

- Calendars, timers, and visual schedules.
- Breaking down challenging activities and tasks into smaller parts.
- Making lists, and
- Having someone to help them who understands these challenges can also be beneficial.

Intervention

- Educate caregivers, teachers, and others who interact with students with PHTS about speaking slowly and at an even pace. Also, provide frequent repetition of important information.
- Ask attention questions to make sure the student receives the information.
- Allow more time for responding, including extra time on complex tasks like school tests, and give more time to respond when playing group games.

Sustained Attention

Some students with PHTS have difficulty keeping their attention focused. This can be particularly true for less interesting (boring) tasks.

Intervention

Strategies to deal with problems with sustained attention:

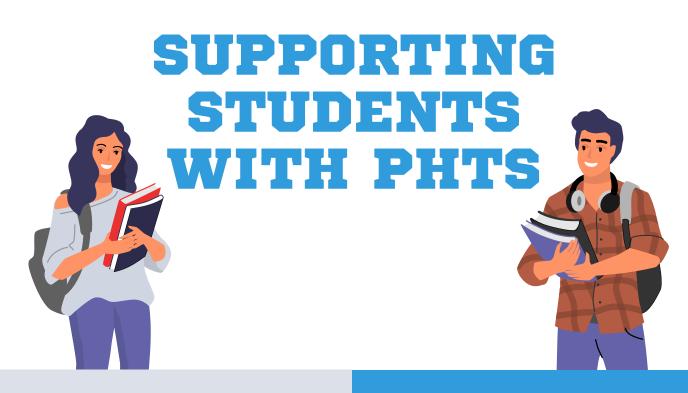
- Ensure you only require attention when the person is most alert and ready to focus.
- Make the information exciting or interesting to the student, and reward sustained attention, especially for complex tasks.
- Individuals might need a referral to a psychologist or psychiatrist for evaluation of possible ADHD.
- Some students with PHTS may need medication or combined medication and therapy for ADHD.

Working Memory

Research demonstrates that some students with PHTS show problems holding information in their memory and acting on it so it can be used or moved to long-term memory for storage. Reading comprehension can also be difficult, but the listed interventions can help.

Intervention

- Provide information slowly in smaller chunks to help manage working memory problems.
- Please make sure that the information to be learned is given only under conditions of optimal attention (e.g., removing distractions and working at times of day when it's best for the student).
- Repetition is helpful to ensure students with PHTS have time to move information learned from short-term working memory to long-term memory.



Fine and Gross Motor Skills

Many young children have gross motor skill issues. This includes the following:

- Jumping and running, or
- Fine motor difficulties like writing.
- Sometimes, these challenges persist into adolescence and adulthood.

Intervention

- If your PHTS student needs it, please seek a referral to occupational and physical therapy, and we recommend active participation groups. For example,
 - swim therapy,
 - horseback riding,
 - or other sports activities appropriate for the individual's developmental level.
- Build strength and motor coordination for younger students with PHTS.

Hyper and hypo-sensory sensitivities

Sensory differences are also common in students with PHTS who have a history of developmental concerns. These differences include:

- Sensitivities to noise or other stimuli.
- Lower responsivity to pain or temperature.
- Sometimes, a pattern of lower energy levels and feeling lethargic while not strictly sensory can also be seen.

Intervention

- PHTS sensory differences may require avoiding loud environments and using headphones.
- If the student with PHTS has hyposensitivity to pain or temperature, make sure they avoid situations that might be dangerous because some people cannot feel pain.
- Be sensitive to children who prefer clothing that feels most comfortable to them.

OTHER CONDITIONS INCLUDING ADHD AND AUTISM

- It is important to note that students with PHTS can experience other neurodevelopmental conditions not listed here that may also benefit from one or more of the intervention strategies listed.
- Additionally, some students with PHTS may need to miss classes due to frequent medical visits and testing. The school nurse and social workers can help coordinate with families to stay caught up on school work.

Intervention

- Behavioral interventions
- Social skills training
- Speech/language therapy
- Medication as necessary



Disclaimer: The information in this document is provided by Dr. Thomas Frazier, a KOL in the PTEN community, and reviewed by our medical board and families. This information is not meant to guide medical care but is beneficial to support children and adults diagnosed with PTEN Hamartoma Tumor Syndrome.