Stimulant Use in Children with Genetic Aortic and Vascular Conditions

Luciana Young, MD

What are some common signs of Attention Deficit Hyperactivity Disorder (ADHD) in children?

The American Psychiatric Association defines ADHD in children as a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development, with several symptoms being present before age 12 years and manifesting in more than one setting.

Inattention in children manifests behaviorally as wandering off task, failing to follow through on instructions or complete work, difficulty sustaining focus, having trouble keeping track of things, or staying organized. Common signs include:

- Failing to pay close attention to details or making careless mistakes in schoolwork
- Difficulty maintaining attention in tasks or play activities
- Not seeming to listen when spoken to directly
- Not following through on instructions and failing to finish schoolwork or chores
- Difficulty organizing tasks and activities
- Avoiding or being reluctant to engage in tasks that require sustained focus
- Losing things necessary for tasks
- Being easily distracted by outside stimuli
- Forgetfulness in daily activities

Hyperactivity and impulsivity refer to being overly active or restless when it's not the right time, having trouble staying still or quiet, and acting without thinking things through first. Common signs include:

- Fidgeting with hands or feet or squirming
- Leaving a seat in the classroom when remaining seated is expected
- Running about or climbing in inappropriate situations
- Inability to play or engage in leisure activities quietly
- Being "on the go" or acting as if "driven by a motor"
- Talking excessively
- Blurting out answers before questions are completed
- Difficulty waiting for their turn
- Interrupting or intruding on others

For diagnosis, at least six symptoms from either the inattention category or the hyperactivity-impulsivity category must have been present for at least 6 months at a level that is more than expected for children of the same age and causes real problems in school, with friends, or at home. The symptoms must be present in more than one setting (e.g., home, school, or daycare) and cannot be solely explained by not following or understanding instructions.

Continued on Page 2

If a parent is concerned that their child with a genetic aortic and vascular condition may have ADHD, what are the steps they should take to seek treatment?

ADHD affects more than just attention—it can influence many parts of a child's life. Without treatment, kids may be more likely to fall behind in school or have trouble getting along with friends. Early diagnosis and treatment can make a big difference, helping children build confidence, do better in school, and thrive socially. If parents notice that their child is having trouble paying attention, seems overly active, acts on impulse, or is struggling in school or with behavior, they should talk directly with their child's doctor. The American Academy of Pediatrics (AAP) recommends that doctors check for possible ADHD in any child aged 4 and older when these concerns come up. Parents and teachers may be asked to fill out questionnaires—such as the Vanderbilt Rating Scales or the Pediatric Symptom Checklist—that help identify patterns of behavior consistent with ADHD. If ADHD or other related issues are identified, the doctor may suggest seeing a specialist, such as a developmental-behavioral pediatrician, child psychologist, or child psychiatrist, for a more detailed evaluation and personalized treatment plan.

What are the unique concerns when treating ADHD in children with genetic aortopathies?

Treating ADHD in children with genetic aortic conditions requires careful consideration of potential cardiovascular risks, with close monitoring and coordination of care among the primary care provider, cardiologist, and behavioral health team.

Stimulant medications can cause high blood pressure, which should be treated promptly, as it puts added stress on the aorta and can increase the risk of dissection. Heart rhythm abnormalities may occur, especially in the setting of Marfan syndrome and an enlarged left ventricle. In general, substances that can further raise blood pressure or heart rate—such as excess caffeine, energy drinks, or certain decongestants—should be avoided.

Treating ADHD effectively is essential for a child's learning, behavior, and quality of life.
Thus, the American Heart Association (AHA) and the AAP advise that stimulant medications should not be automatically ruled out for children with aortopathy, but can be used cautiously with the approval of their cardiologist and close monitoring.

When managing ADHD in children with genetic conditions such as Marfan, Loeys-Dietz, or VEDS, what special considerations come into play—particularly regarding potential cardiac risks associated with stimulant medications?

Stimulant medicines (like methylphenidate or amphetamines) are often very effective for ADHD, but they can cause small increases in heart rate and blood pressure. Although these changes are usually mild and not dangerous for most children, it is important to monitor heart rate and blood pressure closely with their use. Stimulants can also theoretically increase the risk of arrhythmias. Additional side effects may include decreased appetite, gastrointestinal upset, sleep disturbances, irritability, and headache.

Continued on Page 3

What should families understand before starting these treatments?

- Talk with your child's heart doctor before starting medication to treat ADHD. They may recommend additional tests (like an echocardiogram or ECG) beforehand.
- Regular monitoring is important. Your child's heart rate and blood pressure should be checked often when taking ADHD medications, not just stimulants. This is especially important when starting a new medication or adjusting the dose.
- With careful monitoring and approval from the heart doctor, stimulant medications can often be used safely and may greatly improve your child's quality of life.
- Non-stimulant ADHD medications (like atomoxetine or guanfacine) may be considered if there are concerns about heart risks, but stimulants are usually more effective.

What specific warning signs should prompt them to contact their physician or seek urgent care?

Call your doctor or seek emergency care if your child experiences:

- Chest pain or tightness
- Fainting or near-fainting
- Rapid, pounding, or irregular heartbeat
- New or worsening shortness of breath
- Severe dizziness
- Sudden weakness or trouble moving part of the body
- Severe headache or neurologic symptoms
- These symptoms could be signs of a serious heart problem and need immediate attention

Other tips for families:

- Keep your child well-hydrated, as dizziness with changes in position may sometimes occur in individuals with Marfan syndrome with these medications.
- Avoid over-the-counter medicines that can raise blood pressure or heart rate, like decongestants or certain migraine medicines (such as triptans), unless approved by your doctor.
- Let all your child's doctors know about their heart condition and ADHD treatment. This helps everyone work together to keep your child safe.

With careful planning and regular check-ups, stimulant medications can be used safely in children with genetic heart and blood vessel conditions. Always keep your child's heart doctor involved, and watch for any warning signs. If you have questions or concerns, don't hesitate to contact your child's healthcare team.

Do certain stimulant medications pose more risk than others for children with these conditions?

Current research has not found that any one ADHD medication poses more risk for the heart than another in children with these conditions. Studies comparing different medicines—such as methylphenidate, amphetamines, and non-stimulants like atomoxetine—show that these medications can cause small, short-term increases in heart rate and blood pressure.

Continued on Page 4

On average, stimulants may raise the heart rate by about 1–2 beats per minute and blood pressure by 1–4 points. A small number of children (around 5–15%) may have larger increases in blood pressure and thus may require closer monitoring. In contrast, guanfacine and clonidine typically cause a decrease in heart rate and blood pressure.

What monitoring protocols are recommended for cardiovascular safety during attention-deficit/hyperactivity disorder treatment?

The American Academy of Pediatrics (AAP) recommends a thorough cardiac history and risk assessment before starting ADHD medications, including stimulant and nonstimulant agents. Clinicians should review personal and family histories for cardiac symptoms, sudden death, or inherited conditions such as long QT syndrome, hypertrophic cardiomyopathy, and Wolff-Parkinson-White syndrome. If risk factors or abnormal findings are noted, additional evaluation—such as an ECG may be indicated before initiating therapy. Routine ECG screening, however, is not required for all patients and remains a matter of clinical judgment.

While the AAP and AHA guidelines emphasize the importance of monitoring vital signs, the exact frequency of monitoring is not specified. Other expert guidance, such as the New England Journal of Medicine review on pharmacologic treatment of ADHD, suggests checking heart rate and blood pressure before starting medication, after each dose change and about every 6 months.

If a child has a consistently high heart rate, an abnormal heart rhythm, or blood pressure above the 95th percentile for age, the dose should be adjusted and a cardiologist should be involved. Serious cardiovascular events from ADHD medications are very rare, but regular monitoring helps catch any important changes early, especially in children with underlying heart disease or a genetic aortic condition.

Are there particular red flags you watch for in children with Marfan syndrome, Loeys- Dietz syndrome, or VEDS who are prescribed stimulant medications? Are there signs related to stimulant use that would warrant a call to the doctor or emergency care in someone with a genetic aortopathy?

When children with Marfan syndrome, Loeys-Dietz syndrome, or VEDS take stimulant medicines, there are certain warning signs that should prompt quick medical attention.

1. Heart symptoms that need urgent care:
   - Strong, fast, or irregular heartbeats (palpitations).
   - Fainting or passing out (syncope).
   - New chest pain or a new abnormal heart rhythm.

2. High heart rate or high blood pressure:
   - A resting heart rate that stays above 120 beats per minute.
   - Blood pressure above the 95th percentile for the child’s age and height.

Continued on Page 5

High blood pressure increases stress on the aorta and raises the risk of a tear (dissection), so it should be treated promptly and aggressively. In this situation, the stimulant dose may need to be lowered, a cardiologist should be consulted, and medicines that raise blood pressure or heart rate (such as some decongestants or strong vasoconstrictors) should be avoided.

3. Dizziness and feeling faint when standing
- Lightheadedness, fatigue, or feeling like they might pass out when standing up (orthostatic intolerance). These symptoms are common in Marfan syndrome and can be worsened by the use of beta blockers. Helpful steps include good hydration, standing up slowly, and using simple maneuvers like crossing the legs or briefly squatting to help blood flow return to the heart.

4. Sudden severe pain suggesting an aortic emergency.
- Sudden, intense chest pain, back pain, or a new difference in pulse between arms or legs could be signs. of an acute aortic dissection and require immediate emergency evaluation, usually with urgent imaging (such as a CT or MRA) of the entire aorta.

5. Poor growth or weight loss.
- Slowing of expected growth in height.
- Noticeable weight loss or drop-off on the growth chart.

Stimulant medications can reduce final adult height by about 1–2 cm, mainly during the first two years of treatment, and can also affect weight gain. Height and weight should be checked regularly. If growth slows significantly, the dose may need to be adjusted, or a “medication holiday” or alternative treatment may be considered.

6. Concerning changes in mood or behavior.
- Seeing or hearing things that are not there (hallucinations).
- Severe mood swings, unusual agitation, or other psychotic symptoms.
- Thoughts of self-harm or suicide.

These psychiatric side effects are uncommon but serious. Any of these signs should prompt close monitoring, dose reduction or medication change, and consultation with a mental health professional.

7. Special considerations for Loeys-Dietz syndrome and VEDS.
- These conditions carry a higher risk of artery tears or ruptures, not only in the aorta but also in other arteries. It is important to avoid additional medications that can strain blood vessels, such as routine use of triptans for migraines, certain decongestants, and fluoroquinolone antibiotics when alternatives are available.
- Regular vascular imaging, as recommended by the child’s genetics and cardiology teams, and strict blood pressure control are essential to reduce vascular risk.

Continued on Page 6

While stimulant-related cardiovascular complications are rare, the underlying vascular pathology in Marfan syndrome, Loeys-Dietz syndrome, and Vascular Ehlers-Danlos syndrome requires heightened awareness of warning signs. Families and clinicians should be vigilant in looking for signs of acute aortic dissection, arrhythmias, and/or severe hypertension in patients with genetic aortopathies taking stimulant medications, as these represent life-threatening emergencies requiring immediate evaluation.

Are there any extra screenings or tests you recommend before and during stimulant use in individuals with genetic aortopathy?

For children with genetic aortopathies requiring ADHD treatment, cardiology approval should be obtained before initiating stimulant therapy. Baseline cardiovascular imaging assessment should already be in place per standard aortopathy management. An electrocardiogram may be indicated if there is a risk of arrhythmia or if symptoms are present. There is a small risk of sudden death related to arrhythmias in Marfan syndrome, which appears to be more common in individuals with a dilated left ventricle. Close monitoring of heart rate and blood pressure is essential during treatment.

Should there be additional follow-up with the cardiologist once an ADHD medication is started in someone with a genetic aortopathy?

Yes, children with genetic aortopathies should maintain ongoing cardiology follow-up after starting ADHD medication, as these conditions require lifelong cardiovascular surveillance regardless of medication use. The frequency and intensity of monitoring should be individualized based on the specific syndrome, baseline aortic dimensions, and rate of aortic growth, with heightened attention to cardiovascular symptoms and blood pressure control after starting ADHD medication.

If a parent is cautious of stimulants, are there alternative ADHD treatments you would recommend for children with genetic aortopathy?

For children with genetic aortopathies whose parents are cautious about stimulant medications, FDA-approved nonstimulant medications—including atomoxetine, extended-release guanfacine, extended-release clonidine, and viloxazine—represent effective pharmacological alternatives. In addition, behavioral therapy and parent training are well-supported, non-medication approaches that teach practical skills for children and families. The best results often come from combining these strategies, though it's important to know that nonstimulant medicines may not work as effectively as stimulants for some children.

In addition, some lifestyle and complementary strategies can offer extra help. Mindfulness exercises, meditation, yoga, regular physical activity, and good sleep routines are safe and can improve stress, self-control, and overall functioning. Certain nutrition changes—such as omega-3 supplements (fish oil), a general multinutrient supplement, and limiting artificial food colorings—may provide small benefits for some children, though they are not usually enough as the only treatment.

Continued on Page 7

Overall, the best plan is the one that fits your child's needs and your family's comfort level. Many families choose a mix of approaches—nonstimulant medicine, therapy, school supports, and healthy habits—and adjust over time with guidance from their cardiologist, pediatrician, and behavioral health provider.

How can families balance supporting ADHD needs while prioritizing health and safety for children with genetic aortopathy?

Families are encouraged to work with their care team to manage ADHD treatment safely while protecting heart health in children with genetic aortic conditions. The best management plan typically includes appropriate ADHD treatment, regular heart checkups to detect early changes in the aorta, healthy lifestyle habits (such as maintaining good sleep habits and adopting a balanced diet), and ongoing guidance and education to help families stay informed and confident about their care decisions. This approach helps balance both needs—treating ADHD effectively, since leaving it untreated can cause real challenges, and staying alert to the heart condition, which requires lifelong attention.

How do stimulant risks or benefits change as children grow into their teen and young adult years with connective tissue conditions?

The risks and benefits of stimulant medications for treating ADHD in children with genetic connective tissue disorders change as patients grow from childhood through adolescence into young adulthood, with a greater need for cardiovascular monitoring and possible progression of aortic enlargement during teenage and young adult years. While stimulants remain effective and generally safe across all age groups, underlying aortic issues require increased monitoring and personalized risk assessment as individuals mature.

A substantial proportion of individuals with ADHD continue to experience persistent difficulties with attention, hyperactivity, or impulsivity into adulthood, necessitating prolonged use of ADHD medications. Evidence regarding the long-term cardiovascular risk associated with ADHD medication use—especially as patients transition into adulthood—remains limited. Further studies are essential to clarify the risks and benefits of these medications, especially in patients with underlying cardiovascular conditions like genetic aortopathies.

This article is intended for educational purposes only and should not replace individualized medical advice. Always consult your healthcare providers regarding diagnosis and treatment decisions.

For answers to medical questions about genetic aortic and vascular conditions like Marfan, Loeys-Dietz, and VEDS, contact the Marfan Foundation's Help & Resource Center at marfan.org/ask.