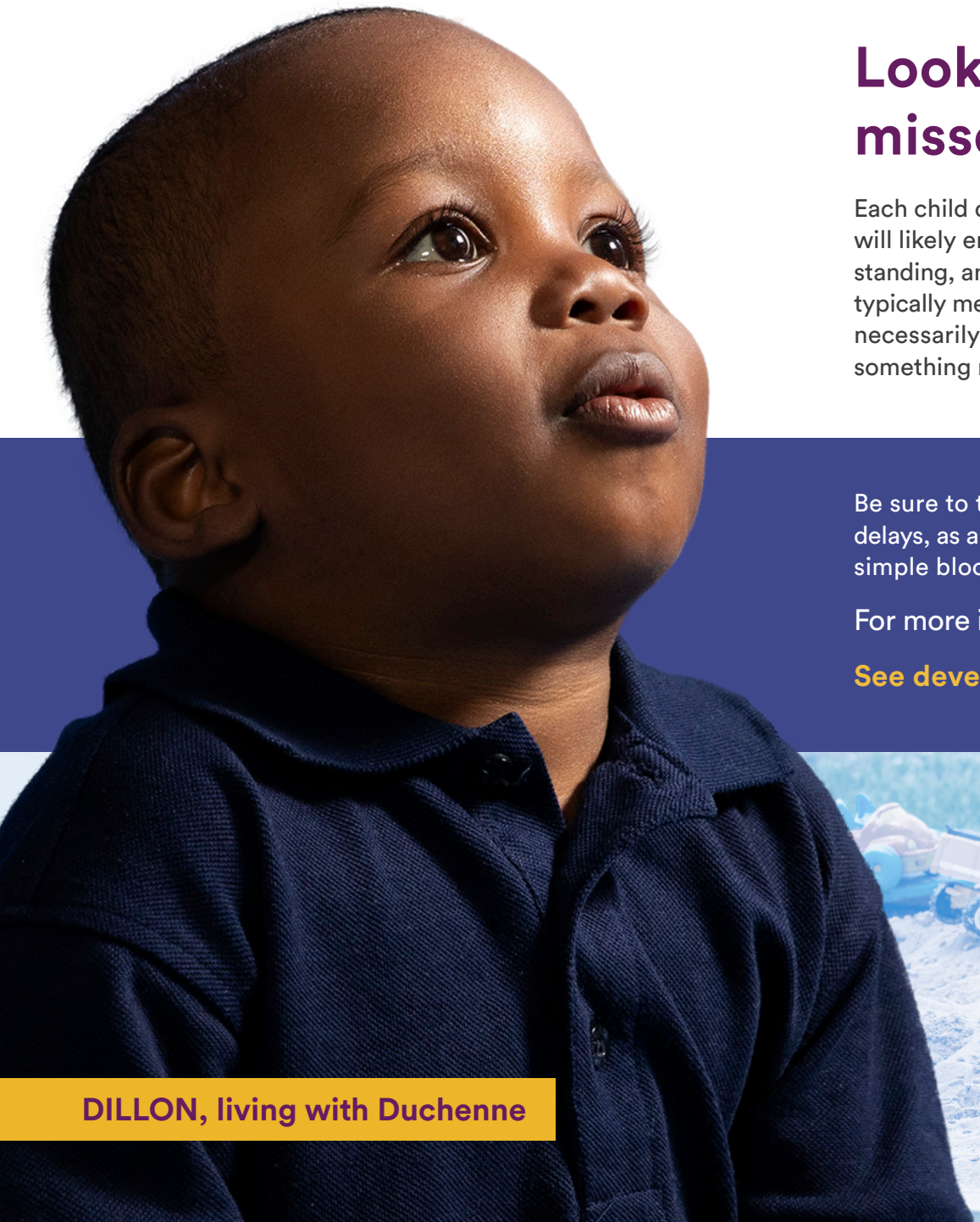
FINN, lives *with* Duchenne.
Lives *for* weekends with his family.

It's helpful to know

10 questions to ask your PEDIATRICIAN

if you're concerned about **developmental delays** and **muscle weakness**

SAREPTA THERAPEUTICS



DILLON, living with Duchenne

Looking out for missed milestones

Each child develops differently, and as your child grows, your pediatrician will likely encourage you to take note of important milestones like sitting, standing, and walking. Though guidelines suggest when milestones are typically met, some children may experience delays. While a delay isn't necessarily a cause for concern, in some cases, it could indicate that something more is going on with your child's muscles.

Be sure to talk to your pediatrician about signs of developmental delays, as an underlying muscle condition can be ruled out with a simple blood test called a **CK (creatine kinase) test**.

For more information, visit **childmuscleweakness.org** ▸

See developmental delay & ask to test CK.

Identifying signs of a neuromuscular condition

Children who display signs of muscle weakness may be slower to sit, stand, or walk. As time goes on, they may also struggle to run or jump. These difficulties may be caused by a neuromuscular condition like Duchenne muscular dystrophy, commonly referred to as Duchenne. Duchenne, which mainly affects boys, is the most common type of muscular dystrophy.

Signs of **muscle weakness** may include:

Falling down often

Enlarged calves

Walking on toes with legs apart and belly pointed out

Difficulty getting up from the floor without help

The specific symptoms of Duchenne may be different for each child. Some are physical, such as falling down and walking on toes. Duchenne can also affect the brain and cause cognitive symptoms, like speech delay or attention-deficit/hyperactivity disorder (ADHD).

No one knows your child like you do. If you think something might be going on with your child's development, don't be afraid to speak up. Oftentimes when parents or caregivers express concerns about developmental delays, they are correct. Although these symptoms do not necessarily indicate a neuromuscular condition, it is important to act early and speak to your pediatrician if you notice them.

Your doctor can take steps to rule out a more serious condition like Duchenne.

The following questions can help guide the conversation with your pediatrician

Recognizing the symptoms early

Before speaking with your pediatrician, it may be helpful to prepare a list of signs and symptoms that have made you concerned about your child's development.

> **Brett was 3 when he was diagnosed. He had a cousin about a year younger he wasn't able to keep up with.**
>
> —Dawn, whose son is living with Duchenne

Capture the questions below so you have them handy when speaking to your pediatrician.

1. **What developmental milestones are important to note, and how do I know if missed milestones may be a sign of developmental delay?**
2. **Are any of the signs and symptoms I've described a cause for concern?**
3. **How do I know if my child's missed milestones could be a sign of muscle weakness?**
4. **Could these missed milestones indicate a more serious muscle condition?**
5. **How can a neuromuscular condition like Duchenne be ruled out?**

FINN, living with Duchenne

Reaching a diagnosis

After you've expressed your concerns about your child's developmental delays, your pediatrician will guide you through the next steps in confirming a diagnosis. If a CK test or other measure suggests the possibility of a neuromuscular condition like Duchenne, your pediatrician may refer you to a pediatric neurologist or neuromuscular specialist. This doctor will likely give your child a genetic test, which can help confirm a diagnosis.

Capture the questions below so you have them handy when speaking to your pediatrician.

6. **Why is early diagnosis of a neuromuscular condition so important?**
7. **If CK test results suggest a neuromuscular condition, what types of doctors may be involved in confirming the diagnosis?**
8. **What type of testing does my child need to confirm the diagnosis?**
9. **What is an early intervention program, and is my child a candidate for this type of program?**
10. **Where can I find more information about identifying and managing a neuromuscular condition?**

CALEB, living with Duchenne

ETHAN, living with Duchenne

Finding sources of support

Recognizing the signs of muscular weakness can lead to an early diagnosis. Remember that you and your family are not alone, and your child's doctors will help guide you through this diagnosis phase.

It's important to build a strong support system of people who understand what your child and family are going through. Advocacy groups and rare-condition organizations can connect you with families facing similar challenges. These organizations can also help you find information on important topics, including genetic testing.

To learn more about these organizations and to access other support resources, visit the following sites:

Duchenne.com/resources ▸

Childmuscleweakness.org ▸

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