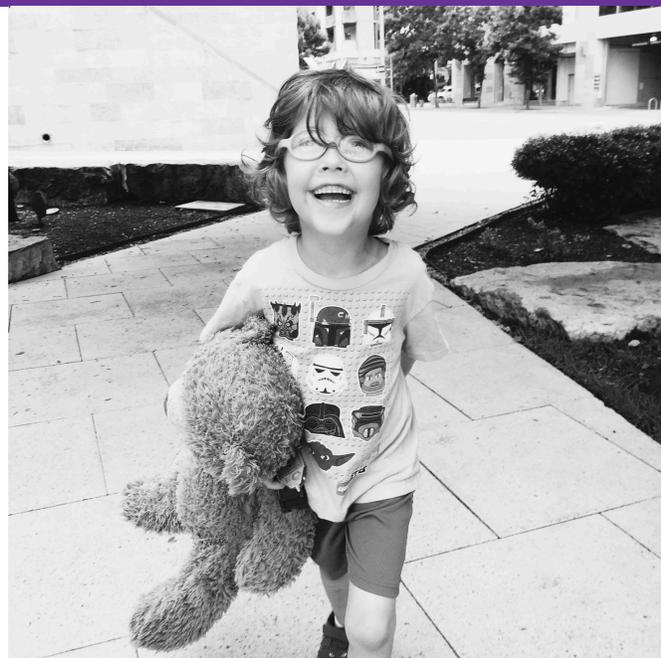




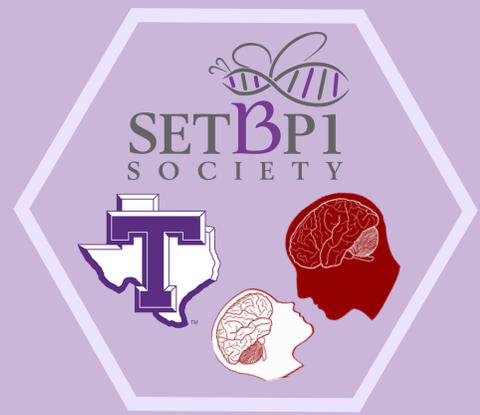
# SETBP1 Haploinsufficiency and Related Disorders (SETBP1-HD/RD) Education Guide



in partnership with



# ABOUT THIS EDUCATION GUIDE



This education guide is a collaborative effort by SETBP1 Society, the SETBP1 Community, and Tarleton State University in partnership with the Brain Research Across Development (B-RAD) Lab at the University of South Carolina. It was developed in response to concerns and insights shared by parents within the SETBP1 Community through the SETBP1 Community Research Study (SCoReS) parent needs assessments.

The B-RAD Lab, led by Dr. Caitlin Hudac, studies how neurodevelopmental differences like SETBP1 affect the brain.

B-RAD Lab members, Sophie Cramer-Benjamin, Ashlan Cheever, Olivia Mace, Wae Man Chan, and many others used information from the SCoReS Phase 2 Study, clinical and academic sources, and resources developed for other rare genetic groups. They also interviewed families in the community to ensure that this book best represented the SETBP1 Community.

SCoReS, a partnership between SETBP1 Society and Tarleton State University, aims to better understand and support the needs of families affected by SETBP1 haploinsufficiency and related disorders.

Our goal is to provide helpful information and resources for families navigating the challenges of SETBP1 neurodevelopmental disorders.

**However, this guide is not intended to serve as medical advice. We encourage you to consult your child's pediatrician and medical team with any questions or concerns regarding their care.**

Most information contained in this book that is specific to SETBP1 is from the publications below. These will be signaled with the superscripts 1, 2, and 3 based on which paper the information is from. Throughout the book there are links and QR codes to other sources, resources, and helpful websites. We are not connected with these organizations or companies. All resources are included at the end of the book with clickable links

1. Morgan, A., Srivastava, S., Duis, J. & vanBon, B. (2024). SETBP1 Haploinsufficiency Disorder - GeneReviews® - NCBI Bookshelf. <https://www.ncbi.nlm.nih.gov/books/NBK575336/>
2. Morgan, A., Braden, R., Wong, M. M. K., Colin, E., Amor, D., Liégeois, F., Srivastava, S., Vogel, A., Bizaoui, V., Ranguin, K., Fisher, S. E. & Bon, B. W. van. (2021). Speech and language deficits are central to SETBP1 haploinsufficiency disorder. *European Journal of Human Genetics*, 29(8), 1216–1225. <https://doi.org/10.1038/s41431-021-00894-x>
3. Oyler, H. O., Hudac, C. M., Chung, W. K., Synder, L. G., Robertson, S., Srivastava, S. & Geye, T. (2024). SETBP1 haploinsufficiency and related disorders clinical and neurobehavioral phenotype study. *Clinical Genetics*, 106(4), 448–461. <https://doi.org/10.1111/cge.14579>

"Your child is going to have a full, wonderful, healthy life. There will be a thousand obstacles to get through but the most amazing moments supersede difficult ones: moments when they go beyond what you think is possible; it's sheer happiness"

-Nancy (SETBP1 Parent)

"Every person is unique and cannot be defined by any single genetic difference. We are a combination of all of our genes."

-Simons  
Searchlight

"Your kid is still your kid! The diagnosis is just a part of them!"

-Haley (SETBP1 Parent)

"Every small step forward makes a difference, and with love, support, and resilience, there is hope for a brighter future for your child. Keep advocating for them—you'll be amazed at what they can achieve!"

-Terry (SETBP1 Parent)

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# ALL ABOUT SETBP1

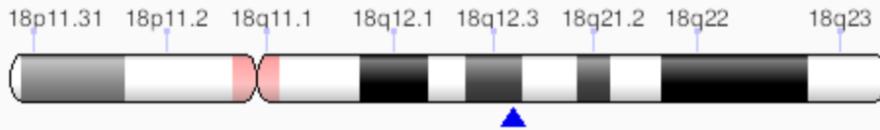
## **In this section:**

- All About SETBP1
- Hear From The Community
- FAQ and Community Connection
- Genetics 101
- All About Diagnosis
- How To Talk To Your Child About Their Diagnosis

# ALL ABOUT SETBP1

SETBP1 haploinsufficiency disorder (SETBP1-HD) happens when there is a change in the SETBP1 gene that causes the body to make less of the SETBP1 protein than it needs. These changes can prevent the gene from working properly.

Simons Searchlight (2024)



The SETBP1 gene is located on the long (q) arm of chromosome 18 at position 12.3.

This gene contains the instructions to produce SETBP1 protein which is important for binding certain proteins together and for typical brain function.

There are multiple kinds of changes that can disrupt the SETBP1 gene.

## Loss-of-Function

A loss of function change means that something happened to the gene causing a decreased amount of SETBP1 protein in the body.

These variants are associated with **SETBP1-Haploinsufficiency Disorder (SETBP1-HD)**. *Haploinsufficiency* means that one copy of a gene isn't enough for it to do its typical function, so when something happens to one or both copies, less protein is produced.

## Gain-of-Function

A gain of function change means that something happened to the gene causing an increased amount of SETBP1 protein in the body either because of overproduction or accumulation.

These variants are associated with

## Schizel-Giedion Syndrome (SGS)

While this guide is made for individuals with SETBP1-HD and SETBP1-RD, some resources may still be helpful for people with SGS

## Other Molecular Function

### Variant of Unknown Significance (VUS)

A VUS is when a variant has been found in a particular gene, in this case, SETBP1, but it has not been identified as SETBP1-HD or SGS. Because research is needed to understand what different mutations do in the body, we don't know what every variant does. Variants with unknown SETBP1 function are associated with **SETBP1-Related Disorders (SETBP1-RD)**. As more research becomes available, some SETBP1-RD variants may later be reclassified as SETBP1-HD.

# LET'S HEAR FROM SETBP1 BEES ABOUT THEIR EXPERIENCES!

## SETBP1 Makes Me...

"Different" -Cole (14 years old)

"Special" -Colton (13 years old)

## What would you tell another kid/person with SETBP1?

"I would help them" -Community Member

"Go to lunch club and try playing Roblox" -Robby (10 years old)

## What are some of your favorite things?

"I love trucks" -Colton (13 years old)

"My favorite thing to do is to look for things, like metal, sticks that look like shapes" -Cole (14 years old)

"Ocean" [AAC]; "Waves" [Spoken] -Rhiley (8 years old)

"I like to play roblox. I like to play squid game. I like to play with my cousins." - Robby (10 years old)

"My favorite ice cream flavor is cookie dough" -Robby (10 years old)

## What do you like to do with friends?

"Basketball, ride bike" - Colton (13 years old)

"Play outside" -Cole (14 years old)

"Take pictures with friends" -Robby (10 years old)

## What is your favorite thing to do in work/school?

"Do all the recycling" - Colton (13 years old)

"Talking with my friends in school" -Cole (14 years old)

"I like gym. I like to go on the scooter" -Robby (10 years old)

# WHAT IS YOUR FAVORITE THING ABOUT YOUR LOVED ONE WITH SETBP1?

"No doubt my favorite trait of Stella is her empathy. She immediately knows when something is off or when someone needs a hug. Her special ability to recognize when love is needed in a situation is humbling to watch."

-Erica (SETBP1 Parent)

"He's such a happy kid, he makes me smile, he loves to give hugs, he loves sports, just adores sports"

-Nicole (SETBP1 Parent)

"His ability to stop and take in the beauty of the world, even in common everyday tasks."

-Eric (SETBP1 Parent)

"At school she's called the mayor because she's so social to every staff member, every kid in every grade. We could be out and about and everyone says hi. Always smiling, always happy, loving and caring. She can make anybody's day and get them to smile. She's made friends with unhoused people and they look forward to seeing her."

- Nicole (SETBP1 Parent)

"His wicked sense of humor"

- Nicole (SETBP1 Parent)

"Her attitude, her ability to talk to anybody— she just doesn't care! She's very social and will talk to anyone"

-Community Member

"He is a very happy boy"

- Antoine's Mother

"He is full of energy and can light up any room he walks into"

-Lindsey (SETBP1 Parent)

"That's really hard. He's very funny. He's very empathetic. He has a way of making people feel seen."

-Allyson (SETBP1 Parent)

# HEAR FROM THE COMMUNITY: GENERAL GUIDANCE

“Having a child with SETBP1 or autism is an atypical experience. It can be easy to be discouraged by comparing their experience with your other children or friends and families. The most important thing is keeping an open mind and trying to be a more flexible parent.”

-SETBP1 Parents

“Find other special needs parents. No special needs journey is the same, but it’s just nice to have someone who just gets it. To say to a friend, we had a bad day, and they know what that means.”

-SETBP1 Parents

“I don’t think about being different. If someone can do something better than me, I just think I can also do it. I’m not so good with counting and I can’t do math but I can write and I can read and others can’t do that. My friends take me like I am, I take them like they are.”

- Kian (SETBP1 Bee, age 22)

“I would say that ultimately as a parent, you know your child best and that you should advocate for them reaching their fullest potential. It’s ok to get back up and it’s ok to be the squeaky wheel.”

-Erin (SETBP1 Parent)

# MORE ABOUT SETBP1

## What is SETBP1?

Learn about SETBP1 facts and details and the difference between SETBP1-HD, SETBP1-RD, and SGS



## Common First Questions

This resource book contains a lot of information. We will try to answer as many of your questions, but here's a link to the most common first questions!



## Connect with the SETBP1 Community!

This link will take you to the SETBP1 page for newly diagnosed families. Here you can find an easy-to-follow checklist to get connected to other families that have been where you are now!



## What is SETBP1?



## Types of Variants in SETBP1



## Videos!

Check out these videos narrated by Jordan Whitlock, PhD to learn about SETBP1



# SETBP1-HD VS SETBP1-RD

From the 2021 SETBP1-HD Resource Guide

## SETBP1 Haploinsufficiency Disorder (SETBP1-HD)

### Description

A neurodevelopmental disorder consisting of moderate to severe speech impairment, mild to severe intellectual disability, hypotonia in childhood and behavior problems.

### Cause

A loss-of-function (LoF) change in one copy of the two SETBP1 genes causing the body to not produce enough of the SETBP1 protein. This type of change is referred to as a loss of function change/variant.

### Inheritance

De Novo (Not inherited)  
Possibility exists of germline or low-grade somatic mosaicism inheritance  
Inherited from SETBP1-HD parent

### Location

Variants located throughout the SETBP1 gene, which is located on chromosome 18.  
A deletion may include part or all of the SETBP1 gene.

## SETBP1-Related Disorders

A neurodevelopmental disorder similar to SETBP1-HD; however, the individual may have more symptoms than those identified for individuals with SETBP1-HD.

A change in one copy of the SETBP1 gene (not linked to SETBP1-HD or SGS) with one of the following outcomes: it is unclear whether the change affects the body (Variant of Unknown Significance, or VUS), or it's unclear how it affects the body.

De Novo (Not inherited)  
OR  
Inherited from either parent

Variants located throughout the SETBP1 gene and not within the SGS atypical or classical region.

# GENETICS 101

## Genetics 101!

If you are curious to learn more about genetics, check out this resource!

### What is a genome?

What you call ALL the genetic material in our body's cells

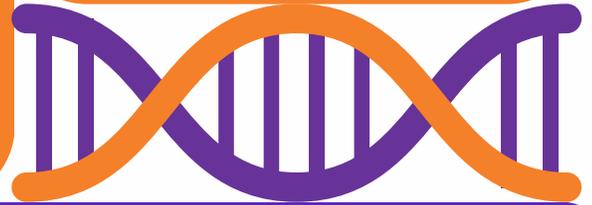
### What are genes?

Genes carry the information that determines what you look like and how your body grows and develops

### What are genetic changes?

Each of us contain differences in our genomes that make us unique. Most of these differences have little or no impact on our health. But some do.

Scan this QR code below to learn more about some basics of genetics!



## Common Questions about SETBP1

Scan this QR code for a specific Genetics 101 of the SETBP1 gene!



### Have you ever wondered:

- What is a SETBP1 mutation?
- What causes a SETBP1 mutation?
- Who can get a SETBP1 mutation?
- What does a variant of unknown significant mean (VUS)?
- What is SETBP1 haploinsufficiency disorder (SETBP1-HD, SETBP1 Disorder)?
- Is SETBP1 Disorder and SETBP1 haploinsufficiency disorder the same?
- What is SETBP1-related disorders?
- What are the symptoms of SETBP1-HD?
- How is a SETBP1 mutation diagnosed?

This resource above is written as a guide to help parents better understand the specific mutation mentioned on their child's genetic report.

The SETBP1 gene's job is to create a specific protein called SETBP1 protein. Since individuals inherit 2 copies of every chromosome, they have 2 copies of every gene including SETBP1. SETBP1 haploinsufficiency disorder is caused by a SETBP1 mutation affecting one copy of the SETBP1 gene. The one working copy of the gene is not enough for the body to function normally, which is referred to as haploinsufficiency.

If so, check out this resource for in-depth answers!



# ALL ABOUT DIAGNOSIS

Things to consider after diagnosis

## Process and Seek Support

Take time to absorb the information and acknowledge your feelings  
Reach out to family, friends, the [SETBP1 Parent Support Group](#),  
and/or a therapist to help process your feelings



## Learn more about SETBP1-HD and Related Disorders

Check out the [Newly Diagnosed page](#) on SETBP1 Society's website  
Understand your child's specific SETBP1 diagnosis based on their  
[genetic report](#)

## Explore Financial Support

- Sign up for [state waivers](#) if you haven't already
- Depending on your child's age,
  - Sign up for early intervention services ([Infancy/Toddlerhood](#), [Toddlerhood-Childhood](#))
  - Look into [Social Security Disability \(SSI\)](#)
- Connect with any local government agency to discuss options for [case management](#), [respite services](#), and extra support

## Understand your Child's Rights

Request an [Individualized Education Plan \(IEP\)](#) or [504 Plan assessment](#) through  
your child's school

## Build out your Medical and Therapy Team

Work with your child's pediatrician or primary child's doctor to get  
any needed referrals for therapies including [speech](#), [occupational](#),  
and/or [physical therapy](#). Ensure your pediatrician has a copy of the  
[SETBP1 haploinsufficiency disorder GeneReview](#)



# HEAR FROM THE COMMUNITY: GETTING A DIAGNOSIS

“We were absolutely terrified, but it’s not as bad as it sounds. They are still kids, they still like to play, they’re still very active. This is not a disorder that is so impactful that you can’t do things as a family and go and try new things, you just have to modify your approach to them a bit”

- Nicole (SETBP1 Parent)

“It might come as a shock, please know that your child will continue to progress. They will grow in skills, personality, activities, and you will look back and recognize what a blessing your child is in your life. There will be hard times, but overall, it will be a true blessing”

- Nicole (SETBP1 Parent)

This is a marathon, not a sprint.

It's 100% normal to go through a grieving process after receiving your diagnosis.

-Lindsey (SETBP1 Parent)

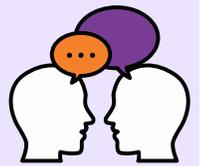
“Take your time and don’t worry your child will demonstrate that he/she is able to make a lot of progress”

- Antoine’s Mother

# HOW TO TALK TO YOUR CHILD ABOUT THEIR DISORDER

- Use simple, honest language – avoid overwhelming details
- Start with basic concepts and let questions guide the depth of the conversation (more questions may come up with development/relevance – you don't have to have every conversation/cover each topic all at once, you can wait to share more information until it is more relevant)
- Encourage questions, if appropriate
- Focus on abilities and strengths
- Prepare for repeated conversations
- You can use visuals and storybooks

This will vary based on age, cognitive ability, and the specific child.



Genetic counselors can be a great resource for these conversations! They can develop a plan with parents, gauge the child's level of understanding and what they need to know, and help a parent explain why they are getting certain tests and what the results mean.

## Here is an example of what one caregiver might say to their SETBP1 bee:

"We are all unique and different, which makes our world wonderful! Everybody's brain works differently, everybody has things that they are good at and things that they have a hard time with. One of your differences is that you have SETBP1-HD/RD. That means that you might have a hard time talking to your friends, reading books, [other things the particular person has trouble with]. You are also so kind and creative [add specific strengths]. Do you have any questions?"

# HOW TO TALK TO YOUR CHILD ABOUT THEIR DISORDER

## LET'S HEAR FROM THE COMMUNITY:



It's usually a 3-4 sentence conversation and young kids may not have follow-up questions. Until it has tangible significance, like meeting other kids with SETBP1 at a family meeting, it may not mean much for the individual. It doesn't have to be a big/scary conversation.

-Haley (SETBP1 Parent)



I think Kian was maybe 12 or 13 years old when we first talked about his handicap. I told him, 'Everyone has things they can do well and things that are harder. That's true whether someone has a handicap or not.' We talked about how being different doesn't mean being less. Everyone is different in some way. We also watched the Special Olympics and Paralympics and talked about how you can do anything if you are dedicated and follow your goals

- Nena (SETBP1 Parent)

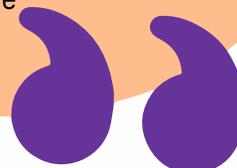


I would tell parents to tell their children they have a handicap and SETBP1 and they should go to the conference and meet others with the same handicap"

- Kian (age 22)

[context: Kian loved meeting all of the other people with SETBP1 at the 2024 SETBP1 Family and Researcher Conference- "going to the conference last year helped Kian a lot to see that he's not alone and that there are so many others that are like him and are really good people

-Nena (SETBP1 Parent)]



# CO-OCCURRING CONDITIONS AND COMMON TRAITS OF INDIVIDUALS WITH SETBP1-HD/RD

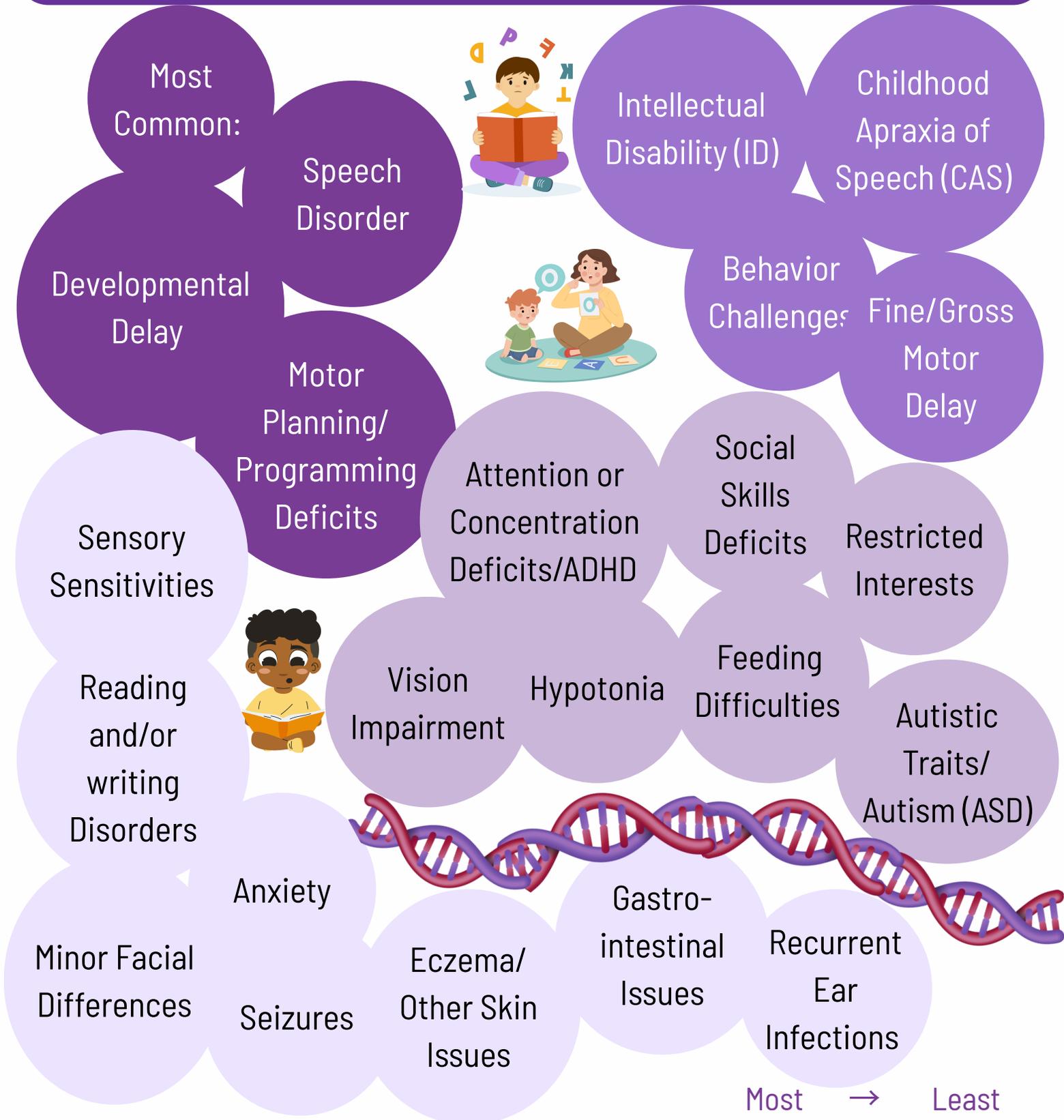
## **In this section:**

- Developmental Delay
- Intellectual Disability
- Autism
- Attention/ADHD
- Medical Challenges
- Emotion Regulation
- Challenging Behaviors

People with SETBP1-HD/RD may have all or some of these characteristics regardless of their specific genetic change. The purpose of a diagnosis can be for therapies, educational support, medications, qualification for government programs, or just to have a better understanding of the symptoms you or your child experience. Regardless of a diagnosis, strategies and therapies listed in the next section can be helpful!

# OVERVIEW OF COMMON CO-OCCURRENCES AND TRAITS

## SETBP1-HD Characteristics



# ALL ABOUT DEVELOPMENTAL DELAY

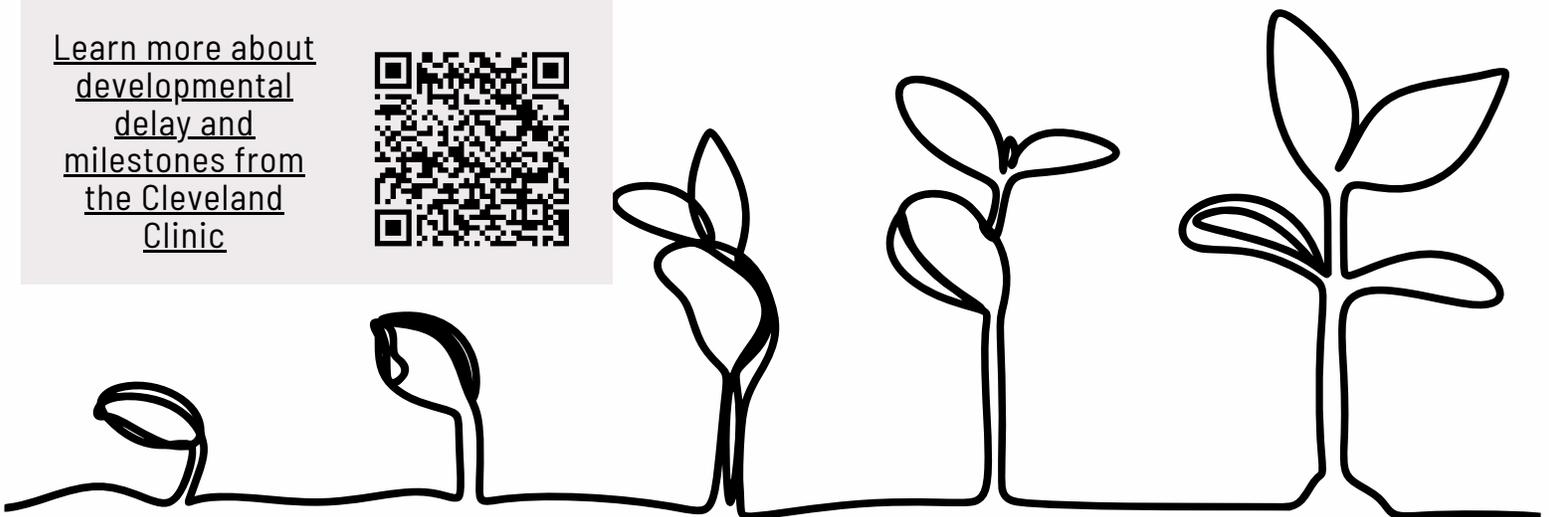
**Developmental Delay** means that a child has not gained the skills or reached the milestones that experts expect children to have at their age. Milestones are important because skills develop in order, so they give information about important later skills that the child might need help with. For example, if a baby is having trouble sitting up, it may be harder for them to walk and may need physical therapy.

Milestones are usually addressed at well-visits with the pediatrician. Children meet developmental milestones at different times for many reasons and sometimes end up following their own path and not needing any intervention to reach later skills.

## Milestones fall into four main groups

1. **Social and emotional-** How the child shows emotions and engages in back-and-forth interactions, like smiling.
2. **Language and communication-** How the child makes sounds and uses nonverbal communication, like cooing and raising their arms to be picked up
3. **Cognitive-** How the child thinks, learns, and solves problems, like putting an object in their mouth to learn about it
4. **Motor-** How the child moves and develops physically, like sitting up and rolling over

[Learn more about developmental delay and milestones from the Cleveland Clinic](#)

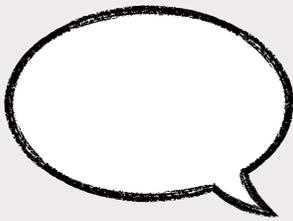


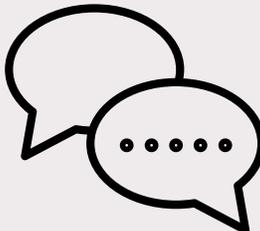
# DEVELOPMENTAL DELAY IN SETBP1-HD/RD

In 2024, we looked at our SETBP1 registry hosted by Searchlight and documented the clinical characteristics of 22 individuals with SETBP1-HD and 5 individuals with SETBP1-RD. Here is what we learned about milestones from that study:

\*Not everybody answered every question, so sometimes there are fewer than 27 total people in the results

<p><b>SETBP1-HD</b> <b>13/19 (68%)</b> <b>experienced delays</b> At the time of the study, 94% of individuals were walking</p> <p>Walking started between ages 1-3.5 years</p>	<p><b>Walking</b></p> 	<p><b>SETBP1-RD</b> <b>5/5 (100%)</b> <b>experienced delays</b> At the time of the study, 100% of individuals were walking</p> <p>Walking started between ages 1.5-4 years</p>
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<p><b>SETBP1-HD</b> <b>17/17 (100%)</b> <b>experienced delays</b> At the time of the study, 88.9% of individuals had said their first word</p> <p>Individuals in the study said their first word between the ages of 1.1-4 years</p>	<p><b>First Words</b></p> 	<p><b>SETBP1-RD</b> <b>5/5 (100%)</b> <b>experienced delays</b> At the time of the study, 100% of individuals had said their first word</p> <p>Individuals in the study said their first word between the ages of 1.1-5.5 years</p>
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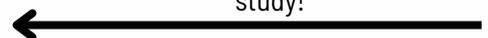
<p><b>SETBP1-HD</b> <b>15/15 (100%)</b> <b>experienced delays</b> At the time of the study, 80% of individuals used combined words</p> <p>Individuals in the study started using combined words between 2.5-8 years</p>	<p><b>Combined Words</b></p> 	<p><b>SETBP1-RD</b> <b>3/3 (100%)</b> <b>experienced delays</b> At the time of the study, 66.7% of individuals used combined words</p> <p>Individuals in the study started using combined words between 4.5-over 7 years</p>
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<p><b>SETBP1-HD</b> At the time of the study, <b>10/13 (80%)</b> of individuals were <b>toilet trained</b> and <b>9/13 (69%)</b> were <b>bowel trained</b>.</p> <p>Individuals in the study gained this skill between ages 2-9 years</p>	<p><b>Toilet Trained</b></p> 	<p><b>SETBP1-RD</b> At the time of the study, <b>2/3 (67%)</b> of individuals were <b>toilet trained</b> and <b>1/3 (33%)</b> was <b>bowel trained</b>.</p> <p>Individuals in this study gained this skill between ages 5-over 7 years</p>
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[Oyler, H. O., Hudac, C. M., Chung, W. K., Synder, L. G., Robertson, S., Srivastava, S. & Geye, T. \(2024\). SETBP1 haploinsufficiency and related disorders clinical and neurobehavioral phenotype study. Clinical Genetics, 106\(4\), 448-461. <https://doi.org/10.1111/cge.14579>](#)



Scan this QR code or click the citation to read the study!



# ALL ABOUT INTELLECTUAL DISABILITY

Intellectual Disability (ID) is a term used when a person has certain limitations in mental functioning that will cause the individual to learn and develop at a different pace than an individual without ID.

**Also called:  
Cognitive Disability or ID**

## **Children with ID may:**

1. Sit up, crawl, walk, or learn to talk later than other children
2. Have trouble remembering things
3. Have trouble with social rules
4. Have trouble understanding the consequences of their actions
5. Have trouble problem solving and/or thinking logically

**A study of 306 people with ID found strengths in love of learning, honesty, fairness, appreciation of beauty, and curiosity!**

(Umucu et al., 2022)

ID is usually diagnosed through **neuropsychological tests** that look at how a person learns, thinks, solves problems, makes sense of the world, and communicates. These also ask about **adaptive functioning skills** like getting dressed, feeding oneself, and following rules.

**For more information see the [Neuropsychological Testing](#) section**

**Often, a diagnosis of developmental delay will be given to a younger child before an ID diagnosis is made. This is because tests for ID are less reliable in infants and young children.**

# ALL ABOUT AUTISM

**“Autism is often called autism spectrum disorder, or ASD, because people with autism have a range, or spectrum, of differences. Autism is a neurodevelopmental difference. It is caused by differences in the way the brain functions.” -Simons Searchlight**

Every person with autism is unique and is unlikely to exhibit all of the features. Many of these symptoms are also found in people with ADHD, as well as other neuropsychiatric diagnoses.

Autism diagnosis depends on characteristics in 2 main areas

**Social Communication and Social Interaction**

**Restricted and Repetitive Patterns of Behaviors, Interests, or Activities**

SEE THE NEXT PAGE FOR COMMON CHARACTERISTICS OF AUTISM

When talking or reading about autism, you might hear people talk about **‘levels’ of autism.**

These are categories in the Diagnostic and Statistical Manual 5th Edition that providers use to make diagnoses. Some people find levels helpful for communicating with other people about their strengths or challenges. Other people find them misleading and not representative of their experiences.

**Simons Searchlight:  
What is Autism**



For more information about how autism labels have changed throughout history and what the different levels mean, check out this resource from Children’s Hospital of Philadelphia:



**Autism is associated with numerous genetic conditions and is not caused by a single genetic factor. Hundreds of genetic variations linked to autism have been identified.**

# EXAMPLES OF AUTISM CHARACTERISTICS

**Note:** If your child is displaying some or all of these characteristics, they might fit criteria for autism and you can choose to talk to your pediatrician about getting an assessment.

## Restricted and repetitive interests and behaviors

Lines up toys or other objects

Plays with toys the exact same way every time

Gets upset by minor changes

Likes specific parts of objects (e.g., spinning fan blades, wheels)

Has unique and/or very specific, focused interests

Has to follow certain routines

Stims (e.g., flaps hands, rocks body, spins self or objects, peers at fingers or objects)

Has sensory differences including oversensitivity to textures, smells, or sounds

## Social communication and interaction

Does not respond to name by 12 months of age

Avoids eye contact

Prefers to play alone

Has flat facial expressions or expressions that don't fit the situation

Has trouble understanding other people's feelings or talking about their own feelings

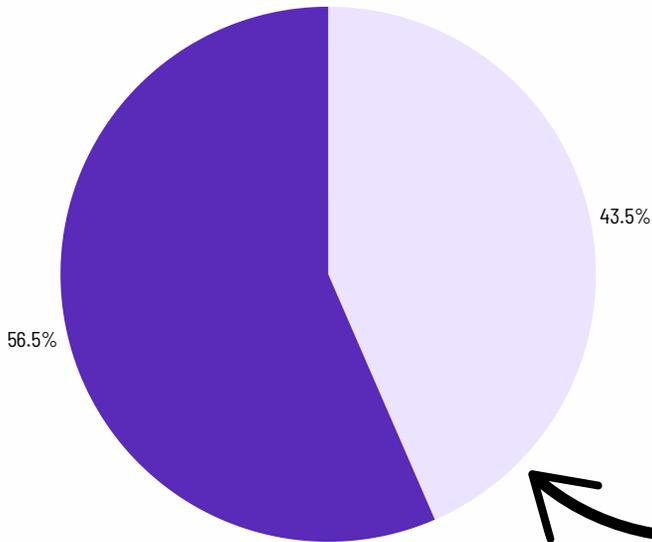
Does not pretend play

Reverses pronouns (says "you" instead of "I")

Talks in a flat, robot-like, or sing-song voice

Has trouble understanding personal space or boundaries

# AUTISM IN SETBP1-HD/RD



As of 2024, 6/19 people (32%) with SETBP1-HD and 4/4 (100%) people with SETBP1-RD were reported as having an autism diagnosis or characteristics of autism (43.5% total)<sup>3</sup>

Not everyone with SETBP1 has a diagnosis of autism. In fact, many people with SETBP1-HD/RD will not be diagnosed with autism but many still show characteristics of autism and might find related tools helpful!

Diagnostic tools for autism were originally created with mostly young, white boys in mind. Because of this, it can be more challenging to get a diagnosis for girls and non-white people. There are also challenges with diagnosing people with co-occurring conditions, which are common in SETBP1.

## Common in autism and ID

### Vocal stimming

Many caregivers of individuals with SETBP1 have reported that their SETBP1 bees tend to get fixated on words or sounds and repeat them over and over. This is referred to as vocal stimming and is common in autism and ID.

Here is some advice for how to respond to repeated questioning and/or vocal stimming:

- **Learn the purpose!** Sometimes people do this because they're anxious, curious, or bored.
- **Give the same calm, clear answer each time.**
- **Avoid overexplaining.**
- **Ask them to repeat your response back to you:** "What did I say when you asked that question before?"
- **Grab some headphones!**

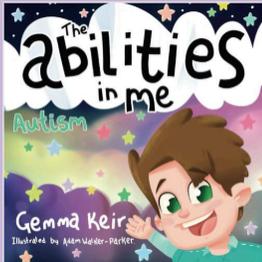
# AUTISM RESOURCES

## National Autism Resources

has ear defenders, sensory toys, sensory furniture, and much more!



Autism is both a diagnosis and an identity! If you or your child do receive a diagnosis or relate to experiences associated with autism, connecting with autistic self-advocates and other similar groups in your area or online can provide a lot of support and information!



### **The abilities in me: Autism**

This picture book is dedicated to children diagnosed with Autism, also known as ASD - Autistic Spectrum Disorder. Explore the day in the life of a young girl and boy with...

 [abebooks.com](http://abebooks.com) / \$10.75



## The Abilities in Me: Sensory Processing Disorder



This children's book is designed to help young readers understand sensory processing disorder by sharing relatable stories, fostering empathy, and promoting awareness for children who experience sensory challenges.

## Visual Supports

any visual item that helps a person understand others, communicate, anticipate what is going to happen, or become more independent

## Social Stories

simple, clear descriptive sentences about what will happen and what the child may experience

# ALL ABOUT ATTENTION/ADHD

**Attention-deficit/hyperactivity disorder (ADHD)** is a mental health condition that is often diagnosed in children. ADHD can make it very hard for children to focus on their schoolwork or other tasks, pay attention and sit still. People with ADHD have a harder time controlling themselves than other people their age, which can lead to challenges at school and at home.

**ADHD includes three separate kinds of behaviors:**

## Inattention

1. Easily distracted
2. Making "careless" mistakes
3. Hard time following instructions
4. Forgetting or losing things
5. Trouble staying organized
6. Appearing not to listen when someone speaks to them
7. Avoiding things that involve a lot of thinking or effort
8. Seeming unaware of what's going on around them

## Impulsivity

1. Constantly talking or interrupting others
2. Being very impatient

## Hyperactivity

1. Having a lot of energy and struggling to sit still
2. Fidgeting all the time
3. Often running around and climbing on things
4. Difficulty playing quietly

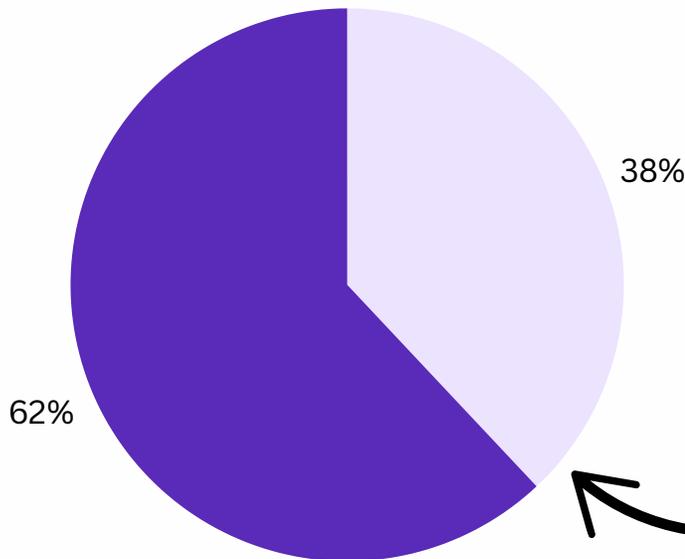
People with ADHD are oftentimes very creative, flexible, and introduce new ways of thinking to the world!

**Some with ADHD only show inattentive or impulsive or hyperactive behaviors, but most have a combination of behaviors**

[Learn more about ADHD from the UC Davis MIND Institute](#)



# ATTENTION IN SETBP1-HD/RD



**As of 2024, 11/17 people (65%) with SETBP1-HD and 2/4 (50%) people with SETBP1-RD were reported as having attention issues or being on medication for ADHD (62% total).<sup>3</sup>**

## **People may not have an ADHD diagnosis but still have challenges with attention.**

Many times people with SETBP1-HD/RD have another diagnosis that “overshadows” ADHD symptoms, have attention challenges that don’t meet the threshold for a diagnosis, or haven’t been tested. It is uncommon to formally diagnose ADHD in children younger than Kindergarten age.

However, resources for attention challenges and ADHD can still be helpful!



[Information from UC Davis Child Mind Institute about ADHD medication](#)

Many people who struggle with attention find stimulant and non-stimulant medications helpful! ADHD medications have been shown to be safe and effective for people who need them but always talk to your doctor about medications for yourself or your child! In a 2024 study, 61.1% of people with SETBP1-HD and 50% of people with SETBP1-RD were reported as taking medications for ADHD symptoms, this is a total of 59% of people surveyed (13/22 people)

“This [inattention] is mostly managed by medication, but he still has episodes of inattention, we will try to reduce distractions and give prompts to assist him in completing tasks” -SETBP1 Parent

“I do not believe that ADHD medicines change a child’s brain. I do believe that brains have neuroplasticity and that ADHD medicines can help a child become regulated enough to learn and practice adaptive behaviors which is a good thing. I always say that if I kid needed eye glasses to focus better, no parent would hesitate to get glasses for their kid. I feel like it should be considered the same way” -Erin (SETBP1 Parent and pediatrician)

# ATTENTION IN SETBP1-HD/RD

## RESOURCES & SYMPTOM CHECKER

Check out the UC Davis  
MIND Institute Information,  
Resources, and Symptom  
Checker



[Link to Symptom Checker!](#)



[ADHD Resources for Parents!](#)

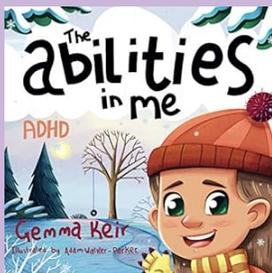
## SETBP1 EXPERT TALK

Watch a talk from Dr Sid  
from Boston Children's  
Hospital on navigating  
the challenges of ADHD  
in SETBP1-HD/RD

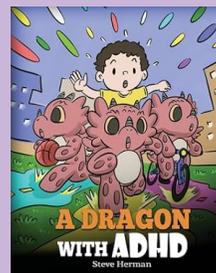


## CHILDREN'S BOOKS ABOUT ADHD

The Abilities in Me: ADHD



A Dragon with ADHD: how to get  
organized, focus, and succeed



# ALL ABOUT SPEECH & LANGUAGE

**SPEECH:** focused on speech sounds; includes accuracy, articulation, etc.

**LANGUAGE:** involves the understanding and use of words and sentences

## Common Speech & Language Features in Children with SETBP1-HD

**Motor Speech Disorder:** difficulty planning speech; they know what they want to say, but their brain struggles to coordinate their lips, jaw, and tongue for clear speech. Common motor speech disorders include Childhood Apraxia of Speech (CAS) and Dysarthria

**Phonological Disorder:** difficulty understanding and using sounds to convey meaning

**Expressive Language Impairment:** difficulty organizing and producing words or sentences

**Receptive language impairment:** difficulty understanding language or words

**Oral apraxia:** a disorder that makes it difficult for a child to coordinate and initiate non-speech oral movements of their lips, tongue, jaw, and soft palate; it can affect speech and feeding skills

## How are motor speech disorders, like CAS, different from speech delay?

A speech delay is when a person is following a "typical" speech development path at a slower rate than expected, whereas motor speech disorders have a different developmental path due to differences in how the brain and body produce speech.

CAS may require targeted, more intensive speech therapy.

(See [apraxia-kids.org](http://apraxia-kids.org) for more information)

## Speech Pathology (SP)

Input from an SP should start early & include assessment and therapies that are tailored to each individual. Families can seek advice from their local practitioners about the services available to them in their region.

**[Check out the Fact Sheet for Phonological Disorders!](#)**



**[Check out the Fact Sheet for Childhood Apraxia of Speech!](#)**



**[Check out the Fact Sheet for SETBP1 Speech & Language!](#)**



**[Check out the Apraxia Kids website to locate an SLP with training on CAS!](#)**





# ALL ABOUT MEDICAL CHALLENGES

## Low Muscle Tone

(hypotonia)

1. Baby/kid is “floppy”
2. Can affect a person’s ability to do tasks like sitting up, walking, writing, or drawing
3. Can affect endurance and ability to exercise
4. Can affect speech, eating, and swallowing

## Gastro Symptoms & Feeding Difficulties

1. Digestive problems
2. GERD (reflux)
3. Feeding difficulties
  - Poor sucking and slow feeding
  - Some children experience problems chewing lumpy or solid foods
  - Some children may require nasogastric tube feeding
4. Ankyloglossia (tongue-tie)

## Febrile Seizures

(seizures associated with fevers)

See next page for more info!

## Ophthalmologic involvement (vision challenges) most common

1. **Refractive errors:** vision problems that occur when the shape or length of the eye prevents light from focusing on the retina
  - **Hypermetropia** - far sighted (difficult to see objects close up)

## Less common vision challenges:

1. **Astigmatism** - irregular shaped cornea or lens, causing blurred or distorted vision at all distances
2. **Myopia** - nearsighted, trouble seeing far away
3. **Strabismus** - disorder that causes eyes to be misaligned or not point in the same direction (“cross-eyed”)

**Other challenges reported have included: Delayed motor milestones, cryptorchidism (undescended testicles), recurrent ear infections, and eczema**

# ALL ABOUT SEIZURES

## What is a seizure?

The cells in our brains (neurons) use electrical signals to communicate with each other! A seizure is when there is abnormal electrical activity in the brain-- usually from too many neurons firing/sending signals all at once.



## There are many different types of seizures. Here are some examples:

**Generalized Tonic-Clonic**- muscle stiffening, loss of consciousness, and jerking of the body

**Absence (generalized)**- loss of awareness of what is happening. Sometimes people flutter their eyelids, rub their fingers together, or make chewing motions

**Myoclonic (generalized)**- brief upper-body twitches. Usually awake and can think clearly during and right after the seizure

**Focal**- Affect one side of the brain, also called a partial seizure. During these, people can have changes in their senses, some muscle twitching, and can be aware (simple-partial) or unaware (complex-partial) of their surroundings

## Febrile Seizures

are seizures associated with **fevers**. They typically occur in children between the **ages of 6 months and 5 years**. They are **generalized tonic-clonic** and **resolve in less than 15 minutes**. If the seizure doesn't fit these criteria, it is still a seizure, but not necessarily a febrile seizure. All seizure types are more common when a person is sick and/or has a fever.

The treatment for seizures depends on their cause (if it is known) and the type of seizure.

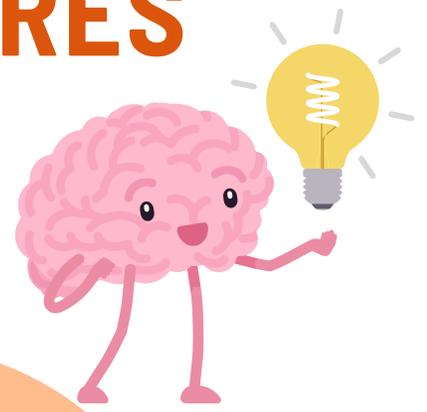
Some, especially febrile seizures, won't need any treatment. Medicines can help with many types of seizures.

[Scan the QR code or click this link to learn more about seizures from Nemours Children's Hospital](#)



**20%** of individuals with SETBP1-HD have been reported to have infantile febrile seizures. Three individuals have been identified as having epilepsy with generalized seizures.<sup>1</sup>

# ALL ABOUT SEIZURES



## How to recognize a seizure:

1. Stiffness and twitching
2. Loss of consciousness
3. Irregular breathing
4. Eyes rolling back
5. Vomiting
6. Wetting or soiling
7. Unresponsiveness

The individual may be sleepy, irritable, or confused for up to an hour after the seizure

## If someone around you has a seizure

1. Stay calm!
2. Gently place the person on the floor and on their side
3. Remove any nearby objects
4. Watch for any trouble breathing
5. DO NOT put anything in their mouth or try to prevent the shaking

### Keep track of:

1. When it happened
2. How long it lasted
3. What happened right before the seizure
4. What happened during and after the seizure

Sometimes it can be helpful for doctors to see a video of the seizure.



Scan the QR Code to learn about seizure preparedness and safety from The Epilepsy Foundation



# HEAR FROM THE COMMUNITY: MANAGING MEDICAL CHALLENGES

“She has epilepsy [focal cortical dysplasia, type 2] which has all of the same symptoms as SETBP1 so the most challenging part is figuring out what is coming from which diagnosis. We travel very far for medical appointments and are waiting to see if insurance will cover an epilepsy monitor. If they don’t we will pay for it out of pocket. We have found support with the DannyDID foundation for medical grants.”

-Community Member

**What do you do at doctor’s appointments? What do you like about them?**

**“I play and I like to talk to my doctors” -Community Member**



The Little Hercules Foundation has information about grants for medical services and equipment

The DannyDID Foundation provides grants to support families in purchasing medical equipment, specifically for seizures and epilepsy. Grant applications are typically due in May.



“We went through 3 pediatricians before we got genetic testing. Trust your instincts as a parent. Reach out to people.” -Erica (SETBP1 Parent)

# ALL ABOUT EMOTION REGULATION

**Emotion Regulation** is the process of changing behaviors in the presence of feelings or emotions to fit a situation.

For example: calming down when you're mad, trying not to laugh, and navigating anxiety are all forms of emotion regulation

Challenges with emotion regulation are connected to co-occurring diagnoses of **anxiety**

**Alexithymia** means difficulty understanding and communicating emotions. This is very common in people with neurodevelopmental differences and disorders and can make emotion regulation more difficult.

Children **taught emotion regulation strategies** typically have **better academic success and fewer disciplinary referrals** in schools than children not taught

Read about parent and teacher reports of how children with intellectual disabilities regulate their emotions:

[Parents](#)



[Teachers](#)



People with **neurodevelopmental disorders** tend to have more challenges with emotion regulation and **regulatory behaviors** (what they do to regulate their emotions) which may **look different** than what neurotypical people do.

**Here are some examples of strategies that can be common for people with neurodevelopmental disorders:**

**Self harm, "aggressive" behaviors, non-compliance, escape/eloping**

See section on [challenging behaviors](#)

**Repetitive behaviors**

Stimming helps a lot of people calm down or express that they are excited

**Rumination**

Focusing or getting 'stuck' on one topic. This can look like repeated questioning (see [Autism in SETBP1-HD/RD](#))

**Avoiding information or distraction**

This can look like pretending not to hear something or changing the subject of a conversation

**Maintenance of routine**

Keeping a predictable routine can help people avoid dysregulation

**Adding or removing sensory elements**

Adding or taking away sound, light, tactile pressure, etc. can help a lot!

# RECOMMENDATIONS FOR EMOTION REGULATION

## The Zones of Regulation

Click to learn more!



## Social Thinking

- helps people understand themselves and others to better navigate the social world, foster relationship development, and improve their performance in different settings
- learner led approach
- educational resources, online training courses, and a library of free articles and webinars available

## Feelings Charts



Download and print these free charts to help your child express their emotions

Learn more on their website!



## Mindful Breathing

becoming aware of your breathing and how you can use it to calm your mind and body

**Clarify consequences for specific behaviors, not emotions**

## ECPN Webinars

- MANAGE EMOTIONAL DYSREGULATION
- LEARN TO TEACH EMOTION REGULATION
- DE-ESCALATION & EMOTION COACHING PARENTING
- PRESENTED BY DR. YAMALIS DIAZ



# HEAR FROM THE COMMUNITY: EMOTION REGULATION

"I've found that the best way to help him is just to give him space and opportunity to calm down on his own"

-Nicole (SETBP1 Parent)

"One of the best approaches I have learned over the years is to respond in a calm manner with short direct phrases. When he is emotional, his energy will rise as mine does. He also will not hear most of the things I say so keeping it short and simple helps."

-Haley (SETBP1 Parent)

"It has helped to get down on his level and slow the situation down. We usually ask him to take 3 deep breaths and that helps him reset."

-Lindsey (SETBP1 Parent)

"Keep calm and wait until the storm passes. Ask for medical or therapy help. Some medications can help."

-Antoine's Mother

"We found ABA extremely helpful. We learned strategies with him to help him cope. We all needed to provide flexible transitions. Our toolkit includes: deep breaths, feel your heart beat, drink some water, ask for a break, squeezes, sensory tools like pop its, chewies, massages, back scratches, time."

-Allyson (SETBP1 Parent)

## What do you do to calm down?

"Put a cool mask on"

-Community Member

[This community member use(s) temperature to regulate their body. They sometimes use a cold cap that is typically used for migraines or asks for cold water to be dumped on them.]

# ALL ABOUT CHALLENGING BEHAVIORS

**Challenging behaviors** refer to persistent actions that interfere with learning, relationships, or safety, either for the individual or those around them.

## Examples of challenging behaviors

- **Physical aggression:** biting, hitting, kicking, punching, pinching, pulling hair, slapping, spitting
- **Non-physical aggression:** screaming, tantrums
- **Destruction:** damaging or throwing things
- **Eloping:** running away from caregivers and/or safety
- **Self-Injurious Behaviors:** biting, pulling hair, head banging, self-hitting, skin picking

## Behavior is an issue if it:

1. Hurts someone
2. Prevents the person from being included
3. Stops personal development
4. Causes major disruption to family life
5. Is not legal/acceptable (e.g., removing clothes in public)

[Read about self-injurious behaviors in children with intellectual disability:](#)



**Challenging behaviors can be difficult to handle and taboo to talk about.**

**Some caregivers feel like they have failed in some way if their child does not 'behave'. It is important to remember what your child does well and the ways you, as a caregiver, have succeeded.**

[Check out this awesome resource about challenging behaviors:](#)



## Reasons why people might engage in challenging behaviors:

- They learn their actions will give them a response or reward
- They have a need, preference, or other desire they want to communicate
- They have a medical, emotional, or physical need that isn't being met
- They have a sensory sensitivity
- Sudden changes in behavior can indicate an underlying medical, physical, or emotional problem

# RESOURCES FOR CHALLENGING BEHAVIORS

Try to think about behavior as a 'message' your child is sending

## Positive Behavior Supports

Reward and praise behavior you want to see, including neutral behavior. For example: "I see you watching TV so calmly", "I love how you're playing with your toys"

Learn about  
Positive Behavior  
Supports from  
[Parent Center Hub](#)



## Anticipate Problems

- Offer alternative items for the person to bite, throw, or hit
- Use ear defenders or other sensory supports if over- or under-stimulation tend to result in challenging behaviors
- Use timers or [visual schedules](#) to anticipate change and transitions

## Functional Behavior Analysis

Keep track of the ABC's of challenging behaviors.

**Antecedents:** what comes before or causes the behavior?

- Examples: being given a direction, being ignored, being told to stop something

**Behavior:** what is the behavior? What does it look like?

**Consequence:** What comes after the behavior?

- Examples: Getting adult or peer interaction (attention), avoiding or delaying an activity or task (escape), getting a favorable toy/activity (tangible)

There are lots of pre-made charts online designed for this tracking. Search "FBA ABC chart" to find one that works for you!

You/your child may also be referred to or receive a professional Functional Behavior Assessment. This usually occurs in Applied Behavior Analysis (ABA) clinics or schools and tends to be done by Board Certified Behavior Analysts (BCBAs) or School Psychologists

# HEAR FROM THE COMMUNITY: CHALLENGING BEHAVIORS

We asked SETBP1 community members what challenging behaviors they experienced with their loved ones and how they managed them. Their responses are all kept anonymous for privacy:

## Challenge: "Incontinence"

"We will have him go to the bathroom roughly every hour when home. This is a bigger issue when he is doing something he enjoys and doesn't want to stop to use the bathroom."

## Challenge: "Physical aggression"

"This usually stems from inability to communicate due to being nonverbal and it happens in cycles. When he has an occurrence, we discuss what caused it and provide alternative, acceptable responses."

## Challenge: "Defiance"

"We had to come to the understanding that, although his physical age may be 5, his mental capacity was closer to that of a toddler. This helped us manage our expectations with behaviors. We kept clear, consistent boundaries with him regarding his behavior. Over time, things seemed to finally "click" around the age of 6 or 7."

## Challenge: "Impulsivity, emotion regulation, and emotional expression"

"We work on these things during OT and find a lot of these difficulties stem from his communication struggles. We are still on our communication journey, but just received our first AAC. We are firm believers that behavior is communication. Sometimes it takes some work to figure out what a certain behavior is trying to tell us."

## Challenge: "Impulsivity, constantly getting in trouble at school for hitting kids or saying things he shouldn't say"

"Medication and meeting with his teachers at the beginning of every school year. Also working with a behavioral therapist to help him understand how to stop, think, and ask for a break when he is tired or frustrated."

# HEAR FROM THE COMMUNITY: CHALLENGING BEHAVIORS

“He has MANY challenging behaviors. They have waxed and waned over time. His impulsivity and lack of emotional regulation have been pervasive since he was younger. When he was younger, he did not seem able to link actions with consequences which made typical rewards and punishments nearly impossible to implement. Occasionally he becomes very dysregulated and is intrusive / interrupting / perseverating on the same topic/ showing aggression when he is frustrated. He has some flashes of oppositionality, but he really wants to be a sweet kid and in many ways is very empathetic and caring when he is regulated.”

---

“Try asking your developmental pediatrician or checking with local services for parent training programs that focus on positive behavior reinforcement. They've honestly saved my sanity more than once and offer practical, effective strategies.” - Haley (SETBP1 Parent)

“I really believe that all kids WANT to do well and are doing the best they can with the skills that they currently have. I spend a lot of time and energy looking to meet him where he is at and keep his nervous system regulated. I provide a lot of warnings before transitions, give him a lot of choices, praise good choices and look for opportunities to find emotional connection with him. I make sure that he is eating healthy foods and getting to spend time exercising outside daily. I love the Nurtured Heart Approach as well as the work of Michelle Garcia Winner in Social Thinking.”  
-Erin (SETBP1 Parent)

# THERAPY, MEDICAL CARE, AND SERVICES

## **In this section:**

- Diagnosis and Testing
- Commonly Used Services
- Finding Care and Advocating in Therapy and Medical Settings

This guide is not intended to serve as medical advice. We encourage you to consult your child's pediatrician and medical team with any questions or concerns regarding their care.

# A NOTE ABOUT SERVICES AND THERAPIES

**This next section is about medical care, therapies, and other services that members of the SETBP1 Community have used.**

**This information is NOT medical or therapeutic advice; please consult a professional to discuss what is best for you or your child!**

**There is a lot listed because there is a lot out there! Some things may be recommended by doctors and considered necessary, but most are just suggestions to try and see what works best for you or your child!**

“Keep fighting for the answers. Don’t take no for an answer if something is not right. You as a parent know your child best. Make sure you have every possible resource available to you. You and your child both deserve that” -Nicole (SETBP1 Parent)

Scan the QR or [click here](#) for more information about each of these different therapies and services.



# ALL ABOUT COMMONLY USED SERVICES

In 2021, SETBP1 Society summarized findings from 2 publications: Morgan, et al 2021 and Jansen, et al 2021. The collected data was provided in the 2021 SETBP1-HD Resource Guide from data reported for 34 individuals.

**86%** required learning support access across all settings

**94%** required occupational or physical therapy

**Many** required behavior plans for challenges related to social skills, attention difficulties, anxiety, and aggression

**Most** required speech therapy starting at an early age

**23%** had a frenectomy (surgery) due to a tongue-tie

Out of **13** individuals, **8** reported taking medications to help with behavior and ADHD, **3** reported taking antiepileptics, **2** reported taking medications for gastrointestinal issues, **1** reported taking antidepressants, and **1** reported taking melatonin for sleep

**These numbers are informational and no medications or medical services should be tried or adjusted without physician support and guidance!**

Scan these QR codes or click the citations to read the articles written with this data



[Morgan, A., Braden, R., Wong, M. M. K., Collin, E., Amor, D., Liegeois, F., Srivastava, S., Vogel, A., Bizaoui, V., Ranguin, K., Fisher, S. E., & van Bon, B. W. \(2021\). Speech and language deficits are central to SETBP1 haploinsufficiency disorder. \*European Journal of Human Genetics\*. 29:1216-1225](#)



[Jansen, N. A., Braden, R. O., Srivastava, S., Otness, E. F., Lesca, G., Rossi, M., Nizon, M., Bernier, R. A., Ouelin, C., van Haeringen, A., Kleefstra, T., Wong, M. M. K., Whalen, S., Fisher, S. E., Morgan, A. T., & van Bon, B. W. \(2021\). Clinical delineation of SETBP1 haploinsufficiency disorder. \*European Journal of Human Genetics\*. 29: 1198-1205](#)

# ALL ABOUT FINDING CARE

**The first step to finding care is to ask your child's doctors and other service providers. They will likely know of trusted resources in your community that they can recommend.**

**You can also reach out to the SETBP1 Community on Facebook and other local Facebook groups for parents with children with special needs and ask advice about where others have found services in your area.**

## **Visit the Little Hercules Foundation Database**

This database was created by another rare gene group and has information about thousands of services! Type in your zip code, keyword, or service name to find resources near you!

**\*This is an online searchable database; we have not vetted and cannot recommend specific services found**



## **The Complete Guide to Getting Good Care - UC Davis Mind Institute**

1. Does My Child Need Help?
2. Where to Go for Diagnosis Help
3. What Should I Look for in Diagnosis?
4. Who Can Assist With Treatment?
5. Pre-Treatment Questions to Ask Your Doctor
6. How Do I Know if I'm Getting Good Treatment?
7. What if My Child Has Multiple Disorders?
8. What About Problems With Diagnosis or Treatment?
9. What About Alternative Treatment Options?
10. What Should I Do if My Child Has Learning Issues?
11. How Do I Get School Services for My Child?



# HEAR FROM THE COMMUNITY: GETTING GOOD CARE

**We asked some caregivers of people with SETBP1-HD/RD about their experiences and with getting good care and strategies that have worked for them.**

**Here's what they said:**

"In terms of treatments being evidence based or not - I would say talk with your pediatrician. Unfortunately there are predatory people who make a lot of money preying on the hopes of desperate parents who would do anything for their child. You can always check resources like PubMed and the American Academy of Pediatrics to see if there is a paper or position statement on the issue. Some things are pretty low risk, but they may not have a significant benefit (of course they cost time and money) and some things are objectively harmful. There is a limited amount of time and money for most people and so taking a practical approach makes sense for all therapies" -Erin (pediatrician and SETBP1 Parent)

"Do your research on everything, but also trust your gut. You know your kid best. You can trust the professionals and lean on their expertise, definitely give things a chance - particularly the newer, more difficult things, but ultimately if it doesn't feel right, trust your gut. Consult with other caregivers as part of your research as well. Not everything you read online is true and current." -Jennifer (SETBP1 Parent)

"For me it is all about their communication. If they are not willing to have me involved to some degree, then I don't want to work with them. I know the importance of generalization of skills to the natural environment, so I want to be able to help ensure that is happening. As a practitioner, I know to review current literature for the effectiveness of a treatment. I specifically look for evidence-based practices." -Jennifer (SETBP1 Parent)

"More than likely when you are seeing most of your providers, you will be the expert in the room on SETBP1. Find a provider that is willing to listen to you in order to learn about your child's condition and willing to try your suggestions. Try to find providers that have expert knowledge on the secondary diagnoses your child has as a result of SETBP1, for example, a speech therapist that specializes in apraxia, or an occupational therapist that specializes in sensory processing disorder or autism. Don't be afraid to ask them questions. Ask them what the best evidence-based treatments to address this diagnosis are; ask them what they have seen work the best in their experience." -Casey, OTR (SETBP1 Parent)

# HEAR FROM THE COMMUNITY: GETTING GOOD CARE

**We asked some caregivers of people with SETBP1 about their experiences and with getting good care and strategies that have worked for them.  
Here's what they said:**

"Don't be afraid to switch things up if you feel like it's not a good fit or you're not seeing the progress you want to see."

-Casey, OTR (SETBP1 Parent)

"Their treatment philosophy and communication style need to be compatible with our family. Their social interaction, and ultimately their treatment interaction, need to be compatible with your child. I.e. how firm/gentle, how they pick up on non verbal cues, and how they handle difficult behaviors."

-SETBP1 Parents

"I need a provider who listens to what I am saying and respects my intellect. I have had providers only half listen to what I say, and therefore recommend things that I have already said I've tried or recommend things that I specifically say are not a good fit for our family."

-SETBP1 Parents

"We have tried treatments/therapies that ultimately do not align with our philosophies and stopped. I am not afraid to try new things, but I'm also not afraid to say, "no, stop". It is important to me that he is respected as a person, and I will not do anything to him that I wouldn't want done to myself."

-SETBP1 Parents

# INTERVIEW WITH RARE PARENT ABOUT GETTING GOOD CARE

**Colleen is the mom of Meghan, an adult with DDX3X-Related Neurodevelopmental Disorder. This is a rare genetic condition, like SETBP1, associated with autism, ID, speech and language disorders, and medical complications. We asked her advice about getting good care in multiple different domains.**

## **How do you know Meghan is getting good care in her residential home?**

"I have regular communication with the house manager, and I expressed my concerns in a respectful but straightforward manner. I then follow up to see what changes can be made to address those concerns. I make it a point to have a verbal conversation either in person or by phone with the house manager about every other week. Get to know this person and show them kindness."

## **How have you known if medications are or aren't working for Meghan?**

"Data, data, data."

As far as medications go, keep a running list of medications as a word document on your computer. Keep track of what the medication was prescribed for and whether it has been effective. If it has not been effective, make note of that as well. You would be surprised how many times a doctor might want to circle back and try a medication that was unsuccessful or had unpleasant side effects. If you have this list and you maintain it, it can be useful to you. I have also found it useful when a new health insurance company wants to have you use a medication on their formulary that you know has not been effective. You will have the date and the dose and what the result of that medication was so that your doctor can write to the insurance company for approval of a different medication."

## **What about therapies?**

"As far as therapies go, be aware of what the goals are, and whether they are being met. Be mindful of whether the goals are actually challenging your child or if they are too simplistic. The goals should be changing and becoming increasingly more difficult ideally. Sometimes your child may plateau on a particular skill and that's OK. That is just life, but make sure it is a plateau and it is not ineffective therapy. Go to the therapy sessions occasionally and observe."

# ALL ABOUT SPEECH THERAPY

**Speech therapy improves your ability to communicate by speaking or using AAC (like sign language or special devices)**

## Speech Assessments

**Goal:** Understand nature and severity of speech and language challenges

- May be required at multiple points in development
- Used to make recommendations for appropriate therapies

### Assessments typically test:

- Speech production skills to evaluate for specific speech diagnoses
- Expressive (producing) and receptive (understanding) language skills
- Social and pragmatic language skills
- Feeding and swallowing abilities

In addition to targeting speech sounds, social pragmatic skills may need to be taught, as well, as specific language skills. Speech therapy should change to address the child's needs as they age and grow.

[Scan the QR code or click the link to read the SETBP1-HD Speech & Language Fact Sheet](#)



Speech therapy is usually provided by a **Speech Language Pathologist (SLP)**. Speech therapy can occur in schools, private clinics, or in the home!

Almost all individuals with SETBP1-HD and related disorders have speech and/or language difficulties. Get started early! Talk to your pediatrician for a referral or contact the early childhood intervention (ECI) program near you. You do not have to wait for a referral from professionals to get an evaluation and start speech therapy.

Feeding difficulties may be identified in infants. A feeding therapist may be needed. Oftentimes, feeding therapists work alongside SLPs and some SLPs are also trained to be feeding therapists.

[Scan the QR code or click the link to learn more about speech therapy from the Cleveland Clinic](#)



# ALL ABOUT MOTOR SPEECH DISORDERS

**A motor speech disorder is a condition that affects a person's ability to plan, coordinate, or produce the muscle movements needed for speech. The most well-known motor speech disorder is Childhood Apraxia of Speech (CAS).**

**SETBP1-HD is the most known genetic cause of pediatric motor speech disorders!\*\***

## **What does Speech therapy for Motor Speech Disorders look like?**

- Speech therapy for CAS involves lots of practice and repetition to help them learn and coordinate speech movements.
- Frequent, shorter sessions are encouraged, especially for younger children with shorter attention spans.
- Visual, verbal, tactile and/or touch cueing are incorporated
- Speech/sound production feedback is provided to the child
- Careful consideration for speech sequencing is continually considered

Scan the QR code or click the link to learn more about key factors for therapy for CAS



**Unfortunately, Childhood Apraxia of Speech is NOT simply a developmental delay that a child will "grow out of."**

## **What motor speech disorders have been identified for individuals with SETBP1-HD/RD?**

- Childhood Apraxia of Speech (CAS)
- Dysarthria (often more evident when CAS resolves)<sup>2</sup>
- Stuttering



## **Below are examples of Evidence Based Programs for Childhood Apraxia of Speech (CAS):**

1. Nuffield Dyslexia Program
2. Rapid Syllable Transition Treatment
3. Dynamic Temporal and Tactile Cueing
4. Prompts for Restructuring Oral Muscular Phonetic Target

Scan the QR code or click the link to learn more about Keeping Kids Motivated and Successful in Speech



# HEAR FROM THE COMMUNITY: SPEECH

"If you are offering choices and can have the choices physically available (e.g. holding an apple in one hand and a banana in another) this may help to make the choices more concrete. Also, narrating your actions can help, using the same simple words/signs/pictures (e.g. You model "mmm, I want more. More blueberries" as you reach for more")."

- Jaclyn (SETBP1 Parent and SLP)

"Augmentative communication was a big game changer too as it was easier for her to express herself and she was the cool kid in the class as she was allowed a laptop which enabled her to participate in class."

- Kathy (SETBP1 Parent)

"Our son started Speech Therapy at 12 months old. With the help of his care team, he has consistently made gains and never regressed with his speech"

-Lindsey (SETBP1 Parent)

"The biggest key is to model speech for them so I was constantly talking to him as a baby saying things like "Look at that red car" or "Wow, it's a beautiful day". Anytime we were in the car, I would speak out loud to him about things happening around us."

-Lindsey (SETBP1 Parent)

"Modeling without expectation helps! So when you want something you can say (or model with gestures/pictures/device) "I want water" and get yourself water. Same with needs. Eventually he may begin to imitate. Also lots and lots of positive reinforcement for the times he does independently do those things."

- Jennifer (SETBP1 Parent)

"We started learning and teaching him ASL at one year. We began speech services two to three times a week and increasing to four times per week starting at 18 months."

- Allyson (SETBP1 Parent)

"Due to the high prevalence of Childhood Apraxia of Speech (CAS) in children with SETBP-1, it is best to find a speech language pathologist who is trained in evaluating and treating motor speech disorders. Apraxia kids.com offers a great provider directory which allows you to search in your geographical area."

- Jaclyn (SETBP1 Parent and SLP)



# ALL ABOUT AUGMENTATIVE AND ALTERNATIVE COMMUNICATION (AAC)



## What is AAC?

- Augmentative & Alternative Communications (AAC) refers to all the different ways a person can communicate besides speaking
- Unaided AAC or no-tech AAC includes gestures and sign language
- Aided AAC includes picture communication boards and dedicated electronic devices/programs for communication

AAC Fact Sheet



## How do I know if my child needs AAC?

- AAC is typically considered for children who have less speech than expected for their age, have unclear speech, or do not consistently use speech to communicate
- A variety of children and people need AAC, including those with ID, Autism, and developmental delay
- An individual does not need to have a diagnosed condition to use AAC
- A child can learn AAC and focus on other speech therapy goals at the same time

Scan to learn about the difference between Assistive Technology & Adaptive Technology for Augmentative & Alternative Communication (AAC)



Information about Speech Tablets for Apraxia



Ask your pediatrician and/or speech pathologist about AAC!

# ALL ABOUT PHYSICAL THERAPY (PT)

## Goals of PT

**Gross Motor Skills-** using large muscles for sitting, standing, walking, running, etc.

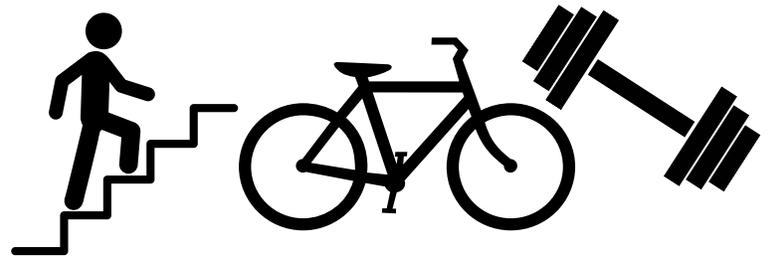
**Balance/Coordination-** Coordinating the brain, bones, and muscles for smooth movements like climbing stairs and jumping.

**Strengthening-** Building muscle for support and endurance

**Functional Mobility/Motor Planning-** Moving through space, day to day, for independence and efficiency

People with SETBP1-HD/RD typically need PT to address low muscle tone (hypotonia), balance, and coordination.

PT is usually done by a **Licensed Physical Therapist (PT)** or **Certified Physical Therapy Assistant (CPTA)** being supervised by a PT. It can occur in schools, private clinics, or in the home!



Scan the QR code or click the link to learn more about PT from the [American Physical Therapy Association](#)

Scan the QR code or click the link to learn more about the role of a pediatric physical therapist for autistic children from [Children's Hospital of Philadelphia Center for Autism Research \(CHOP-CAR\)](#)



# ALL ABOUT OCCUPATIONAL THERAPY (OT)

## Goals of OT

**Fine Motor Skills-** grasp and release things like toys, pencils, and shoe laces

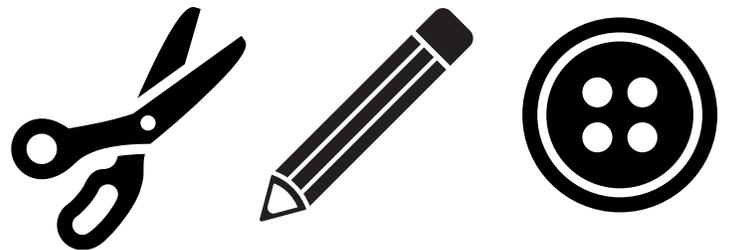
**Hand-Eye-Coordination-** Coordinating the brain, bones, and muscles for smooth movements like throwing a ball and copying from a board in school.

**Life Skills-** Support with bathing, getting dressed, brushing teeth, and self-feeding.

**Sensory Processing-** Learn to meet individual sensory needs through activities that help people keep themselves feeling calm. Sometimes this is done with a “sensory diet”

People with SETBP1-HD/RD typically need OT to help with sensory processing challenges, fine motor skills, and social-emotional regulation

OT is usually done by a **Licensed Occupational Therapist (OT)** or **Occupational Therapy Assistant (OTA)** being supervised by a OT. It can occur in schools, private clinics, or in the home!



Scan the QR code or click the link to learn more about OT from the [Cleveland Clinic](#)

## Q&A from SETBP1 Bees!

What do you do in OT?

- “Collect the trash” - Colton (13 years old)
- “I play a game with my friend. All the time we play” -Community Member

# ALL ABOUT BEHAVIOR THERAPY

The most common type of behavior therapy is **Applied Behavior Analysis (ABA) Therapy**

## Goal of ABA:

Increase behaviors that help people with daily living such as communication, social interactions, independent living skills (e.g., brushing teeth, cleaning up, cooking), and following directions. Therapy based on ABA principles also tries to reduce challenging behaviors such as self injury, eloping (leaving a safe area or sight of a caregiver without permission), and any harmful behaviors towards others.

**ABA** is typically covered by insurance in the U.S. for people with an autism diagnosis and has scientific evidence for improving the quality of life for autistic people.

[Study looking at impact of ABA on children and youth with Autism Spectrum Disorders](#)



Although ABA has gone through many changes since its development, it is important to consider the needs and wellbeing of your child when choosing an ABA provider as services can vary greatly by provider.

**ABA** is usually prescribed as an intensive treatment, with anywhere from 12-40 weekly hours prescribed depending on the needs of the patient.

If you, your family, and your therapy/support team decide that it is best for your child to receive this many hours of ABA, you can advocate for your child to have early dismissal or late arrival to school to accommodate for therapy. The BCBA (or BCaBA) can provide a school excuse for missed time since ABA is considered medically necessary. This will not only make it easier to find services (as many clinics operate during school hours), it will be much less exhausting for your child!

-Jennifer, BCBA

Some autistic individuals disagree with the use of ABA because, in its original form, it used punishments as well as rewards to change behavior. While punishments are no longer used, some providers' focus on reducing behaviors rather than building skills, the repetition, and number of hours of therapy sometimes recommended are also critiques of current ABA.

[Read more about this from the UC Davis MIND Institute:](#)



# MORE ABOUT BEHAVIOR THERAPY

Blurb modified from Fragile X Syndrome Educational Guide:

ABA is not a specific program but rather a behavioral framework from which specific therapeutic interventions (e.g., Lovaas therapy, verbal behavior, discrete trial, etc.) have been developed. As such, there may be wide variability from one ABA program to another. It is important to keep in mind that systematic instruction, careful ongoing assessment, positive reinforcement, and attention to the ABCs (antecedents, behaviors, and consequences) of behavior are essential aspects of any successful therapeutic program, regardless of whether or not it is designated as "ABA." Decisions about the appropriateness of ABA services for a child with SETBP1-HD should be made after careful evaluation of the individual. Discrete trial training (DTT) and intensive table teaching (ITT) procedures may need to be less direct and may include another student to utilize peer modeling or turn taking. Staff working with these students should continue to glean ideas and potential strategies from well-established programs while keeping in mind the individual characteristics of each student.

A note from Jennifer, SETBP1 Parent and BCBA

"When interviewing clinics, ask about the individualization of the treatment plan. A good ABA program will provide an individualized treatment plan for each patient. It should also be fluid (to some degree, often determined by funding sources - insurance, etc.) so that as the BCBA (or BCaBA) observes the patient and analyzes the data, they can make appropriate modifications to programming. If a patient masters a skill quickly or something is determined to be no longer necessary, you will want a treatment plan that will allow you to move on to something else."

# ALL ABOUT VISION THERAPY

## What is vision therapy?

Customized treatment program to treat visual problems

## Goals of vision therapy are to improve:

- Eye tracking
- Focusing
- Eye teaming
- Convergence
- Hand-eye coordination
- Visual processing

## Examples of various visual problems that vision therapy can treat:

- **Amblyopia** (Lazy eyes)
- **Strabismus** (Eye turns)
- Binocular vision

## What do vision therapists do?

Vision therapists use tools like lenses, prisms, and filters to teach skills and techniques. They also perform vision therapy exercises to improve vision function.

Sometimes vision therapists also suggest **eye patches** or special **glasses** to help with strabismus (crossed eyes) and/or amblyopia (lazy eye). These help strengthen the eye that is having difficulties

**Vision therapy teaches how the brain controls the eyes.**



Read this article from Boston Children's Hospital to learn more about vision therapy.



# ALL ABOUT RESPITE CARE

## What is respite?

Short-term care for individuals with disabilities that is intended to provide free time or relief for the primary caregiver.

## How does respite support and help?

- Supports independence skills for individuals with disabilities and provides them with community and social support and experiences
- Some respite providers will also include and care for non-disabled siblings
- Some groups have activities and outings for members

Check out the QR code and link below for a **parent's guide to respite!**

**Availability and cost of respite services vary by location!**



## Some questions to ask yourself to figure out if you might benefit from respite care

1. Do you currently have difficulty finding temporary care for your child?
2. Do you think that you would be a better parent to the child with special needs if you had a break now and then?
3. Would you be comfortable using a trained and reputable respite provider to care for your child?
4. Do you ever feel guilty that you don't have enough time to spend with your other children?

If you answered "yes" to any of these questions, you and your family could benefit from respite care and should investigate the resources in your community.

## Types of Respite Care:

Respite services may be provided in your home or outside the home (community).

# MORE ABOUT RESPITE CARE

## Before finding a respite provider

1. Prepare a “What you need to know...” guide, that provides necessary information about your home and your child for the future respite provider.
2. Request a letter from your pediatrician that “tells the story” about your child’s medical condition.
3. Look for respite care before you actually need it.
4. Decide what kind of respite care will work best for you.

## Finding a respite provider

- Ask your doctor, hospital, or care manager for referrals. Your child’s teacher may also have suggestions.
- Locate a nearby support group, and ask other parents about providers they’ve used and would be happy to use again. Most hospitals can tell you if there is an appropriate support group in your area.
- If you qualify for services or funding through a state agency, ask the agency for help in locating a qualified respite provider in your area.
- Call 2-1-1 or Child Development Info Line 1-800-505-7000 and ask about respite services.

### Visit the Little Hercules Foundation Database

- Enter your zipcode
- Click “Care”
- Select “Navigating the System”
- Search “respite” and explore options in your area



# ALL ABOUT OTHER THERAPIES & SERVICES

This list showcases a range of therapies to help you choose the best fit.

## Family Therapy

“In family therapy, the family unit works together to assess how they organize around their child’s diagnosis. The goal is to promote family resilience as they navigate the challenges they face.”

-Darci Cramer, PhD, LMFT



**In the 2022/2023 SCoReS Phase 2 Study, 33% of SETBP1 Parents surveyed said they would benefit from marriage counseling.**

## Case Management/Wrap-Around Services

These services help families find and coordinate care across medical, therapy, and school settings. They can help organize appointments and information, facilitate providers talking to each others, and help with advocacy in these settings



## Visit the Little Hercules Foundation Database

- Enter your zipcode
- Click “Care”
- Select “Navigating the System”
- Select “Case Management” and view available resources in your area



## Genetic Counseling

Counseling done to answer questions about your diagnosis, specific variant, impact on family, and other concerns.

# OTHER THERAPIES

Click on the name of each therapy for a link with more information!



## Art Therapy

Art therapy is used to help people be expressive and communicate. It is not used as a diagnostic tool, but rather as a medium to help with emotional issues.

## Music Therapy

Music therapy can help children and adults relax and de-stress. This can involve playing instruments, singing, or listening to music. It can help with behavioral, social, and emotional difficulties.



## Play Therapy

Using crafts, role play, puppets, and good-feeling items such as play-doh, play therapy can help children with anxiety and trauma, and help with communication issues.

## Animal Assisted Therapy

This therapy can be with personal family pets or with visits to therapy animals through trained volunteers or organizations. Provides social and emotional connections, reducing stress and anxiety.



## Hydrotherapy

This water-based therapy can help improve physical movement and serve as a form of low-impact exercise. Hydrotherapy includes pools, warm water baths, saunas, and immersion therapy.

## Equine Therapy:

Therapy involving horseback riding can be used to help improve physical mobility functioning, such as improved strength, balance, and coordination. Relationships with the horse(s) can also be calming.



## Adaptive Sports

Adaptive Sports like Special Olympics provide a fun place for kids to be included and supported as they get exercise and learn skills like teamwork and communication.

# HEAR FROM THE COMMUNITY: ADVOCATING IN THERAPY AND MEDICAL SETTINGS

"If someone is making you feel rushed or like you are not important, they are not the right provider for you. If you are not seeing progress, you may need to make a change, or it may even make sense to take a break for a time and then come back."

-Erin (pediatrician, SETBP1 Parent)

"I kept a close eye on the normal developmental milestones so I knew where our son was falling behind and so that I had specific information to discuss at our doctor's appointments. At first, our doctor wanted to take a wait-and-see approach, which I went along with in the beginning. However, as he continued not meeting milestones, I became more direct with wanting further medical evaluation. Through my own research, I found and requested referrals to various specialists including a speech therapy clinic that specializes in apraxia, a developmental pediatrician, neuropsychological testing, and genetics. Once our son received his SETBP1 diagnosis, I shared information about the condition with his medical team. Having a doctor who was willing to listen to our concerns and open to referring to other services as requested was paramount to our son's early diagnosis and allowing him to begin treatment interventions as soon as possible."

-Casey, OTR (SETBP1 Parent)

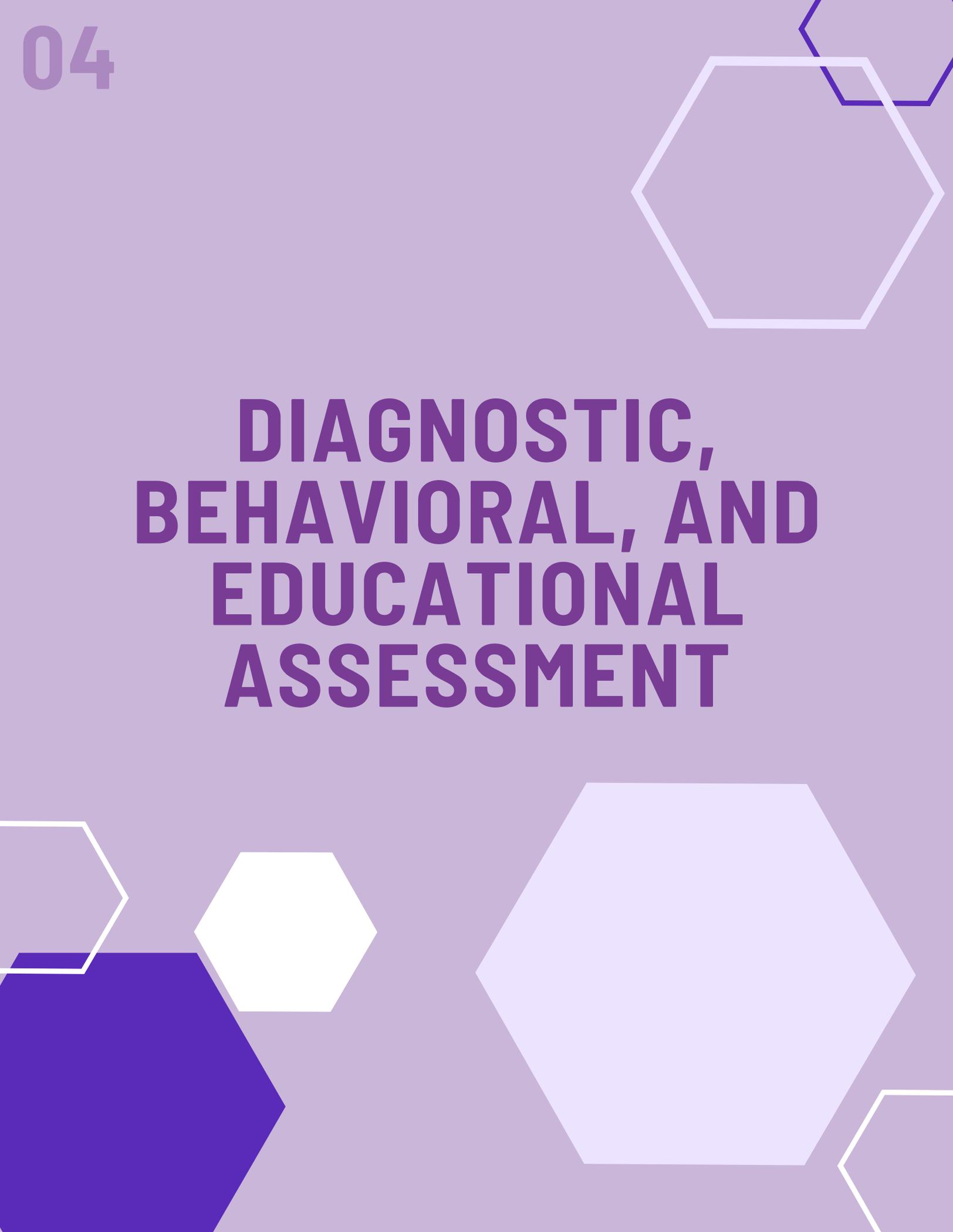
"Make sure you have the best doctors and don't stop looking for the best doctors. We were told by so many doctors that nothing is wrong— she'll walk when she's ready, she'll talk when she's ready. It wasn't until we got to [clinic redacted for privacy] and it still took her having a seizure to get an MRI. I'm not accepting that she has all these things and they're not connected. You have to demand more answers. You have to prove to me that nothing is wrong"

-Community Member

"Don't be afraid to just ask for a new therapist or a new clinic if their treatment philosophy doesn't align with yours. The therapists and doctors are not gods, they are just people following the current medical recommendations. You don't have to blindly do what they say, especially if what they tell you doesn't feel right in your heart and your child doesn't like it. Your child will be more successful in a therapy setting when they are happy and comfortable."

-SETBP1 Parents

**DIAGNOSTIC,  
BEHAVIORAL, AND  
EDUCATIONAL  
ASSESSMENT**



# ALL ABOUT NEUROPSYCHOLOGICAL TESTING

**Neuropsychological testing evaluates an individual's academic ability and learning strengths and weaknesses! These tests help better understand how people learn!**

## How can neuropsychological testing help?

- It helps clinicians, teachers, and parents understand how a child is learning and processing information compared to other children of the same age.
- It can provide important information about the nature of a child's learning strengths and challenges.
- Testing can target a child's learning deficits and challenges them to perform tasks that are particularly difficult because of those deficits, which can help make recommendations for methods to compensate for those deficits.

For example, a child might be able to articulate very complicated concepts and yet have trouble reading about those concepts, or a child might read very fluidly and yet have very poor comprehension.

### Generally,

- It is **important** to explain to your child that this is a test where the evaluator expects you not to know all the answers.
- Your child should be well-rested and fed before testing begins.

## What do you get after neuropsychological testing?

Testing will result in an **integrated report**, which is an official document that explains the tests that were conducted, the results of the tests, and suggestions for interventions.

- This document can and should be shared with the child's other doctors and their school to implement accommodations.
- The psychologist conducting the testing should also meet with the parents and child following testing to explain the results and answer any questions.

# NEUROPSYCHOLOGICAL TESTING

## What does neuropsychological testing typically look like?

A full evaluation can be completed in 1-6 sessions. Each session may be 2-4 hours long.

**The session length can also depend on who is doing the testing and the person being tested! Sometimes all of the tests are done on the same day and sometimes they are broken up across appointments.**

### What does testing focus on?

Depending on the child's needs, testing can focus on intellectual functioning, all areas of academic achievement, language and visuospatial development, memory skills, attention, organization, and planning, as well as a review of how a child thinks and feels.

### A typical schedule usually involves:

1. An initial appointment with caregivers to gather background information
2. A testing session with the child
3. A feedback appointment with caregivers

### Different options for testing

\*Availability and quality of services vary greatly by location\*

Setting	Cost	Who is doing the testing	Product/Diagnosis
Private Services	\$500-\$2,500+	Clinical psychologist or neuropsychologist	Diagnostic info: yes Educational info: yes
Private School	Sometimes included in tuition or for an extra fee	School psychologist, clinical psychologist, or neuropsychologist	Diagnostic info: likely no Educational info: yes
Public School	Typically free	School psychologist	Diagnostic info: no Educational info: yes
State/Community Services	Free or sliding-scale cost	School psychologist, clinical psychologist, or neuropsychologist	Diagnostic info: yes Educational info: maybe
Research Labs**	Free and will likely be paid for participation in a study	Clinical psychologist, neuropsychologist, or student/research staff member being supervised by a licensed psychologist	Diagnostic info: likely yes Educational info: likely no

\*\*These are typically performed as part of a broader research study. If you are interested, look up major universities near you and see if any labs focusing on child development have active studies. You can also search [clinicaltrials.gov](https://clinicaltrials.gov) or [buildclinical.com](https://buildclinical.com).

Be sure to ask about the results/products of testing during your intake interview!

# ALL ABOUT DIFFERENT TYPES OF NON-DIAGNOSTIC ASSESSMENTS

## Developmental/Multidisciplinary Assessment

**Goal:** To understand the individual's cognitive, physical and sensory motor, communication and language, adaptive, and social emotional developmental progress

### What else should I know?

- It involves developmental history, observational checklist, standardized assessments, and questionnaires
- Information is obtained through parents, teachers, and other professionals (e.g., speech, OT, and PT therapists)

### What else should I know?

- It is a problem solving evaluation, usually conducted by a behavior specialist (e.g., Board Certified Behavior Analyst; BCBA) or school psychologist
- Can be used to determine best approach for reducing or eliminating harmful, dangerous, or unacceptable behaviors (see section on challenging behaviors) and increasing adaptive behaviors
- **Outcome:** Positive Behavioral Interventions and Supports (PBIS) Plan and/or Behavioral Intervention Plan (BIP)

## Functional Behavioral Assessment

**Goal:** To determine the underlying cause or function of specific behaviors



## Psychoeducational Assessment

**Goal:** To analyze underlying cognitive processes that may influence an individual's educational performance

### What else should I know?

- Conducted by licensed school or clinical psychologist
- **Outcome:** information about student's strengths and weaknesses to understand areas of need

05

# EDUCATION



# EDUCATION OVERVIEW

## Educational Recommendations

A number of strategies and supports exist within the school system to enhance academic success. We will list a number of legal educational policies, guidelines, and promising practices for supporting the academic and adaptive functioning of your child!

This guide was created by the Fragile X Foundation! Fragile X Syndrome is another rare genetic disorder that has some similar features to SETBP1-HD/RD (common developmental delay and autism diagnoses)



## IDEA

### **Individual with Disabilities Act**

The Individuals with Disabilities Act, or IDEA, is a federal law that requires schools to serve the educational needs of eligible students with disabilities

[Read more about IDEA!](#)



### **Navigating the Special Education System**

- The Center for Parent Information & Resources aims to help families of children with disabilities (birth to age 26) find support centers.
- The website provides an interactive map to locate Parent Training and Information Centers (PTIs) and Community Parent Resource Centers (CPRCs).
- This resource assists parents in understanding their child's education and development needs, and helps parents work with educators, professionals, and policymakers.

**"Advocating for your child is one of the greatest gifts you can give them. Learn as much as you can about their educational rights and available supports. Stay actively involved in their school, and build open, respectful relationships with their teachers and staff. Be approachable so they see you as part of the same team, working together to help your child succeed."** - Haley (SETBP1 Parent)



# TYPES OF SCHOOLS

## Overview of the different types of education available!

### **Public School (Government funded)**

Financing comes from local, state, and federal governments.

Free/non-tuition based.

Must follow a child's individualized education plan (IEP).

#### **1. Traditional**

- a. Must admit all students who live within the borders of their district
- b. Follow state curriculum and testing requirements

#### **2. Charter**

- a. Independently operated but still public (funded publicly AND privately)
- b. Often more flexible in education practices and curriculum
- c. Can specialize in a particular area such as technology or arts
- d. Some target specific populations

#### **3. Magnet:**

- a. Selective schools that draw from multiple districts
- b. Typically have entry tests or requirements
- c. Often have specialized programs for science or the arts and hold high academic standards.

### **Private School (tuition-based)**

Relies on tuition payments, donations and endowments

May have different supports but are not required to follow a child's IEP

Can deny admission or remove child from school

#### **1. Independent schools**

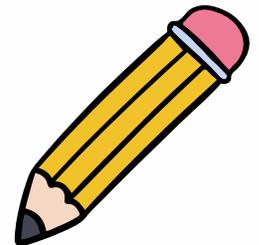
- a. Governed by a board of trustees
- b. May be affiliated with a religious institution but cannot receive funds from them
- c. Some specialize in special education.

#### **2. Parochial**

- a. Church-related schools with required daily religious instruction and prayer.

#### **3. Proprietary schools**

- a. Run/governed by an individual or for-profit corporation



### **Home School**

Children may be educated at home by parents or private tutors, or through online programs. Sometimes homeschooling families will attend school part time, and sometimes families join coops to share resources and learn in a group setting. Some parents who choose homeschooling may choose to give religious or moral instruction, or may be worried about the public school environment/concerned with the quality of instruction or unable to find a good fit for their child's needs.

# INDIVIDUALIZED EDUCATION PROGRAM (IEPS)

## What is an IEP?

An IEP is a legal plan that helps students with disabilities get the support they need at school. It's created just for your child and includes services to help them learn, grow, and participate as fully as possible in school life.

## Key Features

- **Customized Support:** Specially designed instruction and related services tailored to their unique needs.
- **Annual Review:** The IEP is reviewed every year to make sure it's working and updated if needed.
- **Least Restrictive Environment (LRE):** Schools must teach children with disabilities in regular classrooms as much as possible, with extra help if needed. This may include a shared or individual aide.

## Who is on the Team?

- Teachers and aides
- Therapists your child sees at school like PT, OT, and speech
- Additional private therapies may also be helpful and can be recommended by your child's pediatrician.
- **You!** You have the right to ask questions, request changes, and bring others (like advocates or doctors) to meetings.

## Planning for the future

- **Transition Planning:** Around age 14, the IEP should begin to include goals for life after high school – like job skills, further education, or daily living skills.
- **Extended Services:** Public schools must provide IEP services until at least age 21 (this age may vary depending on your state).
- **Vocational Services:** Think ahead! Early planning for job training and work programs (like vocational rehab) can help your child build a meaningful and independent adult life.

## When to request an IEP

- Your child has a known or suspected disability
- Intervention hasn't improved gaps in learning
- Child is regressing or not making progress
- Repeated behavioral or social challenges resulting in early pick-ups, suspensions, or being sent home.

# GETTING THE MOST OUT OF YOUR IEP MEETING

## **Know Your Resources**

Research special programs that could benefit your child, even those outside your district. Visiting these programs can help determine the best fit. Additionally, understanding your district's strengths and limitations, such as staffing or funding shortages, allows for better planning.

## **Ask for Advice**

Seek recommendations from your child's previous teachers, school assessors, district special education administrators, and other parents. Their insights can provide practical advice tailored to your child's needs.

## **Find Backup**

Collect external support to validate your requests for special services. This includes accessing your child's school records, securing independent assessments from professionals outside the school district, and inviting relevant experts to the meeting or obtaining their written statements.

## **Arrive Prepared**

Before meeting to discuss an educational plan, identify the educational programs and services you wish to request. Obtaining and completing a copy of your district's educational plan forms in advance can help you stay organized and focused during discussions.

[Check out this resource from UC Davis Child Mind Institute about making the most of your IEP Meeting](#)



# 504 PLANS

A 504 Plan helps students with disabilities by providing accommodations and modifications that allow them to participate in school on an equal level with their peers.

It's named after Section 504 of a federal civil rights law that protects individuals with disabilities from discrimination.

## Who might benefit from a 504 plan?

Students who do not need specialized instruction (like an IEP) but still need support at school due to a disability, including autism, ADHD, learning disabilities, physical impairments, or chronic medical conditions like epilepsy, diabetes, or anxiety.

## Examples of 504 Accommodations

- Sitting near the front of the classroom
- Extra time between classes or for tests
- Use of assistive technology (like a laptop or speech-to-text tools)
- Help from a classroom aide or scribe
- Modified assignments or extended deadlines
- Large-print materials or other visual supports



# OTHER SCHOOL PLANS AND SUPPORTS

**Behavior Intervention Plan (BIP):** An individualized plan to address specific behaviors based on the results of a Functional Behavior Analysis. It includes specific techniques and strategies that should be included in an IEP. This could include changing the environment or settings, increasing predictability and routines, providing the individual with choices, providing positive reinforcements, and the use of social stories and visual schedules

**Therapeutic & Other Services:** Speech and Language Therapy, Occupational Therapy (OT), Physical Therapy (PT), and Applied Behavior Analysis (ABA) are provided as needed to address communication, motor skills, and behavioral challenges. Assistive technology (AT) and adaptive physical education (APE) supports are additional services available.

**Classroom Environment:** Create a calm, structured classroom with minimal distractions. Use visual aids, schedules, and indirect instruction methods to accommodate learning styles associated with SETBP1.

**Social Skills Development:** Incorporate social skills training through modeling, structured peer interactions, and activities like "lunch buddies" to enhance peer relationships

**Extended School Year:** 4-6 week program designed for students with disabilities who have shown regression of skills over school breaks and have not regained those skills after an extensive period of time. The child's goals and objectives are addressed during the ESY program, but the teacher may not be the same teacher that they had the previous year or the teacher that they will have the next year.

# EDUCATIONAL ADVOCACY

## How to Be an Effective Advocate for Your Child

- **Maintain Detailed Records:** Document your child's educational progress, time spent on homework, emotional well-being, and any lapses in provided services. This information is vital for assessing and addressing your child's needs.
- **Comprehensive Assessments:** Ensure your child undergoes evaluations across various domains, such as cognition, academic achievement, executive functioning, and speech and language, to develop a tailored educational plan.
- **Implement Appropriate Accommodations:** Advocate for modifications that address your child's specific challenges. For instance, if your child
  - has short stature, request a step stool at sinks to promote independence.
- **Foster Open Communication:** Establish and maintain transparent dialogue with educators and school staff to build a collaborative partnership focused on your child's success.
- **Stay Informed About Rights and Resources:** Educate yourself on educational rights and available resources to effectively navigate the special education system and advocate for necessary services.



For more information, scan  
this QR code!



# HEAR FROM THE COMMUNITY: EDUCATIONAL ADVOCACY

"We eventually ended up hiring an advocate. It was very helpful having someone on our side who understood the language used in the ARD meetings, and who is knowledgeable on what the school system realistically can and cannot do. A couple things our advocate advised us on were recording the meetings, and not signing the ARD paperwork at the meeting; she recommended taking the paperwork home and reviewing it first. Also, she told us, if there is something we don't agree with, we do not have to sign."

-Casey, OTR (SETBP1 Parent)

"They are required by law to provide appropriate accommodation in order for your child to learn. Sometimes your request is hard for them to fulfill and they might discourage it, but they have to fulfill it. So our advice is to not let the school system tell you no."

-SETBP1 Parents

"I went to his meetings focused on the fact that my child CAN learn, he just learns differently and more slowly than other kids. I advocated for the least restrictive environment."

-Erin (SETBP1 Parent)

"I ended up hiring a special education advocate who came to the meeting with me and argued so that I would not have to. The school (under threat of a lawsuit from my advocate) agreed to allow my child to try 1 "basic" level class. This was actually hugely successful and the following year, they placed John in all basic level classes. His happiness and behavior improved immensely. This would not have happened if we had not pushed it really hard."

-Erin (SETBP1 Parent)

"Never give up if you feel like there is something your child needs, and don't ask - tell them what you need. I find if you make your needs a statement and not a request that the majority of the time they will do whatever in their power to make it happen."

-SETBP1 Parents

"As far as the education goes, I always made it a point to build a strong relationship with any teacher that might be in the classroom so that we could have open communication. It was not uncommon for me to be emailing back-and-forth with the teacher most days depending on what was happening. You might be communicating back-and-forth every day during periods of transition or any changes. The teachers can be your best ally in getting services so again treat them with kindness and respect. It will carry you far if you run into a bump in the road."

-Colleen (Rare Disorder (DDX3X) Parent)

# HEAR FROM THE COMMUNITY: EDUCATIONAL ADVOCACY (CONT)

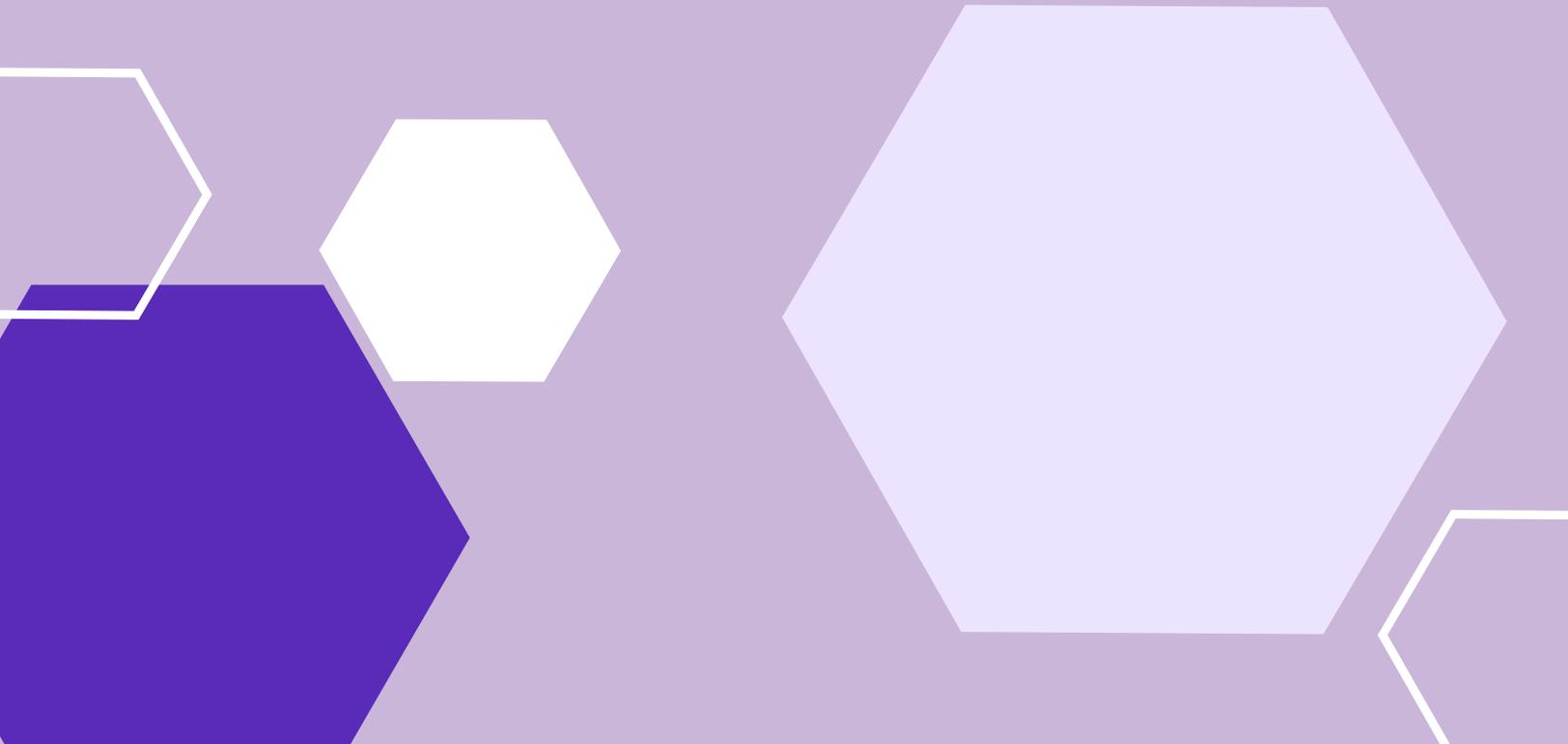
“Educate yourself on what your child is entitled to in those settings. Complete any assessments in a timely manner and as accurately as you can. Discuss progress and regressions with his teachers and therapists so they know how your child is performing in the home setting. Know what your child can have included in their IEP and go into those meetings with lists to make sure all their needs are being met and accommodated. If you have other professionals you are working with (speech therapist, BCBA, occupational therapist), invite them to attend IEP meetings to help you advocate. Invite your child's assorted providers to collaborate with one another, too.

At the beginning of the school year or the onset of therapy, I keep open communication with my child's teachers and therapists. I always approach it like we're all on the same team (because we are), here to help him, and I tell them that I'm happy to contribute in any way that I can since I know that sometimes their resources (particularly at school) are limited. I attend all his IEP meetings and address any concerns I have immediately, offering ideas of potential solutions and inviting them to contribute as well. We've been fortunate that he has had a great team at school and in private therapy.”

-Jennifer (SETBP1 Parent)

06

# FINANCES AND KNOWING YOUR RIGHTS



# FINANCIAL RESOURCES

## **National Disability Institute**

*This non-profit is committed to financial education and empowerment for people with disabilities*

- financial resilience and empowerment
- social security benefits
- credit
- taxes and tax prep
- employment and unemployment
- student loans
- managing money
- housing, food, and transportation



## **Search for Insurance & Services by Location**

Enter your zip code and find information about free or reduced cost services like medical care, co-pay, assistance, food, utility, assistance, transportation, Medicaid waiver forms, and more!



## **Creating a Financial Plan**

Understanding your family's resource is important for creating a family plan, but planning for a long-term dependent goes past traditional financial planning. This website provides some great resources to learn about how government programs work and to help with long-term financial goals and planning.

Learn more about financial planning here!



## **Achieving a Better Life Experience (ABLE) Act**

*In 2014, the ABLE Act was signed into law, allowing people with disabilities to create tax-advantaged savings accounts (ABLE accounts).*



- The money in ABLE accounts can be used for qualified disability-related expenses, such as education, housing, and transportation.
- ABLE accounts allow people with disabilities to save money without losing their eligibility for federally funded benefits such as Medicaid or Supplemental Security Income

## **Sign your child up for state waivers using Kids' Waivers**

Kids' Waivers is a compilation of information about Medicaid waivers, Katie Beckett or TEFRA programs, and other programs for children with disabilities or medical needs.



# KNOW YOUR RIGHTS AND RESOURCES

## Supplemental Security Income (SSI) Deposits

- Children under 18 can be eligible for monthly payments if they have a medical condition that meets Social Security's definition of disability AND their income/resources fall within certain criteria
- The amount of SSI payment differs from state to state, your local Social Security office can tell you more about your state
- Disability reviews will be conducted at least every 3 years for children under 18 whose conditions are expected to improve, however, the office reserves the right to review anyone at any time, in which you must present evidence that your child's disability still severely impacts daily life
- To learn more, including information about when your child turns 18, scan the QR code or click the link below

## Disability Requirements to be medically eligible for SSI:

1. The child, if not blind, must not be working or earning more than \$1,620 a month in 2025.
2. The individual must not have resources above \$2000.
3. The child must have a medical condition or combination of conditions that result in "marked and severe functional limitations"
4. The child's condition(s) must have been disabling or expected to be disabling for at least 12 months, or the conditions must be expected to result in death



[Scan here or click me to read the US Social Security document](#)

## Payments

- The state agency may take 6 to 8 months to decide if your child's condition meets their criteria for disability, but for some medical conditions (see below) they will make SSI payments right away, for up to 6 month, while the state agency decides if your child meets criteria.
  - total blindness and/or deafness, cerebral palsy, down syndrome, muscular dystrophy, severe intellectual disability (age 4+), birth weight below 2 lbs, 10 oz

# KNOW YOUR RIGHTS AND RESOURCES (CONT)

## **Social Security Disability Insurance (SSDI) benefits for adults with disabilities since childhood**

- SSDI pays benefits to adults who have a disability that began before they were 22-years-old.
- For an adult to become entitled to this benefit, one of their parents must be receiving Social Security retirement or disability benefits, or have died and had worked to earn enough to be eligible for Social Security benefits
- Children who are receiving benefits as a minor on a parents Social Security may be eligible to continue receiving benefits upon reaching age 18 if they are determined to have a disability
- SSDI Disabled Adult Child (DAC) benefits continue for as long as they have a disability; marriage of the DAC may affect eligibility

For detailed information about how US Social Security determines disability for adults, read [Disability Benefits \(Publication No. 05-10029\)](#)



## **Plan to Achieve Self-Support (PASS)**

A child who is 15 or older can save income and resources to pay for education and other things needed to work. Saved income and resources are not counted when calculating you child's payment for disability payments/benefits

## **Medicaid**

A health care program for people with limited income and resources. In most states, children who get SSI payments can receive Medicaid coverage

## **Children's Health Insurance Program**

This program is designed to provide health insurance to children from working families with incomes too high for Medicaid, but too low to afford private health insurance. Learn more [here!](#)

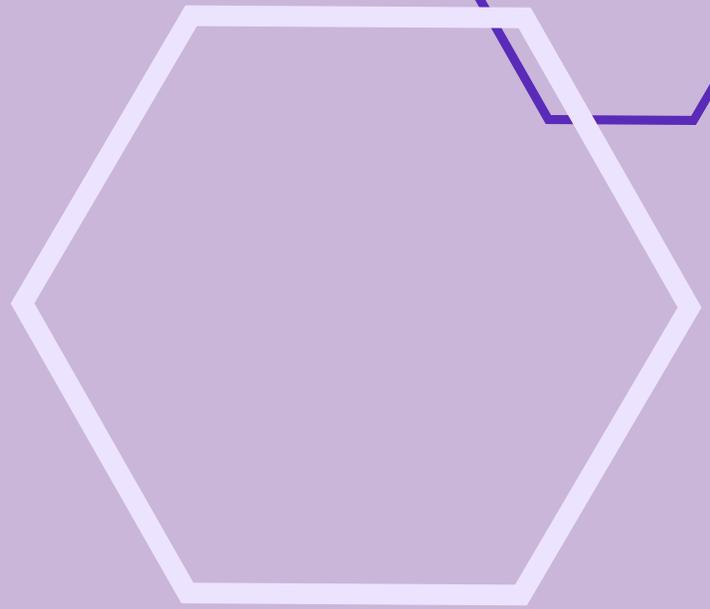


**Contact the USA Social Security Administration:**

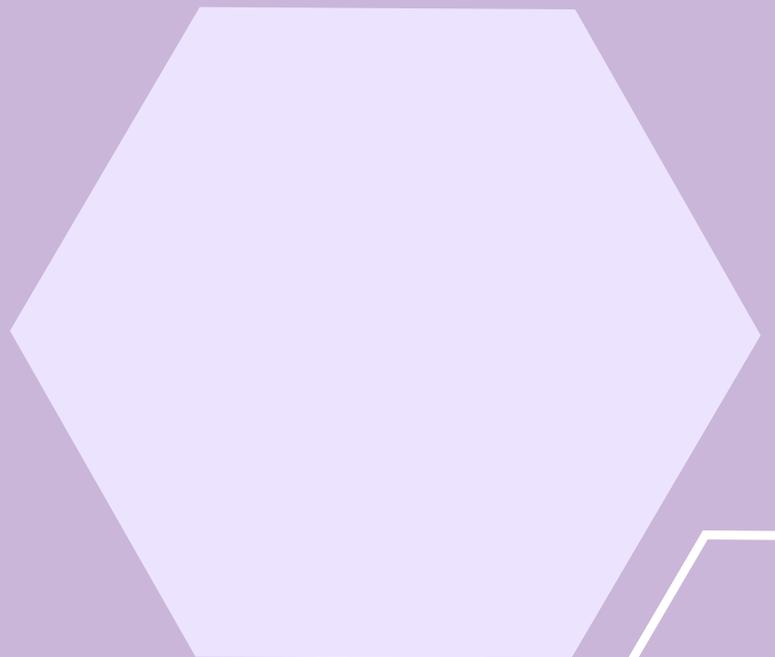
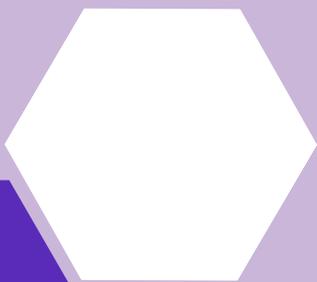
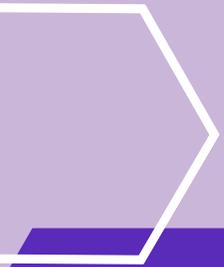
800-772-1213

[www.ssa.gov](http://www.ssa.gov)

07



# ALL ABOUT SIBLINGS



# WAYS DIAGNOSES CAN AFFECT SIBLINGS

Sometimes having a sibling with a disability can be difficult. This is especially true when the sibling requires a lot of attention, resources, and support from the parents, which can take attention away from the non-affected sibling. Often, siblings (or **sibs**) are asked to take on roles that are more traditionally done by parents which can add a lot to their plate. The term "**glass child**" is sometimes used to describe sibs whose parent's attention on their sibling makes them feel see-through or that their needs aren't seen.

## → What effects can this have?

This can create mental health challenges like depression and anxiety as well as feelings of guilt and difficulty recognizing their own needs. Being a sib is also associated with being an incredibly kind, caring, responsible, and resilient person, especially when surrounded by social support!

([Hanvey et al., 2022](#))



## **Tending the Siblings Guided Pathway Resource**

*This resource from Courageous Parents Network offers insights into the unique emotions, challenges, and strengths of growing up with a sibling who has a serious illness or disability. By checking out the QR code, you will:*

- Understand the sibling experience
- Hear and see the common worries shared by other parents
- Learn about coping strategies and tools others have used to help their other children, the siblings, cope with having a brother or sister with a serious illness



# HEAR FROM THE COMMUNITY: INTERVIEW WITH SIBLINGS

What is your favorite thing about your sibling?

“He is funny and kind” -Harper (SETBP1 Sibling)

“I love how much John cares about the people he loves. He always makes sure everyone in our family is happy and is the biggest peoples pleaser. He loves giving notes and small presents he got at school to my sister and I, and he constantly sends me emails while we’re at school telling me how much he loves me. I also love how friendly he is. I will walk down the halls with John at school and random people will stop to say hi and give him a high 5. Everyone at our school knows John and loves John.”

-Meredith (SETBP1 Sibling)

“My favorite thing about my brother is how much he cares about everybody around him.”

-SETBP1 Sibling

“He is more optimistic than other kids his age.”

-SETBP1 Sibling

“He is the most amazing person ever! Always very happy and cares about others.”

-Jackson (SETBP1 Sibling)

“He is a bundle of energy and his humor never fails to make me smile.”

-Brielle (SETBP1 Sibling)

# HEAR FROM THE COMMUNITY: INTERVIEW WITH SIBLINGS (FAV)

What is your favorite thing about being a sib?

"He always have someone to rely on. He's very fun to play with. He is a nice person and I learn from him."

-Harper (SETBP1 Sibling)

"I love having grown up with my siblings. It's such a special experience to be able to share your most formative years with some built in best friends. Because we live together, John is there for all of the most memorable moments from my childhood and having his bright enthusiasm and loving heart in all of those moments has been such a blessing."

-Meredith (SETBP1 Sibling)

"Having a younger brother who has so much time to see me and hang out with me, partially because he isn't doing normal "teen activities."

-SETBP1 Sibling

"I can get into all the national parks for free."

-Hugh (SETBP1 Sibling)

"He'll want to converse or play with me basically no matter what."

-SETBP1 Sibling

"I love being there for my brother. Whenever he needs help, I want to be his lifeline."

-Jackson (SETBP1 Sibling)

"I think it's really cool to have a different perspective than a lot of other people who don't have special needs siblings. It allows me to see all sides of a story sometimes, even when it doesn't involve my brother"

-Brielle (SETBP1 Sibling)

# HEAR FROM THE COMMUNITY: INTERVIEW WITH SIBLINGS (HARD)

What is the hardest thing about being a sib?

“He sometimes gets out of control and starts being annoying. He can get very upset and it's hard to calm him down sometimes.”

-Harper (SETBP1 Sibling)

“Having to have extremely patient at all times. It can be extremely overstimulating having a sibling who won't listen to the word “no” and won't leave you alone when you are with friends or studying.”

-Meredith (SETBP1 Sibling)

“Feeling frustrated when my parents don't understand my struggles with my brother.”

-SETBP1 Sibling

“Having conversation about anything other than surface level things is very hard.”

-SETBP1 Sibling

“Having to sometimes take on a parental role”

-Jackson (SETBP1 Sibling)

“I think it can be difficult doing regular family activities sometimes because my little brother doesn't have the attention span for some of the things I want to do, but he'll still try his best, especially when I take him out with my friends”

-Brielle (SETBP1 Sibling)

# HEAR FROM THE COMMUNITY: INTERVIEW WITH SIBLINGS (WISH)

What do you wish your parents knew about  
being a sib?

"It's harder than you think"

-Harper (SETBP1 Sibling)

"My parents are honestly so great and understanding. Although, my parents often say "it takes two to tango" when John and I get into a fight and so I end up getting in trouble, but honestly, sometimes it only takes one to tango with John. I wish they knew that with a sibling with special needs sometimes it really is a one sided fight sometimes."

-Meredith (SETBP1 Sibling)

"Sometimes, even when my brother probably doesn't know what he is saying, he says things that hurt my feelings and he doesn't understand how he is upsetting me."

-SETBP1 Sibling

"That it is really hard."

-Hugh (SETBP1 Sibling)

"I wish they understood how taxing it can be sometimes because we aren't a parent, but sometimes we have to fill that role."

-Brielle (SETBP1 Sibling)

# HEAR FROM THE COMMUNITY: INTERVIEW WITH SIBLINGS (ADV)

## What advice do you have for other sibs?

"There can be rough days, but in the end we still love each other and they don't really mean anything mean that they say. There will always be a solution when you work with your sibling."

-Harper (SETBP1 Sibling)

"I would say to think before you react and to spend time with your siblings. For a person like John, he craves attention and I have learned that he is most annoying when he wants you to hang out with him because he is trying to get your attention. I try to involve John in things I am doing and play games with him every once in a while. I also understand that when you are trying to do something and your sibling is constantly bothering you it is your instinct to yell at them to get out of your room, but I have found it way more beneficial to explain to John calmly what I am doing and why I need some time alone to focus. When I talk to him slow and soft he understands better and normally leaves. I would also say just try to remember that your siblings brain works differently than yours and they are often trying really hard and they often don't know that what they are doing is wrong. Having this mindset has helped me understand John so much better."

-Meredith (SETBP1 Sibling)

"There are so many amazing things about siblings with SETBP1, and even though they can be annoying, siblings without SETBP1 can sometimes be more annoying."

-SETBP1 Sibling

"Try and be as patient and understanding as possible."

-SETBP1 Sibling

"Love your sibling with all your heart, and they will do the same!"

-Jackson (SETBP1 Sibling)

"Don't be afraid to take your sibling into public, and don't be ashamed of them because it's other people's problems if they make fun of you or your sibling; it is not a reflection of you or your sibling, but a reflection of them. Some people are also really kind to your siblings and seeing that is just amazing."

-Brielle (SETBP1 Sibling)

# SUPPORTING SIBLINGS

## Sibling Support Toolkit

This resource provides essential guidance for families supporting siblings of children with disabilities. It includes practical tools, personal stories, and links to support networks, empowering siblings to navigate their roles with confidence and resilience. Scan the QR code or click on the link for more info!



## **Below are some key points described from the toolkit!**

### **Feelings and Emotions:**

Parents and siblings describe how siblings experience a range of strong feelings like feeling marginalized and invisible.

They have strong negative feelings including fear, anger, sadness, and abandonment. Siblings also describe experiencing positive feelings including being protective of their sibling with the disability, and pride about their contribution to family life.

Siblings have been shown to demonstrate enhanced: empathy, problem-solving skills, ability to be flexible, small acts of kindness at home and with friends, willingness to help, and being unafraid to take on tough tasks.

### **Important things to always keep in mind:**

Good days are peaceful and go smoothly. Other days, big emotions surface. It is important to know that these feelings are okay.

Keep in mind that the child with SETBP1 is not the only member of the family that needs specific attention and emotional assistance to help them adjust and work through changes and difficulties.

Although siblings may realize why their sibling requires a lot of attention, their emotional and mental health can still be impacted.

### **How parents/caregivers can help:**

1. Assess each sibling's desire to be included in caregiving and care-related discussions
2. Share some information about their sibling's disability in a developmentally appropriate way
3. Make connections and join groups with other families and friends in similar situations
4. Seek out resources and information to help them deal with their feelings and emotions
5. Practicing mindfulness exercises
6. Engage in fun activities together
7. Spend 1:1 time with each child
8. Talk about future issues

### **Some quotes from other rare siblings!**

"Some of our concerns include will my children have disabilities; will I have to take care of my sibling if something happens to parents."

"We may feel that our future options are limited (finding a partner, school, career, etc.) due to our sibling's needs. Help us make our future plans."

"We might have guilt for being the one without a disability and for living a typical teenager's life. We may not tell you this."

### **Parent-sibling agreement sheet**

This sheet is made for kids with serious medical conditions but could be modified if needed!



# BOOK RECOMMENDATIONS FOR SIBLINGS OF ALL AGES

## **The Sibling Slam Book: What It's Really Like To Have A Brother Or Sister With Special Needs (ages 11+)**

Siblings of special-needs children discuss hopes, fears, frustrations, resentment, and triumphs regarding their life with their siblings.



## **Views from Our Shoes: Growing Up With a Brother or Sister With Special Needs (ages 9+)**

Offers advice to siblings of developmentally disabled children, assuring them that they are not alone, and that other kids have had similar experiences.



## **Thicker Than Water: Essays by Adult Siblings of People with Disabilities**

A collection of personal essays exploring the diverse experiences, challenges, and deep bonds of adults who have grown up with siblings with disabilities.



## **The Abilities in Me: Superstar Sibling**

This children's book empowers siblings of individuals with disabilities, helping them understand their important role in their sibling's life while promoting acceptance, love, and inclusion.



Listed directly below are sibling stories specific to Angelman Syndrome but are very relevant and for most ages!

## **Getting to Know You (Sibling Stories)**



Siblings of children with rare disease are in a unique role. Their series highlights that role using real and fictional stories to discuss the dynamic aspects of being a sibling to a child with Angelman syndrome.

## **Genetic Gems**



This is a book that breaks down complex genetic concepts into accessible insights, helping readers understand the impact of genetics on health and family dynamics.

## **Sibling Stories: Making Memories**



This is a collection of personal stories and experiences from individuals who have siblings with disabilities.

## **By Siblings, For Siblings**

Siblings of people with disabilities supporting other siblings of people with disabilities by Natalie and Nicole Hampton



# SIBLING SUPPORT RESOURCES

For more information, check out these resources below!

## Supporting Siblings of Children with a Rare Genetic Condition Resource



This resource from the Rare Chromosome Disorder Support Group, provides guidance for families, caregivers, and communities on how to support siblings, helping them navigate their feelings while fostering resilience, understanding, and inclusion.

## Profound Autism Sibling Action Network Resource



This resource from the Sibling Action Network provides support, resources, and advocacy for siblings of individuals with profound autism. They work to provide practical information and resources developed by siblings for siblings.

## Sibling Leadership Network



This initiative provides educational tools, emotional support, and access to confidential discussion groups, helping siblings navigate their unique roles.

## All about SibShops



SibShops provide a fun, engaging, and supportive space for siblings of individuals with disabilities. These events connect kids with peers who share similar experiences.

## Siblings with a Mission



This organization serves to support siblings and families of individuals with complex health conditions and developmental disabilities. Their mission is to provide international support, spread awareness of health conditions, and inspire siblings to make a difference.

# AGE-SPECIFIC RESOURCES



# INFANCY/TODDLERHOOD BIRTH-3 YEARS

## Services/Early Intervention

- Focuses on helping eligible babies and toddlers learn basic or brand-new skills that typically develop during the 1st 3-years of life like reaching, rolling, crawling, learning, talking, listening, understanding, playing, feeling secure/happy, eating, and dressing)
- May include assistive technology, audiology or hearing services, speech and language services, counseling and training for family, medical services, nursing services, nutrition services, occupational therapy, physical therapy, psychological services.

### Milestones



## Am I eligible for services?

- Available in **every state** because of IDEA part C
- Provides evaluation of developmental delay free of charge (add info about contacting birth-to-three)
- Eligible if delayed in any milestones.
- Search for your state's definition of developmental delay.

## Record Keeping Worksheet!

Use this to record the conversations that you are having with service agencies!



## More questions?

Search for your local regional center or state department of developmental services

## Beginning Therapies?

Go up to the Therapy and Medical Care section for getting started in OT, PT, Speech and more.



# TODDLERHOOD/CHILDHOOD

## 3 - 10 YEARS

### What is a developmental pediatrician?

A pediatrician who has completed additional training in evaluating and treating developmental and behavioral problems. Their expertise may make them a good choice for children with complicated medical or developmental problems.

### Specialized Education

Children ages 3-5 who meet state eligibility criteria because they are experiencing **developmental delays** can receive services through preschool programs in their local school district. Check out the link above or the QR code below for a step guide to getting your child special education.



### Child Find



Schools must find and evaluate children who may need special education through a process called "Child Find" in the United States. If a child qualifies, the school must provide free services to meet their needs. This is required by law under IDEA. The school has 45 school days to complete a screening after you report concerns about your child's development.

### Managing Meltdowns

Emotional dysregulation is common in groups with neurodevelopmental disorders.

See **All About Emotion Regulation** section for more information

See **Diagnoses and Testing Section** to understand types and process of getting evaluations and diagnoses.

Learn more about the difference between IEP and 504's in the **Education** section!

Learn more about different therapies in the **Therapy, Medical Care, and Services** section!



Thinking about the Future -> see **Finance** section

# ADOLESCENCE

## 11-18 YEARS



### Puberty and Hormone Changes

- Puberty occurs during adolescence and is when a youth's body starts changing into adult bodies.
- So far, all information points to pubertal development being the same in kids with and without SETBP1-HD/RD

**RareChromo resources for talking to your child or teen about puberty.**



**Puberty with IDD Resources!**

Tom and Ellie books by Kate E. Reynolds. Reynold's son was diagnosed with autism and wrote books to better explain puberty and sexuality education



**Supporting adolescents with intellectual disability resilience article**

**Around the age 13-14, teens should start being an active participant in their education plan!**

### **Social and Emotional Changes**

Social and emotional changes during puberty can include things like the desire for more privacy and an increasing need for independence. During puberty, you might notice that your youth's feelings and expressions of those feelings are more intense. These changes might be large or small depending on the youth's developmental disability.



# EARLY ADULTHOOD

## 17-26 YEARS

### **Conservatorship**

A guardian who manages the financial affairs or property for an adult who is not able to do so for themselves. The decision for a family member to become a conservator over another is a personal decision and should be considered seriously. This decision must happen before the individual turns 18!

Alternatives: [Guardianship and Supported Decision](#)

[Making](#)



See this link for [Guardianship laws by state](#)! Other countries coming soon.

See **Finance** section for Information about Assisted Employment!

### [Transition to Independence](#)

For parents of children with a rare gene disorder, transition can be a very scary and difficult time. Having come through the 'school years' with your child, the thought of them leaving the safety and security of school and school life is very worrying. See this resource for useful guides for this transition.



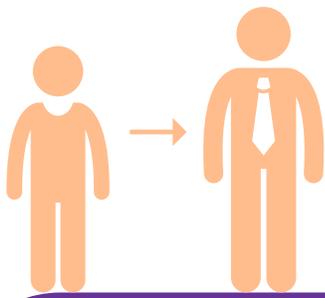
**Encourage your young adult to feel confident and capable by involving them in all important decisions.**

### [Comprehensive Transition and Postsecondary \(CTP\) Programs](#)

CTP Programs are designed to support students with intellectual disabilities who want to continue academic, career, and independent living instruction to prepare for gainful employment.

Find CTP Programs in your State!





# ADULTHOOD



## Long-term Care and Independent Living

There are various housing options for individuals with disabilities:

1. **Living with Family**
2. **Independent Living**
3. **Supported Living:** Living in a private residence with support services tailored to the individual's needs, promoting independence while ensuring necessary assistance.
4. **Group Homes:** Shared living arrangements with other individuals with disabilities, staffed by professionals providing assistance with daily activities and fostering a communal environment.
5. **Supervised Living:** Facilities offering 24/7 supervision and support, ideal for individuals requiring continuous assistance.
6. **Residential Care Facilities:** Institutional settings providing comprehensive care, including medical and personal support, for those with significant needs.
7. **Assisted Living Facilities:** These offer private apartments with non-medical support like cleaning and medication management.

### Resources for Independent Living

[What is Independent Living](#)

[List of independent living resources and sites by state!](#)



# INTERVIEW WITH RARE PARENT ABOUT RESIDENTIAL CARE

## What advice do you have for parents considering residential care for their loved one with IDD?

"First, I would say that you should understand that the care is unlikely to meet your expectations. At least that has been my experience. You have to accept that. You will need to compromise on things that you would never compromise on if your adult child was living in your house. The way that someone else brushes their hair for example might seem like a small thing to the staff at the group home, but is a big thing when you are that person's parent. Your standard of cleanliness is not likely to be met both in terms of the house and in terms of their physical person. The way that we work around this is to ensure that we are giving baths or showers at our house on a regular basis so that the extra added hygiene things are being covered.

As far as the cleanliness of the group home goes if the house does not meet your expectations, you may want to have a family member take your loved one out and you clean the room yourself. I did this several times at the first group home that my daughter lived at, but I have never had to do it in the three years that she has lived in her current home. I am in the group home a lot. Nearly every day some family member is interacting with my daughter and I always go inside the house when I drop her off or pick her up. Be friendly with the staff, even if you find it necessary to provide unpleasant feedback. Do it in a kind and respectful way because this is more likely to be received and acted upon positively.

I provide homemade food to the house that consists of one meal for everyone in the house about once a week. I also buy food that my daughter likes and I bring it to the house. For special occasions or parties, I contribute to the party. We also will randomly create a party by purchasing pizza for the house and dropping off desserts or things of that nature. I always send enough so that the staff can eat if they want to. You may want to find some version of this that works for your family and meets your budget, but I do think that a little kindness with food goes a long way toward people feeling appreciated.

My daughter moved to the group home when she was 24. I would not have made the decision to have her go at that age and would have waited much longer, if I were only considering my wants and needs. My daughter made it very clear that she wanted to do the same kinds of things that her siblings and her cousins were doing in terms of moving out and living with their peers. This was a primary motivating factor that led to her going to the group home. Keep in mind that none of these decisions are irreversible. If you don't like the way it's going you can bring your person home with you. As a practical matter, at least where we are in New York State, if you were to bring your person home from the group home they're unlikely to get another placement unless there is a crisis such as your own illness or if you were to pass away. No one will explicitly tell you this, and the people making these decisions are likely to deny it, but that seems to be the reality from everything I have observed."

-Colleen (Rare Disorder (DDX3X) Parent)

# INDEPENDENCE

What are some ways you support independence in your child/adult?

"He has attended a supported week-long sleepaway summer camp each summer for the past 3 summers. He started when he was 11 years old."  
-Haley (SETBP1 Parent)

"He loves to help with small jobs. We give choices. He is in control of what he wears. We use checklists and schedules to help him navigate his own day."  
-Allyson (SETBP1 Parent)

"He walks to/from his school on his own each day, which is just under a mile away. One day, when he was 12 years old, he just decided he wanted to walk it without his dad or I and although we were nervous, we let him make the decision."  
-Haley (SETBP1 Parent)

"Independence gives our kids a sense of confidence. We are constantly pushing our son to try new things. One phrase we use often is "You can do hard things", usually during tasks like getting dressed, brushing his teeth, riding a bike, or jumping in the lake."  
-Lindsey (SETBP1 Parent)



"I have realized that I always want to help my son too much by doing things for him and it's not a good idea. Setbp1 children need to learn by themselves and try and try again and again."  
-Antoine's Mother

# SEXUALITY AND HEALTHY RELATIONSHIPS



**The Healthy Understanding of Our Bodies (HUB)** provides essential sexual health education for youth with intellectual and developmental disabilities, who often face barriers to accessing this information. Check out this resource for videos, learning tools, and links to national organizations.



**The Pregnancy and Parenting Support project** addresses the unique challenges individuals with disabilities face when considering pregnancy and parenting, ensuring their voices shape future resources, training, and policies.



## **Being a Parent**

Having an intellectual disability does not preclude someone from being a parent. Read more about this [here](#).



**This report on sexual violence** sheds light on the lived experiences of survivors with disabilities, raising awareness about the prevalence of abuse and the need for better protections, support systems, and policy changes.

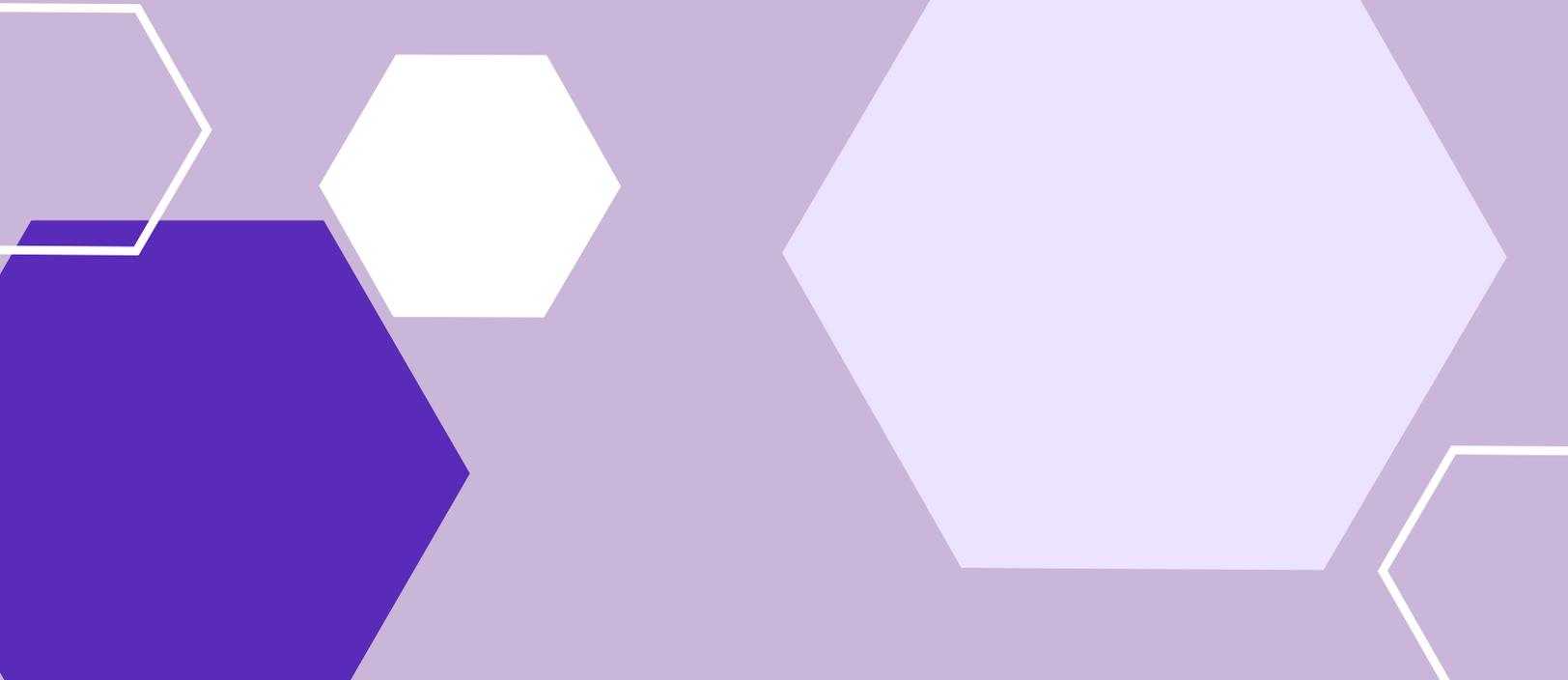


**The ELEVATUS Toolkit** offers helpful resources for families to start conversations about consent, healthy relationships, and sexuality with their loved ones who have intellectual and developmental disabilities (IDDs). It also provides guidance on recognizing and preventing sexual abuse, as well as support and resources for individuals with IDD who have experienced abuse.



09

# FOR FAMILY AND COMMUNITY MEMBERS



# TAKING CARE OF YOURSELF AS A CAREGIVER

"It's important to give yourself grace and prioritize things that are important to you. This is your opportunity to reset and be in a better state to support your child. I like to play tennis or go on walks while listening to a podcast."

-Lindsey (SETBP1 Parent)

"We have respite care through regional center in order to have some time away. We also lean heavily on our extended family."

-Allyson (SETBP1 Parent)

"Look for reasons to laugh and keep an eye out for joyfulness. Listen to music often and sing out loud. Trust me you're singing could not be worse than mine. It is good for your mood and your spirit."

In my view, the most important thing is to surround yourself with other people who can provide you with both emotional support and physical labor. In our situation, often my oldest would need to go to the hospital so I had a group of people that I knew I could call day or night to take over the care of my other children. Your needs might be different, but identify them and then figure out who might be able to help you. Think about the talents that each person has and try to cater your request to their talent. Don't ask the same people all the time. Spread it around. People like to help. It gives them a sense of satisfaction.

As far as actual self-care focused only on you, that may be something as simple as getting up 15 minutes earlier in the morning so that you can have those minutes to yourself before the day starts.

The amount of time you have for such a thing is going to fluctuate, but as your child gets older, it's likely to increase. There were times when I would have a therapist or aide present in the house so that I could be doing other relaxing things while they were providing their services. Go upstairs if they are downstairs and just have some time to yourself. Self-care doesn't have to be anything major. It doesn't have to take hours. It can just be simple things that keep you steady. I have found exercise to be critically important. Sometimes all that looks like is a 10 minute walk around the block and other times it can be an hour at the gym. I do think it's important to do some physical activity most days, even if it is only 10 minutes. The consistency of it will help you to feel better in my experience."

- Colleen (Rare Disorder (DDX3X) Parent)

# EDUCATION FOR THE FAMILY

## **Family Guide for navigating life after a rare genetic diagnosis**

This resource is designed to help caregivers and families navigate the complicated world of rare disorders. It covers the steps from genetic diagnosis to finding resources and potential treatments for rare genetic neurodevelopmental disorders.



## **Family Guide for more medically complex kids**

This guide is designed for caregivers of people with very medically complex people. Most information is likely not relevant to the SETPB1 Community, but some information about practical and medical information, and insights from parents and clinicians about common experiences may be helpful.

## **On Radical Acceptance (& Not Fixing Your Kid)**

This blog post explores radical acceptance in parenting children with disabilities, encouraging parents to embrace their child as they are rather than trying to “fix” them. It reflects on the emotional journey of acceptance, societal pressures for interventions, and the importance of valuing a child’s unique self over perceived deficits.



## **NORD Rare Disease Education**

This resource provides expert-reviewed information, research updates, and patient materials to support education and advocacy around rare diseases. It connects patients, families, and healthcare providers with tools and communities to enhance knowledge and support.



## **Rare Mamas**

Empowering  
Strategies for  
Navigating your  
Child’s Rare Disease

## **The Essential Guide for Families with Down Syndrome: Plans and Actions for Independence at Every Stage of Life**

Practical roadmap for lifelong  
independence for individuals with IDD



**Need some guidance and help in figuring out how to talk to family about SETBP1?  
Check out this resource from Global Genes**



# HOW TO SUPPORT A DISABILITY FAMILY

## Ways to Help at Home: **Lend a Hand at Home**

Small tasks can make a big difference

- Leave dinner at the door
- Fold laundry or help put it away
- Stock and organize monthly supplies
- Offer to grocery shop or pick up essentials
- Help with dishes or kitchen cleanup
- Tidy up common areas



## Ways to Support: **Show Up with Support**

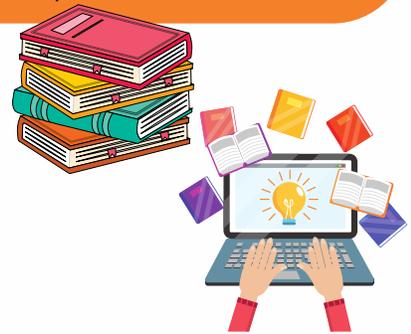
Your presence and understanding mean everything

- Sleep over for a night
- Come over and send them on a walk for self-care
- Take time to get to know their child
- Include their child in playdates, events, and conversations

## Ways to Be Active: **Learn and Advocate**

Knowledge leads to meaningful change

- Ask for a book or podcast recommendations to learn more
- Talk about rare disorders
- Spread awareness and educate others
- Volunteer or engage in SETBP1/related events



## Ways to Stay Connected: **Keep Friendships Strong**

Friendship and consistency matter

- Keep inviting them, even if they can't always join
- Check in regularly, your support is appreciated
- Treat them the same as before, they are still them
- Understand that they be more overwhelmed than usual sometimes

## Ways to Be Considerate: **Be Mindful in Conversations**

Words and conversations carry weight

- Talk about your child's personality, not just achievements
- Be mindful and sensitive when venting about parenting struggles



# REFERENCES AND ADDITIONAL RESOURCES

All references include  
clickable links

[AAC Fact Sheet](#)  
[AAC vs. Assistive Technology](#)  
[ABLE Accounts](#)  
[Abilities in Me Books](#)  
[Administration for Community Living](#)  
[American Physical Therapy Association](#)  
[American Art Therapy Association](#)  
[American Hippotherapy Association](#)  
[American Music Therapy Association](#)  
[Autism Speaks 100 Day Toolkit](#)  
[Apraxia Kids: Speech Tablets for Apraxia](#)  
[Association for Play Therapy](#)  
[Boston Children's Hospital: Vision Therapy](#)  
[CDC Signs and Symptoms of Autism](#)  
[Center for Parent Information and Resources: ID](#)  
[Cerebra: Self Injurious Behaviors](#)  
[Child Find](#)  
[CHOP: Autism Diagnosis](#)  
[CHOP: PT](#)  
[Cleveland Clinic: Developmental Milestones](#)  
[Cleveland Clinic: OT](#)  
[Cleveland Clinic: Speech Therapy](#)  
[Comprehensive Transition & Postsecondary Programs](#)  
[Courageous Parents Network: Siblings](#)  
[DannyDID Foundation](#)  
[DDX3X Website](#)  
[Early Childhood Providers Network](#)  
[ELEVATUS Toolkit: Sexual Health for people with IDD's](#)  
[Feelings Charts](#)  
[Find a Genetic Counselor](#)  
[Fragile X 101](#)  
[Fragile X educational recommendations](#)  
[Girgis et al. \(2023\) Emotion Reg](#)  
[Gitimoghaddam et al. \(2022\): ABA Review](#)  
[Global Genes: Discussing Genetic Disease with Loved Ones](#)  
[Global Genes School Advocacy Toolkit](#)  
[Global Genes: Biomarkers](#)

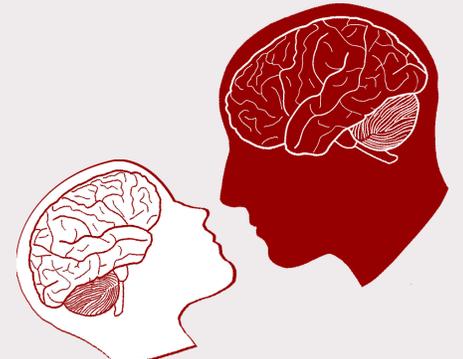


SETBP1  
SOCIETY

[SETBP1.org](https://SETBP1.org)



[SETBP1 Community  
Research Study  
\(SCoReS\)](#)



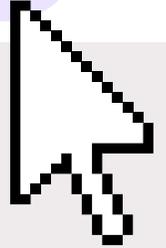
[Brain Research  
Across Development  
\(B-RAD\) Laboratory](#)



# REFERENCES AND ADDITIONAL RESOURCES

[Hanvey et al. \(2022\): Sibling Experiences Help Your Dragon Books IDEA](#)  
[Insure Kids Now](#)  
[Jensen et al. \(2021\): SETBP1 Clinical Paper Library](#)  
[Little Hercules Foundation](#)  
[Mayo Clinic: Febrile Seizures](#)  
[MIND Institute: ABA](#)  
[MIND Institute: Guide to Getting Good Care](#)  
[MIND Institute Symptom Checker](#)  
[MIND Institute ADHD Guide](#)  
[MIND Institute: Make the Most of IEP Meetings](#)  
[Mindful Breathing](#)  
[Mitchel et al. \(2025\): SETBP1 link to CAS](#)  
[Morgan et al. \(2021\): Speech in SETBP1](#)  
[National Center for Education Statistics](#)  
[National Autism Resources](#)  
[National Disability Institute](#)  
[Navigating Life after a Rare Genetic Diagnosis](#)  
[Nemours KidsHealth: Seizures](#)  
[NeuroJourney Financial Planning](#)  
[NIH Refractive Eye Errors](#)  
[National Organization for Rare Disorders](#)  
[NORD Rare Disease Education](#)  
[On Radical Acceptance \(& Not Fixing Your Kid\)](#)  
[Oyler et al. \(2024\): SETBP1 paper](#)  
[Parent Center Hub: Bullying](#)  
[Parent Center Hub: Positive Behavior Supports](#)  
[Parent Center Hub: Special Education Terms](#)  
[Parent Center Hub: Special Education](#)  
[Parent Center Hub: Record Keeping](#)  
[Parent's Guide to Respite](#)  
[Pediatric Palliative: Sibling Support Toolkit](#)  
[Pregnancy and Parenting Support for People with Disabilities](#)

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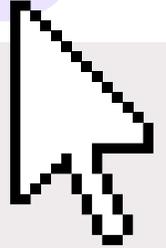
[Brain Research Across Development \(B-RAD\) Laboratory](#)



# REFERENCES AND ADDITIONAL RESOURCES

[RareX](#)  
[Raising Special Kids](#)  
[Rare Chromo: Challenging Behavior](#)  
[Rare Chromo: Puberty](#)  
[Rare Chromo: Sibling Support](#)  
[Rare Chromo: Transition to Adult Services](#)  
[Rare Chromo: Therapies](#)  
[Rare Chromo Website](#)  
[Report on Sexual Violence on People with IDD](#)  
[Samson et al. \(2022\) Emotion Reg Paper](#)  
[SCoReS SETBP1 Resource Book](#)  
[SETBP1 Gene Review](#)  
[SETBP1 Society Website](#)  
[Sibshops](#)  
[Sierra Phillips Ultimate Resource Guide](#)  
[Simons Searchlight Genetics FAQ](#)  
[Simons Searchlight Guardianship](#)  
[Simons Searchlight Family Guide](#)  
[Simons Searchlight: What is Autism](#)  
[Simons Searchlight Resources Page](#)  
[Simons Searchlight: SETBP1](#)  
[Social Thinking](#)  
[Special Needs Alliance: Independent Living](#)  
[Special Olympics Adaptive Sports](#)  
[Special Olympics ID Guide](#)  
[Special Olympics Inclusive Health](#)  
[Supporting Youth with IDD through Puberty](#)  
[Telecommunications Equipment Distribution Programs](#)  
[The ARC: Healthy Understanding of Our Bodies](#)  
[The ARC: Parents with IDD](#)  
[Tom and Ellie Puberty Books](#)  
[Umucu et al. \(2022\): ID Strengths](#)  
[US Social Security Benefits for Children with Disabilities](#)  
[Vision Therapy](#)  
[Visual Supports and Social Stories](#)  
[Voice of Reason Advocacy Group](#)  
[Ways to Help a Special Needs Parent](#)  
[Zones of Regulation](#)

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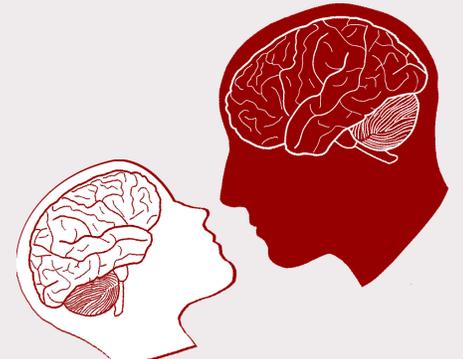


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# SETBP1 Haploinsufficiency and Related Disorders (SETBP1-HD/RD) Education Guide



**SETBP1**  
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in partnership with

