



## **Book of Brett**

# **Helping Brett Develop to His Fullest Potential**

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Denise Rehner



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# Background and Medical History

- Brett has a rare **GRIN1** Genetic Mutation that is the cause of **global delays** including motor, fine skills, speech, and intellectual disabilities.
- Brett has **hypotonia** (low muscle tone).
- Brett eats **PUREES ONLY** as he does not yet chew.
- **No Seizures...YET:** Brett has NOT had any clinical seizures to date. However, seizures in GRIN1 individuals **can occur at any age.**
- Brett has **CVI** (Cortical Vision Impairment).
- Brett wears **AFOs** (Ankle Foot Orthotics) and **should always have these on when weight-bearing.**
- Brett is **non-verbal** and uses multi-modal communications and learning. He can often **demonstrate his preferences** non-verbally.
- Brett is currently receiving private PT, OT and speech therapy (AAC).
- Brett has **flared ribs** and therapy is working on building core and obliques to pull in ribs.
- Brett had cranio surgery at 9 months old to correct a **prematurely-fused metopic suture.** He has a wavy scar from ear-to-ear.

# Safety Information

- **Constant identified adult** (trained to Brett's needs) assigned to assist Brett throughout school day to support Brett's mobility, safety and to aid with Brett's participation with peers.
- **Falling:** Brett does not have self protection abilities to prevent falls and therefore needs full support for sitting, transfers, etc.
- **Sudden head and/or body movement: Brett throws his head and/or body back suddenly so ANTICIPATE this happening without warning.** Be extra careful when walking through **doorways** or close to objects when carrying him as he can throw himself backwards without warning. He will often drop his head forward when fatigued so **hard surfaces must be cushioned**. Safety concern with Brett throwing his head back or dropping his head forward- \* safety for staff and for Brett – soft foam placed on a table or other items for when his head drops/ safety from a person or equipment for his head thrown back.
- **Choking:** Brett eats **purees only** as he does not chew. **Do NOT give him anything other than what parents/caregivers bring for him.**
- **Brett puts everything in his mouth** so keep all small objects (anything that can fit in a toilet paper roll) away from him. Be careful other children **do not leave small objects** (food pouch tops, small blocks, etc) **within his reach.**

# Safety Information (cont)

- **Seizure activity:** Although no seizures have been diagnosed, Brett will sometimes arch backwards and to the right and gets stuck in this position. If this happens, gently remove him from the position (**pick him up and place over your shoulder**). He sometimes goes through laughing/twitching episodes that are triggered by over-stimulation and/or temperature changes or wind. Try to **keep him from scratching/hurting himself** as he tends to scratch at his mouth.
- **Falling backwards:** Brett can now sit himself up from **prone (laying on stomach)**. **He can push his torso too far upright and fall backwards.** He can sit up by pushing up on his right side from laying on his back.
- **NO fast-flashing lights** as these trigger seizure-like activity or over stimulate Brett. Slower flashing lights are OK.
- **Biting:** Brett is orally motivated so he might bite your arm if placed in front of his face. He bites his hands so we keep gloves on his hands. He will place his hands in his mouth sometimes so far as to make himself vomit.

## Outdoor Activities:

- Brett should wear a hat and sunscreen when he is in direct sunlight for extended time (beyond 10 minutes).
- Caution around fast-moving objects such as balls and children running.
- Playground monitoring especially around swings and slides.

# General Helpful Information

- **Brett eats ~every 3 hours:** Generally: ~8 a.m.: cereal with scrambled eggs 11:30-noon lunch: 2-4 containers such as chicken and gravy, macaroni and cheese, chicken or beef and veggies, vanilla pudding. 3~ another lunch type of meal but often not as big as 1<sup>st</sup> lunch, ~6 p.m. mashed potatoes with veggies and chicken.
- **Signs when hungry:** sticks out tongue, chews hands or other's hands, or smacks lips.
- **Oral Fixation:** He puts everything in his mouth. Likes putting his fingers in others mouths.
- **Drool:** Brett wears drool bibs. Please wipe his drool when possible as it irritates his skin. Parents use Healing Balm as a barrier after drying his chin.
- **Pain:** He will often open his mouth, draw his lips tight over his teeth, and arch backwards.
- **Startles easily:** Sudden and loud noises startle him.
- **Gets elbow stuck rolling:** Often when rolling from front to back, his elbow gets stuck.
- **Pulls hair:** He likes to pull long hair as it seems like a toy to him.
- **Calming Brett:** Hold him, rock him, bounce him gently, sing or hum.
- **Brett needs processing time:** Give him time to process information. DON'T RUSH HIM.
- **Takes breaks:** Often checks out for 10-20 seconds. Give him time.
- **Cat naps:** He might take a cat nap. When he wakes he often shakes his head to wake himself up.

# Likes and Dislikes

## Likes:

- **Vibration:** Vibrating toys and chewing toys.
- Gentle **Bouncing:** On physio ball, on your lap in trampoline.
- **Lights:** toys that light up but make sure NOT to use fast flashing lights.
- **Music:** Mom often soothed him as an infant with music and dancing.
- Sensory input on **hands and feet:** water, shaving cream, bubbles, food
- Vestibular input (**swinging, bouncing, rocking, rolling, spinning**) revs up his system.
- **Social:** Brett loves people and craves affection. He likes watching other children play and feeling like part of the play.
- Technology: **cell phone, laptops, ipads, remote controls.**

## Dislikes:

- Being on his **back on hard surfaces.** Diaper changes are challenging on hard surface.
- **Transitions:** Such as getting into car seat or stroller, changing clothes especially after bath.



Brett Likes People,  
Animals, Technology,  
and New Experiences





# Favorite Toys

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# Strengths and Challenges

## Some Things I'm Really Good At:

- Engaging in story time
- Exploring small spaces
- Engaging w/others through eye contact and touch
- Exploring new textures
- Eating
- Smiling and vocalizing in response to yes/no questions or to indicate like vs. dislike
- Making choices by looking at and/or reaching for the toy/item I want
- Activating switch toys
- Rolling for independent mobility
- Sitting on a bench with light support during circle time
- Riding an adapted bike
- Expressing when I need a break

## Some Things That Are Tricky for Me:

- Feeding myself (but I want to so much!)
- Sitting independently/functionally for extended periods of time
- Maneuvering around bigger and less familiar environments
- Controlling/grading my body movements (grasp and release)
- Exploring with my hands without assistance
- Standing (requires maximum support)
- Understanding more abstract concepts like a name sign or emotion switches
- Being understood by those who are not familiar with my non-verbal communications
- Indicating my needs and wants

# Brett's Strengths

- Determined
- Hardworking
- Social
- Engaging
- Musical



A loving and supportive family that continues to provide Brett with a variety of experiences to learn and grow.



# Concepts and Words Brett Understands/Emerging

Brett understands **turn taking** and can make choices of familiar **objects/activities of up to 4 items**.

He understands language that goes along with daily routines and activities.

Activities of Daily Living (ADLs), Routines and Activities
Do you want more? Are you all done? We're all finished.
Stop/go, fast/slow, up/down, left/right, on/off
Let's: clean up, get you dressed, take a bath, change your diaper, wipe your face/hands
Let's go: for a stroll, to the park, swimming
Are you hungry/thirsty? Do you want: Baba (Bottle)/Water/Tapioca
It's bath time, time to eat, bedtime, clean up, wash your hair, brush your hair/teeth
Let's Get Up – "123 Up", reach, take off, get it, let go, can I have it?
Let's snuggle "snuggie", give me a kiss
Do you want to watch cartoons? Read a book? Play? Breathing Game?
How are you feeling? Let's calm down, deep breaths
We're going for a ride, to the mall, to Monkey Bizness, Target
We're going to see: Sara, Ashley, Jill, Erin, Jim, Danielle, etc.
Sara's coming to pick you up, I'll see you later, bye bye
Do you have an ouchie? Is your mouth/head/tummy ouchie?

Words:
Doggie, Kitty
Tired
iPad, Massager, bubbles
Mama, daddy, Rebel (dog)
Talker Menu:
Me: Play "let's play", feelings "let me tell you how I'm feeling", again, different
Play: book, ipad, music, massager, make noises, breathing game, phone, again, different
Read a book: turn the page, touch it, who's turn? Mama's turn? Brett's turn? Etc. again, different
Massager on your: head, back, hand, foot, again, different
Feelings: hungry, thirsty, tired, happy, sad, again, different



# Brett's Optimal Learning Environment

# Brett Needs and Wants to Be Included

- Brett needs **active participation opportunities** that are inclusive, not separated from the other kids (i.e. letting Brett knock down blocks that others stack).
- Brett needs **adapted playground activities** where he can participate like other kids (i.e. obstacle course, adaptive bike).
- Use of the tray on the Rifton chair should be done only when it is not possible for **Brett to be positioned at the table with his peers with his arms on the table.** This will be the most natural way for him to participate with his peers.
- **Recess:** Provide a **rotation of activities** for Brett on the playground. For example one day he is in the stander, the next day he plays in the woodchips with a friend and the next he is in his walker or trike. Brett could be given a tactile cue so he knows which activity he is doing that day. As he gets more familiar with the tactile cues he can start to **choose what he wants to do** during recess.

# Vision-friendly Materials and Environment

- Provide **5-10 minute visual warm-up** period before asking Brett to make choices. Brett often looks away from toys and objects or closes his eyes. Allow him these **visual breaks**.
- **Decrease visual and auditory clutter** when Brett is expected to do a visual task or listen to auditory directions or teaching activities. **Limit background distractions** such as windows and busy prints. Sit Brett facing away from windows.
- Use **high contrast materials** against a **solid surfaces or background**. Using **bright, shiny, high contrast and simple visual materials** is very important.
- Use a **lightbox or flashlight to** improve Brett's visual attention. Spotlight the item you want Brett to attend to or move it forward. **Movement** of the object makes visual tasks easier for Brett.
- **Use touch, vision, and auditory input together** for Brett to improve his attention to toys and objects.
- Brett is attracted to the colors **red** and **yellow**.
- If using **lighted toys**, try to create contrast by **dimming lights**.
- Limit **choices to 2 or 3** and **limit extraneous sensory input**
- Brett will do best visually directed reaching if his **arms are supported on the table or a tray in front of him**.
- Consider copying pictures from books onto **overhead transparencies** and place on light box during literacy time. Enlist peers to help put transparencies on light box and talk with Brett about what is happening in the picture.
- Consider **“reading” the book (via youtube) on Brett's i-pad**.

# Brett Needs **Multi-Sensory, Tactile** Materials to **Experience** and **Understand** What Is Being Discussed

- **Brett needs to INTERACT with all the materials in the classroom as much as possible.** Give him time to process what you are showing him, let him touch it and listen to it.
- Sometimes it may make more sense to just **let him explore tactilely and through sound**, especially at the end of the day when he is getting tired.
- **In addition to presenting an object cue** with each transition to a new activity (centers, recess, circle time, bathroom) **Brett needs a tactile symbol that is the same or is similar in some way** (color, shape) to the tactile cue he is handed. This can be posted on a black or white background somewhere on the wall or a table at Brett's eye level/best visual field.
- **Help Brett to understand what each tactile symbol “means” and relate it to the activity.** For example, going into the BR for a change. Help Brett know he is done using the BR by singing a hand washing song while his hands are wiped. *Clear beginning- middle and end-* First he gets the BR cue, then he gets a change and last he washes his hands.



# Speaking Brett's Language

- Use **relevant** and **meaningful** material in words and materials that he can understand and relate to (i.e. question of the day).
- Use **concrete language** to narrate for Brett **what is happening, will be happening**.
- Use **consistent word choices** for familiar routines-i.e. *pass* Brett the ball versus *give* Brett the ball. Or “time for snack” versus “Are you ready to eat?” Hearing the same words for different actions or activities gives Brett one less thing to have to work on processing. It doesn't matter what you say as long as everyone tries to be consistent during repeated routines.

# Help Brett to Understand the World Around Him

- **Give Brett a verbal and tactile prompt BEFORE being moved from each position or equipment.** When going to a new activity/area, give him his tactile cue before starting the transition. “Time for recess”-as you hand him the cue for recess. A verbal cue for position changes should be as consistent as possible- i.e. “123- up”.
- **Narrate for Brett when possible as he misses out on incidental things happening around him.** If there is a noise, tell him what made the noise for example-“That was a loud bang!” “A bowl fell off the table” or “I hear the ball bouncing, Ari is coming over to shoot a basket.” You can also do this during circle time-“Joey is wearing the weather hat. It looks like he is picking the sun symbol”.
- Help Brett work on **prepositional concepts** through touching a body part and naming it. For example, “*touch your elbow to your knee*” in an obstacle course. Brett can’t do the physical task in his stander, but you can *touch his elbows and knees* and talk about his body and right versus left sides.
- **Comment on who is sitting next to or across from Brett** in circle time or at the table during snack. **Give him a tactile prompt** as well by touching his right arm when you tell him- “Emily is sitting on your right side”.
- **Have Brett help in some way to get materials out and put them away.** It is important for him to understand where things in the environment are coming from rather than having them just appear in his play/work space. Putting things away is also a perfect natural cue that something different is going to happen.

# Strategies to Keep Brett Engaged

- Allow Brett to communicate preferences by **giving him choices** throughout the day (i.e. Do you want to get out of your chair or stay in your chair?)
- **Focus on the goal of the activity:** if it is music the main goal may be listening, if it is literacy it may be looking and listening, when it is time to work on standing or sitting balance it may not be a good time to work on a visual task at the same time. Physical tasks and visual tasks are probably the most taxing for Brett.

## **Brett participates most when:**

- He can **manipulate toys/objects**
- Is **supported/helped** to do so
- Given wait time: Allow Brett **time to respond**. 5 seconds for familiar material and up to 20 seconds for new material/activity.
- Is **familiar** with tasks, activities, toys, books, etc.
- He is **actively involved**
- When all **attention and focus** is on the same activity

## **Brett needs help participating when:**

- Activities are **new**
- He is **not in optimal seating position/equipment**
- The **'motor part' of the task is hard** or is a motor task he can't do



Communication

# Brett Uses Multi-Modal Communication

- Always Acknowledge Brett's Nonverbal communication
  - Facial expressions
  - Vocalizations
  - Looking to/reaching for objects
  - Taps at/on object
  - Kicks his legs when excited
  - Looking away when he's not interested
  - Arches his back to protest
- Augmentative & Alternative Communication (AAC)
  - Object choices, picture choices
  - Communication device using auditory scanning and a Jellybean (small) switch to activate messages



# Goal:

To increase his expressive communication skills, when presented with 2-3 auditory choices, Brett will indicate his preference through movement, vocalization, or by accessing his jelly bean switch in 60% of opportunities.



- **Provide choices** during a variety of motivating activities
- **Give 'wait time'** in between choices to ensure Brett had time to respond
- Ensure Brett has **experienced the choices** being presented (show him the toys)

- Position Brett in **optimal seating** for communication
- Provide Brett with **direct instruction** before giving choices ('You can hit your switch or move your body when you hear what you want')
- **Acknowledge when and how he made the choice** (You smiled when you heard 'book' so we are going to read the book')

# Communications Examples



# AAC with Jill Tullman and Associates

- During our individual speech-language therapy sessions, Brett has shown good potential to use **auditory scanning with single switch activation**, using his right hand, to activate a Jellybean switch, to access vocabulary on the communication device. Auditory scanning is an access method where choices are presented auditorily/spoken aloud by the device, and **Brett activates a single switch to 'make his selection/communicate his preference/activate vocabulary'**.
- While Brett is learning to use this communication device, and the device is used with him during individual weekly speech-language therapy sessions, a large amount of time during our weekly sessions is spent **providing Brett with choices, and supporting him to respond using his nonverbal communication and/or by activating a Jellybean switch.**
- When two object choices are presented to Brett, **objects are presented to him one at a time, labeled individually, and then both held in front of him.** Brett looks to each and then **reaches for the preferred.**
- Brett is also presented with **auditory choices.** Activity choices are presented (i.e., Brett, what do you want? Music/book/iPad/massager). **Choices are presented, and then stated one at a time, with consistent wait time (5 seconds)** provided between choices. This technique is referred to as **partner assisted auditory scanning.**
- During **preferred and familiar activities**, like those stated above, when choices are presented to Brett, he **listens to choices and will/may smile in response** to his preferred choice/what he wants. He recently received his Aspen seat, and he has a manual wheelchair. When he is in his wheelchair and the tray is on, we may present a **Jellybean switch on the right side** of the tray and direct him to activate the switch when he hears what he wants. **When he clearly communicates his preference/desire by smiling, this is always accepted as his response.**



# AAC with Jill Tullman and Associates

- Provide Brett with **choices throughout his day for activities and within activities** (i.e., when he chooses play doh, what choices is he given/can he be given while playing with play doh?).
- Present choices within activities to Brett using **partner assisted auditory scanning**.
- **Ways to present choices** to him, **how to present choices** to him, and **how to identify/know when he responds**/how he responds should be **discussed so that all adults working with him are comfortable and clear on his nonverbal communication** and on **how, what and when to present choices**.



Mobility

# Goal:

To address limited mobility due to hypotonia, Brett will **sustain an upright posture with intermittent weight bearing on arms for 3-5 minutes**, with moderate assistance.



- Offer a variety of upright positions throughout Brett's day (prone, ring sitting, supported sitting, short sitting on a bench, tall kneeling)
- Consider attaching a vibrating toy, turned on intermittently, to his walker to provide additional sensory feedback
- Provide engaging activities above shoulder level to encourage him to sit up
- Use a table, tray, or desk for upper extremity weight bearing

# Mobility Examples





Brett currently **prop, ring, bench, half long, and short kneel sits** with min asst (very close stand by in case he falls or throws his head back or drops forward) inconsistently in variable times for **up to 10 minutes**.

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# Play Skills

# Goal:

To demonstrate improved play skills in order to **interact with his environment**, Brett will **reach for targeted objects** or materials in 60% of opportunities with physical and verbal cues.



- Consider having Brett in a **supported, seated position** when precision is required for fine motor tasks (transferring objects, fine motor game, accessing switch).
- Allow Brett **extended time to warm up to new activities** before moving on to a different activity.
- Use **consistent wording** when prompting him to reach for an object (e.g., 'reach', 'get it').
- Provide **motivating objects** just out of range to encourage Brett to reach for the object

# Play Skills Examples







# Eating Helpful Hints

- **NO food beyond chunky purees provided by family** should be offered to Brett.
- **Brett currently needs 100% assist to eat and drink seated in a supported chair.** Encourage him to hold spoon, cups, drink with straws. All with assistance. Future goal will be to bring preferred food item to mouth with no more than 25% assist and self-feed himself 75% of his meal during snack time.
- **Brett is working on self feeding with squeeze packs.** Help guide squeeze pack to his mouth and apply appropriate pressure to squeeze contents. When nozzle is in the middle of his tongue it helps with lip closure.
- In therapy, he can use a spoon with help but **adult needs to feed him the majority** of volume.
- Brett sometimes does not know he's hungry. **Encourage first bites** and he will eat if he's hungry. Show him a food item (hold up) and ask him "are you hungry"?.
- Offer him a choice between 2 snacks (show him the packages) when available (tapioca or yogurt).
- **Brett likes to feel and play with his food.** This often stimulates him to eat. Brett wrings his hands with his food.
- **Allow him to hold a spoon or "help"**. Be prepared with several spoons as he drops them.
- Cue him by **scraping his bottom lip/chin** with spoon.
- As much as possible, don't clean the spoon for him by pulling up when removing spoon. That does the work for him. Instead, **pull spoon straight out** to encourage lip closure. This develops his mouth muscles.
- **Give him time to pause, process and react.** Sometimes he takes a break and will zone out. When he's done, he will not open his mouth for another bite. If he loses momentum, such as waiting for someone to get more food, he loses interest and usually won't eat more.
- Offer **water when he's done eating** (he can have water at anytime you think he's thirsty).

# Emergency Contacts

**Denise Rehner:** (303) 881-3425 denise.rehner@hotmail.com

**Scott Rehner:** (720) 837-9084 scott\_rehner@hotmail.com

9593 Merryvale Court; Parker, CO 80138

Red binder “estate planning” on kitchen counter.

Letter of intent with Betty Lehman, Disability Advisor

6081 S. Quebec, Ste. 103, Centennial CO 80111

betty@lehmandp.com cell: 303.898.7656

**Sara Moody (Nanny):** 303-523-8184. POA for school, medical, etc.

1886 Granger Circle; Castle Rock, CO 80109

**Mary Lou Fox (friend):** 303-805-8414

Home 303-910-7815 Cell. POA for school, medical, etc.

Pediatrician: **Nancy Lataitis** of Partners in Pediatrics 303-779-1172



# Brett's Schools and Private Providers

## **DCSD:**

Jenny Brown, PhD Principal  
Casey Anderson, SSN

## **Anchor Center:**

Mindy Doyle (TVI and PT)  
Melinda Carter (TVI)

## **AAC Specialists:**

Jill Tullman, SLP  
Callie Robinson, TVI

## **Private Therapists:**

Jim Hedgecock (PT)  
Danielle Braman (OT)

## **Other:**

Michelle Lange, OT/Seating Specialist  
Julie Hagy-Hancock, Education  
Consultant  
Leslie Morrison, OT/Swim Therapy

## **Family:**

Denise & Scott Rehner (Mom & Dad)  
Sara Moody (Nanny)  
Nemo (Yellow lab)  
Toby (ungrateful cat)