

Come In... and Let Me Tell You



COME IN

I step toward this that you have made

Because I want

And wish and hope

To be here too.

You invite me in, not with words,

But with choices

That say to me,

"Yes, you matter."

No trumpets blare nor spotlights glow,

Only what's right.

I pause, breathe, smile,

And step inside.

Kathy Nimmer

Introduction

The *New Critter Barn* is excited to announce that in the building of our facilities, we are also obtaining certification in Universal Design. Universal Design is built upon seven principles, dedicated to ensuring that persons of all abilities are welcome to participate and enjoy our farm. The *New Critter Barn* will be the first facility of its kind worldwide to earn this certification. Through careful planning, the *New Critter Barn* will provide access to all visitors by providing:

- Equitable Use
- Flexibility in Use
- Simple and Intuitive Use
- Perceptible Information
- Tolerance for Error
- Low Physical Effort
- Size and Space for Approach and Use

During the planning process, special education students at Trinity Christian College taking *Communication and Collaboration in Special Education* developed their professional skills by collaborating with the *New Critter Barn*. A small group of students developed the idea of sharing with visitors how helpful Universal Design can be for individuals with a variety of disabilities. They also wanted visitors to know how to be a good friend to a person with a disability if they were enjoying the space together.

The way that the students approached this task involved working together to gather a variety of stories and vignettes from individuals with disabilities. Pulling together research on each disability and personal accounts, the students used creative writing to present each vignette from the perspective of a person with a disability. Additionally, students researched how a variety of individuals may experience Universal Design at the *New Critter Barn* and how these elements could impact their enjoyment of our farm. Our hope is that in sharing the following stories, we can provide a glimpse into how Universal Design opens doors for everyone to actively participate in our mission and how it promotes our dedication to ensuring that all are welcome to “Come In”.

Contributing Authors:

Brenna Groenewold – Trinity Christian College Student
Mariel Martin – Trinity Christian College Student
Amanda Ophoff – Trinity Christian College Student
Dr. Pete Post – Trinity Christian College Professor Emeritus
Matteo Tancredi – Trinity Christian College Student

Edited By:

Christine Scholma – Trinity Christian College Assistant Professor of Special Education

Table of Contents

ADHD	Page 4
Asperger Syndrome	Page 5
Autism Spectrum Disorder	Page 6
Bipolar Disorder	Page 7
Blindness	Page 8
Cerebral Palsy	Page 9
Deafness	Page 10
Dwarfism	Page 11
Dyslexia	Page 13
Epilepsy	Page 14
Muscular Dystrophy	Page 15
PKU	Page 16
Quadriplegia	Page 17
Rhett Syndrome	Page 18
Tourette Syndrome	Page 19
Resources	Page 20

Let Me Tell You About ADHD

Written by Trinity Student Amanda Ophoff in consultation with Kayli McGinnis, a person with ADHD

You may not believe this, but I think my ADHD is a ball of fun! Even though teachers know there are so many things that distract me, I am in love with life and always running from one thing to the next. My ADHD makes it hard for me to manage time, which is why I am always flying around. I easily forget appointments, what class I have next, or things that I have to bring to class or parties. There is just so much going on that my brain is all over the place!

In our brains, electricity flows through certain pathways called neurological connections. In my brain, these connections are not fully developed, so information can get lost on the way to where it is supposed to go. If my friend reminds me that I have to bring my textbook to class today, I might still forget because her comment was not processed all the way inside my head. I promise that I am listening to you and not being rude. I am trying my best. I just need people to understand that I will forget things, even though I try not to. That is why it is important for me to write things down in a schedule so that I don't forget.

Having ADHD makes me a very visual person. My room might seem messy to you, but it actually makes perfect sense in my mind! Everything is out where I can see it. If I put something away, the phrase "out of sight, out of mind" definitely applies to me. If I can't see it, I will forget about it. If my science textbook is on my bookshelf, I will forget that I have science homework because the book is not lying on my desk reminding me about the paper I have to write.

When I work on group projects, it is important for us to work out a plan and break down the work together. Getting a ton of information at one time overwhelms me. I am very intelligent; my brain just processes information differently than most people's brains. Having ADHD can be challenging, but it is also fun, especially on trips to the Critter Barn. Interacting with the animals and visiting the barns gives me so many opportunities to try new things, learn about farm life, and seeing all the action!

Let Me Tell You About Asperger Syndrome

*Written by Sondra Williams, a person with Asperger Syndrome
A contribution from her book, "Reflections of Self"*

They Say

I heard them talking about me, saying I am not like others
I can dance and sing and play, I feel, and cry tears too.
I am more like you, than you think

I heard them say that my silence reflects no emotion, no connections.
I cry many unseen tears, I laugh at life's blunders, although not in ways foreseen.
I connect like you, more than you think.

They say I am intellectually impaired and will never learn to reach my potential
I know about words and explore the world in ways others rarely know.
I am smarter than you think.

The doctor says I will not be able to show affection or relate to my own family
I gave them a smile from across the room, they didn't even notice.
I do know and feel love, more than you may think.

Some say my anger and rages are animalistic.
I tried to communicate my fear the only way I know how, but no one was listening.
I get angry like you, for reasons like you, more than you think

The doctors say there is no hope I am void of understanding
I have dreams and think on them often, but due to my silence I can't share them.
Yes, I have dreams and goals, just like others, more than you think

Strangers say I am out of control and not human.
I have a body, mind and soul, just somewhat challenged.
I am human more than you think.

I heard them talking, saying oh, she has autism, a disability of no hope
If they only knew what is trapped inside me, I think...
They would say she's more like me, than what I used to think.

Let Me Tell You About Autism

Written by Trinity Student Amanda Ophoff based on research and in consultation with Dr. Temple Grandin, a person with autism

I look at the world differently than a lot of people. First, I notice the details, and then the full picture comes into view. The details JUMP out at me—bright colors, vivid designs, and fascinating shapes. Anything eye-catching can instantly tear my attention away from anything I was attending to. If I am talking to someone and a bright yellow bus zooms past, my attention is instantly torn away from that person and glued to that glorious machine roaring down the road.

I never try to be rude to people. When people talk to me, I do not always know how to respond. It seems easy for everyone else to communicate, but it is so hard for me! I cannot always think of the words that I want to say and sometimes my mouth does not say what I want it to. Some people think that people with autism just want to be alone, but that is not always true. Many of us with autism just don't understand how to communicate effectively and we are afraid of messing up by saying the wrong thing, so we often stick to ourselves. We really like to spend time with people! We just need extra time and help to communicate.

When I go to the store with my parents or friends, I get a lot of weird looks. Sometimes I walk funny, clap my hands, or wave my arms. It just feels so good to have the sensation of moving parts of my body. I feel so real when I move. I know that it is not normal to wave my arms all over the place, but this is what my body needs in order to feel balanced.

One cool thing about having autism is that I have deep passions about certain things. My mind holds a lot of information about my passion, and I am extremely knowledgeable in that field. I love it when other people show interest in my passions because it makes me feel important. I find the animals at the Critter Barn fascinating and would hope others would encourage me to enjoy everything that the farm has to offer.

Let Me Tell You About Bipolar Disorder

Written by Marybeth Smith, a person with bipolar disorder

Introduction by Trinity Professor Emeritus, Dr. Pete Post

People who have bipolar disorder can have periods in which they feel overly happy and energized and other periods of feeling very sad, hopeless, and sluggish. Marybeth Smith knows this quite well because she has bipolar disorder. She has written a novel, "Fall Girl," in which the main character must constantly watch out for a brother who has bipolar disorder. She once managed a website, askabipolar.com, in which she encouraged others to learn about more about what it is like to have this diagnosis. Through the wonders of genetics, she passed along the traits of bipolar disorder to her own child. This is how she reflects on how the Critter Barn can welcome people with bipolar disorder to "Come In."

At first thought it's hard to say how universal design would affect someone with bipolar disorder. On the surface it doesn't really seem like there are many challenges to having such a mental disorder. To most people it just means frequent mood changes. However, to someone who has bipolar disorder, it is much more. Something like Universal Design in an animal farm is such a wonderful idea. There are animals and the sensations that they bring such as something so simple as furriness and the ability to touch something soft and gentle. And then there is the very attractive "non-judgmental-ness" that can only come from an innocent animal that has no idea of how a human should be acting. This is one of the most basic things that can bring comfort to someone dealing with an emotional up or downswing in their mood.

Having animals accessible to those who are feeling particularly fragile is an amazing treat that can only be matched by ... well, nothing. Nothing can be matched by the fragile sense of never being abandoned by the creature you are currently loving on. Moods rise and fall like the tides, ebbing and flowing and then coming back at you with reckless abandon. But feeling the love of an animal is something that cannot be shaken. If such amazing experiences can be shared by all with any abilities, why not share as much as possible?

Moods, especially in those with bipolar disorder, can come and go in such a fleeting moment. But the comfort of an animal is something that should be shared and treasured. There are no special circumstances in which such a moment should be shared. Having a mood disorder does not start or stop such a moment from happening. Sure, there are things you can and can't do to help someone with bipolar get through a particular moment in time. But in my experience, having the undying love of a creature other than yourself is enough to get through if only a moment in time. Even if it is small and insubstantial to others, it is probably huge and immensely significant to someone experiencing a terrific depression or being unable to come down from a significant mania.

A moment with an animal can be emotionally grounding and wonderful. Although it appears that no special circumstances need be met to someone suffering a mood swing, the simple act of touch could be all the grounding a person might need to get them through to the next moment in time. And that, although it may seem small to others, can be the biggest moment that person might experience for a very long time. Touch ... it seems simple ... but if that's all you provide between an animal and human, it could be the biggest mood lifter that even drugs can't provide.

Let Me Tell You About Cerebral Palsy

Written by Trinity student Brenna Groenewold based on research and lessons learned from Lisa Cesal and Chris Lenart's book, "They said We Couldn't"

I have Cerebral Palsy because shortly after I was born, my brain was damaged. When I was younger, I wasn't able to learn how to crawl at the same time as everyone else. It is not my fault, or my mother's that these things happened. My parents couldn't love me any more than they already do!

What matters to me is where I'm going, and not just how I got here. I have had surgeries to make my muscles work for me the way your muscles work for you on their own. I have spent countless hours in physical and occupational therapy. I even work with a speech doctor who can help me communicate. I may not be able to do things as fast as you can, but there is no shortage of creativity in how I do things.

Sometimes, it is difficult to be in control of my body because my brain is constantly firing signals to initiate movement. Please accept me for who I am and not for what you want me to be. I want you to know that I have feelings, memories, and passions, even if I can't communicate them the way that you do. I may just need tools and equipment to share my dreams with you and participate in the things I want to. Thanks for understanding when these tools seem different to you.

It may not always be easy for me to move, balance, or maintain my posture, but that doesn't stop me from getting around the Critter Barn. I may not be able to walk on my own, but my wheelchair helps me get around. I may not be able to talk and communicate as easily as you can, but I can't wait to talk with you at the Critter Barn. I am happy to know that places like the Critter Barn have accessible paths and activities at levels I can see and touch from my wheelchair.



Let Me Tell You About Hearing Impairments

Written by Trinity student Matteo Tancredi based on research

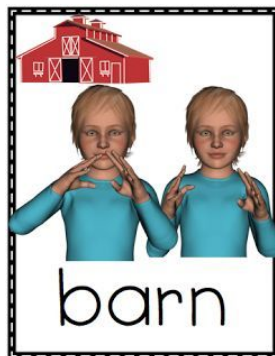
Some people like me may have difficulty with hearing. Hearing loss or being deaf can be different in everyone. It can impact my ability to develop speech, language, and social skills. There are a few different types of hearing loss. Conductive hearing loss is when there is a problem with a part of the outer or middle ear that is blocking sound from going in the ear. This type is usually mild and temporary because often, medical treatment can help.

Sensorineural hearing loss happens when there is a problem in the inner ear or with the connection from the inner ear to the brain. Sometimes this can cause muffled sounds, hearing only some sounds, or hearing no sounds. This type is permanent. Central hearing loss happens when the cochlea is working properly but parts of the brain are not. This is the type of hearing loss that I have, and I also have a cochlear implant.

A cochlear implant is a small electronic device that helps provide sound to me. It is different from hearing aids because hearing aids make sounds louder in damaged ears, whereas my cochlear implant goes past the damage portions of my ear and directly to my auditory nerve in my brain. When I got my cochlear implant, I had to have surgery and a lot of therapy afterwards. I met with a lot of specialists and doctors to see if this was the route to go.

Most of the time I can hear what you are saying to me and yelling at me or shouting will not help me hear any differently. Speaking slowly in a conversation with me can help me understand what you are saying and making sure that you are not covering your mouth when speaking to me helps as well. Some other kids who may not have cochlear implants or other devices may use American Sign Language (ASL) to communicate! Some of my friends and family members have learned ASL and we communicate that way as well.

Some of the time, with early intervention, kids with cochlear implants like me are able to hear normally, just like you. If you see the cochlear implant on the side of my head at the Critter Barn, you can remember that it is helping me hear you, communicate with you, and participate with my class at The Critter Barn.



Let Me Tell You About Dwarfism

Written and illustrated by Isaac Griffin, a person with dwarfism

Of the over 400 diagnosed types of dwarfism, I have the most common one called achondroplasia. In short, it affects my arm and leg bones the most, which are smaller than the majority of the population. My head and torso are of normal adult size. Fun fact: I sit as tall as an adult, but I don't stand as tall as most, even though I am an adult. I stand around 4' 3" and weigh about 100 pounds. The term "little person" has become the most welcomed and recognized title for my condition. "Dwarf" is also pretty much acceptable. To the majority of the little people population, the term "midget" is the most hurtful and condescending. The thing instead, which is better, is asking what our names are. Growing up has had many ups and downs, but I have handled the hardships and have been strengthened from them. Many names and many pointing fingers have been made in my direction, but I am not as easily offended as I was during my childhood. I understand most people are genuinely curious or confused at first when they see me. Children are especially curious. I never blame them for pointing or commenting about my height. I look like a kid to them who has an adult face with a goatee. I listen more closely to what the parents and adults have to say.

The world is not made for little people. What I mean by that is I have to constantly adapt to my surroundings. I have to use stools or chairs to reach things often. I may climb on the countertop to get a bowl for cereal as well as the cereal box. Normal chairs, seats and benches make my legs fall asleep since I can't place my feet on the floor. One footstep for an adult might be 3 footsteps for me, so I have to walk or run with more steps required. I drive constantly and I love to. In order to do so, I have pedal extensions that clamp on and off of any car's gas and brake pedals. They can be removed if someone who is taller needs to drive that car, but I can put them back on when I need to drive and adjust the lengths of the extensions. These types of things are normal to me, but I find the fun in them as well as live with joy as much as possible.

To experience Universal Design as a little person visiting the farm would be an amazing weight off of the shoulders. It would, for a rare and yet wonderful time, allow for someone like me to breathe peacefully. Interacting, reaching, and walking in a place that utilizes designed environments with accommodations would allow a chance to experience normal. By experiencing "normal" and not improvising or adapting on my own or trying to fit in with my surroundings, would be anything but "normal". It would be extraordinary.

I am an artist and, in my exploration, I have begun to include little people into illustrated scenes. These scenes don't have to be anything fantastic, but rather show the blessings and hardships of everyday life living as a little person. I love talking and sharing about my dwarfism. Between speaking at schools and friendly conversations, I will always try to find the time to answer, inform and talk about my life being smaller.

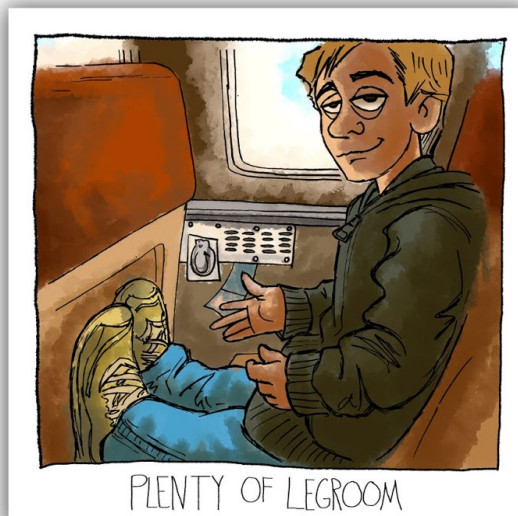
THE BLESSINGS AND CURSES OF BEING A LITTLE PERSON



Crowd Height

© ISAAC GRIFFIN

THE BLESSINGS AND CURSES OF BEING A LITTLE PERSON



Transportation

© ISAAC GRIFFIN

Isaac Griffin, igriffinillustration@gmail.com

Let Me Tell You About Dyslexia

Written by Trinity student Amanda Ophoff in consultation with Kayli McGinnis, a person with Dyslexia

My brain does interesting things when I read. Sometimes, the letters and numbers fly off the page! They really do. They fly away. They move and wiggle, and sometimes they even change color. It's almost magical. But this can make reading a big challenge for me. It takes me a while to read and I have to take it one word at a time. Sometimes my teacher gets frustrated with me for not reading something she assigned for homework. I try my hardest, but I just can't get through the whole thing. I really like to listen to someone else read me the information. I enjoy listening to audio books and the audio signs at the Critter Barn will be a great help for me.

Writing can be challenging too. I know what I want to say, but the words on the paper do not look anything like what I am thinking in my head. Sometimes I can't even read my own handwriting! No matter how hard I try, my handwriting looks like chicken scratch. And don't even get me started on spelling! Even the simplest words like "boat" or "ball" give me trouble. Letters just do not make sense to me. My brain looks at letters like they are a foreign language.

Sometimes people think I am stupid or not trying hard enough. They look at my writing and think, "Wow, she writes like a four-year-old." Comments like these really hurt my feelings. I promise you, I am trying extremely hard. It takes a TON of effort for me to read and write. My friends need to have extra patience with me when I read and write because I take a lot longer. I am just as smart as anyone else, but I just learn in different ways. My brain works differently, and that is okay!

If you see me taking a long time trying to read one of the signs at the Critter Barn, you can just give me extra time. If you want, you could even read the sign aloud for me so that I can listen while I enjoy looking at all of the amazing animals. I can't wait to learn with you there!

Let Me Tell You About Epilepsy

Written by Trinity Professor Emeritus, Dr. Pete Post based on research and experience teaching students with epilepsy

Persons that have epilepsy, like me, can have things called seizures. Some seizures might only seem like I am daydreaming, and my eyes might flutter a little. Other seizures can look quite scary as I may seem to faint, fall down, shake, and maybe drool or even wet my pants. Even though it may look like I am in pain, I really am not feeling bad and will probably not remember what happened.

Epilepsy has to do with my body's connection to my brain. When I have a seizure, the messages to my brain get scrambled and my body loses control. Many people with epilepsy take certain medicines that help to control having seizures. Some people even have a sensor put into their body next to a certain nerve that they can turn on with a magnet if they feel that a seizure is coming. Most of the time seizures last for only a minute or two and then I return to normal except I may be tired and need to rest for a while. But if the seizure lasts more than five minutes, I may need to have more medicine or go to the hospital.

The main thing is to remember what to do and not do if you see me having a seizure. First of all, do NOT try to hold me down or put anything into my mouth. Remember I cannot control what my body is doing, and I don't want you to be hurt. You can move things away from me or put something soft by my head. Please stay calm and stay with me. A good friend will let me know that I will be all right and even help clean up after the seizure is over. Some of the animals at the Critter Barn may have seizures and some animals are trained to help people that have seizures. It is not easy knowing that I might have a seizure, but I am happy about helping you to learn about them.

Let Me Teach You About Muscular Dystrophy

Written by Trinity student Brenna Groenewold based on research and lessons learned from John Terpstra's book, "The Boys: Or, Waiting for the Electrician's Daughter"

Growing up, I felt like any other child. My childhood was full of laughs, dreams, and the occasional bumps and bruises. When I was diagnosed with muscular dystrophy, all I knew was that my muscles had a disease that was going to affect my mobility. I also knew that the signs and symptoms could vary in severity, but I didn't ever imagine what it would truly be like.

When I first started going to school, my muscles began to struggle with holding my body like they used to. This made me fall pretty often without any way to balance. Other kids thought it was funny, but I had a hard time understanding why this might be happening to me. Falling over was just the beginning. As I grew, my ability to move became less and less. During my teenage years I was only able to move my fingertips and turn my head slightly. To get around, I used a wheelchair. Even though I spent time in bed most of every day, I was grateful for every opportunity I received. I needed help with most everything and sometimes I feared for my life, knowing that the heart is the strongest muscle in the body and that I needed it to keep beating. Thankfully, my heart was not alone.

Surrounding me every day, I felt love, community, prayer, spirit, courage, hope in things not seen, and a trust of God that kept me going. I look different than you because of my floppy muscles and use of a wheelchair, but I am the same on the inside. I have a heart and a soul, and humor keeps me feeling lighter. There is nothing to be ashamed of about my conditions or how my life is different than yours.

John Terpstra wrote a book called "The Boys: Or, Waiting for the Electrician's Daughter" about his relationship with his three brothers-in-law, all of whom had muscular dystrophy. He recalls one day when a neighbor, a man the boys referred to as Beer Belly Bob, made the comment that, "It's a real shame about those boys." Although this may be a realistic and understandable comment, John admits that he has a hard time processing it after having gotten to know these amazing siblings. There was nothing to be ashamed of as they were simply GRAND. Knowing that the Critter Barn has taken steps to allow me to enjoy all that they have to offer - also makes me feel grand.

Let Me Tell You About Quadriplegia

Written by Renee Bondi, a person with quadriplegia

I am a mom, wife, sister, daughter, aunt, godmother, teacher, author, and singer. Oh yes, I also am a wheelchair user. Why am I in a wheelchair? Quadriplegia means all four (quad) limbs of my body are paralyzed – both legs and both hands. When I broke my neck, a piece of my neck bone jammed into my spinal cord. Think of the spinal cord as a garden hose going down the inside of my body from my brain to my feet. Have you ever bent a hose all the way so it stops the water from flowing? A damaged spinal cord is like that. When I think, “I want to stand up and run across the room.” This thought gets stuck in a traffic jam in my neck not allowing the message to get all the way down to my feet.

Using a wheelchair sometimes can be nice because I can go fast, but using it while out with my friends can be frustrating because I want to play sports or dance. Before my injury, I was a singer, but when I became paralyzed, I lost a lot of the power to sing because my diaphragm didn't work as well. A friend put weights on my stomach and told me to take really deep breaths. As I breathed deeply, the weights would raise up. My diaphragm was lifting weights, strengthening my diaphragm, giving me more vocal power! My voice started getting stronger and I ended up recording six albums and traveling all over the country as a singer and speaker.

Some ordinary tasks can be challenging. My caregiver often puts a special brace on my hand that holds a pen with an eraser on the end. When I push the eraser across the paper, it turns the page. I love to read, so I'm happy my occupational therapist helped me get this special brace. I have another hand brace that holds a fork or spoon in it so I can feed myself yummy salads and even ice cream.

How do I write if my fingers are paralyzed? I am dictating this essay with a voice activated software called Dragon NaturallySpeaking. I have to correct it sometimes, but it really is amazing how well it works. I even wrote two books using this software! How do I go to the grocery store, movie theater or church? We have a minivan that with the push of a button the door opens, and a ramp comes out from under the floor. I roll up the ramp and sit right next to my husband as he is driving. This makes me feel normal.

When people hold a door open for me, I really appreciate it. When people look me in the eye to talk to me, rather than staring at my wheelchair, I realize they are wanting to get to know me. I appreciate that, too. After all, my mind, creativity, and sense of humor still work! So next time you see me at the Critter Barn, please come over to say hello! Maybe we can even sing a couple songs together!

www.reneebondi.com

Let Me Tell You About PKU

Written by Trinity Christian College Professor Emeritus, Dr. Pete Post based on research and dedicated to Kyle Gallagher, a person with PKU who guest lectured in Dr. Post's courses

The first test that I ever took was only a day or two after I was born. I think that you may have had this test too. A drop of blood was taken from my foot and tested for phenylketonuria or PKU. I do not remember if it hurt but I am glad that the hospital did this because it showed that I did have PKU. We needed to find this out right away because if I did not start my special diet the PKU might have affected my brain and made it hard to learn like others my age.

My PKU means that my body cannot handle foods high in protein such as meat, fish, milk, or nuts. You might say that many foods are poison for me, so I need to be very careful – no hamburgers or pizza for me. But if I eat the right things that are low in protein like vegetables, fruits and even the fries at McDonalds, I will do just fine. I also need to take some special minerals and vitamins to keep me as strong as anyone.

Since they caught my PKU early I am doing fine in school and love field trips. I don't need much special help, but true friends would never tease me about what I need to eat or try to tempt me to eat things that I really should not have. For kids that have PKU that was not caught, they may need more time to learn and teachers, with help from us kids, can make sure that they also do their best. Since I have my special diet, I really like to learn about how plants grow and what the animals at the Critter Barn like to eat as well.

Let me tell you about Rett Syndrome

Written by Amber Catford, a sibling to a person with Rett Syndrome

Introduction by Trinity Professor Emeritus, Dr. Pete Post

Rett syndrome happens only to girls. Girls who have Rett syndrome have intellectual impairment, problems walking and communicating, and seizures. Most lose the ability to use their hands purposefully. This is what Amber Catford-Robinson had to say about having a sister that had Rett Syndrome in the book, "Views from Our Shoes." With Universal Design, the Critter Barn would delight to welcome all children with disabilities and their siblings.

An excerpt from "Views from Our Shoes"

My sister's name is Naomi, and my name is Amber. I am five and she is three. We think Naomi has Rett syndrome and some other things.

I like to play with Naomi. If she cries, I can make her laugh by laughing! Naomi has an electric piano. Sometimes I move her arms and help her push the keys to make music. I love to play with her. She loves me best of all.

Naomi has a g-tube. A g-tube is a tube that goes into her tummy so she can drink a special kind of formula. Naomi throws up a lot, and I don't like it when she throws up. When my parents are dealing with her, I'm alone and nobody pays attention to me. It's like I'm not even there. If she did not have this sickness, I would like it much better.

Last year I went to Camp Me and My Family and met some new friends who have sisters and brothers with special needs. We had a lot of fun! One girl had a brother who has a g-tube and was in a wheelchair and couldn't talk, just like Naomi.

If Naomi didn't have special needs, I would be much happier. Thinking of all the things we could do together fills up my brain with thoughts. We could do all sorts of things – play ball, make up games together, or play in the hot tub.

I worry about Naomi sometimes. When she is in school, I wonder what she is doing and if she is having a good day. When I get home from school, I can't wait to see the art she did at school.

On weekends I like friends to come over to play and meet Naomi. I wish she will get better sometime in her life. But I do not wish she will get better in days, weeks, months, or years. I just wish she would get better the minute I wish it.

Let Me Tell You About Tourette Syndrome

Written by Trinity student Matteo Tancredi based on research

People that have Tourette syndrome, like me, often have tics. Tics are something that I cannot control, and they can cause uncontrolled sudden, repetitive movements in my muscles. When these happen, I might blink my eyes a lot, move my head around, shrug my shoulders quickly, or move my arm or hand around.

I might also have vocal tics like constantly clearing my throat, sniffing, or humming. Some people with Tourette syndrome might have more complex vocal tics that can include saying things do not mean to or repeating other people's words after they say them like an echo.

During more stressful situations, my tics can occur more frequently or for longer periods. Although it may look like I am in pain because I have different facial expressions or jerks sometimes from my tics, they do not always cause pain for me. Sometimes I may accidentally hit my hand against something and that might hurt a little, but I am usually okay. At other times, I may just shake my hand or make a movement with my jaw.

There is no cure for my Tourette Syndrome, but my doctor can prescribe me medicine to help control my symptoms. Tics can sometimes make it difficult for me at school or my daily life. At school, during class time I might need to have breaks from learning to help relax and not get stressed out. You might be afraid if you saw my tics during a trip to the Critter Barn, but you don't have to worry. Just remember that I can't control my tics and I am just having a fun day looking at the animals. If you see me have a tic, just ignore it. Do not laugh or make fun of me or imitate my tics. Once you really get to know the real me, the tics will become unimportant.

Resources

Cesal, L., Lenart, C. J., & Post, P. (2015). *They said we couldn't*. Illinois?

Epilepsy Foundation. (n.d.). <https://www.epilepsy.com/>.

Higashida, N. (2021). *Reason I Jump: One boy's voice from the silence of autism*. S.l.: SCEPTRE.

Hasan, S. (2016, October). KidsHealth.org search results : Health - NEMOURS KidsHealth. Retrieved May 04, 2021, from <https://kidshealth.org/en/kids/k-tourette.html>.

Hearing loss. (2020, October 19). Retrieved May 04, 2021, from <https://www.cdc.gov/ncbddd/kids/hearing.html>

Meyer, D. J. (1997). *Views from our shoes: Growing up with a brother or sister with special needs*. Bethesda: Woodbine House.

Mosca, J. F., & Rieley, D. (2018). *The girl who thought in pictures: The story of Dr. Temple Grandin*. New York: Scholastic.

Terpstra, J. (2006). *The boys, or, Waiting for the electrician's daughter*. Kentville, N.S.: Gaspereau Press.

The NPKUA's mission is to improve the lives of individuals with PKU and pursue a cure.
NPKUA. (n.d.). <https://www.npkua.org/>.

Williams, S. (2005). *Reflections of Self*. The Gray Center.

This booklet represents a collaboration between the *New Critter Barn* and Trinity Christian College. For more information, see websites below.



trnty.edu



critterbarn.org

