the not Forgotten, 1st Hope Lives Here

Newsletter

August 2026

BACK to SCHOOL

In This Newsletter You Can Expect:

What's in Their Backpack?

A new school year often begins with a backpack.

We fill it with pencils, folders, notebooks, crayons, headphones, communication devices, sensory tools, and all the things the school supply list tells us our children will need. But when our kiddos walk through those school doors, their backpacks carry so much more than supplies. They carry pieces of where they have been, what they have learned and what they have overcome.

Pack the Progress
Maybe last year your child learned to ask for a break. Maybe they found a way to communicate, "I need help." Maybe they made a friend, tried something new or tolerated a difficult transition.

Progress does not disappear because the calendar changes. Every skill gained, every challenge worked through, and every small victory becomes something they can carry into the next classroom.

Pack What Works
Our children teach us so much about what helps them thrive. The visual schedule that made the day easier. The sensory item that helped during overwhelming moments. The song that made transitions smoother.

Those discoveries belong in the backpack, too. A new school year does not mean starting completely over. We can bring forward the strategies, accommodations, supports, and knowledge that helped our children before.

Pack Their Voice
Whether your child communicates through spoken words, AAC, sign language, gestures, behaviors, facial expressions, or another form of communication, their voice belongs in every room they enter.

Pack their likes and dislikes. Their strengths. Their interests. The things that bring them joy. The things that overwhelm them. The ways they tell us yes, no, I need a minute, I don't understand, and I'm ready.

Leave a Little Room
Not everything has to be packed before the first bell rings.

Leave some room for the things your child will collect along the way—a new friendship, a new skill, a favorite teacher, greater independence, a discovered talent, a moment of courage, or an accomplishment no one saw coming. There may be difficult days. There may be things we unpack, rearrange, or decide we no longer need. That's okay, too. A backpack is meant to travel.

Before you zip that backpack closed, tuck in one more thing: Hope.

So, as we begin another school year, remember: our kiddos are not walking through those doors empty-handed. They are carrying every lesson, every victory, every person who has poured into them, every piece of progress, and every reminder that they have done hard things before.

The backpack may be filled with supplies, but what they carry within them can sustain them long after the pencils are sharpened and the notebooks are full.

Exceptionality of the Month: Prader-Willi Syndrome

What Is Prader-Willi Syndrome?

Prader-Willi syndrome (PWS) is a rare genetic disorder that affects many parts of the body. It occurs because certain genes in a specific area of chromosome 15 are not functioning normally. PWS can affect growth, muscle tone, metabolism, learning, behavior, sleep, and the body's ability to regulate hunger.

In infancy, babies with PWS often have very low muscle tone and may have difficulty sucking and feeding. As children grow, however, their relationship with food can change dramatically. Many develop **hyperphagia**, an intense and persistent drive to eat that can make it difficult for them to feel satisfied or full. Without appropriate support and supervision, this can lead to serious health complications.

Prader-Willi syndrome affects each person differently. Individuals with PWS may also experience developmental delays, learning differences, short stature, sleep difficulties, behavioral challenges, and other medical concerns. However, with early intervention, appropriate treatment, consistent routines, educational support, and an understanding community, people with PWS can learn, participate in activities they enjoy, develop relationships, and be active members of their communities.

How Does It Affect Lives?

Living with Prader-Willi syndrome can affect everyday life for both the individual and the entire family. One of the most significant challenges is managing hunger and access to food. A person with PWS may continue to feel hungry even after eating an appropriate meal. This is not simply a lack of willpower or discipline—it is a feature of the syndrome that requires understanding, structure, and support.

Individuals may also experience difficulty with changes in routine, emotional regulation, repetitive behaviors, anxiety, or frustration. Learning and developmental needs can affect school, employment, communication, independence, and social experiences.

What Does Support Look Like?

Support for someone with Prader-Willi syndrome often requires a **team approach** and may change throughout the person's life. Helpful support can include:

- Creating consistent routines and clear expectations.
- Providing a structured and supervised food environment.
- Working with healthcare professionals to monitor nutrition, growth, hormones, sleep, and other medical needs.
- Providing physical, occupational, speech, behavioral, and developmental therapies when needed.
- Encouraging regular physical activity that is appropriate for the individual's abilities.
- Providing educational accommodations and individualized learning support.
- Preparing in advance for changes or transitions that may cause anxiety.
- Recognizing that food-seeking and intense hunger are symptoms of the syndrome—not simply behavioral choices.
- Connecting parents and caregivers with respite, support groups, resources, and other families who understand the journey.

Did You Know?

A surprising characteristic of Prader-Willi syndrome is that **feeding challenges can completely change as a child grows.** Babies with PWS often have such weak muscle tone and difficulty sucking that they may need special feeding assistance. Later in childhood, many develop hyperphagia—an intense, persistent drive to eat and difficulty feeling full. Understanding this change can help others recognize that the food-related challenges of PWS are part of a complex genetic condition and require compassion, planning, and appropriate support—not judgment.

For more information about the Exceptionality of the Month: Prader-Willi Syndrome, please research the following websites:

Foundation for Prader-Willi Research
https://www.fpwr.org/what-is-prader-willi-syndrome

Mayo Clinic
https://www.mayoclinic.org/diseases-conditions/prader-willi-syndrome/symptoms-causes/syc-20355997

IN THE SPOTLIGHT: PEOPLE THAT INSPIRE

Samar Waqar
Founder & Executive Director, Kind Theory

At The Not Forgotten 1st, we are continually inspired by individuals who use their personal experiences to create meaningful change for others. This month, we are honored to shine a light on Samar Waqar, Founder and Executive Director of Kind Theory.

As a neurodivergent individual and parent of neurodivergent children, Samar understands firsthand the challenges that many individuals and families face while navigating a world that is not always designed with them in mind. Rather than allowing those challenges to define her journey, she transformed them into a mission to educate, advocate, and build a more inclusive community.

Through Kind Theory, Samar and her team work to increase understanding of neurodiversity, accessibility, and disability rights by centering the voices and lived experiences of neurodivergent individuals. Their work is helping schools, organizations, employers, healthcare providers, and communities better understand how to create environments where people can thrive—not simply fit in.

What stands out most about Samar is her belief that meaningful support begins by listening to those who live the experience every day. She recognizes the power of community, understanding, and shared knowledge, and she continues to use her voice to help others find theirs.

At TNF1st, we often say that every individual deserves to be seen, heard, and valued. Samar's work reflects that same belief. Her commitment to inclusion, accessibility, and human dignity is creating opportunities for countless individuals and families and reminding all of us that disability rights are human rights.

Be a Beacon of Hope: Ways You Can Help

There are many ways you can help, whether you have time, resources, or simply the desire to make a difference. Every act of kindness, no matter how small, matters to the families and individuals we serve.

Volunteer: Your time and energy are a gift.

Spread the Word: Share this newsletter and help raise awareness in your community.

Donate: You can donate to our cause. Your generosity ensures that individuals with exceptionalities and their families are never left behind. When you give, you join us in building a future where families feel supported, included and empowered.

https://www.tnf1st.org/donate

No matter how you choose to get involved, know that you are making a direct impact on the lives of families who have often felt forgotten. You are helping us affirm the individuals and their families that they are not on this road by themselves, and their presence and their voices truly make a difference.

Operation “No One Forgotten” Pop-Up Is Coming to Dallas!

We’re excited to announce that Operation “No One Forgotten” is headed to Dallas on Saturday, December 5, 2026, from 10:00 a.m. to 2:00 p.m.!

After an incredible day of connection, resources, support, and hope at our first Pop-Up in DeSoto, The Not Forgotten 1st is preparing to do it again—this time bringing families, trusted organizations, professionals, and community partners together in Dallas.

Operation “No One Forgotten” was created to help individuals with exceptionalities and their families connect with resources that address real areas of concern, including education, employment, housing, healthcare, transportation, transition support, and more. Families will have opportunities to ask questions, make connections, and discover possible next steps—all in a space created with them in mind.

So, save the date and register today! Although our Dallas location will be announced soon, family registration is now open. Scan the QR code on the Save the Date or visit www.tnf1st.org to register.

We can’t wait to welcome families for another special day of resources, connection, support, and hope—and to remind our community that no one is forgotten.

December 5 is coming. Dallas, we’ll see you soon!

Community in Motion Highlights

Community in motion is what happens when purpose moves beyond conversation and becomes action. At The Not Forgotten 1st, we believe meaningful change happens when families, organizations, advocates, and community leaders come together—sharing resources, opening doors, and creating pathways to support. Each connection strengthens the network surrounding individuals with exceptionalities and their families. These moments reflect our mission at work: meeting families where they are, helping them navigate what comes next, and building a community where no one has to walk the journey alone.

Operation “No One Forgotten” Pop-Up

On August 8, a vision we had carried for months came to life at our inaugural Operation “No One Forgotten” Pop-Up in DeSoto. This was intentionally designed to be different from a traditional resource fair. Families were invited to bring their questions, sit down with knowledgeable community partners, have meaningful conversations, and leave with practical next steps—not simply a collection of brochures.

Throughout the day, families connected directly with resources addressing housing, employment, education, healthcare, transportation, therapies, social opportunities, transition to adulthood, first responders, faith inclusion, and more. With 27 community partner and resource tables, families had an opportunity to explore support based on what they needed.

But the Pop-Up was about more than information. Families received back-to-school supplies, food, household essentials, sensory items, giveaways, and something equally important—the reassurance that there is a community ready to walk alongside them.

We are incredibly grateful to every family who trusted us enough to walk through the doors, every organization that shared its resources, every volunteer who served, and every community partner who helped make the day possible.

As we prepare for our next Operation “No One Forgotten” Pop-Up, we carry this first one with us—the conversations, the connections, the lessons learned, and most importantly, the families.

Community in Motion Highlights

We are also deeply grateful for the many opportunities to engage with our community this summer—from Frisco Flyers' Special Olympics, to Take A Step's "What's Next Event for Special Needs Families", Special Strong's Meet-Up, Tour of Northwood Church's Multi-Ability Ministry, Texas Legends' Legendary Ladies Networking, Tour of Texas Native Health, and LifePath Systems' Quarterly Parent Community Meeting.

Every event reminded us why we do this work. Each conversation, connection, and new partnership deepened our commitment to walking alongside families, listening to their needs, and helping build a community where individuals with exceptionalities and their families feel seen, understood, welcomed, and equipped with the resources they need to move forward with confidence and hope.

Community Events

12
SEP

High 5 for Hope

Saturday, September 12, 2026
9:00am
Johnny Broyles Nature Trail, Little Elm, TX

high5forhope.com

Join us for High 5 for Hope, a family-friendly Fun Run and Walk supporting children with special needs and the families who love them. Come move, connect, and enjoy a meaningful day with our community.

Click Link for More Information

19
SEP

Bridges to Bright Futures: Building Knowledge and Community

Saturday, September 19, 2026
8:30am-2:00pm

https://tinyurl.com/BTBF2026

Topics: Breakout sessions will feature a variety of topics important for families of students with disabilities. Attendees will also hear information and strategies from other parents and a youth panel.

Click Link to Register

24
OCT

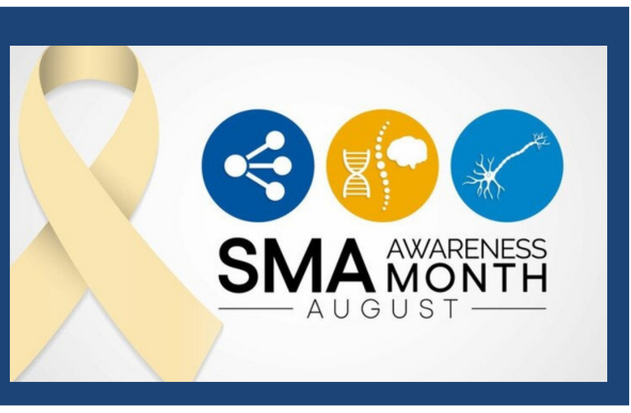
2026 Sneakers & Spaghetti 8th Annual Fall Social

Saturday, October 24, 2026
1:00pm-4:00pm
The Potter's House Dallas

Save the Date
SNEAKERS, BOOTS, & BLING: Step Into Shine
info@tphidd.org

Awareness Month

As we continue forward, we recognize the awareness observances that bring attention to the lives, challenges, and strengths within the exceptionalities community. These moments offer an opportunity to deepen our understanding and to move with intention—choosing empathy, choosing inclusion, and choosing to stand alongside families in ways that truly matter. Each observance is a reminder that when we grow in awareness, we also grow in our ability to care well.



For July:

Anniversary of the Americans with Disabilities Act (ADA)

July 26 marks the anniversary of the Americans with Disabilities Act (ADA), a landmark civil rights law signed in 1990 that protects individuals with disabilities from discrimination and promotes equal access to employment, transportation, public spaces, government services, and more. The ADA has helped remove barriers and expand opportunities for millions of Americans with disabilities. This anniversary is both a celebration of progress and a reminder that the work toward greater accessibility, equity, inclusion, and independence continues.

Disability Pride Month

Disability Pride Month is observed throughout July to celebrate individuals with disabilities and recognize disability as a natural part of human diversity. It is a time to honor the history, achievements, experiences, and contributions of the disability community while challenging stereotypes, stigma, and ableism. Disability Pride encourages individuals to embrace who they are while reminding our communities of the importance of accessibility, inclusion, representation, and ensuring that people with disabilities have opportunities to fully participate in every area of life.

For August:

National Accessible Air Travel Day

Observed on August 20, National Accessible Air Travel Day raises awareness about the importance of safe, dignified, and accessible air travel for individuals with disabilities. Travelers with disabilities can encounter barriers throughout the flying experience, from navigating airports and boarding aircraft to seating accommodations and the handling of wheelchairs and other mobility equipment. This day encourages greater awareness, advocacy, and continued improvements so that everyone has the opportunity to travel with dignity, safety, accessibility, and independence.

Spinal Muscular Atrophy Awareness Month

August is Spinal Muscular Atrophy (SMA) Awareness Month, a time to increase understanding of this rare genetic condition that affects the motor nerve cells responsible for voluntary muscle movement. SMA can cause progressive muscle weakness and may affect a person's ability to walk, eat, breathe, and perform other daily activities. Advances in treatment and research have brought new hope to individuals and families affected by SMA. Raising awareness helps encourage early diagnosis, continued research, greater accessibility, and support for individuals with SMA and their families.

Always Here For You

Hello Friend,

Back to school is here again.

The backpacks have been packed. Supplies have been purchased. Schedules have been adjusted. Teachers have been met, paperwork completed, and you have probably gone over every possible scenario in your head more times than you can count. You have done everything you can to prepare your child for another school year.

But this year, I want to talk about you. The parent. The guardian. The caretaker. The person who holds so much together behind the scenes.

I know dropping your child off at school—especially when you have a child with an exceptionality—doesn't always come with a big sigh of relief. Sometimes, it comes with anxiety. Will they have a good day? Will they be understood? Will someone recognize when they are overwhelmed? Will the phone ring before I even make it home?

I get it. When you have spent years being "on," it can be difficult to turn that off simply because your child is at school. Your body may be at home, but your mind is still right there in the classroom with them.
So, this school year, I want to encourage you to start small.

Give yourself ten minutes.

Ten minutes to sit and breathe. Drink a cup of coffee while it's still hot. Enjoy the quiet. Read a few pages of a book. Pray. Take a walk. Close your eyes. Or simply do absolutely nothing. Tomorrow, maybe you give yourself fifteen minutes. Eventually, those few minutes may become an hour.

Baby steps.
Go to breakfast. Have lunch with a friend. Take a nap without apologizing for it. Watch a movie. Get a massage. Join a support group. Sit somewhere peaceful. Go home, put your feet up, and enjoy the beautiful sound of absolutely nothing. Whatever fills your cup, give yourself permission to do some of it.

And please remember:
Taking care of yourself does not mean you are abandoning your child.

Resting doesn't mean you love them any less. Enjoying a moment for yourself doesn't make you selfish. It simply means you are taking care of you so you can continue taking care of them.

We pour so much into our children. We advocate. We research. We make calls. We attend meetings. We fight battles no one knows about and celebrate victories others may never understand. Sometimes, we forget that the person doing all of that needs care too. You are worth the ten minutes. You are worth the rest. You are worth the quiet.

So, while your children begin another school year, I am giving you a little homework too:
Do one thing for yourself each day. It doesn't have to be big or cost anything. Just start somewhere.
Breathe. Rest. Recharge.

From one parent to another, I am cheering for your children this school year—but I am cheering for you, too. And as I am praying for your children this year, I am praying for you.

Always here for you,

Portia
"Come to me, all you who are weary and burdened, and I will give you rest." (Matthew 11:28)

Thank you for reading!

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