the not Forgotten, 1st

Hope Lives Here

Newsletter

April 2026

In This Newsletter You Can Expect:

Moving Beyond Awareness

Spring is change and movement.

What once felt still begins to shift. What was overlooked begins to come into view. There is a stirring—a call forward—reminding us that change does not happen by simply noticing, but by what we choose to do next. And just like spring, awareness may be where it begins... but it was never meant to be where it stays.

Awareness is the Beginning

April is Autism Awareness Month—a time when conversations begin, understanding is introduced, and many are seeing, maybe for the first time, the experiences of individuals with exceptionalities and their families.

But awareness alone is not enough.

It opens our eyes... but it does not always change our actions.

Acceptance Changes the Heart

Acceptance is what shifts everything.

It moves us from simply knowing... to truly embracing. It allows individuals to be seen for who they are—not as something to fix, but as someone to value. Acceptance creates space for dignity, for respect, and for love to lead the way.

Inclusion Must Be Intentional

Inclusion does not happen by chance—it happens on purpose.

It is found in classrooms, workplaces, churches, and communities that choose to welcome individuals fully. Not just present, but participating. Not just invited, but included in meaningful ways that honor who they are.

Accessibility Creates Opportunity

Accessibility removes the barriers that quietly say, “This space was not built for you.”

When we create access—whether through resources, environments, or understanding—we create opportunity. We allow individuals to move freely, to engage confidently, and to experience life without unnecessary limitations.

Belonging is What We All Need

At the heart of it all... is belonging.

It is the feeling of being accepted without question. Of knowing you matter. Of not having to fight for a place, but instead being welcomed into it. This is what families are seeking—not just services, but connection, care, and community.

Exceptionality of the Month: Bohring-Opitz Syndrome

What is Bohring-Opitz Syndrome?

Bohring-Opitz Syndrome (BOS) is a rare genetic condition that affects development from infancy. It is typically caused by a change (mutation) in the ASXL1 gene, which plays an important role in how the body grows and develops.

Children with BOS often have distinctive physical features and may experience developmental delays. One of the most recognizable characteristics is a posture where the arms are bent at the elbows with the wrists turned inward. Because it is so rare, many families may go years without a clear diagnosis, making awareness and understanding especially important.

How does it affect lives?

Bohring-Opitz Syndrome can impact each individual differently, but many children experience:

- **Developmental delays** (motor and cognitive)
- **Feeding challenges** and difficulty gaining weight
- **Low muscle tone (hypotonia)**
- **Seizures** in some individuals
- **Limited or nonverbal communication**
- **Medical complexities**, including increased risk for certain conditions like infections or, in some cases, tumors

For families, the journey often includes frequent medical appointments, therapies, and learning how to meet complex needs day by day. It can feel overwhelming at times—but it is also filled with deep love, resilience, and moments of joy that deserve to be seen and celebrated.

What does support look like?

Support for individuals with Bohring-Opitz Syndrome is most meaningful when it is personalized, consistent, and compassionate. It may include:

- Early intervention therapies (physical, occupational, and speech)
- Specialized medical care with a team familiar with rare genetic conditions
- Nutritional and feeding support
- Communication tools, including assistive or alternative communication (AAC)
- Educational supports and individualized learning plans
- Respite care and emotional support for families

Just as important is community—having people who listen, understand, and walk alongside the family. Because BOS is rare, connection and awareness help families feel less alone and more supported.

Bohring-Opitz Syndrome may be rare, but the individuals and families living with it are not invisible. They deserve to be seen, supported, and embraced with care—every step of the way.

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

ASXL Rare Research Endowment Foundation
https://arrefoundation.org/asxl-related-disorders/bohring-opitz-syndrome-asxl1/
Bohring-Opitz syndrome
https://bohring-opitz.org/bohring-opitz-syndrome-asxl1/

IN THE SPOTLIGHT: PEOPLE THAT INSPIRE

Nagla Moussa

There are individuals whose work is driven not just by knowledge, but by lived experience, compassion, and an unwavering commitment to make things better for others. Ms. Nagla Moussa is one of those individuals.

As the founder of Moussa Autism Consulting LLC and President of the National Autism Association of North Texas, Ms. Moussa has dedicated her life to advocating for individuals with autism and supporting the families who walk alongside them. Her work spans decades—rooted in both professional expertise and personal experience as a mother of a son with autism.

What makes Ms. Moussa's voice so powerful is not only what she knows, but what she has lived. For over 30 years, she has stood in rooms with families—helping them understand their rights, guiding them through ARD/IEP meetings, and ensuring that children receive the support and services they deserve. She walks with families through the complexities of education, therapies, transition planning, and life beyond high school, helping them move forward with clarity and confidence.

Her journey into advocacy was shaped by both personal and community experiences. After a tragic event in her local community in 1995, she felt a deep calling to educate others and to advocate for greater understanding and safety for individuals with autism.

Through Moussa Autism Consulting, she provides families with more than information—she offers a plan. A plan for progress. A plan for navigating systems that can often feel overwhelming. A plan that helps families see what is possible for their child's future. From early childhood through adulthood, she helps connect families to the right resources, therapies, and opportunities so that individuals with autism can thrive in every stage of life.

Ms. Moussa has also served in numerous leadership and advisory roles across Texas, but beyond the titles and accomplishments, what stands out most is her heart. She speaks often about the joy she feels in seeing individuals succeed and families find direction. That joy is evident in every space she enters and every family she supports.

Ms. Nagla Moussa reminds us that advocacy is not just about speaking up—it is about showing up. It is about standing in the gap, guiding with intention, and helping others find their footing when the path feels uncertain. And because of her, families are not left to figure it out alone—they are met with guidance, understanding, and a way forward.

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.

Spring Highlights

This season has been filled with meaningful moments—opportunities to connect, understand, and stand alongside families and community partners. Each gathering reminded us that when we come together with purpose, real impact and lasting change can take root.

Operation “No One Forgotten” Tactical Support for Exceptional Lives

Our Operation “No One Forgotten” Tactical Support for Exceptional Lives meeting was a powerful continuation of the conversations we began at the Hack-A-Thon. Together with families, advocates, and community partners, we leaned into real-life experiences—asking what families truly need and how we can meet those needs in tangible ways. The heart of this gathering was clear: to ensure that no family feels unseen, unheard, or without guidance as we move from ideas into action.

AUsome Moms Autism Resource Fair

The AUsome Moms Autism Resource Fair was an incredible and impactful experience for The Not Forgotten 1st. We had the opportunity to connect with so many families—offering encouragement, sharing guidance, and helping direct them toward meaningful resources while also stepping into our role as Care Navigators with compassion and understanding. With over 80 vendors present, we were also able to build new connections and learn from others who are serving this community in meaningful ways. It was a powerful reminder of how life-changing it can be when families are met with both care and connection.

Spring Highlights

We are also deeply grateful for the many opportunities to engage with our community this season—from the **North Texas Disability Chamber's Community Connections and Disability Inclusion Summit**, to the joy-filled **Especially Needed Eggstravaganza and the City of McKinney's Autism Acceptance Day Celebration**.

We were honored to contribute to learning and inclusion through **The Well Community Church's IDD Workshop** and to be part of the preparation for **United Rock's Climb Fest**.

Each of these moments strengthened our connections and deepened our commitment to showing up, walking with families, and helping create spaces where individuals with exceptionalities and their families feel understood, welcomed, and equipped for the journey ahead.

Community Events

25
APR

AUsome MOMS

Autism Resource Fair

Saturday, April 25, 2026
10:00am-2:00pm
2435 Kinwest Pkwy, Irving, TX 75063-3434, United States
www.facebook.com

Click link for more Information

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EPILEPSY FOUNDATION

Texas Epilepsy Walk - Dallas / Fort Worth

Saturday, May 2, 2026
9:00am-1:00pm
1989 Colonial Pkwy. , Fort Worth , TX , 76110
www.epilepsy.com

Click Link for more Information

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CHILL TEXAS
CHILDREN'S HEALTH INCLUSION LEARNING LEADERSHIP

Autism Society
Texas

Chill Act Dallas

Saturday, May 30, 2026
9:00am-5:00pm
Plano Event Center, 2000 E Spring Creek Pkwy, Plano, TX 75074, USA
www.chillact.com

CHILL ACT brings together trusted providers, therapists, educators, and kids' activity leaders—all in one place—so families can connect in person, ask questions, and discover real support for their children.
Click Link for Ticket Information

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 March:

National Cerebral Palsy Awareness Month

Cerebral palsy is a neurological condition that affects movement, muscle tone, and posture, often caused by differences in brain development before or shortly after birth. It looks different for every individual—some may have mild challenges, while others may need more support in daily life. National Cerebral Palsy Awareness Month, observed in March, shines a light on these diverse experiences and reminds us that individuals with cerebral palsy are capable, resilient, and deserving of inclusion and opportunity. It calls us to move beyond awareness into understanding, accessibility, and support for every stage of life.

World Down Syndrome Day (March 21)

Down syndrome is a genetic condition that occurs when a person is born with an extra copy of chromosome 21. This can impact learning, physical development, and overall health, but it also comes with unique strengths, personalities, and gifts. World Down Syndrome Day is celebrated on March 21 to represent the triplication of the 21st chromosome. This day is about more than awareness—it is about celebrating lives, advocating for inclusion, and recognizing the value and contributions of individuals with Down syndrome in our communities. It's an opportunity to honor the joy, connection, and perspective they bring—reminding us that a more inclusive world is also a more beautiful one.

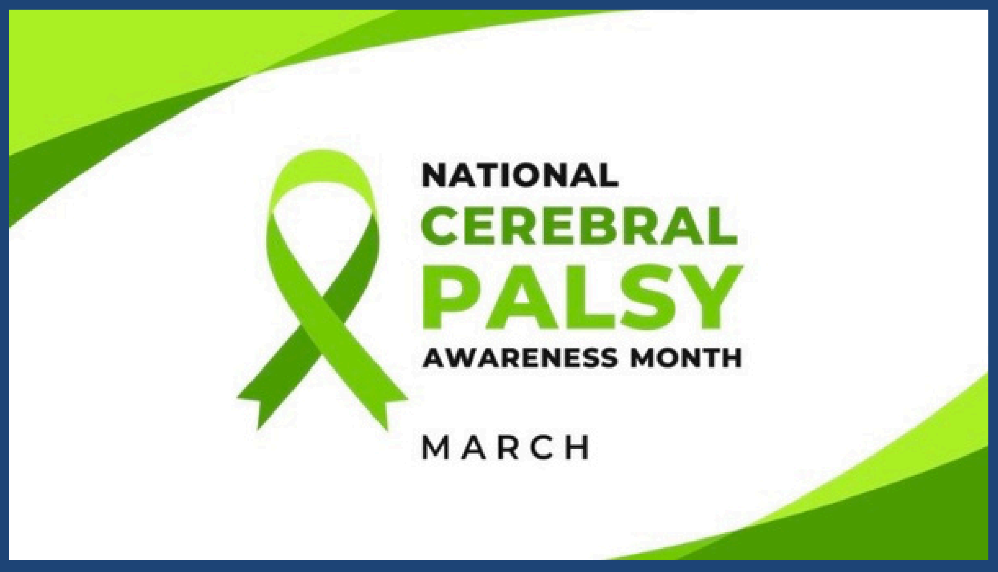
For April:

Autism Awareness Month (April)

Autism, or Autism Spectrum Disorder (ASD), is a developmental condition that affects how individuals communicate, interact, and experience the world around them. Because it is a spectrum, every individual with autism has their own strengths, challenges, and ways of navigating life. Autism Awareness Month invites us to not only learn but to listen—to understand sensory needs, communication differences, and the importance of acceptance. It challenges us to slow down, meet individuals where they are, and embrace ways of thinking and experiencing the world that may look different—but are no less meaningful.

Parkinson's Awareness Month (April)

Parkinson's disease is a progressive neurological condition that affects movement, often causing tremors, stiffness, and balance challenges over time. While it is most commonly diagnosed in older adults, its impact reaches families and communities in profound ways. Parkinson's Awareness Month, observed in April, brings attention to the realities of living with this condition while encouraging research, support, and compassion. It reminds us of the importance of walking alongside individuals and families with understanding, dignity, and care throughout their journey.



Always Here For You

Hello Friend,

We've stepped into another season—another stretch of days filled with both the known and the unknown. And if you're anything like so many of us, there have been moments where you wondered how you would make it through... but here you are.

Still standing.
Still being present.
Still loving with every part of your being.

Walking this journey alongside a loved one with exceptionalities is not always easy to put into words. It's a path filled with questions that don't always have answers, turns you didn't anticipate, and moments that can feel overwhelming. And yet, it is also filled with strength you didn't know you had, love that runs deeper than you imagined, and courage that continues to rise to the occasion. While many of our journeys may share similarities, each story is wrapped in its own experience of the past and present. Each family carries its own rhythm; its own challenges; its own victories—both seen and unseen. And because of that, I can't begin to know the story you walk out daily. But I do understand this...

- There are days when you need support.
- Days when you need encouragement.
- Days when you need someone to simply listen—without trying to fix everything.
- Days when you need to be reminded that you are not failing, even when progress feels miles away.
- And maybe more than anything—days when you just need someone who gets it.

Please hear this clearly and without hesitation: You are AWESOME and you are doing an AMAZING job. The love you give; the advocacy you carry; and the way you show up, even when you are tired, uncertain, or stretched thin—it matters more than you know. Your presence, your consistency, and your care are shaping lives in ways that cannot always be measured in milestones or timelines. You are creating safety. You are building trust. You are making space for growth and belonging. And that makes a huge difference. So today, I simply want to pause and say thank you for YOU.

As we reflect on the awareness and recognition this season brings—from autism to so many other exceptionalities—may it not just be a reminder of what exists, but a reflection of the incredible individuals and families who live their journey every day.

My hope for you, precious heartbeats, and for the families who hold you close, is that the days ahead bring moments of peace, signs of progress, unexpected joy, and a strength that finds you right where you are. In every moment, know this—you are not alone, and you are not forgotten.

Always here for you,

Portia
"It is God Who arms me with strength and keeps my way secure." (2 Samuel 22:33)

Thank you for reading!

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