Western New York Perinatal Bereavement Network, Inc. Newsletter

# Emily's Entry

# By Emily Doring, Executive Director

I want to let you know how blessed I am to be a part of the Western New York Perinatal Bereavement Network Inc. (WNYPBN).

Our former Executive Director, Christine Scott, has given her heart and soul to WNYPBN, growing this organization into what it is today, dedicated to helping any family that has suffered the loss of their baby. Christine leaves behind some very big shoes to fill. She will be missed, but we are excited for her future as she focuses on her health and family. The name and memory of her son, Jacob Wesley Scott, will be remembered as long as this organization exists. We wish her and her family the best! We are grateful to her as she has impacted and touched more lives than she can imagine.

I have been working with WNYPBN since April 2021. When I was recently asked by Christine what my goals for working with WNYPBN were, I jokingly told her that "I want your job!" Little did I know, that really would be my near future. I am humbled to become the next Executive Director. I could never have imagined 9 years ago that this was where my family and I would be.

I would like to share my story and journey with you: My husband of almost 19 years, Todd, and I have 4 children, Preston (17), Kendra (16) and two babies that we lost in 2013 -Baby D and Selah Grace.

The end of 2012 brought a big surprise to our family. We were pregnant with Baby number 3! Everything seemed to be going well, until we got the results of our First

Trimester Screening. The scans looked great, and Baby D's heartbeat to deal with this loss, as I had with was a beautiful thing to hear. A few days later, my OB said that there were some abnormalities in the blood test, but not to worry because it wasn't anything definitive. A few weeks later. I had another ultrasound appointment, but we did not expect to hear the worst news of our lives. The technician didn't even have to tell me. There was no little flutter of a heartbeat on the screen, just silence where once there was that beautiful sound. We had never before been through that type of debilitating, unbearable pain and loss. We lost our Baby (Baby D) on March 11, 2013.

To this day, the week that followed is still a blur, with so many things that happened that were out of our control. The fact that our choices were taken from us, sent me into an even deeper spiral. I was so thankful for my husband. He kept our family together and grounded, while struggling with his own grief. I refused to get help and figured that no one really understood how I was feeling.

In July 2013, we found out that I was pregnant again. It was hard to get excited about this pregnancy when I was so terrified of losing this baby, as well. We got through the First Trimester screening, and everything was good! Just as we were starting to feel hopeful and had gotten past the 15-week mark, we went for another ultrasound. But, the unimaginable had happened again no flutter of a beating heart and no heartbeat for us to hear. We lost Selah Grace on October 30, 2013.

I knew that I couldn't grieve and try Baby D. I decided to get some help, and started going to a Support Group. There I realized that I wasn't alone, and that everything that I was feeling was normal and "okay" to feel. There were other people that truly did understand the loss and grief that I was experiencing. This was the first step towards healing.

Over the next couple of years, I started attending many WNYPBN events. Our family never misses "The Walk to Remember". The first year that we attended, 2014, the tears just rolled down my face as we walked around the path where the babies' name signs were. My heart broke for the families that each sign represented.

I started volunteering with Angel Gowns of WNY, Inc. (AGOWNY) in 2014. It was healing to be able to serve, in honor and memory of my babies. In 2017, I was asked to serve on the Board of Directors. Because of this opportunity, I became more aware of the Infant Loss Community and the large amount of support that is needed.

Throughout the following years, I have had a tender heart towards those that have lost a baby, and I was blessed to begin working with WNYPBN in April 2021. My heart for those in the infant loss community has only grown deeper. When your daily job is your passion, it makes each day more meaningful.

Would I trade this all away to have my babies here with me?

Yes, but I am thankful to have found a place where my heart can continue to heal, a place where my babies will be remembered and honored, and a place where I can personally grow and make a difference in grieving families' lives. My goal and desire is to keep Christine Scott's passion and dedication alive, and to continue to grow and reach more families that are struggling.

I am honored to be your new Executive Director and to grow the Western New York Perinatal Bereavement Network. Remember that you are never alone. We are here for you.

Helping Families ~ Honoring Lives

# IN THIS ISSUE

- **Fundraisers and Events** page 7

# Allote of Appreciation and Thanks

to Christine Scott,
WNYPBN Executive Director
2005-2022

When Jacob Wesley Scott was born, what was meant to be a time of joy and hope became a time of devastating, pain, and grief as Jacob had lost his battle to survive. What added to the devastating pain was that Jacob's Mom, Christine Scott was also gravely ill. Family, friends, and faith rallied as Christine slowly recovered.

Eventually, Christine quietly entered a Western New Perinatal Bereavement Network (WNYPBN) meeting. She listened intently and occasionally, timidly, contributed. Christine definitely had a spark for caring and compassion. When Dr. William Zorn and Fr. Duke Zajak recognized that "spark", they took Christine under their guiding wings. That "spark" grew into a flame. Christine and a few other grieving moms recognized the need in our community for family support following infant loss. The Network previously could not muster up enough support, energy, and time needed to provide the much needed services. Christine moved from volunteer, to part-time employee, and eventually, to a much needed Executive Director. Under Christine's creative, goal-orientated leadership, the WNYPBN grew beyond our greatest expectations. Relationships grew with all WNY hospitals that provided Mother-Baby services. Communication increased with OB/GYN Providers, grief support services and funeral homes. Bereavement packets were sent out, telephone support assistance was established, an active website was developed, and a sibling support program initiated, just to mention a few. Community outreach-support opportunities such as the "Walk to Remember", the "Evening to Remember", a Chicken BBQ, and even a virtual Meat Raffle brought more public awareness and helped support our financial needs. Despite family deaths, changing personal dynamics, illnesses, surgeries, and an International Pandemic, the WNYPBN continued to meet the needs of grieving families, reinventing support activities, and even continuing to grow and maintain financial stability. Staying true to the Network Mission, Christine grew a support system with an active Board of Directors, an army of dedicated mothers, fathers, and volunteers, and a solid relationship with Hospice of Buffalo.

Christine, because of your foresight, the WNYPBN is a strong and stable organization providing support to families at a most vulnerable and confusing time in their life cycle. It is a Network of caring, compassion, and ongoing change. Thank you for sharing your many gifts and talents with all of us. Your thoughtfulness, your kindnesses, and your unending joy and faith have brought sunshine to many, sometimes when they did not think there was light. We love you and will miss your daily presence. God bless you on your future endeavors.



Jan Walkden, President
On behalf of the Board of Directors and
The Western New York Perinatal Bereavement Network

In honor of her tremendous leadership of WNYPBN, the Board of Directors and Staff of WNYPBN presented Christine with a beautiful, personally engraved vase. It is just a small token of what she has meant to the families supported by WNYPBN. Helping Families ~ Honoring Lives



Michael Anthony Anderson

Always, always in our Hearts! Love, Nana and Papa xxxooo

We love you always! Love, Mommy, Daddy, & Mia Parents: Michael and Kelly Anderson

Lilya Raine Arena Hugs to the sky, baby! Mama, Daddy, and little sister, Willow love and miss you.

Parents: Kelly and Michael Arena

Jivae Andrea Báez December 28, 2012

Our beautiful baby girl... we love and miss you every second of every day. Thank you for your sweet baby brother Jamari. All our love all our life. Love, Mommy and Daddy.

Parents: Evelyn and Jarred Báez

March 25, 2021 Benjamin Matthew Brightman

Mommy, Daddy, and Emma love you to the moon and back. "Sweet Dreams Little Man..." Parents: Kurtis and Carrie Brightman

Cecelia Rose Callea

You are our shining moon and shooting star. Thank you for inspiring us and always watching over our family. You are so loved and so missed. Love, Mama, Papa, Thomas, and Matteo

Parents: Tom and Mary Callea

**Rily James Croce** March 8, 2010 over us... now and always. Gabrielle Irene Croce

Baby Croce **December 9. 2013** 

Parents: Lena and Dan Croce

Kayonna Marie Darrell April 27, 2021 Baby Mott Kingston Antonio Darrell

We Love You Always! Not a day goes by that we don't think of you both! You both will forever be in our hearts!! We are sad that you both are not here with us, but it helps knowing that you have each other!! Love, Mommy, Daddy, Big Sisters Elana, Avianna and Savannah. Big Brother Brandon Parents: Ashley Hunt and Wendell Darrell Jr

Juju Dintcheva David February 27-28, 2016 **Baby Dintcheva David** November 17, 2018 August 27, 2019 Frozen Dintcheva David

Miracle Dintcheva David June 29, 2020 Our amazing twins December 2020

Our amazing triplets March 2021

May you all rest in peace and watch over us left behind.

Parents: Elka Dintcheva and Jonathan David

Baby D October 30, 2013 Parent: Lisa Graziano **Selah Grace Doring** 

We carry you in our hearts - Forever & Always, Mommy, Daddy, Preston & Kendra Parents: Emily and Todd Doring

April 5, 2005 Reid Hamilton April 18, 2021

> We miss you more and more each day. We think about you every minute of every day. We know you are watching over us. We love you so very much. Love, Daddy, Mommy, Pierce, Rory, Burke, Reagan, Rilev. and Seamus

September 26, 2009 Parents: Molly and Andrew Hamilton

John Paul Jerebko November 18, 1999

Our little angel! Love, Mom, Dad, Jakob & Jackson Parents: Peter and Lisa Jerebko

**Baby Boy Jonathan** June 8, 2018

I think about you everyday. I wonder what you would look like, sound like. Then I look at your siblings & your nieces & nephews & I can just imagine you would look & sound just like ALL of them. Even though our Lives move on everyday, I miss you more & more. We will never stop thinking about you or Loving you or wondering what milestones you would be accomplishing. Forever Loved & sadly missed by, Mom, Dad, Big Sister's Krysten, Kaytlyn, Kamden, December 16, 2018 Big Brother Klyde, Nephews Kortlnd, Kreese, Delltoh, & Nieces Kenzley & Emileigh Blue Parents: LaRue and Leilan Jonathan

> Marina Kim August 3-4, 2005 Ella Grace Kim June 8, 2007

We love you and think of you often. Please watch

August 3, 2010 Parents: Dawn and Mark Kim

**Bud Charles Mott** September 12, 2005 Theresa Marie Mott **September 12, 2005** October 16, 2018 "Blueberry" Mott January 21, 2014 December 23, 2014

> Miss you with all of our hearts, Theresa, Bud, "Blueberry" and Baby Mott. God knows our pain and sadness. We know that someday, we will see you again. All our love ~ Daddy, Mommy & Allison Parents: Timothy and Beth Mott

October 24, 1992 Michael James Quigley

Miss you more and more! 'Til we meet again! Love, Mom

Parent: Debi Zmuda

May 27. 2000 **Jacob Wesley Scott** 

We love you and think of you everyday! Butterfly kisses, buddy!

Love, Mom, Dad, Thomas, & Mandy Parents: Phillip and Christine Scott

March 11, 2013 Steven James Serrano March 16, 2006

Nicholas Mark Weld

April 25, 2019

'You are my angel, my darling, my star, and my love will find you, wherever you are."

Love, Mom, Dad, Benjamin, Amelia, and Jonathan Parents: Nate and Joanna Weld

Margie Fave Willis May 22, 2019

Parents: Katie and Brandon Willis

**Grace Lee Zimmer** 

April 12, 2012

Until we meet again, fly sweet butterfly, fly! A moment in our arms. A lifetime in our hearts. Love, Mom. Dad. Hunter and Luke

Parents: Donna and Russell Zimmer



Paige Dietz was born to Steve and Stephanie Dietz on May 19, 2021. The family will always remember her brother, David Nelson who was

born to heaven on January 8, 2020.

Parents, Courtney Bajdas and Matthew Barnhardt, welcomed Martha Jean to their family. Martha's big sisters will tell her all about big brother Andrei (October 17, 2011).



"Forget-You-Not" or Safe Arrival to Newsletter@wnypbn.org. Submissions are due by the 15th of the month prior to the issue month. Family and friends are encouraged to provide a submission.

# etter from the By Joanna Weld

I was gifted a copy of Untamed by Glennon Doyle for Christmas from my best friend. As a wellknown author who shares very personal stories about her life, Glennon often receives requests for advice from her readers. In the book, she shared one such request:

"Danielle, a thirty-four-year-old former kindergarten teacher, wrote to me recently. She spends her days and nights watching her seven-yearold die slowly in her arms, tortured by the same disease that killed her first son three years ago. Night and day, she sits by her son's bedside-feeding him, singing to him, soothing him. "I'm broken, Glennon," she wrote. "I don't know what to do."

I wrote back, "Danielle, what is the truest, most beautiful story you can imagine about a mother and her son?"...

She said this: "I've spent the past week considering your question. I can imagine a thousand easier stories about mothers and sons. I can imagine a thousand easier stories about mothers and sons. I can think of a million happier ones. But I cannot imagine a single story truer or more beautiful than the heartbreaking one I'm living now, with my boys" (pp. 68-69).

I reread this part of the book a few times and it stayed with me long after I finished the last page. I thought about the "broken" feeling that is all to familiar. Like Danielle, I'm sure that many of us wish our story had a different ending, but these words helped me to think about the beauty in my son's story and the lessons he has taught me about love and loss.

My husband, Nate, and I found out in late September 2018 that we were pregnant for the third time, after welcoming Benjamin in 2015 and Amelia in 2017. Much to our surprise, at our first sonogram, we found out that we were being blessed with twins. We enjoyed the shock and excitement of this news until the 18 week scan when we were told that there was a problem with the heart of "Baby A". After visiting a Pediatric Cardiologist, we were given the devastating diagnosis of Hypoplastic Left Heart Syndrome, a congenital heart defect in which the left side of the heart does not form correctly. We were suddenly faced with several very difficult decisions. Would we put our newborn through a very risky and invasive surgery, or welcome him into the world and let him pass away without medical intervention? If the first surgery was a success, he would require at least two more to complete

the reformation of his heart in order to allow the right side to compensate for the missing left side. And even if he made it through all three procedures, he would likely need a heart transplant in the future.

Upon finding out that both babies were boys, we settled on the names "Jonathan" and "Nicholas." Around this time, our oldest son, Benjamin, was learning about St. Nicholas in school and kept referring to his brother as "St. Nicholas." As soon as we found out about Baby A's heart condition, we knew that "Nicholas" was the right name for him. We extended our prayers to St. Nicholas, the patron saint of children, in hopes that he would come through with a miracle for our precious boy. In future newsletters, I would like to devote

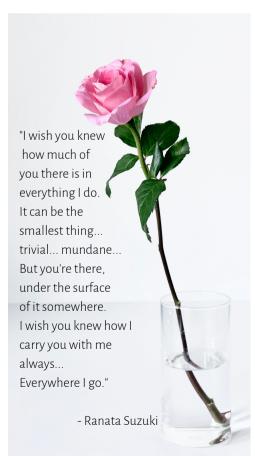
At 31 weeks, our final hopes were shattered when we were told that Nicholas had developed Hydrops. Since his heart was already failing inside of me, he was no longer a candidate for surgery. We had to begin imagining a life without our precious boy. He would not be coming home with us and we would never get the opportunity to watch him grow up alongside his twin and other siblings. We had to face the impossible reality that we would be forced to live the rest of our lives in grief for the part of our heart that would always be missing.

At 34 weeks, On Thursday, April 25th, 2019, Nicholas was born alive at 4:35pm. He was immediately placed in his Daddy's arms and held up close to my face on the operating table. I kissed his sweet lips over and over again as I tried to memorize every feature of his perfect face, every curl of his wispy blond hair, and the precious sound of his weakened cry. I whispered sweet words to him, trying to fit in a lifetime's worth of "I love yous." We were blessed to have him on this side of heaven for thirty minutes and I was able to experience my twins side by side for the first and last time. I held them tight and they held each other's hands as God called Nicholas back.

Now that we are approaching the three-year mark, I have started to find peace in the knowledge that Nicholas's purpose was to be an angel and for his brief appearance in this world, he chose me to be his Mommy. He is a constant presence in my life in the things I can't otherwise explain... songs on the radio, bluebirds around our house, pennies with his birth year. His twin, Jonathan, has a special sparkle in his eye and I know that light is Nicholas shining through.

While I would do anything to have Nicholas here and watch him grow up alongside his siblings, and especially his twin, I recognize the beauty in the intentional love that I give to him. In the ordinary moments with my living children which I don't take for granted, I have to seek out time to devote to Nicholas; to mourn the ways he is gone and find the ways he is still with me. Although my relationship with him looks different, I am constantly in search of ways to mother him and involve him in the chaos of everyday life. I am honored to take over as editor of this newsletter as one more way to honor my angel, and your angels as well.

space to allow for the sharing of beautiful stories from other families. If you are interested in sharing your story, please email Newsletter@wnypbn.org. If there is anything else you would like to see in this newsletter, please feel free to email me with suggestions.



# ara's lage By Tara Petty, LMSW

As we go into the start of the third year of the worldwide pandemic, I think we can all agree the world has changed significantly, including how we access support. One thing that continues to be a constant in this ever changing world is loss, and the grief that follows. Please know that as an agency, we continue to provide support to families who have lost a baby, including our virtual support groups.

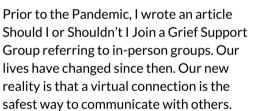
The goal of these groups is to provide a safe space for families to support each other through their loss. The groups are intended to be a peer support, allowing families an opportunity to be seen and to share their experience. Please know that you are not alone as you grieve your loss.

If you are interested in our virtual support groups, we currently have two options available, one for fathers only and one for all parents. Our Fathers' Tiniest Angel group meets on the second Tuesday of each month at 6pm and our original Tiniest Angels for all parents meets on the third Tuesday of each month at 6pm. If you are interested in attending, please email tara@wnypbn.org for the Zoom links.

While many things may look different as we start 2022, one thing that remains is our commitment as an agency to support families through their grief. My hope for you reading this is that you will have access to the support you need to help you, wherever you are in your grief journey.

## **Virtual Grief Support Groups Provide Connection**

What You Need to Know About Participating in One by Nan Zastrow



My original article was all about getting the courage to walk through the door and sit down among strangers to share your inner most thoughts and feelings as you struggled to heal your grief. In the event of the Pandemic, that strategy has changed because we have gone from in-person groups to virtual connections. The fear doesn't lie in walking through the door and sitting down among strangers. The new fear feels different. It's about revealing yourself in front of a camera, in the privacy of your home, still among strangers. However, you may be feeling lonely and secluded because there aren't other participants sitting next to you that parallel the emotions you are feeling.

You would think that would be an inviting atmosphere to those once reluctant to join an in-person group. However, it has brought about a new set of circumstances that still makes the griever hesitant to give into the world of virtual connection.

To address these lingering fears, I've put together a primer of what you might expect in a virtual grief group setting. These points follow the outline of my original article.

Virtual grief groups are only for those
who are tech savvy. On the contrary,
most of us were beginners the first time
we clicked on a "link" to connect with
others. This includes the facilitators.
Virtual has crossed all professions.
Lawyers, physicians, CEOs, and other
high-profile positions are all in the
same predicament of learning for the
first time without aid of secretaries and
technical support. Following the slogan
of the Pandemic, "we are all in this
together." Once you've done it, the next

time gets easier.

- Group dynamics may differ. Nothing has changed there. Virtual connections include individuals with varying degrees of loss and unique loss experiences. What has changed is the ability to connect with people from distant cities and states that you wouldn't have otherwise. And guess what, they feel just like you. We are all in this together.
- Virtual grief groups are not formal therapy or professional counseling sessions. These groups are for mutual support among individuals going through loss –as a place to share experiences and learn. Virtual groups are not a place to work through the complications of grief or resolve the mental or physical ailments resulting from loss. Just a place to validate how you feel and know that you are not alone.

- anonymity, if you prefer that. Some people may feel anxious or embarrassed and that is why they choose not to join any group. Perhaps their losses carry stigmas, such as homicide or suicide, or drug overdoses that they don't want revealed. Men often prefer this too as they don't wish to discuss loss openly. Let your host know that your camera and microphone will be off, and you may remain silent or speak only at will.
- Virtual groups do provide some of the same benefits as an in-person group such as:
  - Not just a place to vent about your sadness, your uncertainty, your fears, and your shoulda, woulda, and coulda thoughts. It's a place to learn how to replace these insecurities with action plans to help you move past your hardest moments.
  - Allow you to voice your regrets and acknowledge outbursts of anger and guilt. After all, these are real. You are protesting how loss has changed your life. These oftenhidden emotions of grief can be uncovered and neutralized with positively reframing your emotions.
  - A place for stories and memories.
     After all, it's the positive memories that remain long after the pain of grief. They are the keepsakes that honor the lives of our loved ones.
     Though some memories may fade, others will continue to bring you peace.
  - Share your feelings without judgement. We don't compare losses as no one can determine that his or her loss is more significant than another's.
  - Help you understand that familial and social relationships are often misunderstood following a death.
     While any support group is not the place to resolve your problems, it can give you a new perspective on how to build the peace.
- Virtual groups provide the same kind of emotional support, education, and knowledge that an in-person group would provide.

- Virtual groups invite and respect the role of all religions and spirituality in grief. These are the core values we honor in life. They play an important role in accepting, healing and moving forward.
- Virtual groups can help you discover choices that may enrich your life in the future. Healing your grief sometimes involves difficult choices, forward planning, and perseverance. No one can "grieve" for you or determine your future path. You will be challenged by changing values and priorities as a result of loss. A grief group can help you recognize your options and share in your discovery that helps you define "Who am I now?"
- Virtual groups, like in-person groups, offer HOPE. Hope thrives when you can set goals motivated by the confidence others give you. You are encouraged to establish goal and given suggestions of a path to achieve the goal. Sharing in these groups motivates participants to grow in self-esteem, establish resiliency, and stability in their lives. Hope is the tool that contributes to our well-being and helps us survive.
- In virtual groups, participants share gratitude for having a connection with others whom they can see and hear, especially when in-person gathering is limited. With permission, group members can decide if they wish to share personal information such as their phone, email, or address with other participants. This is essential for connecting long after the group ends (providing this is a limited week, online group, rather than a continuous support group or drop-in type group.) It's amazing to see friendships and connections made through virtual shared experiences that benefit each other.

Don't shutter or even hesitate when someone suggests connecting virtually with others. Convincing yourself that "this kind of group isn't for you" may be a hasty decision that excludes you from unconditional support and love. Though we can't "hug" physically, every person who

shares is hugged by the sincerity and friendship that radiates across the waves of technology. Technology is not a barrier. It is a bonus that unites and connects. It's here to stay and will thrive for those who embrace it.

Original Article "Should I or Shouldn't I Join a Grief Support Group?" published Vol. 15 #2, Grief Digest magazine. https://centering.org/grief-digestarticles/virtual-grief-support-groups-provideconnection/



# **Tiniest Angels**

**Virtual Coffee Hour** 

### Join us for our monthly support groups

Share your story of loss and find support among other bereaved parents.



For All Parents: 3<sup>rd</sup> Tuesday of the month 6:00pm – 7:00pm For Fathers: 2<sup>nd</sup> Tuesday of the month 6:00pm – 7:00pm

Contact: Tara Petty, LMSW
(RSVP to get Zoom link)
tara@wnypbn.org • (716) 626-6363



# -undraisers & Events





Needs your help!
Check out our Spring 2022 appeal!



Three day online basket raffle April 7-April 9

We need baskets and bidders and a couple volunteers!

Please contact Nadine for info or visit the facebook events page @God Winks Inc

info@GodWinksInc.org 716-510-5259





Please keep an eye on our Facebook page and website for any updates on events.

https://www.facebook.com/WNYPBN
https://wnypbn.org



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### **Our Mission**

The mission of the Western New York Perinatal Bereavement Network, Inc. is to assist the community in meeting the needs of people facing the pain of perinatal death. We promote standards of bereavement care intervention through educational support, community programs and referral services to bereaved parents. The WNYPBN supports an established standard of care following a perinatal loss, regardless of location of where the loss took place.

## **Member Organizations**

Angels Gowns of Western New York, Inc., Baby's Sweet Beginning's Breast Feeding and Maternity Boutique (Lancaster), Brooks Memorial Hospital, Buffalo Prenatal-Perinatal Network, Inc., Catholic Health System (Mercy Hospital, Sister's Hospital, Mount St. Mary's Hospital of Lewiston, Hospice & Palliative Care Buffalo, Inc- Essential Care for Children, Kaleida Health (Oishei Children's Hospital, Millard Fillmore Suburban Hospital), Jones Memorial Hospital, Wilson Support System, Niagara Falls Memorial Hospital, Olean General Hospital, United Memorial Medical Center, UPMC Chatauqua, Wyoming County Community Health Center

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Volume 20, Issue 1 February 2022- May 2022

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WNÝPBN, Inc.

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