



# preemieFAMILY

Vol. VII, Issue 4: April 2020



## A NOTE FROM JENNY

"Prematurity doesn't always end in the NICU." I remember hearing those words as I watched my incredibly fragile micro-preemie through a clear plastic incubator. This isn't the case for all preemies, but for my Joshua, these words proved to be true.

As April is National Autism Awareness Month, this is a great opportunity to promote autism awareness and draw attention to the many preemie families facing an autism diagnosis and to share resources to help navigate this new journey.

- **Autism Speaks** is dedicated to promoting solutions for the needs of people with autism and their families. <https://www.autismspeaks.org/>
- **Preemie Crystal Ball** is working to create a preemie registry to provide better patient outcomes from the NICU to adult years. Join the movement! <https://crystalballhealth.com/>

continued at [premieworld.com/note-from-jenny-2020-Apr](https://premieworld.com/note-from-jenny-2020-Apr)

## STRATEGIC PARTNERS

PROLACTA BIOSCIENCE



[prolacta.com](https://prolacta.com)

KEY TO CP



[keytoop.com](https://keytoop.com)

PREEMIE CRYSTAL BALL



[crystalballhealth.com](https://crystalballhealth.com)

## WANT TO PARTNER WITH PREEMIEWORLD?

Visit [premieworld.com/our-partners](https://premieworld.com/our-partners) to inquire.

## AFTER THE NICU

As we all have learned, prematurity is a life-long journey. Babies born prematurely are at higher risk for developing autism spectrum disorder. Here are some helpful tips as you navigate this diagnosis:

- **Speak up:** Our children are dependent on us. When issues arise, this is the time for us to be persistent with our voice and use it on our children's behalf when dealing with medical professionals, when insisting on getting evaluations done, negotiating with insurance companies and advocating for support at school.
- **Be informed:** Advocacy goes beyond speaking up. Stay informed of policies and current events affecting your child. When attending IEP's, make sure your voice is heard when it comes to your child's needs. Remember: YOU are the expert on your child.

continued at [premieworld.com/afterthenicu-2020-Apr](https://premieworld.com/afterthenicu-2020-Apr)



## PREEMIE STORY OF THE MONTH

**KINGSTON JACKSON GARZA**



*"Your baby is not receiving enough oxygen. We'll be lucky if you make it to 32 weeks."*

Words no pregnant woman wants to hear. I had so many questions but couldn't get the words out. This was my third pregnancy. I never had issues with the other two, so why was this happening now?

“ Overcoming obstacles. Kingston Strong!  
- Kindston's Mommy ”

I was only 20 weeks when I heard these words...

continued at [premieworld.com/premiestory-2020-Apr](https://premieworld.com/premiestory-2020-Apr)



## AUTISM MOMS TOGETHER

ONLINE SUPPORT



Jen Barr, creator of Autism Moms Together was inspired by her 10-year old son to create a place for autism moms to go for support.

Jen states, "There is nothing better than sharing our own personal successes and struggles with other autism moms out there. We are all in this together!"

continued at [premieworld.com/autism-moms-together](https://premieworld.com/autism-moms-together)

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## PREEMIE SWAG



It's not just the cool design or perfect fit- our t-shirts help support our organization.

Each shirt is constructed with 100% fine jersey cotton.



## QUESTION OF THE MONTH

Share a frustrating comment someone said to you about your preemie:

@oneinamulligan: So he just has to gain weight, right? And then he'll be like other babies."

@lizzie\_vandenberg: That I was lucky that my child was born at 1 lb, 4.6 oz and that I didn't have to give birth to a "normal size" baby. No it is NOT lucky, we both almost died...

@aria\_alexandra: "Wow! He looks so normal" or "Wow, he looks so healthy" like thanks...opposed to what?"

## NON-PROFIT NEWS

### GRAHAM'S FOUNDATION

Care packages for parents w/ preemies in the NICU

### HAND TO HOLD

Seeking volunteer peer mentors for NICU families



see more at [premieworld.com/npnews-2020-Apr](https://premieworld.com/npnews-2020-Apr)

## WANT TO SEE YOUR NEWS HERE?

Visit [premieworld.com/contact](https://premieworld.com/contact) to inquire.



## WHAT'S NEW?

### BE FEATURED IN OUR MONTHLY NEWSLETTER!



premieworld

Congratulations to **Toni Sophie Hill**, our Preemie Genius winner of the book, *My Preemie Sister is One* by Alhan Rahimi.

Do you have a product, tool, or item of interest to parents of preemies and professionals? We want to highlight your product!

<https://preemie.us/PreemieGeniusForm>



continued at [premieworld.com/WhatsNew-2020-Apr](https://premieworld.com/WhatsNew-2020-Apr)



## PREEMIE GENIUS



### NIC-JUMPSUIT

For that first NICU outfit, look no further than the NIC-JUMPSUIT by Perfectly Preemie

[www.PerfectlyPreemie.com](http://www.PerfectlyPreemie.com)



[premieworld.com/preemiegenius-2020-Apr](https://premieworld.com/preemiegenius-2020-Apr)



## PREEMIEWORLD TAGS

### MILANI JOLIE ALVARADO



“Milani came into this world as a Warrior,” says Grandma.

Milani is 9-months old and brings pure happiness to everyone. She sits up, loves to eat and play with her toys. As an added blessing, she was born on Grandma's birthday!”

Tag us on Instagram before the 15th of the month for a chance to be highlighted!



continued at [premieworld.com/PWtags-2020-Apr](https://premieworld.com/PWtags-2020-Apr)



## PREEMIE FREEBIES

### INSPIRE - COMMUNITY SUPPORT FLYER

Need community support? Learn more about a FREE virtual global community for parents of preemies, 50,000 family strong. Led by Deb Discenza, Preemie/NICU Mom, Head of [PreemieWorld.com](https://PreemieWorld.com)



get it at [premieworld.com/preemie-freebies](https://premieworld.com/preemie-freebies)

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