



WE LOVE WHAT WE DO

Pediatric

# CARE CONNECTION

A PUBLICATION FOR CLIENTS OF BAYADA AND FAMILY MEMBERS



BAYADA Pediatrics Nurse Mat Gunkel, RN

## The COVID-19 Vaccine: What You Need to Know

BAYADA is committed to providing home health care services with the highest professional, ethical, and safety standards. Part of this commitment includes our comprehensive Infection Prevention Program, which provides the highest standards of infection prevention practices as recommended by The Centers for Disease Control and Prevention (CDC).

Our clinicians pre-screen for COVID-19 before engaging in client care and abide by BAYADA's required Personal Protective Equipment (PPE) standards that exceed standard precautions for the care of all clients. That is why your child's BAYADA clinician is wearing both a surgical mask and eye protection (at a minimum) during every visit or shift.

The COVID-19 vaccine is another layer of protection, and we are offering pathways for our clinicians to be vaccinated. Many BAYADA clinicians have already been vaccinated.

The two vaccines available at the time of the printing of this publication are the Pfizer and the Moderna vaccines, for which the Food and Drug Administration (FDA) has issued an Emergency Use Authorization (EUA). The Pfizer vaccine is approved for those 16 years of age and older, and the Moderna vaccine is approved for those 18 years of age and older.

### Facts about the vaccine and dosage/administration:

- The vaccine cannot cause a COVID-19 infection and is not a "live" vaccine.
- Once vaccinated, your child's BAYADA clinicians must still social distance, wear masks, and wash their hands frequently while not working. When they are providing care to BAYADA clients, our clinicians will follow all BAYADA infection prevention practices, including wearing the required PPE. They will continue to do so until the

CDC relaxes those requirements, which occurs when a significant number of citizens have been vaccinated.

- Two doses of vaccine are required for protection, delivered via intramuscular injection. The Pfizer vaccines are provided three weeks apart, and the Moderna vaccines are administered four weeks apart. The administration of the second dose has a four-day grace period in which it is considered valid.
- The Pfizer and Moderna vaccines are not interchangeable with one another, or with other COVID-19 vaccines. Both doses should be from the same manufacturer.
- The COVID-19 vaccine should not be administered with other vaccines. Individuals should not receive other vaccines within 14 days prior to and after receiving the COVID-19 vaccine.



BAYADA Nurses proudly display their vaccination cards.

### Learn more

To learn more about the COVID-19 vaccine and see how and when you or your loved ones can get vaccinated, visit <http://bit.ly/Vaccine-CDC>.



# Champions Among Us: I Need Help to be a Mom—Not a Nurse



During a typical day for **Massiah**, 7, there's a good chance you'll find him watching his favorite shows, *Alphablocks* and *Numberblocks*, an animated TV series that educates children through the joy of song and dance shows.

"It's how he learned to count," shared Massiah's mom, **LaToya Martin**, who relishes in the accomplishments of this little boy whose special needs cause her constant concern.



LaToya Martin with her son Massiah.

Massiah has an incurable genetic disorder called tuberous sclerosis complex. As a result he has stage 1 kidney disease due to the development of cysts which left him incontinent since the age of three. He also lives with life-threatening epilepsy, is currently undergoing chemotherapy treatment for his airway, and has tubers in his heart, behind his eyes, and on his brain. LaToya likens it to a potato that is sprouting.

Thanks to LaToya's fierce dedication to Massiah's care, he has been able to thrive safely at home with her and with the help of in-home private duty nursing (PDN). However, he lost many of his authorized PDN hours due to COVID-19 and its impact on his ability to go to school.

Always going to any length to be Massiah's voice—and the voice of many other families who care for medically-complex children—LaToya drafted an opinion piece published in USA Today Network's Delaware Online as well as Scary Mommy, a blog read by millions of moms. You can read her article by visiting <http://bit.ly/Op-Ed-LaToya>.

"This pandemic ought to serve as an illustration for the state of how important home care is in keeping medically-complex children like Massiah at home," wrote LaToya in her opinion piece. "Delaware can ensure that Massiah and others like him continue to be healthy and safe by recognizing that private duty nursing needs to be prioritized and adequately funded!"

## Empowered voices for change

**Katie Morton**, whose son **Joey**, 9, receives nursing care at home from the BAYADA Pediatrics office in Milford, DE, couldn't agree more. Delaware has not raised reimbursement rates for the state's private duty nursing program in 16 years, which has driven

nurses to seek employment in hospitals and other facilities that can afford to pay a higher rate. The situation has resulted in an ongoing struggle to attract and retain nurses to care for Joey, and others like him.

Born with Down syndrome, Joey also has a heart condition, severe lung damage, and an immune deficiency that prevents his body from developing antibodies to many viruses and bacteria.

"Advocating for Joey has empowered me. Without nursing, I can't provide financially, physically, and emotionally to my fullest," said Katie. "The key to getting this issue on the top of legislators' minds is to increase the number of affected family members who speak out on behalf of themselves and their children."

Katie and her network of parents have shared their unique struggles with one another and Delaware's decision makers. Recently, she secured meetings with Delaware's Medical Advisory Committee and the Department of Health and Social Services. What's more, Katie's actions caught the attention of Delaware ABC 47 news, where her advocacy efforts were highlighted in a feature story. You can view the story by visiting <http://bit.ly/ABC-47>.

"Joey's nurses have been a lifesaver, they have become like family," said Katie, who encourages other families to advocate for their children. "Your child has rights and you should not have to be concerned to speak up for them."

Both LaToya and Katie started private Facebook groups for parents of children with complex medical needs. They encourage parents to join these groups at the following links:

**Rare Motherhood:** <http://bit.ly/Rare-Motherhood>

**Home Nursing and Patient/Caregiver Advocacy:** <http://bit.ly/Caregiver-Advocacy>



Katie Morton with her son Joey.

There are many ways to advocate for your child, from sending a pre-written email to your legislators, to hosting a virtual legislative visit. To learn more, visit [heartsforhomecare.com](http://heartsforhomecare.com).

# No Mission Too Difficult: How Lillie's Mom Became a Nurse

**Raymond** and **Elaine M.** met in the US Army, in Combat Lifesaving class. So, they already had the Army value of personal courage in common before they married. But when their third child, **Lillie**, was born at only 25 weeks gestation, their courage was tested in ways no one could anticipate.

## The start of their medical journey

At 1 pound 9 ounces and only 12 inches long, Lillie was considered a micro-preemie and extremely medically fragile. At age six, she still is in many ways. Due to her extreme prematurity, Lillie developed bronchopulmonary dysplasia (a chronic lung disease of infancy), pulmonary hypertension (a blood pressure disorder of the lungs that causes chronically low oxygen levels), intraventricular hemorrhage (bleeding in the brain), and retinopathy of prematurity (abnormalities in the eye that can impair vision). She spent her first six months in a neonatal ICU, then another three in a children's rehabilitation hospital.

"We already had our seven-year-old daughter **Kyla** and four-year-old son **Raymond, Jr.**, but Lillie completely changed the ballgame," her mother Elaine recalled. "Everything we had learned went out the window, and the caution and anxiety were like being a new parent all over again."

Grandmom jumped in to help, and Raymond got time off to stay home with Kyla and Ray, Jr. while Elaine spent 12-hour days with Lillie in the hospital. "The hospital taught me a lot, and I had witnessed so many emergencies—unstable vitals, Lillie turning blue—that I started to think, maybe I can be a nurse, because I'm able to tolerate this."

## Surviving and thriving with home health care

BAYADA Clinical Manager **Carlos Serrano** helped bring Lillie home as an infant and managed her nursing care team for the next five years. BAYADA Pediatrics in Queens, NY provided total care for Lillie, tending to her tracheostomy (surgical opening in her neck to keep her airway open), continuous oxygen, feedings, medications, breathing treatments, preventative care, and therapeutic play to reach developmental milestones. When she was diagnosed with sleep apnea and required a CPAP (continuous positive airway pressure) machine to sleep, Lillie's professional nursing care became 24/7.

Still, Lillie was a very fragile little girl and the emergencies continued—especially in her first few months home. But gradually, as Lillie grew stronger and more stable, there were fewer trips to the hospital. Last year was their first with zero hospitalizations!

"Carlos and our nurses have been such a support for us. Especially Eileen (**Eileen Brathwaite**, recipient of a BAYADA RN Hero Award) who was with us from the beginning and was always so dedicated. She would put everything aside when we

needed her and advocated for what Lillie needed," Elaine said. "In fact, Carlos and Eileen helped me decide to go to nursing school. They have mentored me and answered my questions as a parent, and also as a nurse."

## Becoming a nurse to help others

Elaine took the plunge into nursing school at the age of 38, and it was a monumental challenge along with her caregiving responsibilities. "As the parent of a medically frail child, you are always sleeping with one eye open. Setbacks at home would set me back at school. Without our incredible support system—my husband, mom, mother-in-law, classmates, nurses, mentors—I would have dropped out a long time ago."

But she never did. And now, three years later, Elaine has graduated. Looking at her beaming in her graduation photos, Carlos remarked that he has never seen her look so happy. Her college even recognized Elaine's exceptionally hard work with a Certificate of Perseverance.

Elaine told us, "I wanted to become a nurse to emulate the nurses who provided safety and advocacy for Lillie. I want to share the knowledge I've gained and help other families like ours who need nurses in their home."

## A purpose that was meant to be

Carlos feels proud, but not at all surprised by Elaine's achievement. "If anyone could have overcome the odds, it's her. I could see that they were a strong family from the beginning. It can be a rollercoaster caring for a child with chronic illness, but they went into it with realistic expectations, rolled with the punches, and took it day by day."

"Elaine is a natural-born leader with a 'no fear' mentality and 'can do' attitude," he continued. "There was nothing her daughter needed that she wouldn't learn how to provide. She is very resourceful. So I knew Elaine would be a great nurse—because that is everything that nurses are."



Elaine with her daughter, BAYADA Client Lillie



Elaine celebrates her nursing school graduation in full style.



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BAYADA Home Health Care  
4300 Haddonfield Road  
Pennsauken, NJ 08109-3376

[bayada.com](http://bayada.com)



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## Support for Parents of Children with Special Needs

When your child is diagnosed with a serious injury, illness, or disability, it can feel like the world is crashing down around you. Feelings of isolation are common, but it is important to know that you are not alone. In fact, more than 10 million children in the United States have or are at increased risk of having a chronic physical, developmental, behavioral, or emotional condition that also requires health and related services beyond what is required by children generally.

Know that there are plenty of resources to help you, your family, and your child with special needs—resources that will answer questions, support you through difficult times, and help you live life to the fullest.

Typically, some support groups are led by a facilitator while others may have a guest speaker followed by a discussion period. During the COVID-19 pandemic, many support groups are scheduling virtual meetings.

### Here are some tips for finding local groups:

- The quickest way to find support group information is most likely online. You can search relevant terms such as “pediatric support group” or “special needs parents support group” and then add in your area or town so the results can be filtered by what’s local to you.

- In addition to searching for groups that support parents of children with special needs, you may want to look for groups that are specific to your child’s diagnosis. There are many resources for children with autism, SMA, cerebral palsy, muscular dystrophy, and more.
- Contact your child’s school, non-profit organizations, or local children’s hospitals for information.
- The Center for Parent Information and Resources (CPIR) serves as a central resource of information and products within the community. Use their interactive map to find a center that serves your state by visiting [parentcenterhub.org/find-your-center](http://parentcenterhub.org/find-your-center).
- Explore BAYADA’s resource information by visiting <http://bit.ly/bayada-resources>.

