



WE LOVE WHAT WE DO

Pediatric

CARE CONNECTION

A PUBLICATION FOR CLIENTS OF BAYADA AND FAMILY MEMBERS



BAYADA Pediatrics Nurse Mat Gunkel, RN

Help Celebrate Clinicians Who Make our Mission Possible



BAYADA's Heroes on the Home Front have been doing something incredible that has never been done before: making our critical **Mission Possible** amid a global pandemic. With *compassion, excellence, and reliability*, our nurses, aides, therapists, habilitation technicians, behavioral health professionals, and every clinician on the front lines continue to deliver the highest-quality care. **We are proud beyond words to recognize and celebrate these heroic clinicians** for carrying out our mission and making such an important difference in the lives of the individuals and communities we serve.



When our 10-week contest starts on September 20, all BAYADA field employees will be eligible to win thousands of dollars in cash during our weekly, runner-up, and grand-prize drawings. Office staff, fellow clinicians, and community partners will be taking part, and we encourage you to do the same. If you know any BAYADA clinicians who help make our Mission Possible by providing care with *compassion, excellence, and reliability*, please consider recognizing them with a contest entry.

Simply visit bayada.com/contest beginning September 20 to submit contest entries. While each submission gives a clinician the chance to win a prize, your kind words of appreciation alone will make them feel like a winner! If you do not have access to the internet, please call your BAYADA service office to share how your clinicians have made our Mission Possible in the work that they do, and we'll be happy to submit entries on your behalf.

The contest ends November 28—thank you in advance for your participation!

Duchenne Muscular Dystrophy Can't Hold This Young Man Back

Jessica F. describes her youngest son, BAYADA client **Patrick**, 18, as "always happy and smiling" and "wicked, scary smart." Patrick is the one they turn to with questions because he can recall memories and what people said verbatim. "He did well in his accelerated classes, so we are very proud, but not surprised, that he graduated high school with high honors and will begin online classes at Purdue University Global this August," she said.

Online classes make the most sense for Patrick because of his physical limitations due to Duchenne muscular dystrophy (DMD), a disease that causes muscle weakness and difficulty with standing, walking, breathing, and eventually, heart function.

Treatment and prevention keep Patrick moving along

At least twice a year, Patrick travels an hour and a half from his home in rural Berks County, Pennsylvania to the Children's Hospital of Philadelphia (CHOP) where he receives excellent care. He has been taking steroid therapy since he was 5, got his first power wheelchair when he was 10, and has no breathing or heart problems so far. As preventive measures, he takes three cardiac medications and uses a cough assist machine at home to help his lungs expand.

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Back-to-School Tips: 10 Things You Should Know



Providing one-on-one nursing care for children with complex medical needs in the school setting helps ensure they are safe while enjoying the social interactions and positive learning environment of school life.



However, planning to return to school after the summer can lead to stress and anxiety for you and your child. According to BAYADA Clinical Manager **Teresa Clifford, RN**, whether your child has received nursing care in the classroom for many years or is experiencing school for the first time, the following tips can help make this transition easier for both of you.

1. Inform your clinical manager of any changes to your child's care plan, such as new medications, a change in dosage, or a new feeding schedule. Your clinical manager will ensure the nurses on your child's school care team are aware of these changes.
2. Inform the school's IEP team of any changes to your child's care plan.
3. Refill any prescriptions so that your child has an ample supply of medications to bring to school.
4. Be sure your child's medication is in the original container. Ask your pharmacist to give you a full prescription container to keep at home and an empty prescription container with the pharmacy label and directions to bring to school. Place the pills your child will need for school in the empty prescription container.
5. Ask the school nurse about rules for transporting medication to school. Some schools may require that medication be transported in a zippered pouch with a lock. If that is the case, ask if the school will provide the zippered pouch or if you need to purchase it on your own.

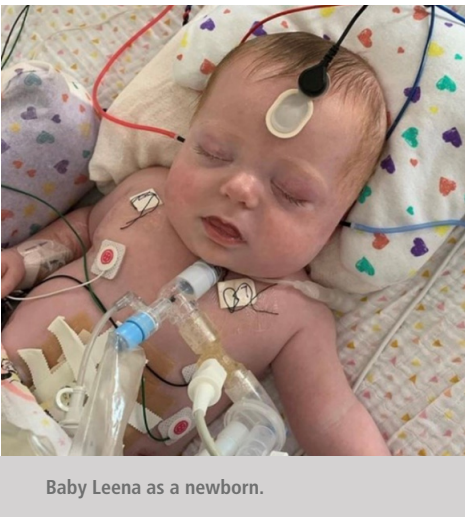
6. Make sure medical equipment is charged so that it lasts all day at school.
7. Keep organized by packing everything your child will need the night before, including medication, food, medical equipment, and a charger.
8. Ask your client services manager (CSM) if you can have a meet-and-greet with any new nurses on your child's team. While this may not always be possible, your CSM will try their best to accommodate your request.
9. Set expectations with nurses who ride the bus to school with your child. For example, when they arrive at your home in the morning:
 - Where should they park?
 - Which door should they use?
 - Would you prefer they knock or just enter the home at the designated time?
10. Contact your clinical manager if you're worried or concerned about a loss of control while your child is at school. Remember, your child's clinical manager is available to respond to any questions you may have and to work with the nurses and the school team to ensure your child has a successful transition and a wonderful school year.



Champions Among Us: Fighting for Baby Leena's Nurses—and Winning!



BAYADA client **Leena S.**, who will turn two in November, is thriving at home alongside her parents, **Alexis and Darryl**, and their two dogs Gabby and Meeko. However, the journey to get to this point has been fraught with challenges.



Baby Leena as a newborn.

During her pregnancy, Alexis received devastating news. Her baby was diagnosed with intrauterine growth restriction (IUGR), a condition where the fetus does not grow as expected. Born at 27 weeks gestation, Leena weighed less than two pounds and was diagnosed with bronchopulmonary dysplasia, meaning her

lungs were not fully developed.

She was put on oxygen and ventilator support and spent three months in the Neonatal Intensive Care Unit (NICU), awaiting transfer to Children's Hospital of Philadelphia (CHOP). After nine weeks in the NICU at CHOP, Leena "graduated" to the Progressive Care Unit, where her parents received intensive training on how to care for their daughter's complex needs.

It would be nine more weeks before home nursing coverage was secured for Leena, thanks to the efforts of three home care agencies and the CHOP case management team. Finally, Alexis and Darryl could take their baby home, but the challenges are ongoing.

"Leena is authorized for 112 hours of in-home nursing care a week, and we can't access even close to that much," shared Alexis. "We have four nurses and no back-ups if there is a call out. On nights when the nurse isn't available, I stay up to monitor Leena until 3:00 am, when I switch with Darryl and sleep until 5:30 am when I have to wake up for work. The lack of nurses puts Leena in danger and it also affects our ability to provide for Leena as fully functioning parents."

Lower wages create a home care nursing shortage

Due to a disparity in reimbursement rates, hospitals can offer higher wages for RNs and LPNs, which creates a recruitment and retention gap for providers like BAYADA that can only compete for a small portion of the nursing workforce. In addition, medically complex clients like Leena, who have a tracheostomy, ventilator, and feeding tube, require nurses with specialized training. Typically, such skills allow a nurse to make more in wages at a skilled nursing facility, however, home care providers are limited by the state of Pennsylvania's Medicaid funding formula, which does not reimburse additional funds for trained nurses who can take on higher acuity cases.

Advocacy gets results!

Parents like Alexis and Darryl are becoming more vocal by calling on state decision-makers to create and improve regulations, laws, and policies—including increasing reimbursement rates—so that parents can access the nursing care they need to keep their medically-fragile children safe at home. And their efforts have been successful! After clients shared their stories with lawmakers and the media, **the Pennsylvania legislature voted to increase funding for pediatric home care nursing in the upcoming budget!**



Baby Leena today, where she is thriving at home.

You can make a difference

From attending in-person or virtual meetings with a legislator and sending emails, to participating in events and sharing your story in the media, there are many ways to get involved in home care advocacy. For more information, visit [heartsforhomecare.com](https://www.heartsforhomecare.com).



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Content in this newsletter is provided as general summary information for our clients and is not intended to take the place of personalized medical guidance. We encourage you to seek the advice of your physician or other qualified health care professional if you have specific questions about your care. BAYADA specialty practices include Home Health Care, Pediatrics, Hospice, Behavioral Health, and Habilitation. Services may vary by location.

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Reliable, compassionate care brings normalcy

Patrick has been a client of the BAYADA Pediatrics office in Reading, PA, since 2013. They provide personal care services from four hours after school and up to 10 hours a day when he's home, enabling his parents to work full time.

"Having reliable, compassionate, qualified people in our home means we are still able to work demanding jobs," said Jessica. "And for Patrick, home care services help him learn how to ask for help and advocate for himself—and help him be as independent as he can be."

A positive attitude—and a big dose of humor—is part of the care plan

Jessica says that Patrick's health care journey has taught her that you need a good support system and a good sense of humor. "Be patient, allow yourself extra time to do everything, and don't take 'I can't' as an answer," she reflected. "Patrick has a great sense of humor. He cracks us up with witty comebacks like, 'I'm not going to stand for that.' Just think positive, live in the moment, and keep doing as much as you can, for as long as you can."

What's next for Patrick?

At Purdue Global, Patrick will be studying Applied Science in Information Technology with a vision to become a video game tester who finds and fixes bugs in software programs. Congratulations, Patrick! We wish you all the best as you live life to the fullest every day.



Patrick celebrates his high school graduation with his mother Jessica, father Rich, and brother Kyle.