



WE LOVE WHAT WE DO

# Pediatric CARE CONNECTION

A PUBLICATION FOR CLIENTS OF BAYADA AND FAMILY MEMBERS



BAYADA Pediatrics Nurse Mat Gunkel, RN

## Taking Care of Those Who Take Care of You: The 2021 Contest for Clinicians Results

The **2021 Mission Possible: Contest for Clinicians** gave you the opportunity to express your appreciation to your clinicians for making a positive impact on you and your family. **The contest results were astounding—with 75,245 submissions—thanks to you!**

### Here's what some of you had to say about some of the clinicians who won cash prizes:

"Jill is our family's hero. Our son uses a communication device to talk. The conversations he and Jill have warm my heart. She finds ways to make sure he has a say in his care and choice in the activities they do together. We are so blessed to have Jill taking care of our son and being his advocate. She is and always will be a part of our family."

—Submitted on behalf of LPN **Jill Tatum**, Missouri East Skilled office, \$200 weekly winner



The Tampa, FL Assistive Care office celebrates grand prize winner HHA **Yerim Bae!**

shift comforting me. She did not have to do it, but she made me feel cared for and loved."

—Submitted on behalf of Home Health Aide (HHA) **Isis Callejas**, Essex County, NJ Assistive Care office, \$200 weekly winner

"Andrea is very knowledgeable and encourages me to try harder and do my best. I appreciate all she has done to help me recover from a major hip surgery and the challenges I face daily due to advanced Parkinson's disease."

—Submitted on behalf of Physical Therapist **Andrea Alvarez**, North Tucson, AZ office, \$200 weekly winner

"Isis is very compassionate and caring. When my mom passed away in May, Isis spent her whole

"Kawehi meets with my son Joshua on Saturdays for his community-based training. Joshua really looks forward to Saturdays when Kawehi actively engages and motivates him with different activities such as going to the park to play basketball and frisbee, walking, or feeding the fishes, eating lunch, going to the shopping malls, doing arts and crafts, and more."

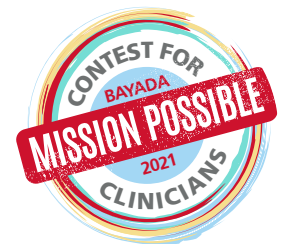
—Submitted on behalf of HHA **Kawehionalani Koki**, Oahu, HI Habilitation office, \$200 weekly winner

Clinicians were also recognized with chances to win for referring individuals with the same passion for healing and helping to join our BAYADA team. Every new hire makes BAYADA's Mission Possible by allowing us to *help more people have a safe home life with comfort, independence, and dignity.*



The Mount Laurel, NJ Pediatrics office surprised grand prize winner LPN **Hawa Khan.**

expressions of gratitude were so deeply appreciated by the clinicians who help you remain safe in the comfort of home.



# Champions Among Us: Fighting for Private Duty Nursing



For **Terry P.**, being a full-time nurse and the mom of seven children is difficult enough, but add on caring for her medically-complex daughter **Kenydii**, 7, and there isn't much time left in a day.



Terry describes Kenydii as perfectly imperfect. The first grader was born with spina bifida, hydrocephalus, and an overactive bladder. As a baby, Kenydii required skilled care and constant supervision to ensure her health and safety were maintained, as she was at high risk for infections.

With support from their extended family, Terry and her husband were able to provide this care. Now, without in-person school due to COVID-19, they had to turn to in-home nursing services to meet Kenydii's needs. However, finding home care nurses to help them has been nearly impossible.

Kenydii is one of about 1,800 North Carolina residents who qualify for in-home nursing care through the state's Private Duty Nursing (PDN) program.

"My daughter is approved by Medicaid for 40 hours of service per week, but we only have coverage for 10 of those hours," explained Terry. "The first nurse we had was amazing, but after a month we lost her to a better paying position at a hospital."

According to BAYADA Government Affairs Area Director **Lee Dobson**, hiring qualified home care nurses has been an ongoing challenge. "Since PDN is state-funded, providers like BAYADA rely predominantly on the funding formula determined by the state legislature," said Lee. "Hospitals and long-term care facilities get higher funding, so they are able to offer nurses higher wages, which draws more nurses to

jobs in those settings. Without enough nurses in home care, medically fragile children like Kenydii are unable to access the in-home nursing services they need."

Home care advocates are urging their lawmakers to fund PDN more adequately with a permanent 15% increase. Recently, the legislature voted to increase funding for other state home care programs by 15%, but left PDN at the 5% level. An equal increase of 15% would provide a long overdue solution to the access-to-care struggles that NC families face every day.

The lack of nurses puts Terry in a difficult situation. "I have to make a choice between taking unpaid time off work to care for my child and risk not being able to pay the bills or go to work and put my child at risk of not having the care she needs," she said.

## Encouraging others to share their voice

Similar challenges are impacting home care in other states as well. That's why Terry encourages families to find their voice and fight for the things that matter to them. "I share Kenydii's story so that families know they are not alone," she said. "Being an advocate is the best thing because nobody knows your child like you do, and nobody will stick up for your child like you will!"



You can get involved in home care advocacy by attending meetings with legislators, sending emails, participating in events, or sharing your story with the media. For more information visit [heartsforhomecare.com](https://heartsforhomecare.com) or scan the QR code.



**Hearts for Home Care**

A BAYADA Community Supporting Quality Care at Home

## COVID-19 News and Resources

BAYADA's comprehensive Infection prevention Program provides the highest standards of infection prevention practices as recommended by the Centers for Disease Control and

Prevention (CDC). To learn more about our commitment to keeping your child safe during the COVID-19 pandemic visit [bayada.com/covid19.asp](https://bayada.com/covid19.asp).



# Spring Activities for Children with Special Needs



The following are ideas for fun and safe activities you can enjoy with your child:

- Locate accessible playgrounds in your area. The Americans with Disabilities Act requires that new or revamped playgrounds have ramps, guardrails, and space for adults to assist children.
- Find information on accessible parks, campsites, sports, and recreation programs by contacting the following resources:
  - Your state or county Department of Natural Resources or Parks and Recreation
  - The National Center on Accessibility: [ncaonline.org](http://ncaonline.org)
  - The American Association of Adapted Sports Programs: [adaptedsports.org](http://adaptedsports.org)

- Create a sensory station outside to help engage and stimulate your child's senses. Fill up buckets with different textures that your child can stick their hands and feet in, such as sand, water, rocks, and soil. Encourage your child to smell and play with them as well. You may also want to include fake grass, silky flowers, plastic insects, or colorful eggs.
- Engage your child in gardening; it can be both fun and educational. Your child can help by watering the plants, touching the dirt, and watching the flowers come to life.



- Blowing bubbles is a fun way to work on motor skills such as lip pursing and breath control. For children who have trouble breathing on their own, an automatic bubble blower can fill the air with a steady stream of bubbles, providing a visual show as they listen to music or enjoy a cool spring breeze.

## We See You, Baby Jesse, Welcome Home!



When you are expecting a child, you start imagining all the joyful “firsts” that lie ahead of you: your child’s first crawl, first steps, first words, first day of school. Yet, many parents reading this probably remember another—more unexpected—set of firsts: their first realization that something was atypical, the first diagnosis, the first time they cared for their child’s feeding tube or catheter care.



So it was for Jen and Cameron, new parents living in northern New Jersey. Jen’s labor came very early, only six and a half months into her pregnancy, and it was a scary experience. Their precious son Jesse, born at 26 weeks gestation, weighed only 1 pound, 5 ounces at birth. Because he was so small and under-

developed, there were many unknowns. Would Jesse get sicker? Was his brain okay? Would he ever be able to see?

### Jesse’s medical journey begins

Like many extreme premies, Jesse was diagnosed with chronic lung disease and to breathe, he still relies on a tracheostomy and ventilator. He was in the hospital NICU for the first 10 months of his life. At three months old, Jesse was transferred to the Children’s Hospital of Philadelphia to receive the best care for his multiple, complex diagnoses. Through it all, Jen and Cameron stayed by his side, even when it kept them uprooted from their home 100 miles away.

One of Jesse’s diagnoses is septo-optic dysplasia, a rare disorder affecting the optic nerve, some structures of the brain, and the pituitary gland. They would have to wait and see what symptoms manifested from his condition—blindness was a real possibility.

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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 provides skilled nursing, rehabilitative, therapeutic, hospice, habilitation, behavioral health, and assistive care services to people of all ages. Services vary by location.

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### **“All hands on deck” to come home**

Jesse has very particular, complex care needs. In preparation for bringing him home, finding enough nurses highly qualified to provide trach and vent care for an infant—and using the new astral vent machine—was a tall order.

“Prior to discharge, BAYADA spent months recruiting and training to get the clinical coverage Jesse would need. We also worked with the family to help get their home modifications and supplies ready,” said **Christine Rios**, director of the BAYADA Pediatrics office in Morris Plains, NJ. “Clinical managers, clinical educators, nurses, a transitional care manager, and office staff from the Hackensack, NJ pediatrics office worked with Jesse’s doctors to make it all happen—in time for him to be home for Christmas.”

### **Mom looks back, and forward**

When your child is medically fragile, the lows are scarier at times, but the highs can be ecstatic. Like when Jesse’s fascinated gaze followed a bunch of balloons around the room, demonstrating that he can see. It will be hard to beat that “first!”

“We had a very positive transition home,” Jen told us. “There is something special about Jesse, and it’s not just how far he’s come. We’re so excited about the developmental progress he’s making and that everything is going in such an upward trajectory.”



Watch a video of Jesse following the balloons: [bit.ly/Jesse-See](https://bit.ly/Jesse-See)

Jen says there’s an adjustment period getting used to clinicians in your home, listening to your gut, and doing

as much—or as little—care as it takes to make you happiest that day. But she and Cameron like the schedule they have now and find it much better than the constant bustle of a hospital room.

Today, Jesse is a hearty 23 pounds and he’s teething—his first tooth should pop out any day now. Everyone is still tired and finding their stride, but it feels so good for Jen, Cameron, and Jesse to be home, under one roof, enjoying those more expected “firsts” and figuring out their new normal together.