



WE LOVE WHAT WE DO

# Pediatric CARE CONNECTION

A PUBLICATION FOR PEDIATRIC CLIENTS AND FAMILIES OF  
BAYADA HOME HEALTH CARE

BAYADA Pediatrics Nurse Mat Gunkel, RN

## Don't Wait Until It's Too Late: The Importance of Knowing When to Call 911

When BAYADA client Eddie complained of tightness in his chest, his nurse, **Kierra Maxwell**, became alarmed by the significant changes in his breathing. She called her clinical manager **Christina Marple**, RN, who agreed with Kierra that she should immediately call 911.

Eddie, who has muscular dystrophy, is dependent on a tracheostomy and ventilator and has a history of lung and cardiac issues. Without emergency intervention, his respiratory distress could have led to serious complications, or even death. Thanks to the decision to call 911, Eddie made it to the hospital where he was successfully treated for pneumonia.

### Tools + training = trust

While some situations are obvious emergencies, sometimes deciding when

to call 911 can be a judgment call. And trusting the professional opinion of a trained clinician—rather than relying on a feeling or a wait-and-see attitude—can mean the difference between life and death.

While it is our goal to minimize hospitalizations and emergency rooms visits, it is our *ultimate* responsibility to take the best course of action to keep clients safe and well. Sometimes, that means calling 911 for immediate intervention.

Families, providers, and insurance companies depend on BAYADA for educated decision making. Our nurses are trained to assess potentially critical situations and determine if they need to escalate it to avoid a tragedy.

### Hesitant to call 911? Don't put your loved one at risk

While a loved one's wellbeing is the highest priority for family members, there can still be some resistance to calling 911. Perhaps some families have had several "false" emergencies when calling 911 and assume this time is no different. Others may want to avoid the cost of an ambulance and prefer to transport the client themselves.



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## Recognize Your BAYADA Clinicians

The BAYADA 2019  
Contest for Clinicians  
is underway



Our clinicians—from therapists and home health aides to nurses and early childhood educators, and all those in between—deserve the spotlight for providing exceptional care and truly creating a difference in the lives of those they serve. We are proud of the *compassion, excellence, and reliability* they demonstrate each day, and we're honored to recognize them individually as *Points of Pride* during BAYADA's 2019 Contest for Clinicians program.

If you believe one of your BAYADA clinicians deserves special recognition as one of BAYADA's *Points of Pride*, we encourage you and your family to submit contest tickets (enclosed in this publication) on their behalf. Each submission will give your BAYADA clinicians a chance to win weekly, runner-up, and grand prizes, including items that suit a variety of

interests from music, cooking, fitness, and fashion, to gift cards valued up to \$1,000.

### There are four different ways to recognize your BAYADA clinicians:

- Fill out and mail the enclosed, postage-paid contest tickets
- Fill out the enclosed tickets and return them to your BAYADA office
- Call your BAYADA office and make a verbal entry
- Submit a digital ticket online by visiting [bayada.com/contest](http://bayada.com/contest)

### Important dates:

- **September 16, 2019** – Contest begins
- **November 24, 2019** – Contest ends
- **December 12, 2019** – Runner-up and grand prize drawings

We look forward to your participation! ■

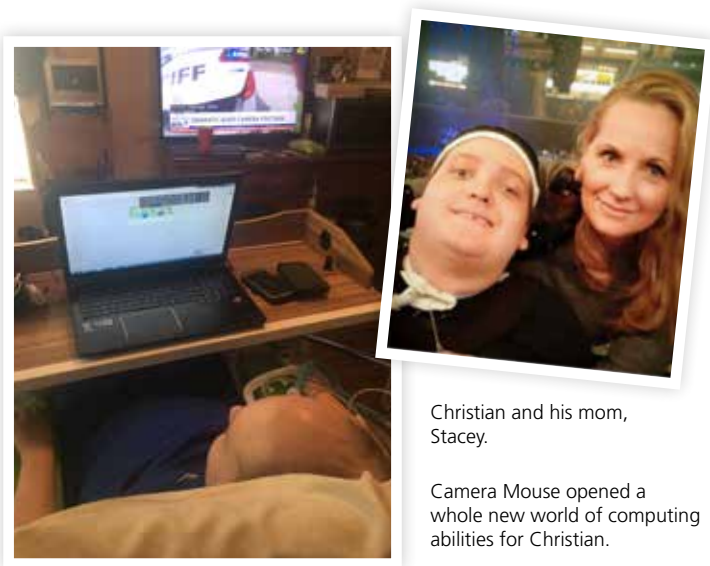
## Adaptive Computer Mouse a Game-Changer for BAYADA Client, Christian

BAYADA client **Christian R.**, 22, learned about an adaptive technology called Camera Mouse that may be able to help him and others like him gain independent access to a whole new world of computing and telecommunication abilities.

Due to a spinal cord injury he sustained in a car accident just before his first birthday, Christian's motor control is limited to his neck and above, and he relies on a ventilator to breathe.

Camera Mouse software works as a mouse replacement system by tracking a chosen feature on his face with a web cam. By moving his head, he can point and click on his computer screen, operate gaming devices, type messages, and even operate his smart phone.

This is a wonderful solution for Christian, who had tried other adaptive technologies that are great for others but didn't work out for him.



Christian and his mom, Stacey.

Camera Mouse opened a whole new world of computing abilities for Christian.

"Everybody is different. An eye-tracking mouse that works for a lot of people just didn't work for Christian. It was frustrating, because it had to be constantly recalibrated," shares his mother, Stacey. "And dictation devices that respond to the sound of your voice weren't working because the ventilator causes reverb."

Christian and Stacey attend an Assistive Technology Industry Association convention every year looking for new ideas to enhance his life. That's where they were introduced to eye-gaze technology, and later, to an adaptive computer that seemed interesting, but came with a prohibitively high price tag.

Seeing how proficient he is with the computer, and how enriching his online friendships and interests are to Christian, one of his nurses helped him find an independent computing solution. She spent hours on her own time doing research—and discovered Camera Mouse.

Camera Mouse software is available to anyone as a free download, because it's being developed and researched at Boston College as part of their mission of education, research, and service. That means users can request new features and benefit from annual updates—all free of charge.

"Prior to Camera Mouse, I had a world of struggles trying to operate my computer independently," Christian says. "Discovering this technology has been a game-changer for me. It has really improved my life being able to communicate with friends and family, compose emails, and answer my cell phone by myself."

Christian got together with his online friend Sage to make a video tutorial for other Camera Mouse users with limited mobility. An updated video currently is in the works. You can find their latest tutorial on The SFC Group YouTube channel by visiting [bit.ly/cameramouse](http://bit.ly/cameramouse).

To learn more about Camera Mouse software and for a free download, visit [cameramouse.org](http://cameramouse.org).

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"Even if the nurse goes in the car with the client, it could be dark or the client could be in a car seat, making it difficult to provide care," explains Manager of Clinical Operations **Kathy Pfeiffer**, RN, BSN. "The chance of a positive outcome is better if the

*There have been many situations in which we have had to rely on our experience and expertise to make the right call, even in the face of family hesitancy...*

client is transported by Emergency Medical Services (EMS) who have the medical equipment to respond to the emergency."

In some cases, families may be hesitant to call 911 without the input of other family members who may be unavailable, resulting in a delay in treatment. Or they are anxious about the disruption it will bring to their lives when they are already trying hard to maintain a sense of normalcy.

"When a child is in the hospital, their parents or family caregivers may be forced to take off work, which can lead to a loss of income and impact their ability to cover medical costs," says Kathy. "While we do our best to address these concerns, our main priority is the client's safety.

There have been many situations in which we have had to rely on our experience and expertise to make the right call, even in the face of family hesitancy.

Clinical Manager **Crystal Lee**, RN, experienced family hesitancy when a 6-year-old child with hypoxic ischemic encephalitis (HIE) developed an elevated heart rate. HIE is a brain injury caused by oxygen deprivation to the brain while in utero.

After implementing the interventions provided by the physician's plan of care, the nurse determined that the child did not return to his baseline status. Despite hesitancy from the child's grandmother, the nurse made that emergency call. If not,

## Introducing Clayton's Voice

A podcast for parents of children with special needs, hosted by a mother who knows the journey all too well

BAYADA Pediatrics Special Needs Advocate **Shelby Myers** sat with her hands on the keyboard and repeatedly hit the backspace button as she tried to find the perfect words to introduce her new monthly podcast, Clayton's Voice, named in loving memory of her son, Clayton.

"I thought about how this show should begin and what would make parents want to take time out of their day to listen," says Shelby, who hopes her story will resonate with parents. "I will use the podcast to share support and resources to help families of children with special needs overcome some of their challenges. I hope this is a place they will bookmark, like, share, listen, and learn."

Shelby's path from the mother of a special needs child to host of a monthly podcast began in 2004. That's when 6-year-old Clayton contracted a rare virus that attacked his brain and created seizures so severe that within 24 hours he was placed in a medically-induced coma.

*She feels privileged to not only be Clayton's mom, but also his voice.*



To listen and subscribe to **Clayton's Voice**, visit [Bit.ly/ClaytonsVoice](http://Bit.ly/ClaytonsVoice)



Podcast host Shelby Myers enjoying time with her son, Clayton.

"After five months in a coma our little boy, so full of life, came home with a ventilator and tracheostomy to breathe, a g-tube to eat, and a wheelchair to move," explains Shelby, a mother of five. "For eight years he battled seizures that would not let him be, but he continued to fight and showed us all the meaning of hope and love."

In 2012, when Clayton lost the battle with his illness, Shelby turned her grief into action. She became a public speaker and authored a book called *Out of the Bubble*, a candid memoir of her family's heartbreaking journey caring for and losing a child. She also served as chair of the State of New Jersey Epilepsy Task Force and founded the nonprofit organization, Clayton's Hope, to raise awareness and funding for epilepsy research. She feels privileged to not only be Clayton's mom, but also his voice.

The podcast will feature guest speakers who will discuss topics such as post-traumatic growth, Individualized Education Program (IEP) challenges, insurance issues, stress management, sibling support, legal resources, therapy options, and overcoming stereotypes and stigmas. The first episode offers simple solutions to helping both children and parents adjust to their new back-to-school routine.

Shelby encourages listeners to reach out with topic ideas or to ask questions by emailing her at [claytonsvoice@bayada.com](mailto:claytonsvoice@bayada.com). ■

he could have gone into cardiac arrest.

"Fortunately, the nurse made the safety of the client the first priority, despite the grandmother's understandable hesitancy," says Crystal.

Clinical Manager **Kathryn Hawley**, RN nearly lost an 18-year-old client whose father wanted to wait to see if his son would get better before calling 911. The client, who has quadriplegia as a result of a cervical injury, had become disoriented and was in and out of consciousness.

Kathryn knew that waiting was simply not an option. At the hospital, the client was diagnosed with an infection that had entered his bloodstream. Later that evening he went into cardiac arrest.

"If he had not been at the hospital when his heart stopped," says Kathryn, "he would not have survived."

### Saving lives and keeping families together

Ana Pierre is grateful to **Carlene Tavares-Walls**, RN for knowing when to call 911 and saving the life of her 19-month-old daughter, Viviana.

The incident happened when the baby, who has paralysis of her larynx and vocal cords, became unresponsive with no heart rate or pulse following a seizure. Carlene instructed Ana to call 911 while she administered CPR, chest compressions, and bag/mask ventilation until the first responders arrived.

"Carlene did everything in her power to make sure we didn't have to say goodbye to our baby," says Ana. "Viviana is with us today because Carlene remained calm, remembered her training, and didn't give up. Thank you, Carlene, for being our guardian angel." ■

**If you have questions about care for you or a loved one, please contact your BAYADA Clinical Manager.**



WE LOVE WHAT WE DO

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BAYADA specialty practices include Home Health Care, Pediatrics, Hospice, Behavioral Health, and Habilitation. Services may vary by location.  
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## Your Voice Makes a Difference

### Client Experience Survey coming in October

In the coming weeks you will receive an invitation to complete your Client Experience Survey. The questionnaire, which should take **less than five minutes** of your time, is your opportunity to let us know what's working well and how we can continue to improve our services for your child.

You will receive the survey via text message, email, or both if we have your updated contact information. You have the choice of completing the survey via text message or email, whichever option is more convenient for you.

The text message will come from the following phone number: **888-647-5961**.

The email will come from the following email address: [kschlager@bayada.com](mailto:kschlager@bayada.com).

Thank you for taking the time to share your honest feedback. If you have any questions about completing the Client Experience Survey, please reach out to your office director. ■

