



Lekotalk

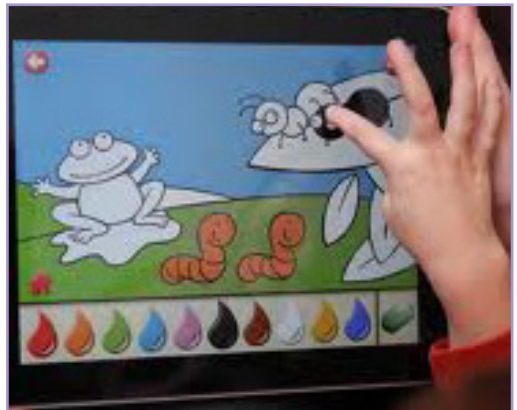


Lekotek of Georgia
Making a Difference for Children with Disabilities

Technology Corner: The iPad

The iPad...a magical device! Weighing just 1.5 lbs. the iPad is a portable and high-powered multi-touch computer device that you can take with you anywhere you go. It has been called a revolutionary tool to help children with autism learn how to communicate and socialize more easily.

The iPad has a special place in the special needs community. “Apps” are the foundation of the iPad and a number of programs have been created with this population in mind. Communication programs are abundant allowing the individual to touch a picture and easily navigate to screens that say exactly what they want to say. With the purchase price starting at \$499, it is much more affordable than most communication devices. And the iPad is not just for kids with autism or speech delays. All children will learn and enjoy the books, movies, educational games, music and web activities that are easily accessible. The iPad syncs with iTunes on the web which has a generous selection of “apps” for all users... even moms and dads. With built in speakers and microphone, it can replace your iPod and book reader, making it even more affordable for most families.



Currently single switch access is not available without an add-on hardware device and software. However, new opportunities for access are on the horizon.

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I Thought My Child Was Perfect...Until Somebody Told Me He Wasn't

by Ima Amare (edited with permission)

The first five years of my son's life were a delirious extended honeymoon. Every time I looked at him – and I looked at him all day long – my heart ached with tenderness. I couldn't stop cuddling and kissing him and in five years I never once felt anger toward him. My mama friends hated me for it, as they teasingly told me all the time. But he was more than I could have imagined and to me the world's most perfect child. And then one day someone told me he wasn't.

From the beginning, Cody moved to his own inner beat. He was a precocious learner, highly motivated with great concentration. His interests, before the age of three, included astronomy, geography and geology. I was not surprised that he had little to say to other toddlers. When I arrived at his preschool, I'd often find him by himself at the edge of the playground, his nose buried in the jasmine, while the other kids drove their big plastic cars and tossed balls. "My own gentle Ferdinand", I thought with a smile.

As Cody's lack of interest in his peers persisted, his kindergarten teachers suggested a full psychological assessment. Initially resistant, his teachers persuaded us that we had nothing to lose by gathering information. By doing the assessment, they asserted we could learn how his mind worked and the best way to nurture his phenomenal gifts. Six weeks and three thousand dollars later, we sat in a carpeted office facing a ponderous wooden desk, while an earnest young man with faded blue eyes told us our son had Asperger's Syndrome. Anyone familiar with Asperger's knows that the diagnosis is both subjective and somewhat nebulous. It's a behavioral diagnosis – there's no lab test that can tell you whether or not someone has it. It's also a spectrum diagnosis which means there is tremendous variation in how it is expressed in different individuals. As the saying goes, "if you've met one person with autism, you've met one person with autism."

Cody is seven now. It's been almost two years since we received the diagnosis. The other day he said to me, "I don't mean to hurt your feelings, but I think you were nicer when I was younger." I was immediately struck by the truth of his statement. I was nicer then. While the addition of Cody's little brother to our family two years ago was probably the largest contributor to the erosion of my once even temperament, there is no doubt that the stress of the diagnosis and subsequent interventions we sought – occupation therapy, play therapy, therapeutic summer camp, etc. – were a major factor as well. Meanwhile, my feelings about the diagnosis continue to evolve. If the word Asperger's can help Cody get support services from our public school, great. If it gives people a framework for understanding his quirks, that's good too. And if it can help him understand himself and feel less alone in the world, so much the better. What I don't like is the tendency it creates in me and others, that there's something "wrong" with him. Before the diagnosis, traits that I used to consider just individual quirks, now cause perpetual worry. There's a fine line between supporting and "fixing", between doing my best to help Cody become the happiest, most fulfilled version of himself and trying to turn him into someone he's not. I'm constantly asking myself – where is that line. How many interventions are too many? At what point does he begin to think he is flawed? Cody will feel defective, if he senses that I consider him so. I cannot, must not, let that happen. How do I find my way back to the truth of my child's perfection? What do I mean by perfect? Only this: My child is exactly as he should be. Cody's essential self – who he is – is precious beyond words; he is an exquisite, utterly unique manifestation of life's miracle. I knew his the moment he was born and beneath all the nervous chatter this process has created, I know it still.

Ima Amare is a writer and the mother of two perfect boys.

Lekotek Announces New Satellite

Lekotek is delighted to announce the opening of a new satellite in the Dawsonville/Gainesville area. With donated space from Walker Therapy, Lekotek will now reach families in Dawson, Hall, Lumpkin, Stephens and surrounding counties. When asked about providing space for Lekotek, owner Nicole Walker responded, "My vision is for Walker to be a community resource and Lekotek will help us reach that vision." Walker Therapy is an innovative, state of the art center. In addition to providing physical therapy, occupational therapy and speech therapy, Walker has an indoor pool for aquatic therapy and an indoor riding arena for hippotherapy.

Lekotek leader, Maria Canaba, will conduct play/learning sessions at this location. Maria was born and raised in California and has a degree in recreation therapy from Fresno State. While working for the Sacramento Parks & Recreation Department and the Shriner's Children's Hospital, Maria learned about the Lekotek in CA. Upon moving to GA, Maria worked for the Roosevelt Institute of Rehabilitation in Warm Springs and then joined the Lekotek staff in 2006. Maria is bilingual and initially helped with translation at Lekotek neonatal play sessions. She has been a Lekotek leader at both the Atlanta and Duluth locations.

From humble beginnings in the basement of Easter Seals, Lekotek now has six sites in Georgia. With the main office in Atlanta, other satellites are located in Duluth, Alpharetta, Kennesaw and Fayetteville. Children's Healthcare has provided space since 1991 for the Duluth satellite and space for the Alpharetta site since 2000. With donated space, more funding can be provided to direct services. Lekotek is extremely proud that our most recent financial statement shows that 92% of all donations are allocated for direct services. We appreciate the generous support of both Children's and Walker in providing homes for satellite operations.

Mark Your Calendar for Upcoming Fundraising & Fun Raising Events

Lekotek's 12th Annual Golf Tournament will be held Monday, May 2nd at Smoke Rise Golf and Country Club. The 19th Annual Lekotek Run will be held, August 27th at Georgia Perimeter College's Dunwoody Campus. Sponsors, volunteers and/or participants are welcome. If you can help, please contact the Lekotek office at 404.633.3430.

Family Profile: Meet the Johnsons

On a Tuesday afternoon, I arrived at my doctor's office 38 weeks pregnant, feeling and looking like I was about to burst. I was measuring a little big and so an ultrasound was ordered. As the technician stared at the screen, she suggested that I go to the perinatology clinic so they could have a closer look. Not the naturally-anxious-type, I packed up my things and asked, "Should I call my husband?" Without hesitation, she replied "yes." Suddenly, I knew something was very wrong. Two hours later, high-resolution images of Trett's brain seemed to jump off the huge, flat-screen monitor showing severe hydrocephalus - a build-up of excess fluid on his brain. As I stared at the huge black spaces, which were enlarged ventricles filled with fluid, I thought "there's supposed to be brain there." As a clinical psychologist specializing in neurodevelopment, I knew what a 38-week-old brain was supposed to look like, and that was not it. A C-section was scheduled the next morning.

On July 15, 2009, Trett was born, big head and all, and was transferred immediately to the children's hospital. I

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am not sure one fully appreciates the first moments after birth until you don't have them. Touching his hand through an isolette just wasn't quite the same as hold



ing him in our arms. Trett showed us his fighting spirit and remarkably easy-going temperament right from the start. While in the NICU (neonatal intensive care unit), Trett continued to get healthy and strong; however, doctors noted feeding and motor problems and that Trett's thumbs were tucked tightly into his palms. Most people attributed these things to the hydrocephalus, and we were all hopeful that with the right intervention, Trett would be back on track in no time. Genetic tests were run and initial results came back negative. One last test that took almost 8 weeks to complete told us otherwise, and suddenly we were in a whole different ball park. Trett was diagnosed with a rare genetic disorder called L-1 syndrome. We had never heard of this syndrome and quite frankly, it seemed like no one else had either. Although each child is different, it usually causes hydrocephalus, adducted thumbs, low motor tone, spasticity, speech delays

and/or aphasia, and varying degrees of cognitive delays.

Using the diligent research skills that got us where we were in our careers, my husband and I quickly began to read anything and everything. This proved largely unhelpful as most of the "research" was based on a few case reports and a few case studies answer questions like "Will he walk?", "Will he talk?", or "Will he know us?" They can't. Like many concerned, conscientious parents, we began seeing specialists and therapists right away. Family members thought I was crazy when I began requesting therapy consultations four days after birth. We soaked up the advice and felt comforted to know that there were things we could do to help our son be the best he could be. However, we became overwhelmed with exercises, stretches, splints, helmets and equipment. It was difficult to watch him spend every afternoon in a waiting room or therapist's office rather than in a swing at the park. Yet, he showed such remarkable effort and grace every step of the way. Despite the worry and the sorrow, mostly what we felt was pride. It was like watching an angel with broken wings learn how to fly... joyous and heartbreaking, terrifying yet exhilarating.

By the time we added Lekotek to the mix, Trett already had a very full schedule and prioritizing what was most important was a constant struggle. As a psychologist who had referred many children to Lekotek, I knew the benefits, but still was a little unsure of what to expect. Much to our amazement, we have watched our 18-month-old son "build" with blocks on the computer, despite the fact that he can't sit alone and has limited use of his hands. At Lekotek, Trett is able to show us what he knows and what he likes. I am sure that during each visit with Ms. Helene, Trett learns something; but more than that, we learn something. Through watching Trett play with computer games and adaptive toys at Lekotek, we are often reminded that there's "a whole lot of brain in there," which brings us full circle from where we started.

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