

TECHNOLOGY AND
MULTIPLE DISABILITIES:

Learning What Works for Cree

By Catherine C. Valcourt-Pearce

My son Cree was born on April 16, 2010, via C-section at Sibley Hospital in Washington, D.C., after 15 hours of unproductive labor. After registering a 7 on the APGAR and then a 9, this beautiful, precious infant was swaddled and given to us to hold. Marveling over this new life, my husband Larry and I had no idea of the adventure that awaited us all.

On that first day, following up on Cree's prenatally diagnosed severe kidney reflux, the tech at the hospital did an x-ray and saw something wrong with Cree's heart. A pediatric cardiology consult determined that Cree had a congenital heart defect called total anomalous pulmonary venous return (TAPVR). He was transferred by ambulance several miles away to Children's National Medical Center (CNMC). We were warned that Cree might need open heart surgery the next morning. I touched my baby goodbye in his portable isolette, still numb from the waist down from my C-section and unable to raise myself out of the bed to kiss him. I didn't see Cree again for four days. When I did, my world fell apart.

The Diagnoses Keep on Coming ... So Do the Specialists

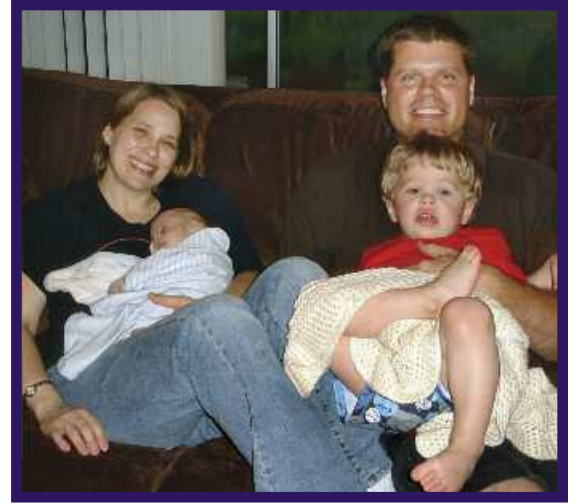
As it turned out, Cree only stayed in the Cardiac Intensive Care Unit overnight. He was then transferred to the Heart and Kidney Unit until he stabilized enough to be sent home so that he could grow bigger and stronger before his open heart surgery.

By the time I was reunited with Cree, however, other conditions had been diagnosed. In addition to his kidney reflux and TAPVR, doctors from CNMC noted that Cree had gastroesophageal reflux disease. He also had severe hypotonia, a poor suck reflex, and unusual toenails. CNMC's geneticists had recommended testing and through fluorescence in situ hybridization, which maps the genetic material in a person's cells, they—and we—learned that Cree had Phelan-McDermid Syndrome (www.pmsf.org), a rare syndrome identified in only



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Photos courtesy of Catherine C. Valcourt-Pearce



Clockwise from top left: Mama and Cree shortly after his birth; first family photo with Cree after he was released from CNMC; Cree being fit for a Kid Kart Xpress, his first wheelchair; relaxing at home usually with a smile or a giggle.



approximately 800 people worldwide at that time. Thirty-four days later, we would learn that Cree's syndrome was even rarer than we'd originally thought; his particular type, called ring chromosome 22, is found in only approximately 100 individuals worldwide. He also has a rare and eventually terminal chromosome disorder called neurofibromatosis 2 or NF2 (www.nfnetwork.org); as a result of this disorder, Cree is missing the tumor-suppressing gene and is at lifelong risk for tumors, especially on the brain, spine, and acoustic and optic nerves.

Before Cree was even a week old, technology had changed our lives almost as much as his birth and diagnosis. Medical technology allowed Cree to live; children like Cree who are not born into societies with strong medical services do not survive. Internet technology allowed

Larry and me to become informed; we spent hours each day researching Cree's diagnoses and related symptoms. Social technology allowed us to join support groups on Facebook and to "meet" the amazing parents around the United States and in other countries who are raising children like our Cree and to not feel completely alone.

Cree eventually failed, and then passed, his newborn hearing screening test. He bounced in and out of the Heart and Kidney Unit until, at 7 weeks old, he had successful open heart surgery. He had successful bladder surgery to repair the kidney reflux at age 2. Also at age 2, he was diagnosed with epilepsy. At age 3, he had the first of several surgeries to remove benign NF2-related tumors. At age 4, he was diagnosed with hearing loss via a sedated auditory brainstem response hearing test at Georgetown

University Hospital and received his first hearing aids. He was also diagnosed with cortical visual impairment, which is "a decreased visual response due to a neurological problem affecting the visual part of the brain" (American Association for Pediatric Ophthalmology and Strabismus, 2014).

Now age 5, Cree has undergone more surgeries, medical procedures, and exams than most people accumulate in a lifetime. He has anywhere from 12-14 medical specialists at any given time. He is a warrior!

IFSPs, and IEPs, and Accommodations—Oh My!

By the time Cree was 4 months old, he already had an Individualized Family Service Plan (IFSP) specifying his goals and therapies through the Montgomery County Infants and Toddlers Program

under The Arc Maryland (www.thearcmd.org). When he turned 3, an Individualized Education Program (IEP) was created for him with new goals and therapists. During these meetings, accommodations were discussed. We pushed for the addition of technology into Cree's therapies; they pushed back, saying it wasn't feasible yet. At that point, we had to agree. Cree simply didn't have the muscle strength.

Due to his severe hypotonia, Cree was, and still is, learning basic skills such as how to roll over onto his stomach, how to hold up his head during supported sitting. He may never crawl, or sit alone, or feed himself. He cannot speak or sign, although he can understand sign language since we've used it with him from birth. He usually has little to no interest in toys unless they play music. All these issues make use of assistive technology a challenge with Cree. Still, there has to be some way of incorporating it into Cree's life, both at home and at school. We want Cree to be able to tell us what he's thinking, how he's feeling, what hurts, what his preferences are to the extent possible. Mastering even "yes" or "no" will be life-changing for Cree (e.g., Are you hungry? Are you tired? Are you hurting? Do you feel sick? Can you breathe?).

Finding the Right Technology for Success

We use American Sign Language (ASL) as our primary mode of communication at home; with the exception of one son, the rest of us are deaf or hard of hearing. Technology is central to our lives. Text messaging, e-mail, FaceTime, and Facebook continue to keep us connected with family, friends, and other parents of children with disabilities. The Internet, closed captions on the television, and alerting devices such as flashing lights for the telephone and iPhone, vibrating alarm clocks, strobe smoke detectors, and baby monitors with light flashers are also a standard part of our daily lives.

For each of our children, we have

tailored technology a bit to accommodate age and interest. For Cree, our only child who is both hard of hearing and has additional disabilities, we have found the following especially useful:

- **Closed captions on a portable DVD player**—While he can't speak, Cree's teacher says he is able to recognize quite a few printed words, so the first type of assistive technology we introduced Cree to was a DVD player. We turn on the closed captions for each movie or show he watches. We believe that between hearing the words and seeing them on screen, Cree has a better understanding of—and surely gets more enjoyment from—his movies.
- **Musical push-button toys**—Cree loves music, especially when wearing his hearing aids. We have several musical toys that are push-button activated. While Cree usually needs help in order to push the buttons, he will reach out to find a specific toy's button himself. He clearly knows how to turn the music on and where the buttons are. These toys not only provide entertainment, but they also offer incentive to encourage Cree's movement and cognitive development. It's also for this reason that we want Cree to begin to use other technology, including an iPad.
- **Software and speech-generating devices**—Cree is learning to use eye

gaze in his Building Bridges (pre-school education) program to answer questions and participate in curriculum-related instruction with his classmates. Currently his teacher—who is both incredibly enthusiastic and extremely dedicated, and who knows Cree and his capabilities better than anyone but us—is using such materials as cards printed with "yes" and "no" and "happy" and "sad" faces as well as word cards for names, days of the week, letters, and numbers. Daily, the teacher asks Cree to choose from among two to four cards to identify his name, a specific word, a letter, a number, etc., and waits patiently while he uses eye gaze to do so. This can be hit or miss depending on how tired or frustrated Cree is; it's a process, but it's a skill that's slowly developing.

As a result, we asked that Cree be evaluated for iPad use; there are many helpful apps for children with disabilities similar to Cree's that might be useful when he gains better control of his arms and hands and which incorporate these same lessons or similar. We were hopeful that this process could begin at school. Cree was considered for Boardmaker Plus software and speech-generating devices such as the BIGmack Communicator (single message speech-generating device), the Step-by-Step Communicator, TechTalk, Go Talk 9+ and GoTalk 20+, Pocket Talker, and Cheap Talk. Since Cree can't sign or speak, this type of software/device could serve as a way for him to express more complete thoughts and ideas versus simply "yes" and "no" and other one-word answers. However, while Cree's teacher and speech-language therapist were supportive of beginning technology use, the Montgomery County Public Schools' InterACT



Helpful Technology-Related Websites

By Catherine C. Valcourt-Pearce

My husband and I often surf the Internet, hoping to discover current and new assistive technology and technology-related information that might benefit Cree as well as our twins. Below are some of the websites we have found helpful, including those that reference technology mentioned above for which Cree was evaluated.

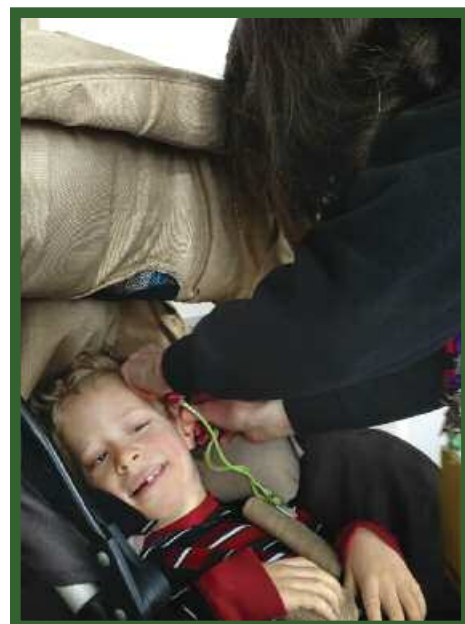
- **American Society for Deaf Children** (see Knowledge Center), www.deafchildren.org
- **American Speech-Language-Hearing Association** (see Hearing Assistive Technology Systems), www.asha.org
- **Apple Store for Education**, <http://store.apple.com/us/browse/home/findyourschool>
- **Attainment Company** (see Go Talk 9+ and GoTalk 20+), www.attainmentcompany.com
- **Center for Accessible Technology in Sign**, www.cats.gatech.edu
- **Enabling Devices** (see Cheap Talk), <http://enablingdevices.com>
- **eSpecial Needs** (see Step-by-Step Communicator), www.especialneeds.com
- **Gallaudet University's Visual Language and Visual Learning Center** (see Storybook apps), <http://vl2.gallaudet.edu>
- **Harris Communications** (see Pocket Talker), www.harriscomm.com
- **Kids Together, Inc.**, www.kidstogether.org
- **Laurent Clerc National Deaf Education Center** (see Deaf Students with Disabilities Network), <http://clerccenter.gallaudet.edu>
- **Maryland Learning Links**, <http://marylandlearninglinks.org/955>
- **Maryland Technology Assistance Program**, www.mdod.maryland.gov/MTAP.aspx?id=2665
- **Mayer-Johnson** (see Boardmaker Plus Software and BIGmack Communicator), www.mayer-johnson.com
- **National Association of the Deaf** (see Assistive Listening Systems and Devices), www.nad.org
- **National Autism Resources** (see PECS), www.nationalautismresources.com
- **National Center for Technology Innovation**, www.nationaltechcenter.org
- **PBS Parents** (see Assistive Technology), www.pbs.org/parents/

(Interdisciplinary Augmentive Communication and Technology) Team who came to evaluate Cree decided, to our dismay, that Cree's responses weren't consistent enough to merit incorporation of these devices and denied the request.

We will ask that Cree be re-evaluated for such technology as the speech-generating devices in the near future, even as we hunt for grants for an iPad for Cree so that we may begin to experiment at home with some of the many helpful apps available for children with multiple disabilities. In the meantime, Cree will continue to work on mastering eye gaze. Already there are companies out there that make devices that give individuals access to the computer and the Internet through eye gaze—something that might become a possibility as Cree gets older.

Next Step ... Kindergarten!

Cree will soon be entering kindergarten, and we have been visiting programs for children with multiple disabilities. We have been impressed with the accommodations and the technology we have seen used already in these classrooms—sign language interpreters,





more deliberate in his responses.

Exciting things are happening technology-wise that afford Cree far more access than he would ever have received even five years ago. Who knows what other kinds of technological inventions are on the horizon for deaf and hard of hearing students with additional disabilities? Whatever they are, we'll be on the lookout—and we'll be fighting for their incorporation. Cree deserves every opportunity to succeed.

Reference

American Association for Pediatric Ophthalmology and Strabismus. (2014, March). *Cortical visual impairment*. Retrieved March 24, 2015, from <http://www.aapos.org/terms/conditions/40>

iPads and apps, PECS (picture exchange communication system), switches, SMART Boards, closed captioning, FM systems, and even a wheelchair lift for one program that has a pool. Programs that combine no-tech and low tech options, such as the printed cards with

words and pictures and switches, with higher tech ones, such as iPads, apps, and SMART Boards—make learning accessible, meeting Cree's needs and capabilities *right now* and as they are developing as well as serving as an incentive as he becomes stronger and

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