

MICROPTHALMIA



ANOPHTHALMIA



PARENT



SUPPORT



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MAPS - Finding Our Way

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Sometimes You Just Have To Laugh, by Gwen S.

To say the least the world of prosthetic eyes has invoked experiences that I never could have imagined, even in my wildest dreams. We, like the rest of you, have had to learn new terminology and learn how to raise a well-rounded blind child (and in our case, well-rounded siblings too). So I would say life is a smidge different than the original blue-print. Yes, different. And not so much because of the drama of explaining to people that Ivey does not actually have eyes, but more so learning to laugh, when we can, in the oddest situations that we tend to find ourselves because of her eyes, or lack thereof.

You all can remember that first visit to the ophthalmologist. I do not know about your experience, but ours was a little rough around the edges. Ivey was only weeks old and there we found ourselves sitting in this office that we never knew existed waiting on this person to come out to meet us and give us a set of eyes. Emotional does not quite cover it. The actual moment of meeting the ophthalmologist was worse than anything I could possibly have imagined. Now do not laugh, but of course at the time I was still trying to figure out just how someone came to actually want to make fake eyes for a living. Obviously, it was not an area I had ever put thought into.

Anyhow, a man welcomed us into this office and began talking, but all I heard was the sound of the teacher in the Peanuts talking. "Wankkkk. Wankkkk. Wankkkk." I was traumatized. He was beaming at photos of people he had made eyes for; all the while I was petrified. He even pointed out a picture of a horse he had made an eye for. Image. Somewhere in the conversation he lifted his closed fist to me, I offered out my open hand, and then about five little eyes dropped into to my hand to only stare back at me. Needless to say the meeting was over for me. Yet we still went home with a set of conformers. Looking back, I can only laugh at

the irony of the situation. I should have gotten a sense of humor sooner.

There are countless stories about Ivey's eyes that we joke about, and only in good humor, but none makes us more proud than recanting 'The Elevator Story'. To make a long story short, Ivey does not like to wear her eyes. Therefore, she literally plucks them out whenever possible. Being that you all 'get' where I am coming from, imagine an eye falling in between the floor and the elevator, which happens to be about an inch wide, if that, down the elevator shaft from the third floor. Sounds impossible, yet it is. When it happened we laughed, those who did not know us must have thought we were nuts. Imagine explaining to security that you need to go down to the basement to find an eye in the elevator shaft. Obviously, that takes some explaining on your part and an imagination on their part. Apparently, for those who do not have children with BA or MA, that particular situation is one deserving of sad tears. Needless to say, we laughed until we cried.

Ivey has not worn her eyes in over a month now. Like I said, she is plucking them out left and right, day and night. On top of that she is putting them in her mouth and chewing on them like bubble gum. So after a long battle, we put them in a drawer until a later time. Last night I opened the box they are kept in just to take a peek at her beautiful green eyes. I miss them sometimes. Imagine my surprise when there was only one. So now we are down to one eye, and so far no chance of finding the other. All of which has nothing to do with the current topic, except to think that somewhere in that there has to be a funny story just biding its time.

My point, sometimes you just have to laugh. We need not always take things so seriously. In between IEPs, therapies, specialist, etc, our children's lives revolve around serious people; it is our job as their parents to laugh, to teach them to laugh. Most importantly, sometimes we *need* to laugh.

*The family stories we print are **personal experiences** of members and **DO NOT** reflect the views of the entire MAPS group*

Hummin' & Strummin'

By Jennie S.



Most of us are very aware of the array of therapies commonly suggested, or even prescribed, by the medical and educational professionals involved with our children's care. There is physical therapy, speech therapy, occupational therapy, services from a teacher of the visually impaired, and the training provided by a certified orientation and mobility instructor - just to name a few. For my son Max (almost 4 with bilateral anophthalmia & developmental delays), most of these therapies have not offered much success. In fact, they have been extremely ineffective. Often, the therapist has never met a child who is blind and is intimidated or struggles to make appropriate accommodations to her strategies. Traditional therapies tried so far simply have not considered Max's learning style and have failed to include any of his interests. Because of this, we dropped most of the related services from his Individual Education Plan (IEP) - we saw no value putting him through an experience that has no productive outcome and only causes him stress. However, recently we decided to try an approach that we are so excited about I simply must share it with you - **MUSIC THERAPY!**

Music has played a vital role in Max's life from the day he was born. At birth, I stumbled upon the best way to calm him after HOURS of crying - Bruce Springsteen's Devils and Dust album! I put it on (to calm myself) and instantly he stopped crying. To this day, we never leave the house without that CD. Max listens to a wide variety of music each day, enjoys playing musical instruments, and although he does not speak - he can hum over 100 songs. Clearly, he relates to music. While attending a local conference relating to blindness, we met a music therapist and were fascinated to learn how she uses this technique as a method to help children with disabilities make gains in every area of development. This is not to be confused with music lessons. Through a certified music therapist, specific, individualized educational and developmental goals are created and then strategies, through the use of music, are implemented.

Using music, Max is learning a wide variety of general concepts as well as communication skills. He enjoys the time with his therapist versus simply tolerating or even screaming through the entire session as with previous therapies. His interests are valued and he is able to approach a structured learning opportunity in a fun and meaningful manner - imagine that?! Also, parents are included in the session so we can carry over the strategies at home.

If your child enjoys music as much as ours does, you may want to investigate the following link and learn more about music therapy.

<http://www.musictherapy.org/>

In the United States, this is a recognized therapy by **SOME** school districts, health insurance companies, and state Medicaid Waiver programs that may provide funding just as they do for more traditional therapies. So, grab that guitar, plink on the piano, bang those bongos, or just get crazy with a kazoo - have fun and learn through MUSIC!

Happy hummin' and strummin'!

SPACE CAMP, by Sheila M.



Jason Polansky



Matthew Alvernaz

Have you ever wondered what it is like to be an astronaut? Have you wondered what it would be like to launch a rocket? Have you ever wished you could attend Space Camp? What about if you are blind or visually impaired?

Welcome to SCI-VIS, Space Camp for Interested Visually Impaired Students. SCIVIS is a week long camp that takes place at the U.S. Space and Rocket Center in Huntsville, Alabama, coordinated by teachers for the visually impaired and is accessible to blind and VI students through adapted speech, large print, and/or Braille materials.

Young men from two of our families had the opportunity to attend SCIVIS in the fall of 2008. Both Matthew Alvernaz and Jason Polansky have bilateral anophthalmia. Here are their reports on attending Space Camp.

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Hi, my name is Matthew Alvernaz, and I would like to tell you a bit about my experiences at space camp in Huntsville, Alabama. It took quite a long time to get there, I live in Vancouver, Canada, we had to take 3 air-planes, but it was totally worth it because of all the extremely fun things we got to do when we arrived there.

We got divided into random teams. I got to do missions with my team, some didn't end up working out, like once when we landed our ship while the doors of the ship were still open! We also got to try some space simulators, like moon gravity simulators and other fun things. We made rockets and launched them into the air, mine didn't really go anywhere though. We played games, went swimming once and did a lot of things that kids do at camp.

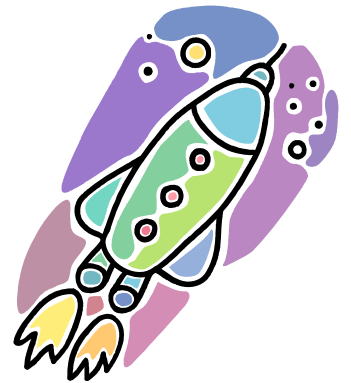
I met tons of kids from many different places in the world, we traded pins and badges. I totally recommend that if you can you should go as this camp is really awesome. I can't wait to go again another year.

Hi my name is Jason Polansky. I live in Thurmont, MD, I am in 7th grade. I had a wonderful time at space camp. One of the favorite things we did was launching a rocket. We had a kit that we put together to make a rocket. Then we took it out into a field and put it on a miniature launch pad and launched it.

Another thing I liked was our pretend mission. We went on a model of a space shuttle and had a script that we followed. I got to be a mission specialist, which I liked because it was hands on, and I like to do experiments. We had to put a new battery in the Hubble Space Telescope.

I won the Max Carpenter award, which is a very special award given to somebody who has a positive attitude and portrays the spirit of space camp. Max Carpenter helped to start SCIVIS when there were only 20 kids and now it has expanded greatly to about 180 kids. Every year they give an award in honor of him. I got a plaque that says Max Carpenter award SCIVIS 2008. We hung it up in my room. Those are some things that I enjoyed about space camp, and I hope to go back again.

For more information about SCIVIS, visit www.tsbvi.edu/space
The 2009 SCIVIS Program will run from September 26 to October 1, 2009 in Huntsville, Alabama. Application forms are now available on their website. And as an alumni on the SCIVIS website says,



"Just because I can't see the stars, doesn't mean I can't reach for them."

MAPS Mission Statement:

MAPS will provide...parent to parent support to others raising children with microphthalmia and/or anophthalmia. By sharing a wide variety of information, MAPS strives to empower parents and reduce the overwhelming feeling of isolation that is all too common when a diagnosis of microphthalmia or anophthalmia is confirmed.

One Family's Experiences With Technology, by Amy H.



A story by a proud mom of a 10-year-old.

Max has anophthalmia and is autistic. He was diagnosed with autism in kindergarten when we realized he was struggling in academics. Even though he was having trouble with Braille we were sure that everything would "click" eventually. We kept trying and kept increasing minutes according to his IEP. In kindergarten he started with 250 minutes of Braille a week and in second grade we were up to 450 minutes a week.

Along with increasing Max's Braille minutes, our IEP team agreed upon having Max repeat second grade. The theory behind this was that he wouldn't have to concentrate on the other work, since he did that the previous year and would really take off with Braille. Well there were definite positives to holding Max back in second grade...he matured a lot that year and his self-esteem soared because he already knew the answers since this was his second time in second grade. He felt good about what he accomplished that year. But he still wasn't any further in Braille.

As a mom you will move mountains to help when your child is struggling. I found out no one really knew what to do with Max. In addition no one was doing any research to try to find out. I stopped relying on school for the answers and started looking elsewhere. I went to my pediatrician, told him my worries, and he put me in touch with a Neurodevelopment Pediatrician. After 4 long months of waiting for the appointment, he told me what I have believed for many years. He said, "If he hasn't conquered Braille yet, he probably won't, stop wasting time and move to technology."

WOW, after all these years someone is finally putting me in what I think is the right direction to help my son. I did my research and found many things to help Max. When I submitted my findings to school, most were skeptical and thought he would never be able to use a computer. They all spoke of his lack of fine motor skills and attention, except for his paraprofessional. She was "all in" and was going to do whatever it took to gain success.

By this time second grade was coming to an end and summer school would be starting in a few weeks. We had started moving full steam ahead with technology. We started by using Dragon Naturally Speaking, a software that Max would dictate all of his information to the computer and it would type everything out on the screen. Due to the reluctance of his Vision Itinerant, his para and I had to load, test and experiment with Dragon. During this time we ran into lots of problems with the school PC running out of memory when the program was running. After many hours of trying different things, we were determined to see this work. Max's para finally tried it on her per-

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Finally, we saw success. He was able to write his very own book report all completely independent. We finally knew that my Neurodevelopment Pediatrician was correct. It was now my mission to get him to use a computer all the time and to find out what other type of software is out there.

Now in summer school we had to find out where I can get the needed technology for Max. The school district was more than willing to get us a PC, but we ran in to the same problems as before. Instead of waiting for school to put more memory in the computer Max was using, I hit the research again. After hour of research, I found Lighthouse for the Blind in Missouri. I applied for a grant, and to my surprise we were approved for more talking software, a laptop computer, and a scanner to scan worksheets to the computer.

In the beginning of third grade, we received the new above items. As you would expect we started using it all immediately. He did great. The new technology helped Max do something he had never done before, grade level work. He was now completing third grade work just like everyone else. This helped Max come out of his shell and show us what he's got. He continued to increase his written communication, which has allowed us to stop receiving vision itinerant services. He is now in the class almost 100% of the time. He continues to practice with Braille, but it is not his primary source of communication. In addition, we started receiving training through St. Louis Society for the Blind to help Max navigate his computer using an application called JAWS. This application allows the PC to tell Max what is on the screen. Max is using his computer for all his work and is doing wonderful. He received his first report card and I was shocked. Straight A's in all subjects and he actually did third grade level work just like all the other kids in class. He is so proud of himself.

I knew Max had this in him and all I had to do was take it upon myself and find out what works. It is important to continue to think out of the box. Don't take no for an answer and latch on to those that are willing to help. Don't give up if your child is struggling, just keep looking for answers and you don't always have to rely on school for help.



We want to hear from YOU

If you have a photo or story idea for a future MAPS newsletter or our website, please e-mail us at owner@maparentsupport.com

ASK THE TVI: Readers Questions answered by Lisa LaDue



Q: My son with monocular vision would like to start soccer in the spring. Are wearing his Plano glasses during practices and games enough protection or does he need sports goggles. If you recommend sports goggles, what are some good brands for a 4-year-old child? I have looked into Rec Specs but they don't come in a size small enough to fit him. Thanks! Maureen Richmond (mom of Morgan w/ right micro).

A: Rec Specs are made to help guard against eye injury. I highly recommend them for anyone playing soccer whether they have a visual impairment or not. Rec Specs have polycarbonate lens material for greater impact resistance. The lenses come in both prescription and non-prescription material. For individuals who are sensitive to light or have photophobia have the option of having the lenses tinted for an additional cost. They can be purchased at LensCrafters ranging between 99.00 and 139.00 dollars. According to LensCrafters, the actual plastic frame is approximately four inches in length, which is the part that fits across a persons face (temple to temple) with an adjustable split head strap to fit any sized head. Another option, buy ophthalmic swim goggles and take them to LensCrafters or any other eyeglass manufacturer and have them put in polycarbonate prescription or non-prescription lenses. When I did a Google search for "ophthalmic swim goggles", a lot of websites appeared .

Q: Child's background: 6 year old boy with bilateral anophthalmia and septo-optic dysplasia (developmental delays include walking and talking and probably cognitive; he is on growth hormone and thyroid medicine, has low muscle tone and is sometimes a little floppy.) He has some sensory issues and tactile defensiveness. He eats pureed foods. He can use a spoon by himself and drinks from a sippy cup. He is not toilet trained yet, though we're working on it. He just started walking on his own in Spring 2007, he doesn't yet produce much "understandable" language though he does try to talk and will try to say anything you ask him to. He loves music, plays the piano, sings, and knows a lot of rhythms to music and learns really well through music. He can follow instructions and seems to understand most of what we say or ask of him. He is definitely not an average 6-yr old level. He is the youngest of five boys, four still at home. His closest brother is six years older. He was in a birth to three program for three years and school district SPED preschool program for three years. He is a kindergartener placed in life skills class and gets no academics, time around "typical" kids, or music. He gets 20-30 minutes per week each in OT, PT, Speech, and 90 minutes with TVI/O&M.. Submitted by Leanne M. Q: Are there any tests out there to determine the cognitive abilities for a blind child with SOD? Or is seeing a developmental specialist the better way to go?

A: Developmental assessment tools are typically used to assess children's skills across developmental domains (i.e. Cognitive, Language, Social, Vision, Compensatory, Self-Help, Fine Motor, and Gross Motor) to determine eligibility for services or to determine children's current level of functioning.

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(Ask the TVI: continued from page 7)

Some of these assessment tools include: The Callier-Azusa Scale "H" by Stillman (1984) which is designed to assess communication, The Callier-Azusa Scale "G" by Stillman (1978) for children with deaf blindness or severe/profound disabilities who are functioning between birth and 6 years of age, Growing up: A Developmental Curriculum by Croft and Robinson (1984) is a assessment tool and curriculum guide that looks at skills in children from birth to 6 years of age, The Oregon Project for Visually Impaired and Blind Pre-school children by Anderson et al. (1991) is a comprehensive assessment and curriculum designed for children birth to 6 years of age, INSITE: Assessment of Developmental Skills for Young Multihandicapped Sensory Impaired Children to provide a comprehensive assessment for young children with multiple disabilities and sensory impairments (the long version for birth through 6 years). The Battelle Developmental Inventory by Newborg (2004) is a norm-based standardized developmental assessment for children birth to 8 years of age. These are some of the more popular ones that we use with our children but there are also other assessment tools.

Q: What are some key things I should be doing or teaching him at home?

A: Since he is working on his language skills reading is an excellent way to increase literacy skills. For example, the book Mother Goose is fun to read because you can recite or sing rhymes. Many of the rhymes include gestures and movement, which make it more captivating for children. Some other strategies to promote learning in the home include, using simple puzzles, puppets, painting, musical instruments, and coloring, making up songs, blocks, and water play. Another fun activity, take a walk in the park and collect items that you would typically find in a park (leaf, stone, grass, pine cone, stick, and a fallen branch from a tree) then back at home make an experience book. These are done by gluing each item on a page or staple a small baggie on each page and place the object in it. Next, using your son's words, write on each page, his experience and thoughts related to that particular item. Experience books are personal and special because they describe the child's interests. In addition, experience books encourage children to use all their senses. Furthermore, they promote concept development and involve children in the whole process from the beginning to the end.



San's Adventures on Sleipnir Morgan Horse Farm



By Britta Denman
Photographs by Elizabeth L.D. McGee

San's Adventures on Sleipnir Morgan Horse Farm is a wonderful new children's book about a dog born with bilateral anophthalmia. Written by Dr. Britta Denman, this book follows the adventures of San, a real dog who, as the book says, "doesn't look like most dogs. His legs are a bit too short for his body. He has knock knees and he was born without eyes."

The story follows San as he explores the farm, scatters the cats, runs through the leaves, plays with the other dogs, visits the horses, chases the guinea hens, and genuinely has a dog-gone good time. The book is also filled with real photos of the real dog San.

San's book is available for \$6.95 at Amazon.com or from his own website, www.santhedog.com

A portion of the proceeds from the sales of the book benefit the charity MEDICA XXI, a not for profit charity co-founded by Dr. Denman.