

MICROPHthalmia



ANOPTHALMIA



PARENT



SUPPORT



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MAPS - *Finding Our Way*

www.maparentsupport.com

VOLUME I, ISSUE I

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Welcome to our first MAPS newsletter

MAPS would like to say “**thank you**” to everyone who has helped us to get our name and new website “out there.” A special thank you to those people who have submitted stories or photos to add to our site. We’ve truly enjoyed getting to know more about all of you.

The MAPS family is an extremely diverse group, including people from many different countries, nationalities, faiths and religions. Many of our family stories, telling of the challenges and JOYS of raising our children, are written by our diverse members. We welcome any and all to join us and share your family’s personal experience with microphthalmia/anophthalmia. The best part? Membership is FREE. Please visit our website www.maparentsupport.com for more information on how you can start benefiting from the support system of the MAPS family today. Please feel free to print and share copies of *Finding Our Way* with anyone you think

might be interested in learning more about MAPS.

Connections. Community. Understanding. Experience. Encouragement. Resources.

That is what MAPS is all about.

From our family to yours,

The MAPS Founding Moms

Max’s mom, Amy (Missouri)

Ivey’s mom, Gwen (Georgia)

AJ’s mom, Heidi (Mass.)

Max’s mom, Jennie (Virginia)

Ella’s mom, Jill (Ohio)

Ava’s mom, Megan (Pennsylvania)

Matteo’s mom, Michelle (Mass.)

Grace’s mom, Sheila (Washington)

Emma’s mom, Tera (Texas)

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

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.

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

Your baby has Anophthalmia

By, *Gwen S.*

(at right) Ivey Elizabeth, in her mother's arms at the beach.

"Only time has allowed my heart to heal so that I can accept Ivey's uniqueness."

-Gwen

Your baby has anophthalmia. Now what? I could sit back and tell you what I personally think you should do, but that is not what you want to hear. So, I will tell you the one thing that I can, what our family did once our daughter was born. You will find that my story is very similar to your own. That is how it is among the members of MAPS. We are all from different places with different components to our families, but we all have the same tie that binds – blind children, our noticeably defined blind children.

My 'Now what?' began as a complete surprise. Ivey was my third child. There were no complications. This is where I could tell you everything will work out fine; there is a purpose for everything, blah, blah, blah. Who are we kidding here? That is definitely not the way it happens. Now, if you are new to this anophthalmia thing, you may or may not agree and if you have already been there, well, most of us do agree upon this next point. Finding out that your child has anophthalmia is a tragic, and I will repeat, a *tragic* moment. It is one moment I will never forget and a moment I never want to relive. Consequently, it is the most *life altering* moment in my life. Guess what? It is okay to feel that way.

What counts now that you are facing new obstacles that you never dreamed your child would have, is how you handle the day after finding out...and the next day...and the next day. All of us here at MAPS have our own ways of coping, but that is the key. We have all found our own means of facing and RISING up to the

challenge.

Figuring out *how* is the hardest part. Initially the shock of the situation almost suffocates you to death. You pretty much don't function outside of involuntary bodily activities. Sleep is impossible. So then you become even more delirious from exhaustion. Right? At some point in time you must move forward. I would say that it requires an undeniable jolt of some sort to zap you back



into the world of the living.

My moment came with a phone call. A friend with a special needs child called me within weeks of Ivey's birth. One, she wanted to congratulate me on Ivey's birth because she (from her own experience) knew that most people had not thought to considering the magnitude of Ivey's medical situation - everyone was in shock. Two, she offered me very tough words that I needed to hear, and the sooner the better. Anophthalmia was

not about me; it was about my daughter. She said, "I don't feel sorry for you. You don't have a choice now. You will get through it. You will do it for Ivey." At first I was stunned, then I realized – she was right.

Through the year we have faced many obstacles that would have never happened had Ivey been a normal child. Our family has adapted to having a home health nurse in our home eleven hours out of the day. We have learned to juggle two sons along with Ivey's medical trivia. We have found ourselves becoming giddy about picking out Ivey's eye color. Seriously, there is a perk. How many parents get to choose their child's eye color? Of course, there is also the ever present battle with the insurance company. The list goes on and on.

Now our family has grown accustomed to having a blind baby around the house. The newness has worn off and she fits like a worn shoe. Of course when we leave the walls of our home, she is still something to see. People do stare and ask questions, but that's okay. Only time has allowed my heart to heal so that I can accept Ivey's uniqueness.

She was not the package I had expected at birth, but now that she is here I can not imagine Ivey any other way. She is Ivey; a one and a half year old blonde baby girl with anophthalmia.

DuPont Case reaches settlement *By, Sheila M.*

MAPS recently became aware, through news articles published in the United Kingdom, that The DuPont Corporation has reached a settlement with some families of children born with anophthalmia and/or microphthalmia. You can find links to these articles on the MAPS A/M News Stories page:

http://www.maparentsupport.com/am_news_stories

In an effort to learn more about this settlement, and what it may mean to other families of children with anophthalmia and/or microphthalmia, MAPS contacted The Ferraro Law Firm in Florida, who represented the families in these current cases. In our conversation with Lynn M. Sasso, an attorney with the firm, we learned that this current settlement involves individual legal cases that have been pending since 1997. This was not a class action lawsuit. Although Ms. Sasso could not discuss specific details of this confidential settlement, we learned some basic background about DuPont, and the chemical Benlate.

Benlate is the registered name of a DuPont fungicide, containing the active ingredient Benomyl. According to the DuPont website, Benlate was introduced in 1970, and was registered worldwide for use on many crops

until DuPont ceased production of it in 2001. According to Ms. Sasso, in the United States Benlate was only used in commercial agriculture, while in the United Kingdom this product was available for home use and could be purchased by individuals at their local garden store. This difference in availability of Benlate helps explain why, in the legal cases brought against DuPont by families, the majority of families lived in the United Kingdom or New Zealand, and only one family lived in the United States.

The United States case was the only case against DuPont relating to Benlate and children with anophthalmia and/or microphthalmia to go to trial. In this case of Castillo vs. DuPont, the Castillo family was awarded a \$4 million verdict, following a jury trial in 1996. During the trial, Mrs. Castillo reported that she was sprayed by a mist of Benlate while pregnant, during a visit to a commercial farm. Mrs. Castillo's son was later born with bilateral anophthalmia. The current legal settlement being mentioned in news stories involves 32 families from the United Kingdom and New Zealand, where the families could document that they used Benlate during pregnancy and their children

were later born with various degrees of anophthalmia and/or microphthalmia. In these cases, the DuPont Corporation has agreed to a \$9 million settlement, divided between the 32 families. According to Ms. Sasso, there was no admission of guilt by DuPont in these 32 legal cases.

When Ms. Sasso was asked if there was a possibility of other families taking legal action against DuPont she stated that if families have been aware of the possible issue of Benlate being implicated as a cause of anophthalmia and/or microphthalmia, and have not yet taken any step towards legal action, then it is probably too late. There is a 2 year statute of limitations in cases such as this, which means that if a family suspects exposure to Benlate during pregnancy, they must file within 2 years of when they first heard about Benlate being suspected as a possible cause. If families have been following these cases for years, without filing suit, it is most likely too late to do so now. Since DuPont stopped production of Benlate in 2001, this could also only involve children born close to or prior to that date.

If any families have further questions about this issue, they may contact their own attorney, or they can contact The Ferraro Law Firm via their website at <http://www.ferrarolaw.com/>

Getting Connected

We have some great ways that you can connect with parents and/or others going through the same thing you are right now. **One:** Check out our website at www.maparentsupport.com. Read our stories. Marvel at the photo galleries. **Two:** There are a couple of excellent, active message boards on Yahoo. They are for moms and dads of children, ages infant to adult, as well as teens and adults living with microphthalmia/anophthalmia. If your child has bilateral anophthalmia or microphthalmia and is totally blind there is also a

private (unlisted) group on Yahoo. Besides parents of blind children, members include blind adults, some parents of blind adults, as well as



some blind teenagers. If you would like to join this group please send us a message through our contacts page on our website, or send an email to owner@maparentsupport.com,

requesting an invitation to this group. We currently have 100+ families, all dealing with bilateral anophthalmia/microphthalmia and total blindness, and we welcome **all** new families/members!

If you are already a member of this group, you can visit it at: <http://groups.yahoo.com/group/bilateralanophthalmia/>

If your child has unilateral anophthalmia or microphthalmia, or has limited vision, there is also a public support group on Yahoo. You can join this group by visiting: <http://groups.yahoo.com/group/Microphthalmia/>.

Join a group today and start connecting.



AJ, wearing his prosthetic shells.

“This may not be the fantasy life I had planned out for myself but it is the one God chose for me.”

- Heidi

We Call him AJ

By, Heidi S.

When I was a little girl, I fantasized about growing up, getting married and having children. In my mind I had the perfect family life all planned. I would have two boys and two girls. As it turns out, I didn't get married until I was 32 and my first child wasn't born until I was 36. I had a beautiful baby girl and I named her Laura May. Three years later I gave birth to my equally beautiful son named Aaron Joshua. His dad wanted to call him "AJ" so we had to pick a first and a middle name that started with an "A" and a "J". All through my pregnancy for AJ I felt that something was very wrong. My husband told me later that as soon as he knew we were having a boy that something was going to be wrong. Oddly enough, we never told each other until after he was born.

We noticed right after AJ was born that one of his eyes didn't open. Our family doctor checked it and said he thought it would be fine. It kept nagging at us though so we mentioned it again at his two-week check-up. The Doctor decided to send us to see a pediatric ophthalmologist just to make sure everything was okay. We went the following week. Both my husband and I knew that something wasn't right but I thought it was just the one eye so I had convinced myself that that was okay as long as he still had one, he could see. When we got in to see the specialist he was very business like and wasn't saying very much as he examined our son. My husband held him still in his lap and I sat in a chair in the corner of the room with tears streaming down my face. Then we heard these words, "Yup, he's blind in one eye, probably blind in the other. He may have brain damage so you should get an MRI". Just like that! Talk about a train slamming into a brick wall!

After that, I cried every night as I held AJ in my arms to feed him his bottle. I did this for about three months as I prayed to God to please let AJ be happy. I just couldn't imagine at that time how he was ever going to be happy about anything. Finally, I stopped and realized that feeling sorry for AJ and myself wasn't going to help us at all and I started to accept the situation for what it was. I vowed not to treat him any differently and that I was going to do everything I could to make his life as normal as possible. The next thing I knew, we were making an appointment to see another pediatric ophthalmologist at Boston Children's Hospital and having an MRI done in a few days. I remember my husband and I sitting at the end of the MRI machine praying for the entire hour that it took to do the test. After it was finished, they told us they needed to do it again because he moved too much the first time. So we sat and prayed for another hour. Results came back

that AJ had microphthalmia in both eyes and no optic nerves. They told us he had no brain damage and we were extremely grateful for that.

At Boston Children's they confirmed all of this and told us they would see us every 6 months for a year or so. In the mean time, we found out AJ needed to have a brain stem hearing test done and an ultra sound on his kidneys. Both came back normal. We went to see a geneticist and they took a blood sample from AJ but no one else in the family. They never got back to us and it took a year of hounding them just to find out they didn't know anything. We decided not to pursue that for the time being and to wait until both kids were older.

At 2 ½ AJ had an eye exam by a different doctor in Boston and this one suggested prosthetics. The one before said he didn't need them. So we were referred to Jahrling Prosthetics, also in Boston, and they were wonderful! We had to have molds made in the hospital because AJ was too young to sit still for them. Our first set was clear and then we got the painted ones a couple of months later. WHAT A DIFFERENCE! It brought tears to our eyes. Up to that point in time, we had not noticed how much different AJ looked until we had that first set of shells put in. Now, we had to learn to put them in and take them out. This was one of the hardest things we had to do because AJ hated it when we did this. He has since been wearing shells for about 3 ½ years and we have gotten quite used to taking them out and putting them in. AJ even sits still for them now.

A year later we saw a new intern at Boston Children's and this one said he had studied this particular eye disease in England for one year. He asked about AJ's growth and was astonished to find out we had not been referred to an Endocrinologist. You can guess what came next. We saw the Endocrinologist and he determined that AJ was on the low end of the growth chart for height and weight but as long as he was on the chart, he was not concerned. We go back once a year to keep track.

We have just finished up 3 years of public preschool where AJ had speech, occupational therapy, vision and physical therapy. AJ didn't walk or talk much until he was close to 3 years old. He has developmental delays but is making steady progress everyday.

AJ IS A VERY HAPPY LITTLE BOY and loves to sing and play the piano. He has perfect pitch and can play most any song he hears right away! This may not be the fantasy life I had planned out for myself but it is the one God chose for me. I believe all children are a gift from God and I am honored to have my two wonderful children entrusted to my care.

Ella's Story

By, Jill I.



Ella Elizabeth,
with her first
pair of blue
prosthetic eyes.

I took a picture of the little home pregnancy test. I had started buying the high tech ones that actually say “pregnant” or “not pregnant.” And *Pregnant* was staring me right in the face. Truth is, I had stared at *Pregnant* **three** times before in the past two years. And each of those times had ended abruptly with no explanation and the mind numbing loss from yet another miscarriage. But on that chilly November morning, I felt much different. Less guarded. More excited. I had a peace right away that I would see this pregnancy through to the end. I would finally hold that sweet baby in my arms we had waited so long to have...and fought so hard to keep. Jeremiah 29:11 had been my inspiration. **“For I know the plans I have for you,” declares the Lord. “Plans to prosper you and not to harm you, plans to give you hope and a future.”** I nearly knocked my husband out of bed as I bounced around waving the test in the air and thinking...**FINALLY!**

Considered “high risk”, I had nearly 20 ultrasounds during my pregnancy, including a Level 2 and a 3D ultrasound. I would leave every appointment with another fuzzy black and white photo of a little peanut dancing around, body parts labeled...chin, arms, legs, face, eyes. Everything always looked normal. I continued to glow as summer arrived – loving every little thing that I was able to get away with and simply blame “being pregnant.” On June 23, 2006, at 34 weeks, little Miss Ella decided it was time to make her grand entrance.

Surprise, Surprise!! The nursery furniture had not even been delivered yet. Every shower gift was still in its box. I had nothing organized! ***Wait!!! I still had six weeks!!!!***

As I was just finishing that thought, Ella was placed in my arms in the delivery room and we stared down at our daughter...drunk with love and affection for this little person we had just met. She kept her little eyelids closed tight. No big deal, right? Not every baby opens their eyes in those first few minutes. *Right?* In a flash, she was taken from me and placed in the NICU where I later visited and wondered why she had not yet opened her eye lids. I gave every excuse. She is so early...she is still so tired from the delivery...she is soooooo sleepy. The nurse left and I was alone with her for a moment. I touched her face, her eyelids. I felt nothing behind them. No. Oh, no. How could this be? I thought for sure with all I had been through, I would have to be a top candidate for a perfect baby, right? ***How could this ever be the plans the Lord has for me?*** I simply prayed that I was wrong.

The next morning when the Doctor confirmed by MRI that Ella was indeed born without both eyes, I felt even the sturdy concrete of the hospital hallway was not going to be enough to hold me as I slumped slowly down the wall. My body shook with tears of sadness and confusion. We were also told that she could possibly have brain damage, hearing problems and heart issues. **“Plans to prosper me and not to harm me?”** I did not think I could take this news. My brain would simply not process it. I wept freely at the death of so many dreams I had for our first child.

We would be transferred in two days to the Children’s Hospital at the University of Michigan where some of the worlds best Ophthalmologists, Cardiologists and Neurologists would access our little girl. I felt as if I might not even last for two days. Back in my hospital room, our friend Lucy Ann was waiting. She had traveled a great distance to see us and our new baby. I felt like I could not face anyone. But, the instant I saw her, I suddenly realized very clearly that I had only two choices. Spend the rest of my life in denial, hiding from people, or embrace the life that the Lord has in store for my family. I know that God sent Lucy Ann that day to help me come to this realization. As she hugged me tightly, I prayed for the strength to face the dark cavern of unknown that lie ahead. The specialists at Michigan ran tests to quickly rule out brain damage and deafness. We were told that the two small holes in her heart would most likely close with muscle growth and that her condition was “isolated” to her blindness. They simply wanted to keep her in the NICU at Michigan until she could eat on her own and gain some weight. **She was healthy!** We had researched her condition, bilateral anophthalmia. We spent hours learning to spell & pronounce it correctly. We made an appointment to see the Ocularist at the Kellogg Eye Center. We were pressing ahead. In mere days we had gone from terrified and unsure to knowledgeable and confident. This much I know is true. God not only held us. He cradled us in the palm of His hand the whole way. **“Plans to give us hope and a future.”** We found comfort in Him even though we were still wondering why He chose us. I recalled the truth of a passage from the book “Let’s Roll!” by Lisa Beamer. It reads: **“The plans God has for us don’t just include “good” things, but the whole array of human events. The “prospering” He talks about in the book of Jeremiah is often the outcome of a “bad” event. Many people look for miracles. Things that in their human minds “fix” a difficult situation. Many miracles, however, are not a change to the normal cause of human events; they are found in God’s ability and desire to sustain and nurture people through even the most difficult situations.”**

I will admit that at the time, I desperately wanted a “fix.” I wanted my little girl to be perfect. What I didn’t realize then was that she WAS perfect. IS perfect. Perfectly the way God created her. I love my daughter so much at times I feel as if my heart might burst right out of my chest. I am so incredibly proud at her accomplishments in her short 14 months of life. She laughs out loud all the time. She leans in to give you kisses on your lips. She puts her little hands over her prosthetic eyes to play peek-a-boo. (really...how the heck does she know to do this????!) Talk about amazing us at every turn. But please don’t get me wrong...there have been & will be many, many times I have ached with pangs of grief at what she will never visually experience. A beautiful sunset over the vast ocean. The raw beauty of a snow capped mountain range. Her Daddy’s handsome face. Not one of us can know why God chooses to give people certain abilities...and chooses not to give those to others. We received a card when Ella was born that contained this quote from Alan Redpath. I am not sure if the person who sent it will ever know how much peace it has given us. **“There is no circumstance, no trouble, no testing that can ever touch me until, first of all, it has gone past God and Christ right through to me. If it has come that far, it has come with great purpose, which I may not understand at that moment. But, I refuse to become panicky, as I lift up my eyes to Him and accept it as coming from the throne of God for some great purpose of blessing, to my own heart.”** Ella has blessed our hearts so much more than we could have hoped or imagined. She teaches us about things that we sighted people take for granted. She is our perfect first child...the one we had prayed for, fought for, dreamed about and loved for so long before she was even born.

**“I will admit
that at the
time, I
desperately
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I wanted my
little girl to
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- Jill**

Please visit our site -
www.maparentsupport.com



Coming Up...in our next issue:
A look at life through the eyes of an Ocularist

**** Check it out ****

Here is a website that we think is really cool.

Check out www.seedlings.org.

It is a great site that offers low cost Braille books for children. On the left-hand side of the homepage, click on "Special Projects."

Next, click on "Anna's Book Angel Project" for a chance to win a **FREE BOOK**.



MAPS...Questions & Answers

MAPS recently sat down for an interview with a relative of one of the Founding Moms. His name is John Pitzen and he was born with bilateral anophthalmia and wears beautiful green prosthetic eyes. John (JP) is 53 years old, and lives on his own in Toledo, Ohio.

MAPS: Please explain your current job in detail and what devices you use to assist you in your job.

JP: I am currently self-employed and I work at home. My job consists of transcribing reports for a psychologist who interviews and tests people who are applying for Social Security disability benefits. The psychologist dictates the reports on tape and brings the tapes to me. The tapes are played on a transcription machine and I enter the information into the computer. I am able to proofread the reports by using the Job Access with Speech (JAWS) screen reader. This program sends the text in the document to the voice synthesizer built in to the sound board which converts the text to speech. JAWS also works well with spell check and other functions. The reports are printed with an HP Office Jet which acts as a printer, fax machine and scanner. I can scan printed material using the scanner and the OpenBook program which converts the printed material to speech. When the psychologist brings more tapes, he checks the printed reports for any mistakes. Then I fax the reports to the Bureau of Disability Determination. I use a Braille writer to label the back of each report with the name of the client and the appointment date. This makes it easier to find a report since scanning a page takes more time than reading the Braille. Prior to my current job, I transcribed medical records. Prior to that, I transcribed reports for the Work Evaluation Department at Goodwill Industries. In the past, I worked in the Industrial Contract Department at Goodwill doing some assembly work.



John Pitzen holding Ella

MAPS: Give your honest feelings about being a blind adult in today's society. For you, has it been easy or hard and why?

JP: I have been blind since birth, and whether it is easy or hard depends on the situation. Assistive technology enables a blind person to do many things now which were difficult or required the help of a sighted person in the past. Talking watches and clocks help a great deal. Braille clocks and watches have been around for a long time, but they can be easily broken. I have ruined a few Braille watches by checking the time with dirty fingers. Paper money identifiers now make it possible to determine the denominations of bills without assistance. However, these devices usually don't work if the bill is slightly worn or wrinkled. Transportation is another problem. The organized blind movement has made a lot of effort to convince the airlines that blind people don't need wheelchairs unless they have an additional disability. I hope they finally got it!

MAPS: What are some things you enjoyed doing as a child?

JP: Some of my favorite things as a child were listening to music, swimming, and riding roller-coasters. I always liked the rides that nobody else could stand. Someone would usually agree to get me seated on the ride and meet me when the ride was over. After waiting in line, sometimes for two hours, the person usually felt too embarrassed to walk away, so they got stuck going on the ride with me.

MAPS: What are some of your favorite things to do now, as an adult?

JP: Two of my favorite things are going on-line to get the latest news and listening to talk radio, especially Rush Limbaugh. I really enjoy listening to music and playing the organ. I also have three cats that occupy my time.

MAPS: How do you best get around? Guide dog, cane, echolocation, etc?

JP: When going anywhere by myself I usually get around with a cane or with the assistance of a sighted person. Sound cues can also be beneficial.

MAPS: What advice could you give to parents of young blind children today?

JP: There are a lot of issues, but one seems to stand out. When talking to a blind person, there is no need to avoid using common expressions such as, "See you later," or "Are you seeing anyone?" You wouldn't say, "Let's go and hear a movie." To see doesn't necessarily mean to perceive something with your eyes. Blind people see in different ways. Avoiding the use of common everyday expressions doesn't help and only makes for awkward conversation. Also, I have heard people say that when you're blind, you can't be prejudiced. After thinking about that for a while, I don't believe this is entirely true. While I don't profess to be an authority on the subject, it seems to me that most hatreds and prejudices have little or nothing to do with skin color. Prejudice is usually passed on from parent to child, even if it is not intentional. Parents who don't want to pass their old prejudices on to their children should keep in mind that sensory impairment does not make the child immune to this.