

# Reaching Out

People Helping People

The WAGR/Aniridia Network

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**Nicholas - 3 yrs.**

Where has the time gone? Just want to say a quick hello to everyone. Hope all is well with you and your families.

Fall is in the air, at least up here in Michigan. I fear that winter will not be far behind.

Nicholas and Ashley are both settled into school now. Ashley started kindergarten this fall and loves school. Nicholas has made the adjustment to school life very nicely as well.

Nicholas attends preschool 4 days a week. He rides the bus to and from school and looks forward to it now. He gets a home visit every Monday.

The views expressed in the Reaching Out Newsletter do not necessarily represent the views of the Coordinators, Professional Advisors or the Reaching Out members. Check with your doctor before trying anything new with your child.

We are noticing changes in Nicholas almost every day. His speech continues to progress wonderfully. I always knew he had it in him, it was just up to him to decide when the time was right.

He is becoming more independent each and every day. He is always saying "By Myself" and loves doing things for himself. Boy, it's true. Kids, they grow up so quickly.

It's been nice hearing from all the new families interested in the Reaching Out Network. To you, we say WELCOME!

This issue is packed with stories from families - parents and kids both willing to share their lives with us all. I would like to thank all of them for without them this issue would not have been possible.

I would also like to encourage everyone to participate in whichever way, shape or form. Not everyone is ready or feels comfortable in sharing an article for the Profile section. However, if you run across a nice poem or article you think may be of interest to our readers, please pass it along. We welcome any and all feedback.

In this issue I have included some questions posed to me from two parents looking for answers on

different issues. We would love to hear from families that may be or may have similar experiences. Please pass along your answers so that I can include them in a future issue of Reaching Out.

Are you a parent with a particular question or concern that our members may be able to help resolve? Please pass it along. You do not have to include your name.

I hope everyone has had the opportunity to take a peak at the web site. I will be making some changes in the weeks ahead, adding some color and a few graphics. Our site is meant to be informative not entertaining, so I am going to keep it as simple as possible.

Well, I hope everyone has a Happy Halloween, Happy Thanksgiving, Merry Christmas and Happy New Year. We will talk to you again in the new millennium - 2000. Take care, and God Bless.

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## PROFILES

**M**y name is Mechelle Morgan and my husband's name is Joe. We have been blessed with two children.

Our daughter Kalee is three years old and our son Michael is seven months old.

I had a semi problem pregnancy with both children. However, with my son I was placed on bed rest from 28 weeks on.

I went into premature labor twice with him and luckily I was able to go full term and delivered only two weeks early.



### **Kalee & Michael Morgan**

When my son was born my husband and I both noticed that his pupils seemed to be dilated, but it had been a while since we had a child, so we assumed it was something that developed over time.

Numerous doctors had looked at our son and flashed lights in his

eyes but no one seemed to notice anything wrong. I took that to mean everything was normal.

Michael had been getting sick all week and it had continued into the weekend so I took him into the ER to make sure he was not dehydrated. It was there at the ER, that the physician noticed that something was wrong.

Dr. Sperring, the pediatrician, sent us to a Pediatric Ophthalmologist, in San Diego, CA.

He had already been informed about what was going on and once he looked at Michael he knew that what he had thought was correct.

He told us that Michael had aniridia and based on the information that we had given him, it appeared to be sporadic aniridia.

They sent us right over to ultrasound. Michael has had three successful ultrasounds.

At first we were crushed and didn't know what to expect. We immediately got online and thus met the aniridia group. Or at least a couple of members.

We have seen a genetic specialist in San Diego and he told us that Michael is not missing the 11p-chromosome and that the only side effect that we really have to worry about is the Wilms' tumor.

I know that our case is nothing compared to some of the stories that I have read, but I wanted to introduce ourselves to everyone and say thank you to those who were there when we first found out.

Everyone has been so patient with all of our questions, and we have had many.

If it weren't for Annie and Hannah James my husband and I would have worried for so much longer. They have really helped us to know what life might be like for our son and given us unlimited support.

Thank you and please feel free to ask us anything and we will help in anyway that we can. We have access to outstanding medical facilities. Maybe we can get answers to some questions.

### **Written by: Mechelle Morgan**

**A**lexander was born on March 9, 1984 in Richmond British Columbia, Canada. First born son of Evelyn and Cesar Romero. Evelyn had a normal pregnancy; she does not smoke or drink.

When he was born, the first thing we noticed was the ambiguous genitalia. He was transferred right away to the Sick Children Hospital in Vancouver.

Because my wife lost so much blood from the forceps delivery, she stayed in Richmond hospital for another three days before joining Alex.

We were fortunate to have a care by parent ward so we were able to take care of Alex while he was recovering from jaundice.

In Vancouver sick kids hospital, a team was formed to examine him.

The team was composed of a geneticist, endocrinologist,

urologist, brain specialist, social worker and others.

They took a biopsy of his skin to be analyzed to determine the cause of the abnormality.

After three months of waiting we discovered that he had 11p deletion. During that time, we never suspected that there was something wrong with his eyes. We thought that it was normal for his eyes to flicker until one day I was playing with him and I noticed that he had no iris.

We went to our doctor and we were referred back to the children's hospital. Now the team of doctors included an eye specialist.

After the examination, we were told Alex had aniridia and nystagmus. His condition was so rare that only one other girl had it.

We were referred to the Canadian Institute for the Blind. We were able to meet with the girl and her family. She was around 10 years old then and attended a regular school. She could read but very close and she had no mental retardation.

When Alex was around 10 months old he still could not stand or walk. We took him to the group again and another member was added, this time, a physical therapist.

I had to massage and stretch Alex's legs 3 times a day. He finally started to walk when he was 14 months old.

His speech was limited to several words like dada, appo juice, mama and others.

He progressed like a normal child and loved music and dancing. He developed asthma. At the age of two and one spring he had an attack that required an overnight stay at the hospital.

We moved to Bakerfield, California when Alex was 4 to change the surroundings. After one year we moved back to Canada to be near to the University of Waterloo, a low vision clinic.

Alex attended St. Anne's school. His learning disability surfaced when he was in grade 2 and the school assigned a special needs teacher.

He was well liked in his school and respected by both teachers and students. During his grade 7 and 8 he even helped the younger special needs children.

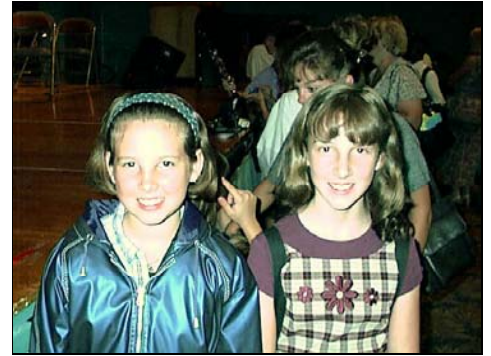
Now Alex is attending grade 10 at St. Mary's high school in a modified program. He stutters when excited and he still has problems reading and writing.

Alex attends music therapy that includes piano, voice and drums. He gives mini concerts twice a year usually before Christmas and the summer.

He loves cooking and car maintenance. He is taking cooking lessons and auto mechanics in high school.

Alex is in the process of forming a rock and roll choir, which he will be singing his favorites songs of the 60's & 70's.

**Written by: Cesar Romero**



**Kristi & Kori Thompson**

**H**i, my name is Gina Thompson and I have a 14-year-old daughter with bilateral sporadic aniridia.

When Kori was born, being a young mother, I noticed Kori's eyes, but didn't think anything of it. I thought newborn pupils were supposed to look enlarged.

It wasn't until my friend had her baby two weeks after Kori was born, that I noticed her eyes. I was surprised then, that the pediatrician didn't notice it either.

When Kori was three months old, I took her to see an ophthalmologist. He told me that she would probably have poor eyesight when she got older and have to wear special lenses.

So far Kori's eyesight is not perfect, 20/30 in the right eye, and 20/25 in the left. She does not need to wear prescription glasses. However, she does wear sunglasses in the sun and colored contacts.

Kori also has pressure checks in both eyes, and she had her last renal ultrasound in September. The radiologist and pediatrician agree that Kori doesn't need

testing for Wilms' tumor anymore, because of her age.

The only other thing the doctors are keeping a watch for is her short stature. Kori is very tiny for her age.

She gets her height and weight measured every 3-6 months. Her pediatrician wants her to see an endocrinologist, as Kori is 4'8" and weighs about 80lbs.

Kori has three younger sisters, which aren't effected by aniridia. Kori enjoys drama at school, playing the flute, and swimming. Kori goes on to live her life as a normal teenager.

**Written by: Gina Thompson**

### **My Least Restrictive Environment**

**Written by: Caroline Larson**

(Caroline is in the 11<sup>th</sup> grade at the Tennessee School for the Blind in Nashville, TN. As part of a military family, she has experienced every type of school setting available to someone with special needs –from inclusion/regular education to this institution.)



**Kelly, Len & Laura Trout, Caroline Larson**

It's Sunday afternoon, and I am packing my bag to go back to school. My dad will take me to school, and then pick me up again on Friday morning.

I live in a cottage with other girls and house parents. My cottage is like being in college. The house parents can be really strict —they go by the rules! But we have cottage meetings so we can work out any problems.

My friends are *pretty cool*. I have the perfect roommate, her name is JoAnn. We all joke around and have a good time going to the mall together and stuff.

My school is pretty cool. The teachers in regular school don't have as much time to help each individual kid. Their classes have a lot of disabilities. The teachers here are willing to help because they have really small classes.

I'll be swimming at school this week, also going to classes. In the evenings I am pretty busy. On Monday I have Girl Scouts or Adopt a Grandparent, (visiting at a nursing home).

Wednesday I get to tune in to my weekly dose of Dawson's Creek. Wednesday is also Date Night.

This Thursday my cottage is going to the mall with the house parents. I can't wait to spend some money!

Also this week I'll start my job. I bus tables in the cafeteria after breakfast. It's no much fun, but I'm not going to do it for a living!

I get paid by the Lion's Club, \$2 an hour. I save the money for things

like my 19" TV, clothes or CD's. I am really into music, especially the Backstreet Boys, InSync, Britany Spears, Joey McIntyre and Jordan Knight.

All around, we have a good principal and good teachers, pretty good everything. I don't love the food though! But I am on a special diet now, so I guess that's why.

This is the best school I've ever been to!

Caroline inspired this poem when she was only two years old....

Caroline  
Like a stream splashing  
Down a mountain  
Sparkling water past bitter snow  
Like aspens in the fall  
Glorious yellow leaves  
Dancing bravely  
Born in the time of wildflowers  
Such fragile life makes  
Simply living  
A tender joy  
For Caroline  
Winter is ever lurking  
But always  
Ever within her  
Ever a wonder  
Invincible streams flow  
Bright leaves dance  
And wildflowers bloom





**“Time and Space”**

Winning Entry 1999 – Helen Keller National Art Show.

**Painted by: Caroline Larson**

***Congratulations Caroline!!!***

Independence, we all want it in any way shape or form. Independence from our parents, from the government, from anything that keeps you down.

When assistance is given we resent it. When can we tell when help is needed, or when we want to fend for ourselves?

I have been legally blind for fifteen years. I have never known any other way of life. I go to my local high school and attend mostly honors classes.



I participate in marching band, and I like to swim. How did I do this? With lots of help from others and a

little independence. Why do I do this? Because I know that I have lots of people behind me that believe in me and are ready to help in anyway.

My parents, my friends, and teachers. Learning to ask people for help is hard, especially in my case. Some people are sympathetic, too sympathetic sometimes.

Most people are unsure about what to do and are nervous. I have to depend on other people to stay in the circle.

I rely on people saying out loud what is on the blackboard and what a sign that is too far to read says.

Sometimes it is a scary feeling. Feeling out of place in a whole world revolving around you. Especially when you know it is there but you cannot see it.

Yes, my life is hard. I work twice as long and hard as most people do. I put in three times as much effort. But, I love my life. It is all I have known.

**Written by: Brooke Hedrick**

**H**i, my name is Jill. For those of you who do not remember my last article, I am a 37-year-old aniridic who also was born with congenital glaucoma. I also have a handsome 10 year old son named Michael, who also was born with aniridia, but has been spared so far from the glaucoma.

My eyesight while I was growing up always required glasses,

contacts, and visual accommodations.

When I was about 16 or 17 years old doctors noticed that I had scar tissue starting to develop. It was not in my “field of vision”, but off to the side.

It was explained to me, that aniridia carries with it a characteristic known as “corneal degeneration”.

My eyesight was monitored, and over time it kept growing towards that “field of vision” they kept talking about.

Years later, after I had gone through my divorce, I went back to college to finish my degree. I was about 28 when I started back and realized I was having a harder time seeing things, especially print. The scar tissue had grown into my field of vision. Nonetheless, I kept on so that I could provide a good life for my son.

I finally completed my degree with a 3.1 grade point average. By this time, I was consulting with corneal specialist to find out if I could get the scar tissue removed.

I went to several doctors. A couple told me that a corneal transplant was very high risk for aniridic patients and that they had about a 50-50 chance for success.

Upon investigating, the 50-50 simply meant that aniridia was so rare they had no statistics and it could go either way!

In fact, there was a good chance that my eyes would re-scar over

and be worse than before the corneal transplant.

Because of these odds, doctors suggested I wait until "my quality of life" was no longer functional. Another doctor told me there was a 90% chance of success.

I was suspicious of this optimistic estimate considering the other doctors and his newness in practice. So I just held off, and dealt with failing vision as well as possible.

Now I am glad I did as it has been found that aniridics chance at a successful corneal transplant by itself is virtually zero.

I once read an article that said, "aniridics had hopeless eyes" because it seemed that corneal transplants never worked on them.

Many aniridics have had 2-3 corneal transplants done, which have all ended in failure.

I am writing now to let you know that we have our first good glimpse of hope. I am so convinced of this procedure, that I am on a waiting list for a donor. I will travel from Tennessee to Minnesota to have this procedure performed.

Dr. Edward Holland of the University of Minnesota is the man who developed this transplant, and is one of only a handful of doctors in the country that perform this procedure. It is technically called a keratolimbal allograft, but it is a stem cell transplant for the eye.

For my Biology degree I had to take many science courses. To

me, this stem cell transplant makes sense.

You see, your cornea sloughs off its cells just as your skin cells slough off its layers. In your skin you have stem cells that manufacture new skin cells for the old ones that slough off.

The same thing is true for the cornea. The stem cells are supposed to make new corneal cells to replace the old ones sloughing off. However, it seems that for aniridics this does not happen.

Guess where the stem cells are located? In the area of the malformed or absent iris. This is known as the limbal area.

The theory is that if your iris area was malformed, maybe so were your stem cells rendering them unfunctional. So over a long period of time our corneal cells are sloughing off but no new cells are being made.

After all the layers are gone, you have no more corneal cells. Your corneal cells by the way are transparent. The cells in the white of your eye (sclera) then grow inwards towards the cornea to "help out" so to speak.

However, since they are not transparent, it can be compared to looking through wax paper. It is actual scar-like tissue growing over the eye.

My scar tissue is so advanced that they predict if I do nothing, my vision will steadily get worse, and I will only see light and darkness in about 7-9 years.

Primarily because even though the scar tissue grows over the field of vision it continues to thicken as time goes on.

When I was younger, bright light was hard for me to use when reading, but now it is essential for me to read. The scar tissue becomes so thick that it bars light from coming into your eye.

In the stem cell transplant I will be going through, the idea is to give me working stem cells.

Two years ago the first keratolimbal allograft procedure was performed. Before that, aniridics who got corneal transplants had better vision for a while.

But in time, once the cadaver's (donor) cornea sloughed off, they still had no way to make new cornea cells and the eye re-scarred over again.

This is where the idea for grafting working stem cells to the aniridics eye comes to play.

Several months after the stem cell transplant is complete, the aniridia sufferer will undergo a corneal transplant. Now with working stem cells in place, once the cornea from the donor sloughs off, grafted stem cells in the limbal area will keep making new corneal cells.

I also the hope if all goes well that the corneal transplant will succeed and not scar up again.

My doctor, Edward Holland, also told me of a case he did where the person did not even heed a corneal transplant afterwards; the scar tissue began regressing.

While this is very rare, it is possible when the scar tissue is fairly new.

This is a really exciting discovery and I will keep you posted on my transplant. Dr. Holland does want to keep watch over my son every year or so as Michael will have this done one day.

Doctors usually do not perform this procedure on young children, although in extreme cases they have and must be put on anti-rejection drugs. These drugs would not be shutting down our immune system to the extent that a heart or liver transplant patient's would.

Aniridia is rare. Most doctors see it once, if that, in their lifetime. Our insurance companies and government officials who work with Medicare are usually not familiar with it.

I have already run into problems. No one can tell me for sure if the surgery or the necessary anti-rejection medication will be covered because they do not have a code for it yet.

I have written President Clinton, Vice-President Gore, each Senator and Representative at their email address in hopes of getting Medicare to be more aware of this.

I got many "form letters" thanking me for my comments but also stating that if I was not a member of their district, the form letter response was all I would receive.

I am going to keep trying to get the message out as this stem cell transplant not only helps aniridics,

but chemically burned eyes, and some other eye diseases.

My Aunt Toby and Uncle Bud, who are very involved in the Lions group, have showed me the great contributions they make through their vision programs.

I am going to join a Lions group and encourage people, especially those who have family members with eye problems, to join also.

My son and your children will one-day need this stem cell transplant procedure.

My hope is by THAT time we can have the information in place where our children will be able to have it done as simply as any other medical procedure.

I would be happy to talk with any parent or person affected with aniridia on this subject.

### **Written by: Jill Nerby**

Email address:  
packrena@aol.com

For further information on stem cell transplants:

<http://web1.po.com/html/medtrib/archive/FP/RESEARCH1.FP.4906131097.shtml>

[http://mipper.carelife.com/yr1997/nov/research\\_971110.html](http://mipper.carelife.com/yr1997/nov/research_971110.html)

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### **Questions from parents**

**M**y latest mission has been to learn about Cortical Vision Impairment (CVI). I believe it explains the R for retardation in WAGR Syndrome.

Unfortunately, CVI is a "last resort" diagnosis when nothing else can

be sound. But it means that there is some damage to the brain tissue that interprets the visual information or the optic nerves that deliver it.

The symptoms that jump out at me include: compulsive light gazing, short visual attention span, an aversion to novelty, good use of color cues, looking away while reaching for something.

I think my daughter's language difficulties further support this diagnosis.

So far everyone has laughed me off because she obviously has aniridia and nystagmus, but those do not explain her other difficulties in and of themselves.

I finally heard one "expert" say that certainly CVI doesn't REQUIRE the absence of optical vision impairments.

The good news is that the brain regenerates itself and re-wires itself to places that work, which means the long-term prognosis, is excellent. How to structure the educational setting now becomes the big challenge.

One article used the analogy that for a CVI child to hold their head at the correct angle to use their vision to complete a fine motor task is like asking a normally sighted person to learn to knit while walking a tightrope.

Has anyone else gone down this path?

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### **Written by: Connie Brooks**

I would love to hear about what kinds of treatments and/or medications are being used for behavior problems such as ADHD, anxiety disorders, and obsessive-compulsive behaviors, all of which hit Alex when he was about 5 years old.

When Alex was younger we thought that our worst problems would be his visual impairment and possible physical and learning problems.

We were totally unprepared for the behavioral problems, which we now know are very typical in kids with many types of genetic syndromes.

Although Alex's vision is worse than we were originally told. It is about 20/400, we finally got a good acuity last year when Alex was able to read all the letters and numbers and write his name. However, this seems to be the least of our problems, as he is managing now with a CCTV and is beginning to read.

The anxiety and obsessive-compulsive behaviors are actually the greatest detriment to his learning now, as well as causing difficulties socially.

**Written by: Karen Rose**

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## Yesterday, Today and Tomorrow

Writer: unknown

There are two days in every week we should not worry about. Two days that should be kept free from fear and apprehension.

One is yesterday, with its mistakes and cares, its faults and blunders, its aches and pains. Yesterday has passed, forever beyond our control.

All the money in the world cannot bring back yesterday. We cannot undo a single act we performed. Nor can we erase a single word we've said-yesterday is gone.

The other day we shouldn't worry about is tomorrow, with its impossible adversaries, its burden, its hopeful promise and poor performance. Tomorrow is beyond our control.

Tomorrow's sun will rise either in splendor or behind a mask of clouds – but it will rise. And until it does, we have no stake in tomorrow, for it is yet unborn.

This leaves only one day – today. Any person can fight the battles of just one-day. It is only when we add the burdens of yesterday and tomorrow that we break down.

It is not the experience of today that drives people mad – it is the remorse of bitterness for something that happened yesterday, and the dread of what tomorrow may bring. ***Let us, therefore, live on day at a time***

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## Newsletter Deadline

**Please forward your letters, poems, photo's and articles for the next newsletter by January 15, 2000.**

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## WAGR@Onelist.com

My Name is Kelly Trout –I'm the mother of Caroline, (age 18). Caroline has WAGR syndrome, and a number of possibly related conditions as well.

Recently, I've joined a couple of email discussion groups concerned with such conditions as kidney disease, and MHE.

They've been great – they are easy, and they're full of the sharing of information, advice and experience that is so helpful when you're coping with medical problems.

But WAGR is different. It's not one problem, but a whole host of them.

Vision and eye problems, cancer, urologic and kidney problems, multi-level special education needs and on and on.

WAGR parents are likely to be coping with many, sometimes ALL of these at the same time. I couldn't find an email group like this – so I've started one!

<http://www.WAGR@Onelist.com>

Joining is free and easy. I hope it will become one more way to help us and our children not only survive – but also thrive.