



Reaching Out The WAGR/Aniridia Network

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<http://www.wagr.org>

Hello again everyone and welcome to all of our new families. We look forward to sharing our family stories and information with you and we hope that you will consider sharing your stories with everyone as well.

We would like to thank Alison Krevitz and Elsie Rowland for sharing their story with us. Alison was born with Aniridia, but has proven to herself and to everyone else that just because a person has a disability does not mean that they cannot make something of their life. Congratulations Alison on your upcoming wedding.

Many of us know what it is like to raise one child with WAGR Syndrome. But could you imagine raising more than one child with this Syndrome? Only Elsie Rowland knows what it is like raising two children born with WAGR Syndrome. She has kindly agreed to share her story and photo's with us.

Catherine Luis is still working hard to update MedQuest 2002. If you haven't updated your child's medical history please do so and forward it to Catherine asap. Feel free to contact Catherine with any questions. cathy273@msn.com

The Vanderbilt University research study by Dr. Bernard Fischbach is still in progress. The goal of this study is to increase the awareness of this

rare genetic disorder by compiling the various clinical findings in patients with WAGR Syndrome and report these clinical findings in the medical literature. To date, no extensive review of WAGR Syndrome has been published. If you would like to participate in this study please contact Kelly Trout 2fish@surfsouth.com for more information.

The March of Dimes has once again provided the RON a grant for publication and mailing of the newsletter. Thank you!!

At this time we would also like to thank everyone that have generously donated money to the Reaching Out Network. As most of you know there are costs associated with running any type

of business or organization. We greatly appreciate all of the private donations we receive.



Nicholas 5 1/2 years old

From the Editor:
Just a quick update. Nicholas has struggled this year with one cold after another. He has been on antibiotics most of the year and he is currently battling a cold. He is a trooper though and does not let his illnesses keep him down for very long.

Continued on page 8

Newsletter Deadline

Submissions for the Summer issue are due by July 1, 2002. Please forward questions for any of our doctors by June 15, 2002.

Submissions can be mailed or sent via e-mail to:

ReachingOutNet@aol.com



In This Issue....

- "Our Story" pg 2-7
- USA Aniridia Network News pg 7
- WAGR Weekend Updates pg 8
- Donation card pg 8

"Our Story"

I was born on March 4, 1977 at Pennsylvania Hospital. I was the first of two daughters born to my parents, Shirley and Ken Krevitz. They were very excited to have their first little girl. Two days after I was born the doctors told my parents that I had something called Aniridia.

As you all know, this was an even more rare condition 25 years ago than it is now. At two weeks of age I was taken to see Dr. Scheie of the Scheie Eye Institute, who was a world-renowned eye specialist. My parents had many questions to ask, and there were many things that they did not understand. One question that I remember them telling me that they asked Dr. Scheie was if they would be able to take pictures of me or would the flash bother me too much. The most important thing that Dr. Scheie could tell them was "to treat me as a normal child".

After this I was taken to the University of Pennsylvania Hospital every six months until I was six years old in order to test for Wilms' tumor. Fortunately, to this day, nothing was ever found. I continued to go on to school and do all of the activities any kid would do.

The summer before I started first grade my parents contacted the local Intermediate Unit, who supplied me with a vision consultant to help me at school. I would see her once a week for an hour during the school day. She helped me with activities and did tests with me to help her learn what kind of help I would need when I got older. I remember my parents telling me once that she told them that she didn't know if I would ever be able to ride my bike or play with other children.

This angered my parents and made them even more determined to make sure I got everything I needed and did everything I possibly could do.

The following year I acquired another vision consultant named Rita Robertson. She was a great help to me starting in second grade and going throughout my high school career. With her help, school was never a difficult task for me to overcome. She provided me with large print books, magnifying glasses, and books on tape. As I got older she lent me a CCTV for the summer so that I could see if this would help me in the classroom with class work or at home with my homework and recreational reading needs. The large print books were a big help to me in my younger years because when we had to read in class I didn't have to have my face in the book when it was my turn. The magnifying glasses were also a big help because one year we had a map to complete each week. We were required to put about 75 locations on it including cities, rivers, lakes, and mountains. I did not like the books on tape. Even with this vision disability I am a visual learner. I would sit and listen to the tape and not retain any of the information. So, after listening to a whole chapter or unit on tape I would have to go and read it all over again so I could understand what I just heard. Also, the CCTV was not for me. I had it on my kitchen counter for about 10 weeks, and only used it a few times because each time I would look at it I became dizzy. This made it harder, rather than easier, to read the material. Besides physical materials, Mrs. Robertson also gave me some very helpful ideas. The first suggestion was that I sit in the front row of the classroom. Although it was still difficult for me to see the board,

I could still see the teacher and what she was doing. Also, I found someone in each of my classes to take notes for me. I would get the notes off of the blackboard from them, and any other notes that I couldn't get because of the pace.

When I arrived at college I pretty much had to manage on my own. I went to West Chester University of Pennsylvania. There was an office for students with disabilities, but they couldn't do very much because of all the students that they had to deal with. I made the transition from high school to college smoothly. I informed all of my professors about my disability. Most of them were very accommodating. Some of them even gave me copies of their notes so I would not have to rely on other students or rely on myself to get what I could.

Others found out who the better students were and asked them if they would mind helping me out. Of course they had no problem with helping me. Another tool that was very helpful with note taking was using a cassette recorder. I would record the lectures and then go back to my room and listen to them and get anything that I missed the first time. College was not only a place to learn, but it was also the place where I met my first boyfriend, and future husband. We met at the Hillel Jewish Student Union. He called me up one Saturday afternoon while I was doing some homework and asked me to go out to dinner. We had never talked before, and I wasn't even sure I knew who he was, but I said yes and the rest is history. It has been five years that we have been going out. He asked me to marry him a year and a half ago, and we will be getting married this May 26th. I am now in graduate school at the Philadelphia College of

Osteopathic Medicine. I am going to get my Masters degree this August in Clinical Health Psychology. I have met some wonderful people in my classes who help me with the notes. It is a lot easier in graduate school because the classes are much smaller and the teachers have a more personal relationship with the students.

Well, I think I have covered my academic history. Throughout my life I have also done many activities including, but not limited to, art classes, Brownies, gymnastics, horseback riding, and summer camp. I was able to do all of these activities just as well as the other people in my group, if not better.

One thing that I think is important to address about my life is my extreme shyness. Ever since I could talk I have been very quiet and withdrawn. I have always attributed this to my vision. I was always the kind of person who cared too much about what other people thought about who I am, the things I do, and how I look. I know that when I would look close at a book or paper I would always think that people were talking about me or laughing at me. Sometimes this might have been true, while at other times it was definitely not. I have also kept my opinions to myself because I did not want to sound like I did not know what I was talking about or have a different opinion than the rest of the group. To this day I am still very quiet, but I am definitely more outspoken than I used to be. Actually, when I get to know someone well, and I feel comfortable with him or her, I have been told that I talk too much.

Another issue that comes to mind while thinking about all of this is the fact that I have never been able to drive. When I was 16 and

all of my friends were sitting around the lunch table talking about getting their drivers license and a new car I felt left out. I couldn't add anything to the conversation, and I couldn't even begin to imagine what it would feel like to have some independence. Also, while they were complaining about having to study in order to pass the test and whining that their parents would not buy them that "perfect" car, all I could think about was that this is one test I wouldn't mind studying for and that they should just be happy that they can drive any car.

Another thing that I have been thinking about recently is the lack of my sense of smell. When I was younger I would always play with stickers, especially the scratch 'n' sniff stickers. I always used to make comments about them as if I were able to smell them, but now thinking back on it, I may have been saying I could smell them because everyone else could. I know for sure that I haven't been able to smell within the past fifteen years at least, and I am fairly sure that I never could. I am going to the taste and smell clinic at Thomas Jefferson Hospital on April 18th, so that I might get some answers.

At 19 years old while I was in college I developed glaucoma in my right eye. I went in for a regularly scheduled eye doctors appointment and my eye pressure was 53. They immediately brought in a glaucoma specialist who gave me medication and saw me the next morning to make sure everything was okay. My pressure dropped overnight from 53 all the way down to 12. We were all relieved and I was told to go home. I had three different eye drops I had to put in my eyes daily. When I went back the following week my pressure

was still very good and it has been ever since. About a year or two ago I developed corneal pannus. I was told to stop wearing my contact lenses. Since then the scarring has stopped progressing. I am now in the process of getting information on the stem cell transplant.

In summary, I would have to say that I have had some obstacles to overcome in my lifetime, but for the most part I think I have done very well. I proved to myself and to everyone else that just because a person has a disability does not mean that they cannot make something of their life. I went from being a quiet, little girl who was unsure of herself, to a young woman with a Bachelor's degree in Cognitive Rehabilitation and a pending Master's degree.

If anyone has any questions or would like to get in contact with me please do not hesitate to do so. Feel free to e-mail me at either cutie3477@hotmail.com or alipsych@aol.com.

Written by: Alison Krevitz

My story starts in an era when things were very different from the experiences of most of you. Eleven days after my 21st birthday I gave birth to my first child. The pregnancy was difficult because my baby was lying in breach position. All efforts to correct his position failed but one month before his birth he righted himself causing me two days of terrific pain.

Yes, I had a boy. He was born on 11th October 1959. The birth was difficult and the labor long starting at midday Friday and my baby was not born till 3pm Sunday afternoon. He was small only weighing 4lbs 10ozs. I was aware something was wrong and I struggled to stay awake. The

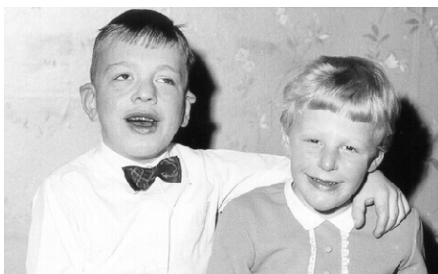
matron was at one side of his crib and the midwife was at the other. Both were blowing into tubes over his nose and mouth.

My son, Ian looked normal and I had no reason to suspect that anything was wrong. The knowledge among medical professionals was nowhere near as advanced as it is today so no one at the nursing home suspected anything either.

Ian did not cry, he screamed and this was pretty constant. He was really difficult and a very demanding baby but I was just too happy to find this a problem at first. As the weeks then months went on this became a strain on me. No matter what I did I could not stop his screaming and as he got older his behavior left a lot to be desired.

I took him to the baby clinic monthly during the first year to have him weighed and to collect a supply of orange juice and cod liver oil. These items were supplied, by the government to all babies to help give them the vitamins they needed to assist growth. This help was given because many foods were still scarce following the war. These visits were the only medical checks for babies at that time.

When he was seven months old we called in at the nursing home where the midwife took him to show him off to the other staff. When she brought him back she suggested I take him to my



Ian & Linda

doctor because they thought there was something wrong with his eyes. This was when we were first made aware that Ian had problems. A visit to the hospital confirmed Aniridia, Nystagmus, and congenital cataracts. He was registered blind and monthly visits to monitor him were arranged.

Taking Ian out was a nightmare. We did not have cars to make life easier. Every outing was either on foot or public transportation. (Buses) Shopping was the worst. We had to queue for counter service. Prams, which were large did not have carriers and had to be left outside.

Going to my parents and the hospital on the bus was not easy with two babies and a shopping bag. This always doubled as a baby bag. I coped mostly on my own as my husband worked permanent night shift and slept all day. I had no family to help me. I often asked my husband to transfer to day shift but he said the firm did not allow this.

I think it would help you understand the difficulties of caring for a child at that time if I explained a few things here. Disposable nappies (diapers) were not invented. We used terry squares. These had to be washed and dried daily, not easy when the weather was wet. (No central heating) We did not have bathrooms and only cold running water. Hot water when needed was boiled, small amounts in kettles and pans on the fire and large amounts in a boiler. Bottles were made one at a time as needed. All housework too was labor intensive. There were no modern appliances.

Young adults like myself were very naïve and inexperienced compared to the youth of today. We would never dare to question people in authority such as doc-

tors, police etc. Woman did not work so money was always in short supply. Starting a home and a family was nothing like it is today.

No matter what time Ian was put to bed he never settled, just screamed. Nothing I did could stop the screaming. When he was able to pull himself up he jumped up and down and rattled and shook his cot so violently that more than once he dislodged the base and it and the mattress would end up on the floor usually with Ian asleep on it. Yes he did eventually go to sleep.

If he pooped his nappy boy did he have fun. Off came his pajamas and his nappy. He picked it up then shook his cot coating it all over the cot rails. He jumped up and down and ran around his cot as usual, treading it all over his bedding. He pulled his hair, another regular occurrence so eventually his body was not a pretty sight. I of course I am blissfully unaware of this going on until I make one of my many trips upstairs to check on him.

Getting him bathed and changed, washing his cot and changing his bedding with no one to lend a hand was a long and laborious job. Remember I did not have hot water or bathroom.

When Ian was nine months old I became pregnant again and as the months past I found it increasingly difficult to cope with Ian and his tantrums along with everything else. I had no company, no help and no social life and did not see a lot of my husband. I just struggled on.

Linda was born on 17th April 1961 and weight in at 7lbs 2ozs. I knew immediately she had the same eye condition as Ian but she was four weeks old before I was able to convince the doctors.

Now I had to take her to hospital once a month. Thankfully she was a much quieter baby and not nearly so demanding as Ian. Even so she was a baby with all the usual needs and now there was twice as many nappies to wash and dry daily.

Ian was now walking and able to be more demanding than ever. When he had a tantrum he would run to the nearest wall, door or piece of furniture, drop to his knees and bang his brow repeatedly on it pulling his hair with both hands at the same time.

The strain of all this was having an affect on my health but there was no respite. I just had to keep on going. By now I was living on my nerves and it was like being on a treadmill.

At school age Ian was sent to a residential nursery school for the blind. It broke my heart to let him go yet I had no choice. His stay there only lasted one term then he had to go to a residential school for the blind. This was nearer home but traveling on public transport meant three buses and took 2 hours.

He was now five and despite his behavior at nursery school no one connected it with anything serious. He was at the school for three years before finally in Dec 1967 his headmaster informed the education authority he could not accept Ian back after the Christmas break as his behavior was proving to be to disruptive for the other children. Ian was now 8 years old and at last the behavior, which I had coped with, was being seen as a problem.

In January of 1967 while he was still at school the stress I had been living with took its toll and I had a nervous breakdown. I went into hospital at the end of January and it was the middle of April before I was discharged,

just in time to take care of Linda and Ian during their Easter break. During my stay in hospital I was given 17 E. C. T. treatments. It was a common treatment then for nerves and depression but as time past it was not considered a good treatment. It had a detrimental effect on my short-term memory something that is a problem still.

By law a child has to be educated so now we had to find a suitable place for Ian. During the next few months I was given appointments for him with child Physiologists, psychiatrists, pediatricians and other specialists. Then I was told he would have to spend two weeks in hospital so that he could be assessed. None of these visits were local and I often had to take Linda too so it was a very trying time.

We took him to the hospital and when I got there I was horrified. It was a long stay hospital for mentally retarded people. This was the label give at that time to anyone who suffered any syndrome known today. I wanted to turn around and take him home but this was not possible. If it was possible to educate him then the authorities had to do everything they could to assess where he should go.

They were two long weeks, but finally they were over. The outcome was he was mentally retarded and could not be educated. Can you imagine it taking almost nine years to have this diagnosis made today? The choice was now mine. I could keep him at home or put him into a mental hospital. This was

common and the only choice of care for handicapped people at that time. I couldn't do it and I kept him at home. Despite these findings I was not offered any help or assistance. There were no visits to any professionals for advice nor was he given any medication. It had been found that he could not be educated so he was in effect written off as useless.

He was fast approaching his 9th birthday and this was the first time I knew there was more wrong with him than just his sight. I had been caring for him (and Linda) all those years ignorant of his condition and with no medical input.

Meanwhile Linda followed in his footsteps, nursery school first then blind school. Now I had Ian home full time and Linda during school holidays. Life continued to get harder and more difficult. I have always been a very tidy minded person (still am) but I was becoming obsessive. No matter how difficult my days were and how Ian behaved (or more accurately miss-behaved) I found I had to do every household chore every day and nothing could be skipped or half done. Needless to say I was piling more stress onto myself but I was like someone driven and could not slow down.

Twelve months after Ian came home permanently I was back in hospital. There was no one to care for him while I was away and he was put into the same long stay hospital were he had spent two weeks being assessed. I hated this but was powerless to do anything about it. I was only in hospital two weeks this time although it was a few weeks after my discharge before I felt able to cope with the children. I mentioned to my husband that I wanted to go and

**Reaching Out Advisors
Ophthalmology**

Dr. Peter A. Netland
Dr. Edward J. Holland
Dr. Michael L. Nordlund

bring Ian home but he would not agree to this. He said I was not able to cope with him. I begged, I pleaded, I cried for my son but all to no avail my husband would not change his mind.

My marriage had not been easy. Things eventually got worse and in 1969 we parted and in 1971 we divorced.

After a time I met and married my second husband and we moved to Coventry. I brought Linda home as usual for her school holiday but was told she could not return, as she was no longer under the care of the local authority there. Coventry authority assessed her to see where she should be placed and after a lot of visits to professionals she too was found to be mentally retarded. This was three months after her 10th birthday.

She was placed in a special school 9:30 am to 3:30 pm and she now lived at home again. Linda as I said was a much quieter baby than Ian but her behavior gradually worsened over time and now at ten she was quite aggressive and violent so again it was not easy. Unlike Ian she was violent towards me. She hit me, she'd bite me, she pulled my hair and charged at me many times. She would physically stop me from doing things like cooking, washing up etc. I was unable to stop her. She was much stronger than I was and as I've said, very aggressive.

I became pregnant again and George was born on 2nd June 1972. He was normal and has been a great blessing to me. Although Linda loved George and never hurt him she seemed to be jealous of the attention I gave him. I would be getting her ready for school then he would wake up and cry. So naturally I would go to bring him downstairs. Linda always beat me to

the bottom of the stairs where she'd stand with her arms spread out and say, "You aren't going to get him." I would be standing there trying to reason with her, to no avail while George's crying would be getting louder. I was eventually able to bring him downstairs but then I had to lie him down somewhere out of harms way while Linda tore into me in her aggressive way. I always tried to stay away from where George was lying on the couch because she often pushed me so hard I'd lose my balance and I was afraid I would fall onto him.



Linda - Fall 2001

Incidents like this were daily occurrences but never when her dad was around. She was naughty around him and other people but nothing that a normal child wouldn't have done. For over four years I lived with this before her headmistress discovered me crying and her sympathy brought the whole sorry story poring out.

My situation was brought to the notice of a hospital Psychiatrist and he arranged for her to go into hospital for one month to give me a break. Neither she nor Ian had any medication during the time they lived at home. There were no visits to hospital for check ups

or any other kind of support. This was 1978 and Linda was 17 years old.

Her month in hospital was extended to three months then I was offered a permanent place there for her. It was a hard decision and I did a lot of soul searching before I agreed to let her stay there.

From then I no longer cared for them at home but services for mentally handicapped were still not good so I put all my efforts into looking after their needs and fighting for their rights and also looking for better homes for them.

From the early eighties services for people with learning disabilities began to improve. I eventually found Ian a home for blind and multi-handicapped people in Birmingham. It was a good home and he settled down well. He moved there in April 1984 and a few months later he began to put on weight. In March 1985 he took ill and this was when his Wilms' tumor was diagnosed. The specialist could not tell us how much time he had left but he lived for just over two years. He died on 21st May 1987.

Linda moved from the hospital to a group home. Then she went to Birmingham where she lived for 11 years and only moved to her present home in October 2000. Her behavior was a big problem wherever she lived and I had many battles on her behalf. No one could cope with her and in Birmingham things got so bad I was asked to remove her and was given one month to find her a new home.

That month was horrendous but we succeeded in finding the home where she lives now. Its proved to be the best thing that could have happened to her.

She's never had such a good life anywhere else and her behavior has improved.

Since 1998 she sees a psychiatrist every 6 months and still visits the eye specialist every 6 months also. She takes a ½ risperidone tablet once a day (reduced from 1 tablet) and she's improved since the decrease.

Unlike the WAGR children of today Linda and Ian were not monitored regularly and they got no treatment at all until they left home Their care has always been reactive rather than proactive which is why there is not a lot of medical information or treatments in my story. My experiences of caring for WAGR children differ so much from that of the families of today.

Today it is still very hard for each one of you but I hope my story will give you encouragement just knowing that it is possible to cope with everything that is thrown at you and still survive.

The strength to carry on comes from somewhere just when you need it and the reward is the satisfaction of knowing your child has had the best life possible and that your efforts and pain have not been in vain.

Written by: Elsie Rowland

USA Aniridia Network News

The USA Aniridia Network, Inc. is in full gear as we have completed our legal filings and have begun many of our projects. One of the most important is our public awareness campaign. This includes creating relationships with the doctors across the country to educate and help us find others with aniridia. Also, it encompasses our FINDERS committee which contacts organizations, blind schools,

etc to reach those who may not have Internet access.

We are finding out that it is and will be very important in the future to create a members database reflecting the current number of people with aniridia. This is because many companies and researchers hear that aniridia is RARE, and then think of rare as just a handful, not worth the money, time or battling the FDA. I have found that this just is not true. There are many of us already and I have only scratched the surface. Not to mention the other aniridia associations across the world.

Our biggest battle will be to CONVINCe those people that we may not be big in numbers like heart disease or diabetes but we ARE numerous and need their help too. By signing up all people affected with aniridia, we can get these statistical numbers to show our need. If someone with aniridia does not wish to be contacted, they can still sign up but there is a box on the member form for them to check. They will not be contacted but counted as a statistical number.

The next biggest and most exciting thing is our first OFFICIAL gathering/medical conference as the USA Aniridia Network Inc. We had a great time in Louisville last year and this year we have invited the WAGR families also. It should be really fun. We have been getting many responses, even from as far as England, and I am getting so excited to meet everyone.

I encourage everyone that has not responded to do so as our meeting space has been booked and there will be limited space on a first come, first serve basis. The registration fee for USAAN members is \$20 and for non-members \$35. You can join on our website:

<http://home.attbi.com/~usaan/>

The hotel is currently drawing up the contract for a reduced rate \$119.00 plus tax per night. You can read about all the free stuff that goes along with that rate and see pictures of the hotel and its amenities in the members only website if you had not do so already. Book early as they have more King rooms than two doubles if you need those.

Some of the amenities are indoor heated pool, sauna, jacuzzi, workout room, suites face a 5 story atrium filled with trees, plants, waterfalls, ponds with fish and ducks, sitting areas to visit among this tropical setting. A free daily breakfast (cooked to your order) is included with the hotel room price, as is the daily managers social at night. This social provides free beer, wine, mixed drinks, soda, and hot snacks to all hotel guests. A great place to meet and socialize for the entire group.

Our mini medical conference will feature several doctors speaking on such subjects as aniridia, glaucoma, corneal problems, genetics, low vision and adaptations, and vision teachers familiar with the ADA, Aniridia and /WAGR Syndrome.

We plan to have "buddies" (kids hate the word baby-sitter) for the kids during the medical conference so that both parents can be present. If your child will NOT need a buddy (one of the parents will be with them), please let us know as we need to recruit our "buddy teams". Also, we hope to have some "buddies" to play with the kids at the park (cookout) we have planned (keep your fingers crossed it does not rain) so the parents can visit.

For the older kids (15+), any who want to sit in on the doctors talks, please let us know so that we

can count them in on the seating. We will have several games (cards, Monopoly, etc.) for the older ones who wish to socialize with their peers. If you would like to bring a game for your child to share, please feel free to do so but put your name on it.

If your child needs special attention please inform us of their needs. This is description is especially needed for WAGR kids attending as the parents can give us an idea of the group they should be placed in. Hope to see all of you there!

Please feel free to contact Jill Nerby with any questions. E-mail: USAaniridiaNet@aol.com

WAGR Weekend Updates

Due to the lack of participation WAGR Weekend - UK 2002 has been **postponed** until the summer of 2003. Future details will be forthcoming as they become available.

WAGR Weekend - Manassas, VA will be held Friday, July 26 thru Monday, July 29.

Friday, July 26, 7-9pm - Cookies and Punch Meet and Greet - conference area at Country Inn & Suites

Saturday, July 27 - Free Day for visiting, swimming, touring, etc. 6-9pm - Family Pizza Night Country Inn & Suites

Sunday, July 28, Noon til ? - Family Brown Bag Picnic at Ben Lomond Park.

Families interested in attending can email Kim Pillow at

towardakim@yahoo.com for more information. Country Inn Suites (703) 393-9797 or (800) 456-4000

(Continued from page 1) Nicholas is doing really well in school and he will be graduating from his current VI classroom this Spring. We will soon be meeting with his teachers to discuss his program for the fall. He will start Kindergarten and will be in an all day program for the 2002-2003 school year.

Nicholas really enjoys school and everything associated with school life. He has accomplished many of the goals listed in his IEP. He can recognize and name most of the letters in the alphabet and numbers 1-10. It is a challenge for him to write his name, but he gets an A for effort.

Nicholas recently had a visit in Ophthalmology. I am so happy to report that his vision remains stable. His cataracts have not changed and although we were not able to get a pressure test, to the touch his eye pressure

seems normal. Nicholas may have to undergo an EUA later this year if we cannot get a reading in the office.

I continue to pray for Nicholas and his good health. I also ask everyone to keep in mind and prayer the RON families and children currently struggling with Wilms' tumor, glaucoma, surgeries and other medical challenges. May God be with you and provide you with strength. Until the next issue, take care everyone. Annie Prusakiewicz



We are very proud to have the March of Dimes, a sponsor of the Reaching Out newsletter for another year. Please support your local chapter whenever possible.

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

Reaching Out - The WAGR Network

Yes! Enclosed is my gift

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