

The Conformer

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ican

International children's
anophthalmia network

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Sharing hopes, joys and challenges

Meet the Board

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Please get involved. We welcome any ideas, suggestions or assistance. You can contact us at any time. To contact a Board member e-mail them at ican@anophthalmia.org and put their name in the subject.

White Cane Safety Day

The white cane in our society has become one of the symbols of a blind person's ability to come and go on his own. Its use has promoted courtesy and special consideration to the blind on our streets and highways. To make our people more fully aware of the meaning of the white cane and of the need for motorists to exercise special care for the blind persons who carry it Congress, by a joint resolution approved as of October 6, 1964, has authorized the President to proclaim October 15 of each year as White Cane Safety Day.

Now, therefore, I, Lyndon B. Johnson, President of the United States of America do hereby proclaim October 15, 1964 as White Cane Safety Day.

With those stirring words President Johnson issued the first White Cane Proclamation which was the culmination of a long and serious effort on the part of the National Federation of the Blind to gain recognition for the growing independence and self-sufficiency of blind people in America, and also to gain recognition of the white cane as the symbol of that independence and that self-reliance.

Within hours of the passage of the congressional joint resolution authorizing the President to proclaim October 15 as White Cane Safety Day, then President Lyndon B. Johnson recognized the importance of the white cane as a staff of independence for blind people. In the first Presidential White Cane Proclamation President Johnson commended the blind for the growing spirit of independence and the increased determination to be self-reliant that the organized blind had shown.

The blind are able to go, to move, to be, and to compete with all others in society. The means by which this is done is that simple tool, the white cane. With the growing use of the white cane is an added element- the wish and the will to be free- the unquenchable spirit and the inextinguishable determination to be independent. With these our lives are changed, and the prospects for blind people become bright. That is what White Cane Safety Day is all about.

GENETICS UPDATE

As many of you new Albert Einstein medical Center has had an ongoing project to identify the various genetic mechanism which lead to A/M and to collect comprehensive medical and developmental information on individuals with A/M. It is our hope that this will help provide more useful information for families.

So far, 113 DNA samples from blood have been collected on individuals with A/M. Of those, 35 have been given a positive result, in other words, a genetic change was found to help explain the cause of A/M. Identifying a genetic mutation helps provide appropriate medical and developmental intervention and provides accurate recurrence risks for family members as well as the individual with A/M.

In fact, the research has come so far that many of the tests can be ordered clinically. These means that the DNA can be sent to a lab, insurance is billed and a result is guaranteed in writing within 10 weeks. Tanya Bardakjian, MS, CGC is available to help anyone interested in the genetic testing-research or clinical.

Genes known to be involved with A/M include but are not limited to SOX2, OTX2, CHX10, PAX6, PITX2, PITX3, FOXE3, BCOR. The clinical findings in each child help us determine which gene/s should be looked at.

For more information contact Tanya M. Bardakjian, Certified Genetic Counselor
215-456-8726 bardakjiant@einstein.edu

Please consider joining the A/M Registry, and help scientists investigate the causes of anophthalmia and microphthalmia. Contact ican@anophthalmia.org or call 1-800-580-ican for more information.

Sharing Stories

ican Conference summary

By Julie Athenson

On the weekend of June 19th, my son Gabriel and I had the wonderful pleasure of attending the 6th Bi-annual ican international conference, held in Los Angeles California. The conference began with a free medical clinic at Jules Stein Eye Institute . Although we did not attend this clinic, we heard many wonderful things from the people who did. Later that evening was a reception to welcome everyone. I know the kids had a great time seeing old friends and meeting new ones too. It was also a great time for the parents to get acquainted again.

Saturday morning started early with a light breakfast , after which the children left for a fun day with the Kid-Sitters. After a heartfelt welcome and a preview of what was to come we were ready to begin. Dr. Adele Schneider & Tanya Bardakjian and their staff did an excellent job planning this conference and deserve many, many thanks.

As we were introduced to the first speaker, Rick Guidotti, from Positive Exposures, the whole group couldn't help but to be excited. Rick has a way of making you feel good. The photos he showed us, first of the Super Models and then of his A-Mazing Friends from around the world, showed us that there is true beauty in all of our differences. This guy loves what he does and it shows!

As Rick set off to photograph our kids we were introduced to a panel of professionals. Dr. Katowitz , a Pediatric Ophthalmologist and Oculoplastic Surgeon , described to us the options available for filling the eye sockets, making them ready for the prosthetics. Included in these options were fatty graft implants and inflatable expanders such as Hydrogel pellets. He stressed that not everything works for everyone but at least there are options. He was a very interesting speaker and it was obvious he cares very much about his patients. We also heard from three different local Ocularist who explained what to expect from your visit with an Ocularist and what different kinds prosthetics are available. Patience is key .

Our Key Note Address speaker was an awesome young woman named Ronit Ovadia Mazzoni.

Ronit was born with Bilateral Microphthalmia in spite of this, Ronit seems to have experienced more in life than many of us could dare to dream. She is a Prenatal Genetic Counselor , entering this field being the first totally blind Genetic Counselor. What she impressed upon me, is to keep trying, and to keep experiencing life. Her attitude is truly inspirational!

After a delicious lunch outside, we met with Nancy Mansfield. She discussed the importance of making time for yourself and your significant others. Often when you have a child with a disability, you loose yourself and your relationship with others can suffer. Next Deborah Chen ,a teacher of Early Childhood Special Education spoke to the need of social interaction, conversation and activities to work on with your child. It was a very interesting topic for me because even though Gabe is 14 we still need to work on this. Steven Bauer spoke next and was quite impressive with his knowledge of access technology. He is a Braille instructor and has been totally blind since birth. He impressed upon us the value of computers and the internet.

Saturday night we were treated to a delicious banquet and had a fun time dancing and singing Karaoke. The kids were awesome and boy could they sing & dance !! Sunday morning it was time to say Good-Bye. During brunch, Rick showed us a slideshow of the pictures he had taken over the weekend. He's right, there is real beauty in all of us. If I had to describe the conference in one word, I would take a

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Logan Riman



Music teacher Michel Gentile celebrates with children as they graduate from Children's Learning Center.
Photo by Joseph A. Rosen

Graduation Services at Preschool For Blind Bring Cheers, Hope

Persistence Contributes to One Severely Disabled Boy's Progress

By Liz Tung
Brooklyn Eagle

DOWNTOWN BROOKLYN — The ceremony at the National Grid Auditorium in Downtown Brooklyn last Thursday morning was a lot like most preschool graduations — beaming parents, fussy babies and graduates who hovered continuously between excitement and crying. It was the same except for one thing: All of the 14 graduates were blind or visually impaired.

As they processed to a flute rendering of "Pomp and Circumstance," the singular quality that bound these 14 preschoolers together became obvious. Some were led down the aisles by hand, some carried, and some were wheeled in chairs and strollers. But all were decked out in blue satin robes and tiny mortarboards in celebration of their graduation from the Children's Learning Center Preschool in Downtown Brooklyn.

Housed under the umbrella of Helen Keller Services for the Blind, a national organization that provides services to the blind and visually impaired, the Children's Learning Center (CLC) Preschool caters not only to children with visual impairments, but to those with multiple disabilities. For this reason, CLC employs a team of specialists who supplement the conventional preschool curriculum of ABC's and singing songs with a range of therapeutic and skill-building activities.

For some students, this means preparing to be independent — to enter an inclusive academic environment by learning pre-Braille skills or how to use a cane. For others with greater limitations, it's a slower and more fragile process of learning to move and communicate.

For Logan Riman, one of the graduates this year, even this basic level of function seemed like a doubtful prospect. He was born with no exposed eyes, an un-

formed nose and a cleft lip, and his parents didn't know if he would ever be able to walk, talk, or interact.

Determined to beat the odds, Logan's mother, Leah Riman, enrolled her son in CLC's Early Intervention Program at the age of three months. Despite CLC's distance from the Rimans' home in Queens — it was a two-hour bus ride each way — Leah stuck with the school, bringing Logan in every day for years.

Persistence

It was this kind of persistence, says Director of Resource Development Deborah Rodriguez-Samuels, that contributed to Logan's exponential progress. "After many operations and lots of therapy, Logan can cat, walk, his language skills are beginning to emerge and he's a happy, happy child," she said through e-mail.

Riman was quick to share credit with CLC's staff. "When I arrived they asked, what are your goals for your

son?" Riman said. "I told them if he's supposed to walk at 12 months, I want him to walk at nine. If he's supposed to talk at two years, I want him talking at one. And they did that."

Near the end of the ceremony, the school recognized Riman's persistence and advocacy work with a Parent Award, which they give out once a year. Antoinette Richards, a social worker at CLC, linked Riman's personal growth with that of her son's. "As Logan grew and progressed, so did his mom," Richards said. "She became his strongest advocate. She stood like a lion before anyone for him."

Riman, a young, teary-eyed woman in an olive dress, accepted the award with a graceful simplicity that seemed to capture the mix of triumph, humility, and gratefulness that filled the room. "The word of the day is thank you," she said. "So thank you to everyone who worked so hard for our kids. Thank you."

The “Artificial Retina”

Alex V. Levin, M.D., MHSc
Chief, Pediatric Ophthalmology and Ocular Genetics
Julia Haller, M.D.
Ophthalmologist-in-Chief
Wills Eye Institute
Thomas Jefferson University

Patients with microphthalmia may have sight limited by a variety of eye abnormalities, for example, cataract, small optic nerves (optic nerve hypoplasia), or glaucoma. The most common eye abnormality associated with microphthalmia is coloboma: a failure of proper formation of parts of the retina during the formation of eye. This defect may be large enough to involve the optic nerve and the important parts of the retina used in vision (the macula). In the search for an answer to this problem, might an “artificial retina” offer a solution?

The “artificial retina” is actually not a retina at all. Rather, a tiny microchip is implanted on the surface of the retina surgically. A camera mounted on glasses worn by the patient, picks up visual images of the world, and sends them to the chip which in turn is directly linked to the nerve cells on the surface of the retina. These nerve cells then go to the optic nerve and back to the brain where, the image can be read. One of the limitations of this technology is that the resolution of the chip is still quite poor. As a result, the chip may only be able to improve navigational vision or allow someone to see the big E on the letter chart in the eye doctor’s office. In other words, at the current stage of technology, this chip implantation would only make sense for someone who already has extremely poor vision. After this device is implanted, that person would only expect to have slight improvements of vision and would still be categorized as visually impaired even with the chip. Yet, this device offers hope for many people with retinal diseases who can only see light or barely see a hand waving in front of their faces. Their lifestyle could be greatly improved by even small increases in their ability to perceive the world. With time, the technological advances will allow the chip to have better and better resolution and therefore improve the vision attainable using a chip.

In order for the chip to work, there must be healthy retinal nerve cells already in place for the chip to connect with. In coloboma this is not the case. The area of the coloboma does not have healthy retina with normal nerve cells. In addition, when the retina is involved with coloboma to a degree that decreases vision, the optic nerve is almost always abnormal as well. The optic nerve is like a cable made up of the collection of all the nerve cells in the retina. If the optic nerve is abnormal then we know the message to the brain is abnormal as well. This would leave the chip with nothing to carry its message to the brain. As a result, “artificial retina” technology is currently not appropriate for patients with microphthalmia and coloboma. Even in the absence of coloboma, the challenge with microphthalmia is that it is present at birth and as a result, the brain never learns to see messages properly. Putting a chip in later in life may send a message that the brain never learned to read thus leaving the patients with vision that does not improve.

Currently the chip is being used only in adults with extremely poor vision due to retinal degeneration, usually from genetic causes, and without microphthalmia. As success is experienced in adults, and already the chip implantation is being done at Wills Eye Institute along with Scheie Eye Institute in Philadelphia, then the scope of the research may broaden to include other patients including children. To restore sight to someone with coloboma, will likely require other technology such as retinal transplantation (stem cell transplant) or some day, transplantation of the whole eyeball. Early genetic manipulation may also be useful. Although these technologies sound like science fiction, someday they will be available perhaps even to the children born with microphthalmia and coloboma today.

Self-esteem Issues for Children and Families of Children with Facial Differences

We all have experienced it; a quick trip to the grocery store for milk resulting in tears and anger because of stares and whispers, another child walks up and asks “what is wrong with your baby”, mothers at the park look afraid of you and your child because his/her eye socket has conformers in them....the list goes on. What can we as parents do to help instill confidence in our child and to deal with We would like to always have a section for parents and older children with A/M to share their experiences and feeling with these issues and to provide any ideas. Our children are beautiful and amazing and this section is geared to help us ensure our children view themselves this way.

Some suggested reading on the topic:

For Parents: *Children with Facial difference: A Parent's Guide* by Hope Charkins
What All Children want their parents to know by Diane Loomans

For Children: *I Wish I were a Butterfly* by James Howe
Rosey, The Imperfect Angel by Sandra Peckinpah

For Teens: *Stick up For Yourself- Every Kid's Guide to Personal Power and Positive Self-Esteem*
by Gershen Kaufman, Lev Raphael and Pamela Epseland

Many tweens and teens have asked us to help find e-mail pals for them so they could share their experiences with someone who understands. E-mail us at ican@anophthalmia.org if you want an e-mail buddy or are willing to be one for someone.

MEMBERSHIP DUES

The fee is \$25.00 per family. **This is very important** as it covers expenses for newsletters, mailings, the 1-800 number and the website. Please help us continue to provide support to you and other families by paying your dues. If you cannot afford the dues, simply contact us and we will make every effort to provide you with member privileges.

Questions

Please e-mail us at ican@anophthalmia.org with any questions. If you have specific questions regarding your child please e-mail the question to us and we will try to have it answered by the appropriate specialist as well as by another parent!