CONTACT INFORMATION

Cure Autism Now Foundation
info@cureautismnow.org
www.cureautismnow.org

Autism Genetic Resource Exchange
5455 Wilshire Blvd. #715
Los Angeles, CA 90036-4234
info@familyagre.org
www.familyagre.org
888-8AUTISM

The Autism Genetic Resource Exchange (AGRE)—AGRE was created by Cure Autism Now to advance genetic research in autism spectrum disorders. Blood samples and clinical data are obtained from families that have two or more children diagnosed with autism, PDD, or Asperger's syndrome. These samples, along with the accompanying clinical data, are readily available to AGRE-approved researchers.

AGRE
Autism Genetic Resource Exchange

Autism Genetic Resource Exchange
5455 Wilshire Blvd. Suite #715
Los Angeles, CA 90036

Summer 2004

Listening To You

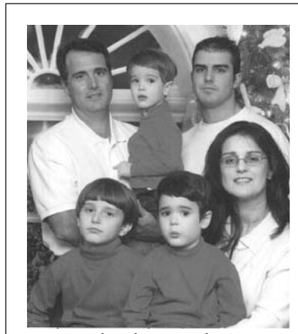
The Newsletter for AGRE Families

Autism Genetic Resource Exchange (AGRE)

AGRE
Autism Genetic Resource Exchange

Articles of Interest:

Family Lives with Autism: disorder affects three of four sons
Ana Marie Echaniz, Fort Valley, VA



The Echaniz Family

When we moved to Fort Valley, Virginia from Florida with my son, Johan, we never dreamed how dramatically the birth of our three sons would change our lives. Gabriel, 7, Dominic, 4, and Yulen, 3, are handsome and dark-haired, reflecting their Hispanic heritage. All three of them have autism.

I did not spot autism immediately in my three children. The things that were wrong were very unique and different in the three of them. Gabriel's disorder was not diagnosed until age 4, when a local doctor realized the reason for his speech and language delays. I was not ready to accept the diagnosis. When the doctor said autism to me, I felt like I had been punched in the stomach. Dominic's diagnosis in August 2002, at age 3, came earlier. His development was "completely on target" until 21 months, when his baby brother, Yulen, was born. Then he regressed almost overnight. He stopped speaking all but a few words and for a while refused to look at him. We thought he was jealous. Later, when Yulen only said "mama" at 15 months, I took him in immediately for an evaluation and he was diagnosed as autistic in July.

Continued on page 8

An Interview with
A.H. M. Mahbubul Huq, M.D., Ph.D.

A.H. M. Mahbubul Huq, M.D., Ph.D.

Assistant Professor
Department of Neurology
Wayne State University
Detroit, MI

Dr. Huq is the recipient of a Cure Autism Now 2003 Pilot Grant Award, **Candidate Genes for Autism on Chromosome 7q.** In addition, he has published 5 scientific publications using the AGRE resource over the last 2 years.

Q: How did you get started in autism research?
A: I am a child neurologist, trained in clinical genetics as well as molecular genetics. The genetics of a complex trait such as autism is an intellectual challenge. As a clinician, I see many patients with autism and want to do something that will one day make a difference for them. Moreover, my colleagues at Wayne State are involved in autism research, so I am in a good environment to do this work.

Q: How would you characterize your approach to the study of autism genetics?
A: The general approach is to look for candidate genes based on chromosomal location. We also use information (already known from other research) about genes associated with "other disorders", such as Fragile X and Tuberous Sclerosis. For example, 70% of patients with Tuberous Sclerosis have autistic features. The same pathway may be somehow involved in the development of autism. This allows us to make more educated guesses and improve the odds of locating specific autism genes. Genes of known identity are tested directly for association with autism.

Continued on page 11

Director's Corner

Clara Lajonchere Ph.D.
AGRE Program Director

Throughout my tenure at the Autism Genetic Resource Exchange (AGRE), many emails and telephone calls from parents have arrived that urgently request information on genetics, interventions, and clinical trials related to autism. While the humanness of each remains in my memory, there is one in particular that I would like to share with you today. This one was a frantic call that I received 3 months ago, from a woman who was living abroad at the time. Having just heard that there was an increased likelihood that her unborn child would develop autism given that she had two other affected children at home, she asked, "Is there a test that will tell me if the baby I am carrying will develop autism?"

In the United States, autism has been estimated to affect approximately 1 in 166 children. One would therefore assume that scientists and biotech companies would have vied for the opportunity to come up with a "test" for such a large population. In fact, this was the vision of the Cure Autism Now (CAN) co-founders, Jon Shestack and Portia Iversen, when they started AGRE.

Scientists estimate that the risk of having a second child with the disorder increases to approximately 5 percent, or 1 in 20, in families with other affected children. This statistic is much greater than the general population risk for other disorders. By soliciting and coalescing funding for research, Jon and Portia hoped more young investigators and seasoned scientists would be drawn to study autism.

Their dream is coming true. To date, there are over 1,000 families registered with AGRE and 148 researchers from 17 countries worldwide accessing the collection. Scientists are working hard to uncover the genes involved in autism and there have been 34 scientific studies to date that have used the AGRE collection. AGRE visits families in their homes year round to collect clinical information and genetic samples to broaden our resource. Our recruitment of new families is ongoing and will continue until we reach every city in the nation.

The most recent genetic findings support the theory that autism is not caused by a single gene. Rather, scientists believe that autism is caused by the interaction of multiple genes in combination with environmental factors. Creating a resource with so many variables is complex and time consuming. By joining forces, AGRE families are accelerating the pace of research, which will enable the faster discovery of early testing methods, such as the one requested by this mother and many other parents.

"Should I terminate my pregnancy?" was one of this mother's more agonizing questions. While I am not in a position to advise anyone regarding such deeply personal decisions, it is the hope of all of us at CAN and AGRE that our resource will yield scientific discoveries that will conquer autism and related disorders once and for all.

I hope everyone has a great summer,

Clara Lajonchere

If you know of an autism support group, family conference or mail list that would support AGRE's recruitment in your area, contact Marianne Toedtman at 888-288-4762 or mt@agre.org

Stay in Touch!

Update Your Family's Contact Information.
Let us know if you've changed your address, added a new email or a cell phone number!
Use our online form at www.familyagre.org or call 888-288-4762.

AGRE was created by the CURE AUTISM NOW Foundation to advance genetic research in autism spectrum disorders. DNA samples and clinical data are obtained from families that have more than one member diagnosed with autism, Pervasive Developmental Disorder (PDD) or Asperger's syndrome. Data is immediately made available to qualified researchers.

AGRE Update

Cover story continued
A.H. M. Mahbubul Huq, M.D., Ph.D.

Q: I notice that in a number of your papers you focus on chromosome 7q. Would you talk about why that is?
A: Chromosome 7q is one of the areas that has been replicated by most groups in almost every genome scan. The strength of the linkage varies, but almost everyone has found some evidence for linkage on 7q, so it naturally became a major focus of our work.

Q: Has access to the AGRE resource been helpful in your research?
A: In our autism research for three years, we have only been able to recruit about 60 families and most of these families have only one child with autism. Without the samples from AGRE we would not have been able to carry out our studies since 60 families would not have been adequate to reach any significant conclusions. Offering DNA samples from well characterized families is incredibly helpful and a very effective way of stimulating research.

Q: Based on the result of your work, what biological pathways or systems do you think are affected in autism?
A: We are interested in the inositol signaling pathway, it is one of the pathways that is involved in cell growth. This is the pathway that is disrupted in Tuberous Sclerosis. Because it is involved in neuronal development, it may be helpful in explaining macrocephaly and abnormal brain development in autism. This pathway is also involved in neurotransmitter action. Whenever a growth factor or a neurotransmitter combines with a receptor, there is a signal for a protein or enzyme inside the cell. Those proteins activate other proteins. Eventually they control cell movement, cell growth, and other actions. These pathways are involved in brain development, neurotransmitter action and growth. We looked at some of the genes in about 200 families and we have evidence that this pathway could play a role in autism. Scientists know that autism is a disorder of brain development and we are interested in how the genes influence this process. We are also studying other genes that affect brain development and neurotransmitter pathways.

Q: What do you see as the role of environmental factors in the development and progression of autism?
A: We are looking at the involvement of immunological genes. We have some interesting data that we have not published yet. If there is an immunological abnormality, it may affect brain development because some genes play a role in both the immune system and brain development. Genetic variation in the immune system may also affect how a developing brain responds to viral infection.

Q: In addition to the AGRE biomaterials, what data do you find useful in the AGRE database?
A: I think that the phenotypic (clinical) data is very, very important. The more phenotypic data there is, the more useful the resource will be. You can think about autism in two different ways. One way perhaps is that autism is a collection of syndromes. Maybe different families have [autism] with a distinct cause, just like Fragile X or Tuberous Sclerosis. There may be other disorders that we have still not identified, that are a collection of syndromes.

If it is not a collection of syndromes, it may be multiple risk factors that interact, including genetic and non-genetic factors. Either way, there is probably a lot of heterogeneity. The phenotypic data may be one of the ways to divide the whole collection of families into distinct subsets in which particular genes are involved. We are using the phenotypic characteristics as a covariate. By controlling for that phenotypic characteristic we will see whether we can distinguish between different subgroups. Phenotypic data also allow us to do a quantitative and a more powerful analysis.

Q: Any additional comments for the contributors, the families and friends of AGRE and Cure Autism Now?
A: We are very thankful for your help and contribution. With your help, I believe we will one day be able to find the causes of autism and how this process can be stopped or modified. Our group's research represents very challenging and stimulating work and it has been made easier and more effective by the contribution of AGRE families.

Mark Your Calendars!

Cure Autism Now and AGRE's Speaker Presentations—stop by and visit our exhibit booth.

ASA's National Conference
"Soaring to New Heights"
July 7-10, 2004 • Seattle, WA
Presentation: AGRE: A Novel Approach to Autism Research
Clara M. Lajonchere, Ph.D., AGRE Program Director
Sarah Spence, M.D., Ph.D., AGRE Medical Director

Texas State Conference on Autism
"Creating Opportunities"
Sept. 9-11, 2004 • Corpus Christi, TX
Presentation: AGRE: Genetic Research Updates
Clara M. Lajonchere, Ph.D., AGRE Program Director
Sarah Spence, M.D., Ph.D., AGRE Medical Director

Interdisciplinary Council on Developmental & Learning Disorders
Nov. 5th, 2004 • Mclean, VA
www.icdl.com
Presentation: Update on Medical Interventions in Autism
Sarah Spence, M.D., Ph.D., AGRE Medical Director

AGRE Staff

Science Watch

Linkage and Association of the Mitochondrial Aspartate/ Glutamate Carrier SLC25A12 Gene With Autism


Article

Linkage and Association of the Mitochondrial Aspartate/ Glutamate Carrier SLC25A12 Gene With Autism

Nicolas Ramoz, Ph.D.
Jennifer C. Reichert, B.Sc.
Christopher J. Smith, Ph.D.
Jeremy M. Silverman, Ph.D.
Irina Bespalova, Ph.D.
Kenneth Davis, M.D.
Joseph D. Buxbaum, Ph.D.

Ramoz N, Reichert JG, Smith CJ, Silverman JM, Bespalova IN, Davis KL, Buxbaum JD.
Am J Psychiatry. 2004 Apr;161(4):662-9

Identification of two gene variants on the short arm of chromosome 2 (2q), shows a strong association with autism in a set of more than 400 families. Most of the family data was collected by AGRE.

Researchers at the Mount Sinai School of Medicine screened families that showed some evidence for an association of autism with chromosome 2q. This region is interesting because it is most associated with deficits in language development.

Several changes in the DNA (DNA variants) were identified as a result of a screening of 10 genes on chromosome 2q of individuals with autism, compared with individuals without autism. These genes were selected based on several criteria, namely their location within the region and existing evidence of the gene's activity in the brain.

The AGC1 gene that contains the DNA variants is involved in energy production within the mitochondria, a cellular structure that serves as the powerhouse of the cell. AGC1 is especially active during neuronal development. The discovery of these AGC1 gene variants is an important milestone in the identification of susceptibility genes for autism.

Genetic Association between Autism and ENGRAILED2 (EN2)

Association of the homeobox transcription factor, ENGRAILED 2, 3, with autism spectrum disorder
Gharani N, Benayed R, Mancuso V, Brzustowicz LM, Millonig JH.
Mol Psychiatry. 2004 Mar 16 :1-11

Scientists believe they have made one of the more compelling cases pointing toward an autism gene – the gene is called Engrailed 2.

Researchers studied genetic information from 167 families of autistic children using AGRE family samples — and found that a variant of Engrailed 2 was twice as likely to be found in autistic children as in their unaffected siblings.

"This is among the most statistically significant evidence for any gene involved in autism," said James Millonig, co-investigator of the study and a researcher at the UMDNJ-Robert Wood Johnson Medical School in New Brunswick. The study also indicates that genetic alterations in the brain's cerebellum could be an important factor in autism.

"If we found somebody with a genetic vulnerability who did not get autism, it could be a powerful way to learn what we can avoid to prevent this illness," said Linda Brzustowicz, co-author of the study and a researcher at Rutgers University and the UMDNJ-New Jersey Medical School in Newark.


IMMEDIATE COMMUNICATION

Association of the homeobox transcription factor, ENGRAILED 2, 3, with autism spectrum disorder

N Gharani[1], R Benayed[1], V Mancuso[1], LM Brzustowicz[2,*] and JH Millonig[1,3,*]

Millonig, who came to autism research with a background in mouse genetics, said he knew that nearly all autopsy studies of people with autism found a malformed cerebellum. The cerebellum is involved in language and attention, the very skills usually impaired in children with autism. Millonig knew certain genes were linked to a malformed cerebellum in mice. He used that knowledge as a road map to find human genes implicated in the same condition. Extensive testing eventually pointed to Engrailed 2.

Millonig said the tests must now be replicated.

"We need to do a lot more to provide further evidence. We need to test more families. We are in the process of doing that," he said. Millonig also wants to use imaging studies to eventually determine if the cerebellum functions differently in people who have inherited the Engrailed 2 gene.

Science Watch and "An Interview with Dr. Huq" were provided by AGRE's Research Liaison, Vlad Kustanovich, Ph.D. For more information contact him at 888-8AUTISM ext 31 or email vkustan@agre.org


Vlad Kustanovich, Ph.D.

AGRE Update

Enrolling New Families

AGRE is always enrolling new families throughout the United States who have two or more children diagnosed with an Autism Spectrum Disorder (ASD). If your family has enrolled and you are waiting to begin participation, please keep in mind that AGRE is a national recruitment effort. This can mean that families may have a waiting period before beginning participation or in between visits. For those families who are waiting for AGRE staff to visit their home, we appreciate your patience and want to keep you updated with the latest AGRE information.

For information on family eligibility contact, Tiffany Torigoe at 888-8AUTISM ext 34 or email ttorigoe@agre.org

Serving the Research Community

AGRE's latest research activities include:

- A total of 436 families are available for researchers to use in their investigations.
- There are 137 AGRE-approved researchers from 17 countries worldwide who have applied to use the AGRE collection.
- AGRE samples were cited in 8 scientific publications in 2004.

Frequently Asked Questions

Q: Can I participate in AGRE if my family is participating in another genetic study?
A: AGRE does not recruit families who have participated in other genetic studies. Researchers frequently combine data sets from various sources in order to identify†the genes most likely associated with autism. Because the identities of AGRE families are kept confidential, researchers do not know when a family is duplicated in a combined data set. As a result, families participating in more than one study could invalidate the results of the research. It is important to let AGRE staff know if your family has participated in another genetic study.

Q: Why does AGRE only recruit families with two or more children with an autism spectrum disorder?
A: We focus on families where two or more children are affected with an autism spectrum disorder (ASD), because it helps us to identify the families where genes are likely to play a crucial role. The more people in a family with an ASD, the greater the likelihood that a genetic component, as opposed to other known causes (e.g., Fragile X, Rhett's Disorder, brain trauma), is involved.

Collaborations

AGRE's collaborations focus on innovative research projects that will add to the overall scientific knowledge on autism. Data from projects are added to our research database for scientists to further investigate autism. A big thank-you to the AGRE families who join our efforts. A summary of findings of projects will be shared in a future AGRE newsletter article.

Currently recruiting CA families!
Lipomics Technologies, DHA Study
Cure Autism Now and Lipomics, Inc., a biotech company specializing in lipid metabolism, are collaborating on a project that examines the effects of Autism Spectrum Disorders (ASDs) on the processing and breakdown of fatty acids in the body. The goal of this project is to compare the levels of docosahexaenoic acid (DHA), an omega-3 essential fatty acid, in blood samples of male children with ASDs with their unaffected male siblings. There has been considerable interest in the role that DHA plays in enhancing memory, attention, language, and motor skills. Therefore, it is important to examine the effect of fatty acid metabolism on the behavior of children with autism. AGRE will be recruiting families in California with one male child affected with an autism spectrum disorder and one unaffected male sibling. Participation in this study will require a blood draw in the home.

Largest national twin study!
Stanford University, Twin Study
AGRE is partnering with investigators at Stanford University to conduct the largest twin study of autism in the nation. The study will focus on families with affected twins in California recruited primarily through the 24 regional centers. As part of the collaboration, AGRE will recruit and complete assessments on 180 twin families (both identical and fraternal) from southern California over a period of 4 years. Stanford will be sharing all of the data from this study with AGRE so that researchers worldwide will have access to this information.

It's never too late to return your SRS!
Washington University, Social Responsiveness Scale (SRS)
AGRE and colleagues from Washington University in St. Louis are collaborating on a study that examines the social behavior of children affected with an ASD and their unaffected siblings. To date, 230 AGRE families are participating.

For information on AGRE collaborations, contact Marin Lutz at 888-8AUTISM ext 37 or email mlutz@agre.org


Brianne E. Cohen

Darnell Carr Newsum
Brooklyn, NY

mother of Taylor and Savannah Newsum

I wanted to formally thank AGRE for sending Brianne Cohen to our home to collect my family's data for AGRE. Brianne is an exceptional clinician but, more importantly, she is a fine human being. Her professional expertise, throughout a very long day and evening, made the process so much easier. My children often mention her name as one of the best test-givers they have had.

I think you should feel confident about the quality of your research with great people like Brianne working on the study. As a family participating in this important research, it is sometimes difficult, on an emotional level, to respond to those questions which often confirm your worst fears about your child's development.

The protocol you have developed at AGRE, made me feel that I had definitely made the right decision to participate in the AGRE research. Thanks again for sending one of your best to our family.

Keep the Porch Lights On, I am on My Way

By Brianne E. Cohen , Clinical Research Associate

I booked my flight, rental car and hotels. I printed out all of the necessary information, including my *Mapquest* directions. I packed my video camera and laptop. I am ready to begin my next AGRE adventure...

Traveling so frequently can be trying, but the incredible people that I meet along the way keep me going. In this past year, I have visited AGRE families in New York, New Jersey, Connecticut, Maine, Massachusetts, Minnesota, Illinois, Florida, Texas and California. From rural areas to the most urban, I have been welcomed with outstretched arms into each family's home.

Working with children with autism has been my passion for quite some time now. I am a board certified music therapist, and believe my past experience in music therapy has been so beneficial for my job today. Instead of working with children to stop certain behaviors and to develop communication and social skills, I am observing these skills through the Autism Diagnostic Observation Schedule (ADOS). I bring a whole suitcase full of toys, books and other activities. In the ADOS, play and social situations are set up to see how the child responds. The children usually enjoy this time, especially since not a lot of demands are placed on them!

The majority of time spent in your home is doing the Autism Diagnostic Interview-Revised (ADI-R). This is an extremely comprehensive interview that is done with the primary caregiver. The purpose of the ADI-R is to ensure that AGRE is using the same diagnostic criteria for ASD as all the other researchers around the world. The ADI-R asks questions about every aspect of development and takes an average of 2 hours per child to complete. I truly love learning about your children and your family!

After visiting with so many families in their homes, I have seen a lot. Please don't feel like you have to "warn me" or "apologize" for your children taking their clothes off (because they hate wearing clothing) or constantly rewinding and playing the same part of a movie (because they love watching that certain part).

In fact, thank you. I look forward to meeting many more amazing families in the future!

★ ***In December 2003, Angie Fedele was awarded the Cure Autism Now staff recognition award for her commitment to families and the organization since 2000. She is a Senior Clinical Research Associate and joined AGRE in October 2000. Her duties include administrating clinical assessments to families in their home.***


Angie Fedele

Getting to Know AGRE Families

By Angie Fedele, Senior Clinical Research Associate

Working as the Sr. Clinical Research Associate for AGRE has given me the opportunity to meet the most amazing people. I am so lucky to be able to travel all over the United States to meet such wonderful families. Every child I have encountered along the way has touched my heart.

When I go into a home the first thing every family notices is my huge suitcase. Families, please do not be alarmed, I am not moving in! Typically I am only at your home for a day or two. While I am in your home, I will be conducting a number of assessments that collect information about the clinical diagnosis of your children.

I cannot express enough how much my job has meant to me over the past four years. I have so much fun getting to know all of the families. Time and time again I am impressed when I see how each and every family copes with autism. I am always moved by how much the families welcome me, not only into their homes but also into their lives.

Are You CONNECTED?

Be sure to sign up for CAN's eNewsletter, *Connections*, at www.cureautismnow.org

Click on "get eNewsletter" to receive news and updates in one convenient biweekly email.

CURE AUTISM NOW Announces New Executive Director and CEO

Cure Autism Now is pleased to announce the appointment of Peter H. Bell as Executive Director and CEO effective April 5, 2004. Bell, the father of an 11 year old with autism, assumes the chief executive's role after twelve years with the Johnson & Johnson family of companies.


The Bell Family, Chicago, 2004 Walk Now

WALK NOW COMING TO A CITY NEAR YOU

Join tens of thousands of walkers and volunteers around the country to make 2004 an incredible year for WALK NOW!

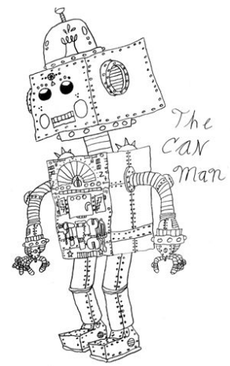
2004 WALK NOW Event

Honolulu, Hawaii	**$40,000 Raised!**
Los Angeles, California	**$737,000 Raised!**
Chicago, Illinois	**$510,000 Raised!**
Seattle, Washington	August 21, 2004*
Orange County, California	August 29, 2004*
Philadelphia, Pennsylvania	October 2, 2004*
San Francisco, California	October 24, 2004*
Houston, Texas	November 20, 2004*

2005 WALK NOW Scheduled Events

Hawaii	March 12, 2005
Los Angeles	April 2005
Chicago	May 2005
NYC	June 2005

Stay tuned for more 2005 events!
For more information or to register, go to www.walknow.org or call 1-888-8AUTISM



Original artwork by Kyle Leahy Walsh. He lives in Warwick, New York. He recently graduated from 5th grade at the Pine Island Elementary School.

CAN Chapter Contact Information
For chapter information contact Jeremy Sidell, Chapter Development Director, at 888-8AUTISM ext 21 or email him at jsidell@cureautismnow.org

Family Matters

Mark and Lisa Grzywa, Downers Grove, IL

An "alternative lifestyle" is how we describe our life with our two sons with autism. The plan was to raise our boys in a suburb of Chicago and enjoy a "typical" life. However, when Collin, now 11 years old, wasn't developing like a typical child by 19 months, our plan dramatically changed. Our other son, Aaron, now 9 years old, showed similar delays at the same age. We knew things would never be "typical".

Early on we were focused on intervention and trying to fit into the typical world. It ended up being just too overwhelming for us. Over the years, we've learned what works and what doesn't. We've managed to develop our own lifestyle; short visits work best, going places early, getting tag-a-longs so we could take family bike rides. Using Thomas the Tank Engine to get Aaron to do his homework, centering vacations around swimming. Using special park programs and other resources to give the boy's opportunities and us respite. Setting up schedules. Sometimes we realize that it's easier to stay home.

As Collin and Aaron approach adolescence, it's much more difficult to try to fit in. Collin is non-verbal and severely socially impaired. Aaron has limited verbal skills and many behavioral issues. Even though it's a decision tinged with sadness, it's easier on our family to make our own world.

We continue to have our ups and downs and realize that that there are many challenges ahead. It is our hope that by being part of the AGRE, other families may be able live a "typical" rather than an "alternative" lifestyle like ours.

Colin and Aaron Grzywa

The Kirpes Family
Tucson, AZ

Hunter Toedtman
Aptos, CA

The Keylon Family
Crawley, WV

Cover story continued
Family Lives with Autism: disorder affects three of four sons

An average day for us can be challenging. It is difficult because of the children's constant demands and difficulties in communicating and interacting with others. We have no relatives nearby to help out, one of us must always be with the children. The duties are endless and attention must be constant, since some things they do may be unknowingly dangerous.

My friend, Kathy Wakeman, and I have started a support group called Mom's Autism Network of Shenandoah, or MANOS, Spanish for hands. I admit to having to cope with feelings of sadness and anger. I am learning to channel them to aid others. One thing that still scares me is knowing my husband and I are going to die before our kids and there is no one to take care of them. So this is my goal: to make these children self-sufficient so they can live together as brothers on their own when we're gone.

Welcome New AGRE Staff

Marin A. Lutz

Marin A. Lutz, Collaborations Manager, received her undergraduate degree at UC Berkeley and returned to academics to pursue a second degree in Molecular Biology and Genetics. After working for several years in the Molecular Genetics Department at Specialty Laboratories, she transferred to UCLA to pursue her research interests. Marin worked as a molecular biologist for seven years at UCLA investigating chemokines and chemokine receptors. In the Physiology Department she examined how chemokines contribute to the development of atherosclerosis and their role as co-receptors for HIV viral entry. She pursued additional research at the Pulmonary Department and investigated how chemokines were involved in regulating lung cancer metastasis. However, after learning that her only nephew was diagnosed with autism, she shifted her research interests and began looking for opportunities related to autism research. Marin joined AGRE in December 2003 to promote autism research and contribute to an organization that provides a collaborative approach to science. As the Collaborations Manager, she helps to provide scientists with the resources from our AGRE families to facilitate autism research. Email her at mlutz@agre.org

Tiffany K. N. Torigoe

Tiffany K. N. Torigoe, Family Recruitment Specialist, graduated from the University of Hawaii at Manoa with a Bachelor's degree in Psychology. She moved to California from Hawaii in January 2004 and joined AGRE in February. During her time at the University of Hawaii, she conducted "directed research" in the Child and Adolescent Anxiety and Stress Program at the University's Cognitive Behavioral Clinic under the supervision of Dr. Bruce Chorpita. She feels that AGRE is a perfect fit for her because of her desire to work in the scientific community and make a difference in children's lives. Email her at ttorigoe@agre.org

Jocelyn Furr

Jocelyn Furr, Clinical Data Coordinator, received her Bachelor's degree in Biology from Boston University. During her senior year in college, she interned for the Research and Development Department at a small biotech company in Boston that specialized in rare genetic diseases. After graduation, she was offered a job in the Quality Control Department at the same company, controlling the receipt and distribution of biological samples and data. She moved to Los Angeles in January 2004 and joined the AGRE team in February. She is responsible for managing the data that is collected by the clinical research associates, as well as maintaining the quality of the internal and web-based databases and patient files. She is excited to devote her talents to help maintain the quality of data available to AGRE researchers, and is dedicated to AGRE's mission.
Email her at jfurr@agre.org

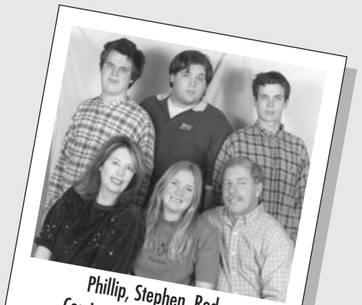
Congratulations Angela Hunt!

Angela will be leaving AGRE in August 2004 to pursue her doctorate in Clinical Psychology at Pepperdine University. Angela worked closely with families; enrolling, scheduling, and answering questions. She will be missed!

Angela Hunt

Lifetime Television has announced that it will air "Miracle Run", the true life story based on the lives of Stephen and Phillip Morgan, identical twins with autism and their family in August 2004. Tom Patricia of Patriarch Pictures is the Producer and Michael Maples wrote the script.

Many people involved with Cure Autism Now and AGRE may know Stephen and Phillip as speakers at fundraising events and the family participates in the AGRE program.



Phillip, Stephen, Rod, Corrine, Ali & Doug Morgan

Corinne Morgan, Agoura, CA

Stephen and Phillip had more sounds than language until they were 11 or 12. Even then it was never conversation, it was disjointed, they were always crying, and situated in a school system which had no specialized training or funds to help them. Although they were intelligent, their behavior interfered with every aspect of their daily lives.

I realized that their behavior was not 'bad', it was a medical condition, and inside they were suffering. Stephen and Phillip were trying to tell teachers and peers they wanted to be included. We never gave up hope.

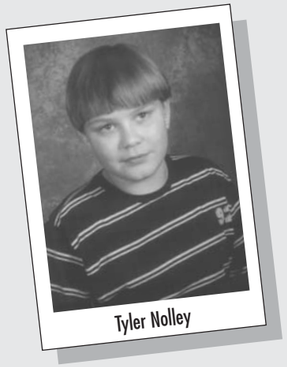
Stephen and Phillip were kept in special education classes throughout high school. But the important thing was that my husband Doug and I kept a good relationship with teachers and counselors who were supportive, positive and truly wanted the twins to excel. Soon the twins could go to school knowing it would not be a negative experience, but a social and educational one. We made mistakes. I would get angry or show my frustration. I learned to communicate with school staff, so they would help me. I took the twins everywhere so the community would get to know them.

Stephen (reading speech) and Phillip Morgan
Agoura High Cross Country Team

Doug and I got involved. It was hard, and sometimes embarrassing. Things would happen. We would go home and work on them. Many times we felt alone, but our love for Stephen and Phillip overcame every obstacle, we prayed as a family, and soon they began to find lives of there own.

Because your child with autism does not speak today, does not mean he will not speak tomorrow. There is a great probability your child will have a happy future for many years to come.

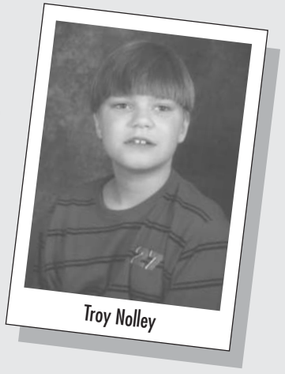
The Nolley Family, Fort Pierce, FL



Tyler Nolley

It all started back in 1992 when I found out we were having twins. The birth was a dramatic one to say the least. With an emergency C-section when I was just seven months pregnant, I knew if Troy and Tyler could stay strong they would be able to conquer anything. We went through evaluations every three months with the medical staff saying they were doing well for their "adjusted age".

I'm not really sure when all this started, but I was seeing odd behavior in their "play" as early as 10 months old. Some of it included turning over their big wheels and spinning the tires, obsessing about ceiling fans, and flipping graham crackers in front of their eyes. Family and friends thought it was cute, but I knew something was wrong. Finally, the word "autistic" was said by one of the neurologists. I knew deep down that it was true.



Troy Nolley

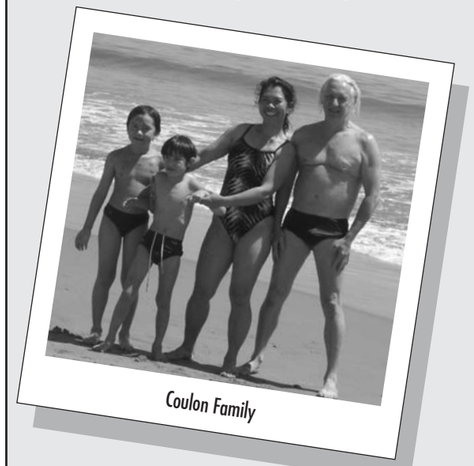
I was flooded with emotions. Why, when, how could this happen? What did I do wrong? One of the school's staff gave me a lot of literature on autism and support groups. One of the pamphlets was from an organization called Cure Autism Now (CAN). CAN was looking for families with multiple family members with autism for the gene bank-AGRE. I would like to go on record as saying that everyone I have come into contact with at AGRE has been absolutely wonderful!

Every day is a new adventure in our household. Sometimes the boys switch behaviors and that always keeps me on my toes. They have a younger brother, Devin, who has helped me in so many ways. He's a very good brother and a great son. Through time, I have learned that this is not anything I did or didn't do. I'm at the "I know we'll be ok," phase. My husband, Dave, still gets sad and wonders why. I think his dreams for them are suppressed, but I pray someday we can be at the same place, because, I know if we are strong **together**, the boys will exceed beyond our dreams for them. At 11 years old, we face a new phase -puberty! So, I guess we'll just take one day, hour, minute, at a time.

Robin Coulon, Berkeley, CA

My wife and I met and married in her hometown of Davao City, Philippines. We live in Berkeley, California where I have been a contractor for many years. Our first son, Niji, was born in a local hospital. Our second son, Taiyo, was born in the front seat of our minivan on the way to the hospital!

For the first year of his life, Taiyo seemed normal. He took his first steps around 18 months, but still didn't have any words by this age. When he was 2, my mother, a nursery school teacher, began to suspect autism. We enrolled him in a special education pre-school when he was 2 1/2 years old. No one there spotted his autism because he was friendly, affectionate and demonstrated good eye contact.



Coulon Family

Taiyo Coulon

At 3, Taiyo began attending public school special education classes. Although he frequently vocalized, he had no recognizable words at this age. His teachers began to realize that he was autistic. He didn't play with most toys appropriately, but was very fond of spinning objects. He was nearly 6 when he began to use his first recognizable words, "Oh Shenandoah", to request a song I sing to him each night. It wasn't until he was nearly 7 that he began to get an appropriate education in school. He now has more than 100 words, but they still lack the context of language. He remains a loving child, popular with students and teachers alike.

Taiyo loves to travel with our family and has seen all of the 48 states and six provinces of Canada, as we drive back to New Hampshire every summer. His brother Niji has been diagnosed with Asperger's syndrome, but he is very high functioning. The boys get along very well together. They love to swim and often play together in the water either in the pools of the local YMCA or in the fresh water lakes of New Hampshire. Taiyo has learned to swim without instruction by just letting the water teach him.

I learned of AGRE searching the internet for autism resources.

Jean Yates, Westchester County, NY

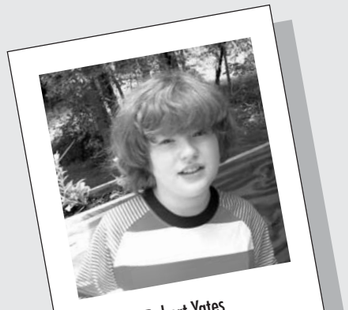
For the past eight years I have worked to help other parents in our school district with their situations and the services their children need. Helping others has given me a way to "accept" (I love that word) life's challenges.

My husband Jim manages to remain good humored and patiently takes the children to their appointments while I babysit whoever is home. We have three children in the house at the moment, the oldest of the three at home is Ian. He will be 14 this summer and is a typically developing child. He has an inordinate love of computers and is very talented at flash animation.

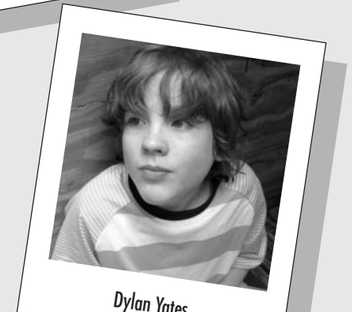
Dylan turned 12 in January. He is in a private school paid for by the district that he will attend until age 21. He continues to be a little difficult and requires his own one to one aide because of this. Dylan is nonverbal and uses the PECS system, which is great. He loves going for rides in the car to Burger King with his dad. He likes to have the extra large size onion rings. When he is in the mood, he flings them with wild abandon into the way back of the car.

Robert turned 10 in January. He is sort of a savant. Before you think I am brazenly showing off, please realize there are drawbacks. Yes, he knows things like capitals, and currencies, and actually gets to levels on Nintendo games his oldest brothers never saw, and his middle name is "Computer Search" (I find him on eBay all the time!). Robert's language is a bit better than Dylan's, and his receptive language is in place. This is good, but he is still classified as severely autistic, like his brother. The "talking problem" is a major part of what holds him back.

I continue to have a firm belief that contributing to the AGRE program is a choice that will eventually help countless people.



Robert Yates



Dylan Yates