Workers' Compensation Group Self-Insurance Fund and Group Insurance Pool

MARYLAND ASSOCIATION OF BOARDS OF EDUCATION

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April is Autism Awareness month.

Autism is a complex neuro-biological disorder which affects all areas of a child's development; mainly communication, social skills and self-help skills are impaired. Autism is classified as a pervasive development disorder or PDD. Autism is recognized as a spectrum disorder (ASD) meaning the characteristics can vary greatly depending on the severity. No two children are alike on the spectrum and it is difficult from outside physical appearances to

IN THIS ISSUE:

FEATURED STORY:
AUTISM 2011 - PAGES 1 - 5

8 QUESTIONS WITH
KIM QUICKLEY - PAGE 6

NEWS BRIEFS - PAGE 7

tell that a child has autism.

In the past four years, the diagnosis rate has escalated from 1 in 150 to 1 in 110 children according to statistics from the Center for Disease Control (CDC). Statistics show that boys are four times more likely to receive the diagnosis and yet there is no clear reason why.

You may be wondering how far science has come along in diagnosing and treating this disorder. What about the future of these children as they mature into adulthood? We have had the opportunity to speak with several doctors at the renowned Kennedy Krieger Institute in Baltimore about the present, the past and the future of Autism.

## DIAGNOSIS: AUTISM

Dr. Rebecca Landa who is the Director of the Center for Autism Related Disorders (CARD) at Kennedy Krieger Institute discussed programs available for expectant mothers and young children whom have recently been diagnosed as well as how Autism is diagnosed differently today.

What new challenges are there in diagnosing a child with Autism today?

“The biggest challenge continues to be the amount of variability we (Kennedy Krieger Institute) see from child to child”, according to Dr. Landa. “Autism spectrum disorders can appear so differently from one child to the next that it makes diagnosis very challenging. For this reason, we ensure that our staff is highly knowledgeable and often utilize a multidisciplinary evaluation model to ensure that we get the best information to form our diagnostic decisions”, she adds.

“We (Kennedy Krieger Institute) are also learning more about the high prevalence of co-existing mental health disorders, such as anxiety and depression, among individuals with autism. The process for teasing apart the different groups of symptoms in order to properly diagnose children can be quite challenging. In addition, despite the increased awareness of symptoms of ASD, we still have many parents who tell us that, despite their concerns, their physicians and other providers indicated that their child did not need an autism evaluation. Given what we now know about the importance of early intervention, this is always disheartening to hear. For this reason, Kennedy Krieger has started a "Why Wait and See" campaign in order to help educate the community”.

What are the different services that CARD provides to children who just receive their diagnosis?

“Kennedy Krieger’s Center for Autism & Related Disorders (CARD) offers a variety of services to children and their family members. For newly diagnosed children or other children exhibiting communication, play, and social skill deficits, we have several classroom-based treatments and parent training programs for children beginning in infancy through preschool age. Some of these treatments can even be offered for free through our research studies”.

“In addition, we offer medication management and additional treatment services including: speech-language therapy, occupational therapy, social skills treatment, genetic counseling, individual therapy for children experiencing distress, and family therapy for parents and family members who are struggling with the challenges of raising a child with an autism spectrum disorder” Dr. Landa adds.

Dr. Landa, can you explain the EARLI program and why a parent might want to get involved?

"Kennedy Krieger Institute and Johns Hopkins University have formed a unique collaboration to explore risk factors for and early detection of Autism Spectrum Disorders. The Early Autism Risk Longitudinal Investigation (EARLI) is sponsored by the National Institutes of Health and conducted at four U.S. research sites. EARLI is reaching out to women who have a child on the autism spectrum and who are starting a new pregnancy, or even considering another pregnancy. Information will be collected regularly from the mother and father during the study. The new sibling will receive three years of free developmental assessments by trained professionals at Kennedy Krieger. Families will be compensated for their time, and reimbursed for travel expenses when visits to a study clinic are necessary".

"The Maryland State Department of Education is working with EARLI to recruit families in nine central Maryland jurisdictions, but the study is open to other families who live within 2 hours of Baltimore. More information is available at www.earlistudy.org" she concludes.

## THE STATISTICS AND GETTING INVOLVED

We asked Dr. Paul Law the Director of the Interactive Autism Network (IAN) at Kennedy Krieger questions about the diagnosis statistics and treatments available today throughout Maryland and at Kennedy Krieger Institute.

Is the number of children diagnosed with autism still increasing? Those numbers are still 1 in 110 correct?

"The CDC has set up a system to carefully count ASD cases in the same way, and over time. The last count was 1 in 110, and we are now waiting for the next one which will be the best number available as far as knowing if there is an increase. Most researchers agree that the apparent increase to date results from a combination of expanded diagnostic criteria and a true elevation in the number of cases" he adds.

Dr. Law, for a child diagnosed as being on the spectrum, what is the lifetime cost a parent might incur? The Harvard School of Public Health released a figure of $3.2 Million dollars over their entire lifetime is that figure accurate?

"The IAN Project has data that is used to provide input into costing models that estimate the total cost of autism treatments by month, year or lifetime, but we do not have data on all aspects of life with autism to provide a more comprehensive picture. I'm not aware that any one organization has this type of data".

"I believe that the cost specialists aggregate data from many sources to calculate numbers such as the $3.2 million that you referenced."

How does a family find the funding for treatments if their personal health insurance does not cover this disorder and they don't quality for public or government assistance?

"In some instances, families are able to fund treatments or therapies without using insurance or paying out-of-pocket. For example, some families participating in the IAN Project have reported that they were able to arrange therapeutic horseback riding for their child with ASD thanks to funding from the United Way or private corporate donations."

"Others have reported that grandparents contribute financially to support the needs of children with ASD. The IAN Project is providing data to advocacy groups and lawmakers to help in the various legislative attempts to mandate insurance coverage for autism treatments."

We asked Dr. Law to tell us more about the IAN Project and why families with children on the spectrum are encouraged to participate
"The Interactive Autism Network, known as the IAN Project, is an innovative online project

bringing together tens of thousands of people nationwide affected by autism spectrum disorders (ASD) and hundreds of researchers in a search for answers. Run by a team at the Kennedy Krieger Institute in Baltimore, the IAN Project invites individuals with an ASD and their families to share information in a secure setting and become part of the largest online autism research effort in the United States" Dr. Law said.

"The data collected by the IAN Project both facilitates scientific research and empowers autism community leaders to advocate for improved services and resources. Families who register with the IAN Project are also matched with research studies for which they qualify in their own communities" he adds.

"This type of network is not new, other diseases for which huge strides have been made are the result of families and researchers partnering to advance understanding and treatment. The IAN Project allows families to tell their stories in a way that can advance research and care, while also learning about other exciting research projects that they might want to join. I think it is a winning combination for all involved", he concludes.

## AUTISM EVALUATIONS

Dr. Brian Freedman is the Clinical Director of the Center for Autism Related Disorders (CARD). We asked him about how children are evaluated today and what about teens and young adults.

What types of evaluations are done at Kennedy Krieger today to diagnose ASD?

"Our preference is always to conduct multidisciplinary evaluations, where a child is seeing two or three professionals from different fields in order to conduct a comprehensive assessment of different areas of development. This follows the guidelines set forth by the American Academy of Pediatricians (AAP) for diagnosing autism. We also utilize instruments that are considered to be the "gold-standard" in diagnosing an autism spectrum disorder and ensure that our staff are trained and kept up-to-date on the latest measures and new discoveries in the field".

"Our diagnostic teams include any combination of the following disciplines: developmental pediatrics, neurology, neuropsychology, clinical psychology, speech/language pathology, occupational therapy, social work, and genetic counseling".

What is being done at Kennedy Krieger for

teenagers and young adults? What types of programs are available to them?

"We understand the challenges faced by teenagers with autism spectrum disorders, and the Center for Autism & Related Disorders (CARD) provides individual, group, and family therapy services delivered by mental health experts. These treatments focus on teaching coping strategies for dealing with difficult or anxiety-provoking situations, building social skills, and helping families learn how to communicate with one another and prepare for the transition to young adulthood. In addition, we have psychiatrists on-staff who can help the family determine if medication would assist in helping that teenager to be successful".

"Although we do not currently provide services for young adults, we actively partner with members of the community to provide training and resources to individuals and families in need of support and service providers".

"Additionally, many teenagers with ASD attend Kennedy Krieger's school programs, including the Kennedy Krieger High School Career and Technology Center, and the LEAP Program. The Kennedy Krieger School LEAP Program serves students on the severe end of the autism spectrum who struggle with behavioral challenges. It is an intensive, 12 month program that focuses on providing a highly structured and safe environment that helps students to participate in and derive benefit from educational programming. The LEAP Program is an approved Maryland State Department of Education (MSDE) non-public day

program".

"Since education and early intervention are vital to a child on the spectrum's outcome, we asked Dr. Elizabeth Stripling who is the Assistant Director of Outreach and Training at the Center for Autism & Related Disorders to explain what Kennedy Krieger is doing to help schools understand Autism better" he claims.

Dr. Stripling, can you explain the programs Kennedy Krieger is currently working on within the public school system (give county names) to help teachers and staff better educate children with autism?

"Through collaboration between the Maryland State Department of Education (MSDE), Maryland school districts and Infants and Toddlers programs teachers and staff may apply for and participate in either the Professional Classroom Immersion Training and/or Technical Assistance programs. These programs are offered free-of-charge to districts".

"The Professional Classroom Immersion Training Program is a comprehensive training program, which allows professionals who work with children with autism to be integrated within CARD's evidence-based intervention program for toddlers with ASD. Professionals receive intensive training from the CARD Staff and are then guided on how to apply the model upon return to their school or treatment center. Counties currently participating in the professional immersion program include: Caroline, Frederick, Prince George's, and Washington County".

"Technical Assistance programs provide targeted training, consultation, and observation for those directly involved in teaching and supporting the developmental and educational needs of children with autism in early intervention and classroom settings. Current counties receiving technical assistance include: Baltimore City, Anne Arundel, Washington, Queen Anne's, Talbot, Baltimore County, and Harford".

"In collaboration with MSDE and Baltimore City Infants and Toddlers, CARD offers a classroom-based program paired with parent education for toddlers with autism spectrum disorders. The intervention provided through this classroom is evidence-based practice, blending the strategies anchored in the developmental and applied behavior analysis sciences".

## THE FUTURE

Many families worry about the future and who will take care of their loved one after they pass. They look towards other family members and people with whom they can entrust to carry-on their life's work. Some children with autism can live independently while others will require a lifetime of care with support from schools, medical institutions, relatives and the community. Parents hope to find peace of mind by knowing their son or daughter will have the care they need as they move from childhood and into adulthood.

We at MABE SafetyNews would like to thank Dr. Rebecca Landa, Dr. Paul Law, Elise Welker, Dr. Elizabeth Stripling, and Dr. Brian Freedman for generously providing us with their responses to our questions.

For more information about Kennedy Krieger Institute please visit their website at www.kennedykrieger.org.

# 8 Questions With Kim Quickley

**1) What is your job title? Describe what you do.**

I am a Liability Adjuster. I handle auto and liability claims for all seventeen Maryland County Public Schools. From start to finish, I investigate and resolve each claim.

**2) What do you like most about your job?**

What I like most about my job are my coworkers and the atmosphere. Also, in regards to adjusting claims, I like the fact that no two claims are exactly alike, which makes the job more interesting.

3) **What do you consider your greatest accomplishment?**

My greatest accomplishment was receiving my Bachelor of Science Degree while working full time and raising my teenage daughter alone.

**4) What is your favorite movie?**

I cannot say that I have one favorite movie, as I have several. However, one of my favorite movies is "Enough" starring Jennifer Lopez and Bill Campbell.

**5) What is the last great book you read?**

The last great book I read was "The Worth of a Woman" written by Tracy Price-Thompson.

**6) What is your favorite song? Eight Questions with Kim Quickley**

I have several favorite songs, but I can honestly say one of my favorite songs is "1999" by Prince. On New Year's Eve, 1999, one radio station played only 1999 all day non-stop and I enjoyed it. I figure if you can listen to one song all day and still like it, it has to be one of your favorite songs.

**7) What was the best vacation you ever had?**

The best vacation I ever had was in 1989 when I went to Jamaica to attend a wedding. However, my most memorable vacation was in 2009, when my family, my mother and my sister's family went to Atlanta to attend a family reunion; as it was the last vacation we spent with our mom before she passed away last year.

**8) When you were 12 years old, what did you want to be when you grew up?**

When I was 12 years old I wanted to be a writer.

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# NEWS BRIEFS

## Association of Governmental Risk Pools Meeting Informs and Inspires

The Association's (AGRiP) Conference held March 14 to March 16, 2011, provided Pooling staff and trustees with many valuable educational opportunities. There were numerous sessions assisting with the understanding of Pool finances, financial audits, loss funding, actuarial studies and appropriate Pool surplus.  Other discussions focused on health care issues, social media in the workplace and IRS regulations that apply to Pools. The attendees also heard an excellent presentation from Dr. Robert Cialdini, who has written and lectured extensively about leadership and the power of persuasion. Guitar Humorist Mike Rayburn energized the conference with his entertaining musical presentation, asking members to expand their horizons and consider "What if"?

## Winners of Risk Management Scholarships will Attend Public Risk Management Association Conference

Two scholarship winners will join other public employees from across the nation at this year's annual Public Risk Management Association (PRIMA) Conference which will be held June 5-8 in Portland Oregon.  The scholarships will pay for conference registration and all travel expenses for Cathy McLin, Claims Representative, from Howard County Public Schools and Michael Howie, Risk MABE Specialist, Baltimore County Public Schools to attend this year's conference.

## John Magoon Meets Colleagues in St. Augustine, Florida

On March 26, John flew to St. Augustine to meet with loss prevention and risk management professionals employed by insurance pooling groups. The group has been meeting to discuss current issues and  to other attendees of a school risk management group which has been meeting on an annual basis since 2005.