

Report by:

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It has been 16 years since I entered “the world of autism” with the diagnosis of my then two-year old son. Our family has faced many challenges, frustrations and successes over the last decade and a half, but, for me, one source of continued optimism has been the explosion of ASD research, particularly in the last few years.

As the recipient of Autism Ontario’s Community Leader Bursary, I was privileged to attend the 7th Annual International Meeting for Autism Research. It was my third time attending IMFAR and each year I have seen a greater and more diverse research community represented at the conference.

Though the conference is primarily by and for researchers, it is also attended by a handful of parents, adults with ASD and community representatives. This year’s meeting was fully enrolled – an exciting confirmation that ASD research is garnering greater attention. Among the attendees, there were approximately 800 researchers and students with over 600 poster presentations, more than 150 oral presentations, 3 keynote addresses and a Lifetime Achievement award presented to Dr. Isabelle Rapin. Though the volume of information was overwhelming, and it was not possible to attend every presentation, there was a wealth of intriguing new information.

From the “simpler” times when autism was considered to be a mostly neurologically-based developmental condition and ASDs represented a continuum of characteristics of that condition, today’s multi-disciplinary research suggests that ASDs are much more diffuse, complex and elusive conditions than we imagined. Indeed, the heterogeneity of ASD has been a focus of interest for several years and, as Francesca Happé posited in the first keynote address, may be one of the underlying problems in our attempts to understand the mechanism of autism. In her talk she proposed that the traditional “triad” of impairments within the spectrum may in fact have separate causes and thus there might not be a single unifying explanation for any one case of ASD.

The oral presentations and posters covered the gamut of ASD research. As in the past, there were many studies of the neurology of ASD (biochemical, anatomical and functional). There were also studies of genetics, heritability and the broader autism phenotype. As well, a substantial body of research examined epidemiology, behaviour, social skills, communication, learning abilities, teaching strategies, clinical practices, diagnostic tools, and outcome measures.

Of interest was a number of environmental research projects. The effect of environmental toxins has been a concern in the parent community for some time and some of the

studies suggested there may be a correlation to exposures and the development of ASD. Findings from a study of household pesticide use by Hertz-Picciotto *et al* suggested a correlation between the use of flea and tick shampoos and an increased risk of ASD. Another study of pesticide exposure in farm workers by Eskenazi *et al*, found that maternal exposure to organophosphates (as measured by urine metabolites) increased risk of ASD.

Some other intriguing presentations included examinations of the role of pre and post-natal immunity issues in ASD and a study of immune co-morbidities by Croen *et al* in which a large scale review of health records showed immune differences (less asthma, more environmental allergies, more auto-immune conditions) in the ASD population.

One unfortunate trend was a number of new studies of maternal/child interactions attempting to link dyadic qualities to outcomes and improvement measures. This was disturbing on two levels – firstly, it harkens back to the “refrigerator” mother days and secondly, most of the studies looked only at mother/child interactions with just two studying father/child interactions. While there is certainly a role for investigating the impact of ASD on families, especially as it relates to increased stress levels, risk for depression and need for family supports, I’m not sure it serves a purpose to be attempting to link parental personalities and parenting styles and/or risk to negative outcomes. A family that is struggling to cope does not need the added guilt and grief of the implication that they might be worsening their child’s condition. Interestingly, in a study by Meirsschaut *et al*, a sample group of ASD mothers showed no differences in their

overall responsiveness in comparison to control mothers but showed that the impact of interaction style was limited on children with ASD.

There were many more thought provoking presentations at the conference, however it is not possible to mention them all, even briefly. For those who wish to read more about IMFAR 2008, a 449 page summary of the presentations and posters is available at www.autism-insar.org. Select the “Annual Meeting (IMFAR)” tab and click on “Archive of Abstracts”.

Another 2008 development was the launch of *Autism Research* magazine, a peer-reviewed journal which will be published six times a year. The premiere issue, released in February, was handed out at the conference. Magazine and subscription information can be found at the INSAR website (address above) under the tab “INSAR Journal”.

For all that was exciting at IMFAR 2008, there are still some areas where I would like to see greater study:

- For the majority of studies presented, sample sizes were very small and most lacked adequate control groups. It would be nice to have funding for more rigorously structured large-scale studies.
- There is a need for greater examination of medical issues, especially as it relates to mitochondrial disorders and GI problems. From a parent’s perspective, this research is critical – sick children have difficulty learning.
- There is little study of the special talents and strengths of people with ASD. This avenue of research might not only give ideas of how to use abilities to the benefit of the person with ASD but might also

provide insight into other disorders. For example, developing and testing curriculums for visual learners might also be useful for those with dyslexia. Researching the eidetic memory talents displayed by some on the spectrum might lead to a treatment for memory disorders.

- Considering that a large percentage of children on the spectrum are taking either prescription medication, dietary supplements or both, there is a strong need for proper double-blind research on medications, vitamins and nutritional supplements.

Other areas where more research is needed:

- Resolving some of the big questions: ASD prevalence, the vaccine connection, diet, etc.
- ASD through the lifespan, especially the school years, adolescence and adulthood.
- Teaching strategies – beyond ABA: curriculums, language training, life skills programs, adult education, etc.

- Adult issues – housing, mental health, job training, quality of life, societal acceptance, etc.
- The role of hormones in ASD. Since the condition largely affects boys, it surprises me that there is so little research in this area. The few of studies presented so far are intriguing and suggest more research is necessary.

Where do we go from here? The progress of research is always slower than we would like. It will be many years before the burgeoning research of today can give us definitive answers to the causes and treatment of ASD. Each year, however, the inexorable progress of research and expanding body of knowledge brings us that much closer to understanding ASDs and how we may improve the quality of life for those living with it. I look forward to IMFAR 2009 in Chicago.