

# Can-A-Gen

Canadian Autism Genetics



Hello to everyone and we hope that you are enjoying this beautiful season. You may have noticed a different name on our newsletter. We have changed our name from Family Link to Can-A-Gen. Although our name has changed, our purpose has not! Can-A-Gen will continue to keep families who are participating in our research studies of autism spectrum disorders informed of our progress as well as on other topics of interest. We welcome and appreciate feedback. You may contact: Bev DaSilva at (905) 521-2100 ext. 74728 or [dasilvb@mcmaster.ca](mailto:dasilvb@mcmaster.ca).

Are you a family (or know of a family) who has two or more children with ASD? How about two or more children with ASD in your extended family or one child with ASD with a known chromosomal abnormality? If this describes your family and you are interested in participating in our study, please call Shannon Werner at (905) 521-2100 ext. 7732 or 1-888-328-8476 or [werner@mcmaster.ca](mailto:werner@mcmaster.ca).

## Reminders

- Are you expecting or have an infant at home? You may be eligible for infant sibling study. If you are interested, please give us a call.
- If you have changed addresses or are planning to move, please let us know so that we can keep our records updated.

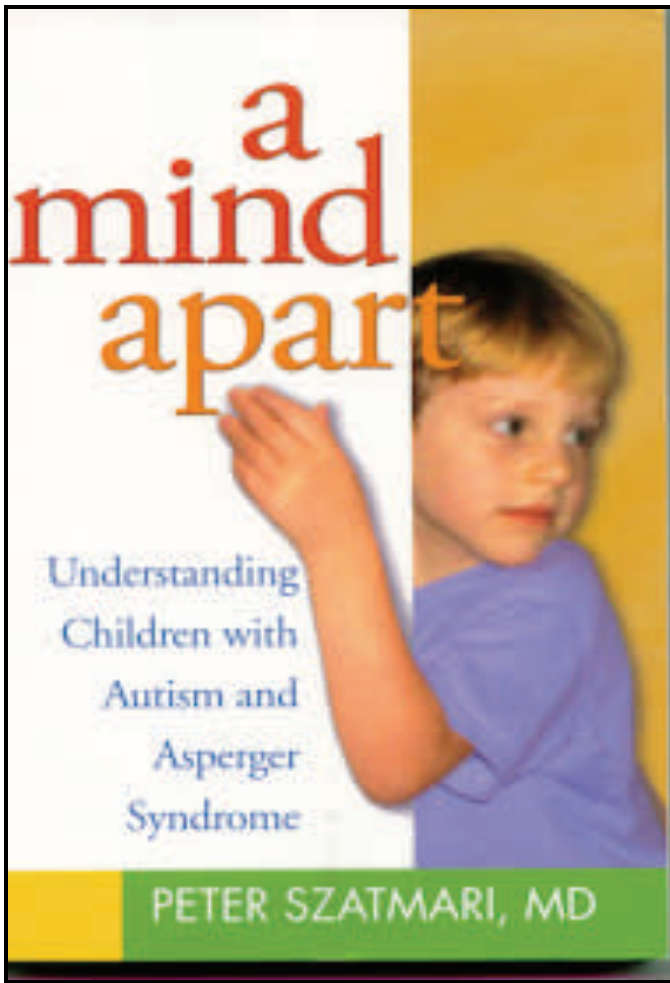
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# What's New at Can-A-Gen?

## “a mind apart”

Introducing Dr. Szatmari's book now available through the Guildford Press. Below is the advertisement Guildford Press uses.



How do you know if your child is happy or sad, tired or hungry, when all he wants to talk about is wasps--or the color of subway train doors? What can you do to reassure a nine-year-old who asks questions about death hundreds of times in a day? And how can you build a nurturing relationship when your little girl hates to be touched?

Questions like these make parenting a child with autism or Asperger syndrome (AS) a journey through uncharted terrain. That's why understanding how kids with these disorders actually think and feel--and the striking ways in which their minds work differently from those of typical children--is so important. Through moving stories of children he has worked with, Dr. Peter Szatmari helps you see the world through your child's eyes. Revealed is what lies behind the intense preoccupations, communication problems, and seeming lack of affection that often accompany autism and AS, and what your child's mystifying behavior might really be trying to tell you. This compassionate book shows how gaining a better sense of your child's experience can deepen the bonds that support learning and growth--and help you lead the way toward a happier future.

## Meet our new psychometrist Shannon Werner

Shannon joined the McMaster team in April 2004 and will be working as a research psychometrist. Shannon received her undergraduate degree from Queen's University in Kingston and continued her education at the graduate level in Waterloo. She completed her MBA and MA in Psychology at Wilfrid Laurier University. Before joining the genetics study, Shannon worked for the Hamilton-Niagara Regional Early Autism Initiative and administered early intervention to young children with autism. Shannon is married and enjoys traveling and windsurfing with her husband.



# Newfoundland joins Can-A-Gen, meet the team

Dr. Fernandez obtained an MD from Memorial University in 1994, and trained in the Royal College's Medical Genetics program at the University of Toronto. She is the Medical Director of Newfoundland's Provincial genetics program. In addition to autistic spectrum disorders, her research interests include inherited forms of pulmonary fibrosis and cerebral aneurysms. She has also studied the burden and epidemiologic distribution of genetic diseases in Newfoundland. Finally, like many other clinical geneticists, she is interested in characterizing new genetic syndromes and improving our understanding of the clinical manifestations of syndromes that have already been identified.

In 2003, Dr. Fernandez and her team joined the Toronto-McMaster Autism project. The Newfoundland group includes 3 developmental pediatricians (Drs. Cathy Vardy, Sandra Luscombe and Vicki Crobie), 2 research nurses (Ms. Barbara Noble and Kathy Whitten), a clinical nurse (Ms. Eva Tucker), a clinical psychologist (Ms. Nadina Ouaida) and a speech-language pathologist (Ms. Diane Whelan).

Dr. Fernandez and her team intend to offer enrollment to the parents of all children with autism in the province. Newfoundland and Labrador have a unique population structure, so that any children with autism whose parents are from the province is eligible, even in the absence of a family history.

Earlier this spring the Newfoundland team was pleased to welcome Dr. Wendy Roberts, from Toronto's Hospital for Sick Children to the Janeway Child Health Center in St. John's. She helped the team achieve reliability with the ADOS and the ADI-R, two important tools for making the diagnosis of autism. Since then, Ms. Eva Tucker has spent 2 weeks at the Hospital for Sick Children receiving additional ADI training. Thanks to this project, the Janeway's Child Development program intends use both instruments routinely in the evaluation of children with autistic features.

Meet the Newfoundland team:

front row (bottom of stairs to top):

Dr. Bridget Fernandez (clinical geneticist and site leader)

Ms. Eva Tucker (child development clinic nurse)

Dr. Cathy Vardy (developmental pediatrician)

Back Row (bottom of stairs to top):

Dr. Vicki Crobie (developmental pediatrician)

Ms. Barbara Noble (research nurse)

Ms. Kathy Whitten (research nurse)

Ms. Diane Whelan (speech and language pathologist)

Dr. Sandra Luscombe (developmental pediatrician)

missing from photo: Ms. Nadina Ouidada (psychologist)



# Genetics Project Makes Substantial Progress

By Dr. Peter Szatmari

This has been an important year in the progress of Can-A-Gen (Canadian Autism Genetics) project. We have continued to enrol new families from all across Canada. We now stand at over 170 families and extend from British Columbia to Newfoundland. Our research staff have travelled to BC, Alberta and Manitoba in the last year to collect clinical information on the families that have two or more children with an Autism Spectrum Disorder. This makes us one of the largest autism genetics projects in the world and we have certainly have collected more extensive clinical information than most other studies. We have also made substantial progress in our plans with our international collaborators. As you know, we have joined with several international groups to form a consortium called the NAAR-AGP (National Alliance of Autism Research-Autism Genetics Project). Last July, we signed a memorandum of agreement with these other groups that outlined the process of collaboration while at the same time maintaining the integrity of our project. We could then ensure that collaborating would now be a win-win situation. I was honoured to be asked to write this memorandum of agreement by my international collaborators and was happy to do so with a lot of advice from our own group. Since that time, many decisions have been made in terms of putting that memorandum into action. Most important, NAAR-AGP has decided that all the existing samples of all the genetic material will be sent to the Centre for Inherited Diseases Research (CIDR) to do a common analysis. It has been difficult to compare and contrast the results of the various genetic studies

since the different research teams around the world have used different methods. By pooling our genetic material and scrutinizing it with a single methodology it will be much easier to identify regions that contain the genes that cause autism. This is very exciting because once we identify genes that increase the risk of autism, we can then understand the biochemical pathway that causes autism and develop treatments that might alter or reverse that biochemical pathway. I want to emphasize however, that while we will be sending some of our genetic samples to CIDR, all information will be anonymous and nobody can be identified in any way. We will also be retaining most of the genetic material ourselves so that we can continue to work on it intensively. This process will also allow us to have access to DNA and genetic material from the other research groups around the world. This will increase the capacity of CAN-A-GEN to find autism genes enormously. We are all very excited about this prospect and it does truly seem like a win-win situation.

In the meantime, Dr. Steve Scherer and his research team at the Hospital for Sick Children are continuing to work on our DNA samples. They are following up all kinds of leads that they themselves have discovered as well as trying to replicate findings from other research groups. We have a number of very exciting preliminary results from a number of different genetic regions and we will be trying to confirm these in the coming months. Keep in touch and we will keep you informed as part of this exciting discovery.

I was an autistic individual myself once. Living and growing in this strange indescribable world was never easy to deal with, but I do know that anything is possible if you put all of your energy and mind into it. You can't let autism or any other neurological disorder control your life. Somehow, you have to learn to fight it and learn to control it.

I have just graduated from Sheridan College for Interpretive Illustration. Because of all the years of my family support and self-motivation to accomplish anything, I was able to lead myself into a normal life. Never give up, because there is always hope.

David Beresford

# Preliminary Findings using the Early Learning Measure (ELM) in Early Intensive Behaviour Intervention

by Dr. Jo-Ann Reitzel

Intensive behaviour intervention (IBI) has been available in Ontario for young children at the severe end of the Autism Spectrum for nearly 4 years. Children with Autism Spectrum Disorders (ASD) in the IBI program learn from instructional programs and positive behaviour support programs that are based on the principles of applied behaviour analysis. The children with ASD gain measurable skills in attending, imitating, communicating, playing, interacting socially with adults and peers and becoming more independent in self-help skills.

Our aim in IBI is to improve the child's developmental outcomes. While IBI is a relatively new program at McMaster Children's Hospital we are working hard to develop excellent evidence-based services for the children and their families to achieve this goal. Still, little is known about many aspects of IBI. We have been interested in studying the ingredients that help to create successful outcomes. We believe some of the ingredients may be child related, family related and program related. Scientific inquiry is needed to better understand the characteristics that impact on successful outcomes from IBI.

With the support of the families in the program, McMaster Children's Hospital and the Offord Centre, McMaster University we have begun to examine characteristics of the children that may be predictors of successful outcomes in IBI. This work is possible due to the generous financial support of the Lawson Foundation.

**“Squeeze every bit of love you can out of life, And life will HUG you back like never before”.**

**Brian G. Jett**

Research has proven that a proportion of young children with Autistic Spectrum Disorders respond favorably to intensive behaviour intervention (IBI) if applied early. Research suggests that some child characteristics may influence IBI success, i.e. age and IQ (Handleman and Harris, 2000). However, predictor measures such as IQ scores are relatively static measures reflecting a snapshot of skills and abilities at a point in time. We are interested in whether dynamic assessment measures of a child's early learning skills are also related to success in IBI.

The Early Learning Measure (ELM) reported in a study by Smith, Groen, Wynn (2000) measures basic pivotal learning skills in four key domains:

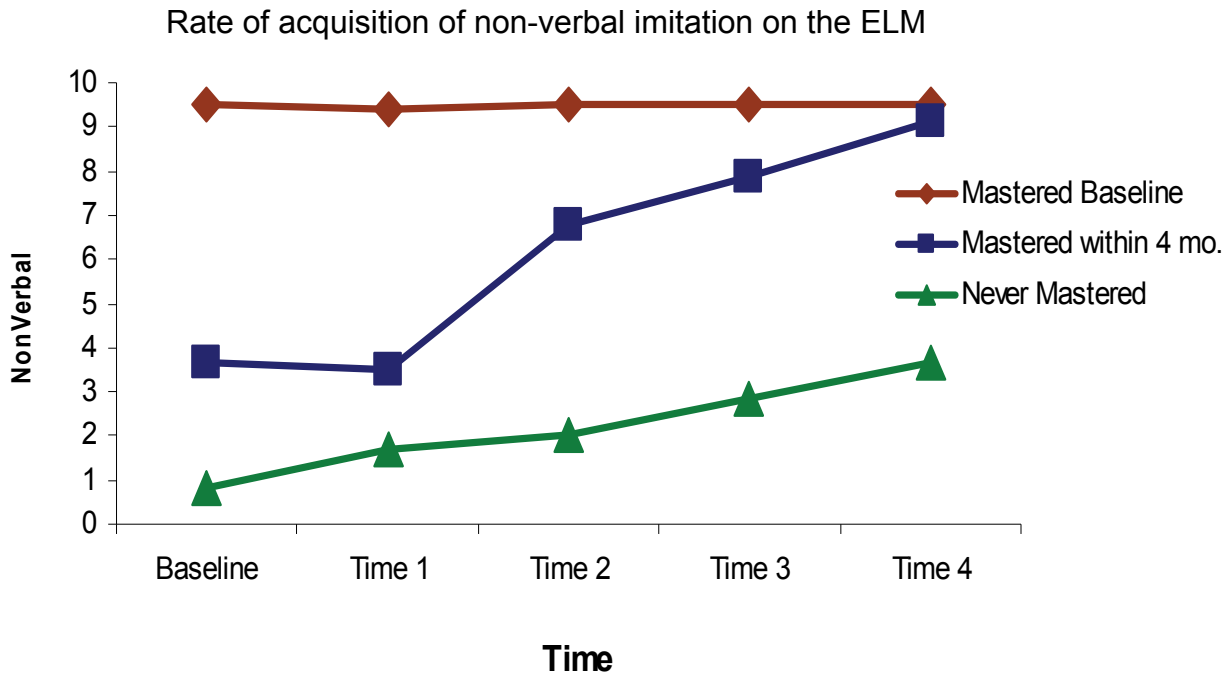
- receptive 1-step instructions, i.e., “come here”
- expressive labels of objects, i.e., Show a book and say “What is this?”
- verbal imitation, i.e., “Say mama”
- nonverbal imitation i.e. “Do this” while doing an action such as touching nose.

The purpose of our initial study is to determine whether the Early Learning Measure (ELM) is sensitive to change and thus useful as a dynamic assessment measure. We examined the ELM scores to determine if the ELM differentiated the children with ASD who are receiving IBI according to their mastery on ELM pivotal learning skills in the first 4 months of IBI.

Twenty-two children between the ages of 2 and 6 participated. Initial IBI intensity was set at 15-20+ hours per week at the time of entry to the IBI program. The ELM was administered to children once at the beginning of IBI as a baseline and scored by two separate observers.

The same children were re-assessed at approximately one-month intervals for the next four consecutive months.

The following graph illustrates the mastery trends that we found for nonverbal imitation. The pattern is similar for each domain.



From preliminary analyses:

Three patterns of responses emerged on each of the domains.

- We found that a portion of the children with ASD mastered the skills at the time the baseline measurement was taken.
- A second group of children with ASD did not master at the time of baseline but achieved mastery of the skill after baseline and within the first 4 months of IBI.
- A third group of children with ASD did not master the pivotal learning skill in the first 4 months of IBI. (Mastery was defined as 80% correct on the items for each domain.)

We also examined the improvements among the ELM domains. We found that improvement on motor imitation significantly predicted improvement on verbal imitation and receptive instructions, but improvement on nonverbal imitation was not related to change on the expressive labels domain.

From our preliminary studies it appears that the ELM is sensitive to change over a short period of time and enhances the description of the child's skills and abilities.

This is important because the ELM provides unique information that is not available from the static measures that are gathered at the time of entry to IBI, i.e., age and IQ. In the future, the ELM warrants further study because it may be another predictor of successful outcome in IBI.

Acknowledgement:

We are grateful to the children and their families who voluntarily participate in IBI. It is because of their involvement and participation that we are able to chart the growth of the children's skills, study their gains during IBI and learn more about strategies to help.

References:

1. Harris, S. L. and Handleman, J. S. (2000). Age and IQ as predictors of placement for young children with autism: A four to six year follow-up. *Journal of Autism and Developmental Disorders*, 30, 137-142.
2. Smith, T., Groen, A. D., and Wynn, J. W. (2000). Randomized Trial of Intensive Early intervention for children with pervasive developmental disorder. *American Journal on Mental Retardation*, 105, 269-285.

# Infant Sibling Study Continues to Grow and Develop!

By Dr. Lonnie Zwaigenbaum

For the past 4 years, we have had the opportunity to monitor the early development of younger siblings of children with autism spectrum disorders (ASD). The commitment and enthusiasm of families has been outstanding! The main goal of this study is to better understand the range of developmental patterns that can occur in younger siblings. Our play-based assessment at 6, 12 and 18 months examines early development and behaviour, and helps us observe for what parents and home video studies tell us may be some of the earliest signs of ASD, such as poor eye contact, decreased interaction (e.g., during a game of peek-a-boo) and repetitive behaviours. On average, siblings show about 3 times as many of these early signs at 12 months of age, when compared to low-risk control infants. As well, the siblings with the greatest number of early signs at 12 months have tended to those with the greatest number of concerns at age 2-3 years. As well, siblings of children with autism may have delays in the development of language, and in some cases, motor and general learning skills. We are finding that siblings are more likely to have language delays than a full diagnosis of ASD, and that delays in vocalizing may be apparent in the first year of life.

Although there may be more developmental concerns among siblings of children with ASD compared to other infants, the majority of siblings in our study are progressing well. Parents have told us that having the extra attention to their infant's early development has given them peace

of mind, and a strong sense of reassurance regarding their infant's progress.

There are some exciting new components to this study that are just getting started. Although the focus to date has been on the younger siblings, we will now be inviting parents to bring in their older children who have already been diagnosed with ASD for an updated assessment. The main goal is to see whether there are any similarities between siblings (e.g., personality style, sensory issues, language skills). We will also be starting a more detailed study of head growth early in life, and will be contacting parents to we can get permission to request birth records and growth charts from the child's community physician. Patterns of head growth (changes in head circumference) may be an important early clue to which children are at greatest risk of autism, as changes in head growth may be apparent before some of the behavioural signs. We are leading an international consortium of research groups working with younger siblings of children with ASD, which will strengthen our efforts to learn more about the early signs of ASD.

This research is ongoing. If you have a child diagnosed with ASD and an infant younger than 12 months of age, we hope you will consider joining this study. Families can be seen at either our Hamilton or Toronto sites, and travel expenses are reimbursed. Please contact our study coordinator in Hamilton at 905-521-2100 ext 74939 or in Toronto at 416-813-1500 ext (Bev - please add ext) for more information.

## Calling all Kids!

If you love to express yourself creatively then please read on! We'd love to show off your special stories, poems or pictures by posting them on our web site. Please send us your art or written works so we can share your talent. Hurry because we're really looking forward to receiving it!

**Note: Parents must send in written permission with all submissions.**

# Brief summary of the presentations from the Parent Conference November 2003

## Update on Genetic Studies

Dr. Peter Szatmari Presentation

Dr. Szatmari noted that there are 4 major questions/issues currently under investigation by our team: 1) findings indicate that there are two types of repetitive and stereotyped behaviours (RSB) in autism: a) insistence on sameness and b) repetitive behaviours. 2) findings show that there is a genetic independence of non-verbal IQ and language skills, 3) using social-communication without RSB to refine PDDNOS, and 4) combining information for making a diagnosis.

In the area of genetic research there are 4 major questions/issues that are under investigation: 1) chromosomal translocations and deletions, 2) screening genes on Chromosome 7, 3) genes that affect IQ in autism; control serotonin and NE (NOREPINEPHRINE, a neurotransmitter) metabolism.

Dr. Szatmari gave a brief update on the state of the autism genetics field. According to Dr. Szatmari, to date, no autism mutations have been identified. The best candidates are SERT, GABBA, and Chromosomes 2, 7, 13, 16, and 17. Signals increase if sub-set under investigation is composed of sib-pairs and especially those most similar on language and RSB. Dr. Szatmari noted that because ASD is heterogeneous, sample size is a huge problem, but not the only one. It appears as if ASD can be identified in the same genomic regions as SLI (speech and language

impairment) and ADHD (attention deficit hyperactivity disorder).

According to Dr. Szatmari, some of the key issues to consider in the autism genetics research are: a) what are the most informative similarities? b) how can we combine data sets with different genetic markers? c) what if there are no mutations, just normal variants? d) are there different genes for different subtypes?

Dr. Szatmari described a new study by our research team, "The Language Grant". The objective of this study is to look at families where language impairments are common, do language testing on parents, sibs and other relatives, and to look for genes associated with language in ASD.

As far as the future of our research program goes, Dr. Szatmari noted that there is funding from CIHR till 2008. We currently have roughly 200 sib pairs, 100 singletons, on whom we plan to complete data collection. We also plan to complete our own genome scan at 150 pairs. NIH awarded funding to combine 6 different data sets and NAAR provided funding to start again with international collaboration. In the NAAR-AGP (National Alliance of Autism Research-Autism Genetics Project) collaboration, a memorandum of agreement with all major groups; CAN-A-GEN; CPEA; IMGSAC; AGC was signed on July 1<sup>st</sup>, 2003. This memorandum includes \$10 million pledged from NAAR for 1000 sib pairs, 5000 trios, and the development of a common repository of DNA and clinical data.

Finally, Dr. Szatmari noted that the objectives for next year are to a) complete genome scan, b) set up cell lines for a permanent supply of DNA, c) complete blood collection, and d) get consents to send anonymous DNA and anonymous clinical data to NIH.

## Blood Collection

For those **multiplex families** who are in Dr. Szatmari's Genetic Study, if we have not yet collected your child's blood, and your child is having his/her blood tested for any other reason, please contact *Ann Thompson* at **(905) 521-2100 ext. 77831**. We may be able to arrange to have our research blood collected at the same time.

# Intensive Behaviour Intervention Agenda

Dr. Jo-Anne Reitzel Presentation

Dr. Reitzel briefly described some of the main characteristics of the provincial and regional program of intensive behaviour intervention (IBI) for children with autism. According to this program, in order to receive IBI, children must meet the age criterion: a) children may receive service until their 6<sup>th</sup> birthday (if they begin treatment prior to their 5<sup>th</sup> birthday), b) children who begin service after their 5<sup>th</sup> birthday are eligible to receive up to 12 months of service, c) children who reach their 6<sup>th</sup> birthday while waiting for service unfortunately would not receive IBI as they would no longer be “age eligible.”

Dr. Reitzel provided useful information on the Hamilton-Niagara Regional Early Autism Initiative (H-NREAI). According to Dr. Reitzel the mission of the Early Autism Initiative is to deliver an evidence-based, high quality intensive behavioural intervention to improve the developmental outcomes of children with Autism Spectrum Disor-

ders. This will be done by respecting family goals and priorities and involving community service partners.

Dr. Reitzel noted that currently, there are four service providers in the region: Chedoke Child and Family Centre, Hotel Dieu, Haldimand-Norfolk REACH, and Family Counselling Centre of Brant. The leading agency responsible for H-NREAI is Hamilton Health Sciences. IBI Services include eligibility screening and determination, entry assessments including comprehensive curriculum assessment, 20-40 hours of IBI, regular progress reports every 3 months, updated curriculum assessment every 6 months, discharge assessments, individual support plans (ISP), and family involvement. Finally, Dr. Reitzel noted that 30 years of scientific evidence shows the IBI techniques are the most effective for producing comprehensive and lasting improvements for children with autism

## Adolescents and Young Adults with Autism

Dr. Jane Summers Presentation

Dr. Summers noted that nowadays, there is growing interest in adolescents and adults with autism. Adults with autism have been de-institutionalized, and are part of the community. Dr. Summers described some of the key issues in relation to this developmental period such as onset of seizures, changes in cognitive/behavioural functioning, emergence of mental health problems or worsening of pre-existing ones, dealing with several important life-transitions, and physical and sexual maturation.

According to Dr. Summers, a number of outcome studies have taken place over the past few years involving adolescents and adults with autism. Some of the factors reviewed in outcome studies were: a) language functioning, b) social relationships, c) independent living, and d) employment. The results demonstrate that a wide variety of

outcomes are possible. There is some evidence that overall outcomes have improved in recent years, possibly due to earlier recognition and better treatment, inclusion in the community.

Dr. Summers also outlined some issues regarding treatment and management of adolescents and young adults with autism. More specifically, Dr. Summers suggested the following: continue to teach social and functional communication skills, look at individual's interests and strengths, develop vocational skills, increase recreational and leisure interests, teach community awareness and survival skills, don't confuse skill deficits with lack of interest or need, check for seizures, anxiety or depression if there are behaviour changes, behaviour management for dangerous and inappropriate behaviour, continued skill development, and planning and advocacy for these individuals.

# Canadian Baby Sibs Research Program

Dr. Lonnie Zwaigenbaum Presentation



Dr. Zwaigenbaum described the main goals of the Canadian Baby Sibs Research Program: a) to better understand the early development of siblings of children with ASD, and b) to identify early 'risk markers' that predict status of child development at age 3 years.

Currently, there are 125 siblings and 60 comparison infants participating in the program. The study protocol includes the Autism Observation Scale for Infants (Bryson, Rombough, McDermott, Brian, Zwaigenbaum, 2000). The AOSI is an 18-item observation-based scale that draws from markers suggested by parent's retrospective reports, home videotape studies, case reports, and the author's own work and experience to date.

According to Dr. Zwaigenbaum, results from analyses show that sibs with autism at 24 months have delayed language, motor and cognitive development at 12 months compared to non-ASD groups. There seems to be considerable variability

within groups: a) some siblings with autism are not delayed at 12 months, and b) some children in non-ASD groups show mild developmental delays. At the same time, male and female siblings are remarkably similar.

Dr. Zwaigenbaum then described some of the other studies that take place as part of the larger program: Dr. Jessica Brian leads an intervention study aiming to assess autism treatment strategies in 12-24 month-olds with early signs. The study focuses on early communication (including joint attention), social engagement, imitation and attention to the environment.

The Family Study focuses on comprehensive assessment of the older, previously diagnosed sibling, looking for similarities between siblings, features that may influence recurrence risk. At the same time, the study investigates genes that may influence the development and outcome of younger sibs

The ongoing Follow-up of Siblings includes continued follow-up examination every 1-2 years in order to detect children who may be diagnosed later than 3 years. In this study, the focus is on learning, emotional, and behavioural issues across the spectrum.

Dr. Zwaigenbaum noted that this program is part of an international NAAR-NICHD collaboration in which several research groups are following the early development of siblings of children with ASD. Finally, Dr. Zwaigenbaum noted that the team is collaborating with Dr. Baron-Cohen to assess the Q-CHAT, an autism screening tool.

1. CAIRN: Generating & disseminating evidence-based research on autism.  
[www.cairn-site.com](http://www.cairn-site.com)
2. Geneva Centre for Autism: Outline resources available at The Geneva Centre in Toronto.  
<http://www.autism.net>
3. Asperger's Syndrome Information and Support: A web site dedicated to information on Asperger's Syndrome.  
<http://www.udel.edu/bkirby/asperger>
4. Autism Society of America: Provides a library of information on autism/PDD (click the 'information' tab).

# Brain Imaging and Pharmacotherapy in Autistic Disorder

Dr. Rob Nicolson Presentation

Dr. Nicolson presented two different issues related to autism: a) brain imaging, and b) pharmacotherapy. Dr. Nicolson noted that brain imaging studies using different modalities are beginning to provide details regarding the abnormalities of brain development underlying autism. In particular, patients have an elevation in brain volume, at least early in life. Longitudinal studies are necessary to delineate the course of brain development and may help to resolve inconsistencies

When speaking about pharmacotherapy, Dr. Nicolson noted that there are no treatments for autism per se. Treatment is therefore aimed at reduction of behaviours which interfere with the individual's daily functioning. The goal of medication should be to enhance other treatments (behaviour modification, education, speech therapy, etc.)

Dr. Nicolson noted that target behaviours for pharmacotherapy include aggression, inattention and hyperactivity, and anxiety/ritualistic behaviour.

Pharmacotherapy for aggression in Developmental Disorders might include antidepressants, or antipsychotics. Pharmacotherapy for inattention and hyperactivity in autism might include stimulants, or antipsychotics. Pharmacotherapy for anxiety in Autism might include Antidepressants (SSRIs), or antipsychotics. Some alternative therapies in autism include B vitamins, Vitamin A, Vitamin C, DMG (dimethylglycine), DMSA, and Secretin, which have not been found to be effective.

Finally, Dr. Nicolson emphasized that all pharmacotherapies noted above are lacking solid evidence for effectiveness. Medications should not be viewed as a treatment for developmental disorders. They should be viewed as a treatment which can make other interventions (education, behaviour therapy, speech therapy, etc) more effective by reducing behaviours which interfere with these therapies.

## MISSION POSSIBLE

Mission Possible is an employment service that helps adults who are differently-abled to become successful, contributing members of their communities. We specialize in helping adults with Asperger Syndrome (AS), More-Able Autism and other PDD's to acquire vocational skills and find meaningful work.

Gail Hawkins is the founder of Mission Possible. She is an experienced, innovative vocational consultant and practitioner who has specialized in the field of autism, AS and PDD for 15 years. She is also the author of *How to Find Work that Works for People with Asperger Syndrome* (Jessica Kingsley Publishers, 2004).

For more information, please visit their website at [www.anythingispossible.ca](http://www.anythingispossible.ca).

## Clinical Concerns? Who Do You Call?

When you wish to consult Dr. Szatmari regarding a clinical concern (medication, behaviour, etc.), please call his personal secretary, *Joan Whitehouse* **521-2100 ext. 77367**. She knows Dr. Szatmari's schedule and can see he gets the message promptly and arrange a time when you can talk to him. Even if you live outside of the Hamilton area Dr. Szatmari and Dr. Zwaigenbaum will see families involved in our studies for clinical reasons.

# The Cooking Club

by Penny Gill

Stroll into the Dundas Community Centre at lunch hour or supper time some days and you'll find yourself enticed by delicious smells of blueberry streusel muffins, or cheddar cheese bread; hoisin meatballs, or oven-BBQ'd chicken; warm Caesar pasta salad, or broccoli and cauliflower à la Suisse. Many Community Centre visitors find these aromas leading them irresistibly to the kitchen of the Cooking Club, a class for autistic adults.

What distinguishes this course from others is not only the exceptional quality of food, but also the one-on-one instruction provided to students.

Each member of the class works through recipes while personally supervised by a cooking coach. All coaches must have prior *successful* experience working with autistic individuals before participating in the program, and each of them receives further training in effective instructional methodologies to use with our students.

The Autism Family Alliance, a parent-driven charity dedicated to supporting families with an autistic adult living at home or independently in the community, operates the Cooking Club. It aims to equip individuals with cooking skills that will allow them to make significant contributions at home. Having an accomplished cook at home can enhance the quality of life for every family member.

The Cooking Club attempts to expand students' eating repertoires, since many start the course with a limited range of accepted foods. Using a food preferences checklist completed by each student, we introduce them to new recipes they are likely to enjoy given their past eating habits. Often a dish one student prepares is a hit with others, who request to cook it, too. Some families have reported that after participating in the Cooking Club their children exhibit greater willingness to try new foods at home. Reducing the need for dual-track family meal preparation is enthusiastically welcomed by parents, an early benefit of the cooking class.

Meals shared at the end of each class (of the dishes prepared that day) present the perfect opportunity for students to practise conversing with others. At the table, students are seated close to each other, but also close to their cooking coaches, who quietly prompt them (through cues, verbal modelling and written examples) to engage in conversation with others. Our students are fully competent in responding to questions, but need guidance in initiating conversation—in asking suitable questions of others, for example, or in paying compliments. We've seen nice progress in these areas.

The club operates in seasonal sessions—spring, summer and autumn. Each session runs for 8 to 12 weeks, once a week. A small celebration marks the end of each session, when students are each awarded a certificate of achievement (noting all the recipes he or she completed), as well as a gift of a cooking utensil (expanding their stock of kitchen tools).

Cooking Club participants must be at least 18 years old, verbal and literate. The latter is essential since they work through task-analysed recipes—written recipes broken down into miniscule steps. Students are working with the full range of kitchen utensils (chopping knives, 450° F ovens, pots of boiling water), so they cannot exhibit any behaviour patterns which might put themselves or others in the room at risk.

To inquire about joining the cooking club, either as a student or as a cooking coach, please telephone Penny Gill at (905) 627-4847.

The Cooking Club depends on charitable donations, which can be made payable to "The Autism Family Alliance" and mailed to: 94 Sydenham St, Dundas, Ontario L9H 2V3. Tax receipts are issued for all donations. A supporter has offered to match, dollar for dollar, any charitable donations we receive in 2004, so the contributions you make will be automatically doubled in our hands. Your help would be most welcome.

# Great Program! Why does it have to end?

## Galloway Friends, A Success Story

Galloway After School Program was a great program. This is socialization, life skills and activity group for mildly to moderately developmentally handicapped and dually diagnosed adolescents who require the experience of a peer group to help them develop social skill and life skills. Everyone connected to the program really were very sad and dismayed when due to space and age concerns his or her youth were discharged from the program. Parents continued to come to the parent meetings held by the program even after their youth were no longer involved. They told a grim story of how much their youth missed the program and how there did not seem to be another program out there so good and with a great philosophy in dealing with the youth. Galloway After School Program still runs and is an incredible resource for youth and their parents. East Metro Youth Services in Scarborough operated the Galloway After School Program. One of the workers there suggested that perhaps the parents could start a program of their own. A group of twelve parents got together in 1995 to discuss the idea and decided to start a group called Galloway Grads.

They started with \$100.00 donation and the use of a basement donated by East Metro Youth Services. The basement was in need of furnishing and repair work. Everyone got into the act with some of their own money and getting supplies and services from local businesses and service organizations. The parents learned to advocate for their youth. This was hard work often working, painting, flooring not to mention the paperwork and organization. The youth also helped with the work. There was enthusiasm and optimism because this was for their youth. Friendships and informal networking were an important part of the fun, because it was not all work but fun as well.

The purpose of the group was to provide unique programming for their special sons and daughters, a safe meeting place where they could socialize with their peers and work towards independent living.

After a year of hard work the program was up and running in 1996. At first most of the programming was in-house and run totally with parent volunteers. The basement had been renovated and now included a meeting room, quiet room, games room, kitchen/serving bar and a bathroom. East Metro Youth Services sanctioned the ongoing availability of the Supervisor of Group Services along with access to additional mental health consultant on an as needs basis, to act in a supportive, consultative role to the project. Lastly East Metro Youth Services provided free access to office equipment such as telephone, computers and fax machine along with other office supplies.

Further down the road grants were applied for with the assistance of East Metro Youth Services. They were forthcoming which allowed for the group to hire staff to help the parent volunteers on meeting nights. The group remained a parent run and driven organization. A membership fee of \$25.00 was a requirement from the beginning and an additional two-dollar fee per evening. The parents also provided payment for some community outings. The youth met every second Friday during the school year. Three mandatory parent meetings per year were held. One meeting was to vote in the executive and to organize committees. Informal gatherings of parents continued to happen encouraging networking and friendships.

Did the program last and flourish? Yes it did! Today the program now called Galloway Friends, serves twenty-one youth and young adults. The program is split into two groups. One, which consists of the more independent participants that need direction but less supervision, which has nine current members and the others who still, need more direction and supervision. There are three community outings for every in-house meeting. Community outings are paid for from fundraising efforts. Community outings now include three-day camping trips. continued

Three dances open to other youth are held per year. There are still three mandatory parent meetings a year. Next year the plan is for the youth groups to meet with no parent volunteers but just staffing again provided through East Metro Youth services and paid for from our successful fundraising efforts. The organization is still run by parents. All parents upon having their youth join must agree to volunteer to sit on committees and participate in fundraising. Next year the plan is that parents can also buy their way out of fundraising if they wish. Hours of service have been extended. There is a membership fee of \$75.00 per year. There is no longer a fee per evening charged.

This kind of organization is not for everyone. Those looking for a traditional program where the decisions are made only by the organizers, where participation mainly involves payment of a fee and where attendance is optional have not found that

in Galloway Friends. Participation is a must. Although participation is not usually a problem, we have had to regrettably ask a few participants to leave the program when they seldom attended. These actions are a necessity as it is difficult to hire the appropriate number of staff without knowledge of attendance and we do have a waiting list.

In order for a program like this to work it is necessary to raise funds, get corporate sponsorship, to have all parents pulling their weight by serving on the executive and on committees, have an organization like East Metro Youth Services helping behind the scenes, well trained staff with knowledge of the youth and lastly to have enthusiasm for the work. It is rewarding to see the youth develop friendships and skills and work towards independence. Given the current governmental restraints families have a primary role to play in initiating and maintaining these programs.

## Autism & Language Genetics Study

**Investigators:** Dr. L. Zwaigenbaum (Principal Investigator), Dr. P. Szatmari and Dr. J. Goldberg, McMaster University, and Dr. S. Scherer, University of Toronto.



**Do you have a relative who has speech delay or who has had difficulty with language in writing, reading and spelling?**

This study explores the language abilities of relatives of children with Autism Spectrum Disorders (ASD) and the specific genetic factors that may be involved.

If you think your family and your relatives might be interested in participating, please contact Ellie Deveau at 905-575-0515 #74906 or by e-mail: [deveau@mcmaster.ca](mailto:deveau@mcmaster.ca)

## Keep us up to date

Please keep in touch with us so we have an up-to-date record of your address and phone number. This helps us to keep you informed. If you have received questionnaires from us, we would ask that you return them as soon as possible. If you have misplaced the forms or the return envelope, please contact **Bev Da Silva** at **x74728**. Messages can be left on her voice mail in the evening, if this is more convenient for you.