311 schools across Ontario accepted our challenge and participated in the first annual Toonie for Autism Day Campaign raising approximately $90,000.00 - exceeding our expectations! Below are excerpts from the dozens of letters received by Autism Society Ontario that tell of the creativity and excitement in promoting awareness of ASDs and in raising much-needed funds for autism research in Canada. We’re excited that the 2003 Toonie Campaign has begun. The committee members for this year’s campaign are Ron Harrison and Bonnie McPhail (Co-Chairs), Susan McCreary (Media Relations), John Keating (Promotions), Jean Woolford and Ethel Berry (Project Coordination). This year’s campaign will continue to target all Public and Catholic Schools across Ontario and will be expanded to include over 700 private schools. The committee will be working closely with ASO’s 29 chapters and other interested groups and individuals to reach this year’s goal of 1500 participating schools.

Excerpts from letters to Autism Society Ontario in response to Toonie for Autism Day:

– “...On our “Autism Awareness Day”...staff and students wore orange and/or purple...This whole event was a huge success! The students and staff at Woodville Elementary School supported this event in a tremendous way.”
– “We have a number of children in our school in the (autism) spectrum, so the cause is quite close to our hearts.” (St. Luke School, Nepean)
– “I read the (boy with autism) story to all the students in an assembly and showed the pictures. You could hear a pin drop! Super discussions took place in many classrooms after and a parent was in tears as she told me her adult brother was autistic...Thank you for letting us be part of the awareness.” (Southwestern Ontario)
– “Dear Autism Society Ontario, ...the best part of a Toonie for Autism day was that our students at Ellengale are more aware and educated about Autism”
– “Take Notice That April 26, 2002, is hereby proclaimed as “Toonie for Autism Day™”
– “...of 340 students...4 students are diagnosed with P.D.D....Our parents were impressed that we took the time to further educate our students as to the abilities of our autistic children...” (Hamilton)
– “Thank you for lending us the videotape about autism. It stimulated an insightful conversation among our grade six students...”
– “...What I found was that peers had many questions and many misconceptions about the students with Autism...” (St. Joseph the Worker Catholic School, Thornhill)
– “...We had a great guest speaker who taught us to be nice to people that are autistic because they are exactly the same as us in many ways. You have taught us a lot.” (The grade 5/6 class from Ernie Cheekers Public School and Mme Albert)
– “We have already started thinking about our program for next year...A hands-on display where students can become more aware of unusual reactions to normal stimuli, is just one of the suggestions that we are working on...” (Thunder Bay)
Annual General Meeting and Autism Conference

This year’s AGM held on June 22, 2002 was a day filled with relevant information and inspiration for all in attendance. Hugh Vallee gave his parting address as ASO’s President and Christine Dade was welcomed as the newly elected President.

Highlights from Hugh Vallee’s speech.

– Not only have we made inroads in our relationship with the current government, but have managed to maintain that relationship to the extent of increasing funding for their IBI Initiative.
– Although our initiatives with respect to dealing with young people have been extremely productive, we have not been able to persuade the government to extend their initiatives to encompass assistance for adults and school age children. Bearing in mind that our children can be in the school system for upwards of seventeen years, it is imperative that we focus more attention towards the education system and its inherent problems.
– As you are well aware, we have had inaugural meetings and facilitation with respect to the formation and goals of the S.E.A.C. Council. Given the amount of time that people with Autism Spectrum Disorders spend within the system, it is imperative that we keep this initiative moving so that we can act responsibly, making sure that our constituents receive a proper education. We must make firm policies with respect to views of our organization so that all S.E.A.C. members can speak with one voice when lobbying at their school boards. We must educate the educators the funding is extremely short of what is required and has been spread out to cover all people who suffer from a variety of disabilities.
– Given the complexities of dealing with a variety of ranges of disability which fall into Autism Spectrum Disorders, it is incumbent upon us to make sure that the government provides funds focused directly toward people with ASDs for transition from school to the work place, proper and appropriate housing focused towards ASDs and long term initiatives with respect to ongoing education and leisure activities.
– In the past our organization has been child-centred. We have therefore failed to meet the needs of some of our members and former members. As a group we must take on the responsibility of advocating and educating society with respect to our adolescents and adults, and also educating society about the different aspects of Autism Spectrum Disorders and their ramifications. We worked long and hard to form a vision and mission statement, and if we do not work for adolescents and adults, we will be falling short of our objectives.
– We have had several meetings, and have maintained our contacts with the current Provincial Government. We have been requested to provide input into the budget process for the past three years. We have been able to secure funds to assist people with Autism Spectrum Disorders through government programs.
– Cycle for Autism has been developed into our major fund raising program throughout the Province. It continues to evolve and new initiatives on “The Big Ride” are in the works to include riders from the North, the Northwest and Eastern Ontario, all converging on Toronto. 2003 is the target for planning this new ride in conjunction with our 30th anniversary in Ontario.

Leslie Price explains how parents and educators can assist students with anger management strategies.

Dr. Tara Kennedy presented compelling research on the reporting behaviour of physicians who diagnose young children with PDD/Autism.

– Toonie for Autism, our promotion to the school boards for funding for research has made a wonderful start. Lots of funds were generated through lots of hard work from our members, and volunteers, and we thank you for that.
– In parting all I can say is let’s continue to move forward, continue to work hard and advocate so that our vision and mission statements will become a reality.

The McCrearys told us about a new sensory tool kit called FidgitKitz.
By Amy Baskin

Like most parents we’ve tried many strategies to help our nine-year-old daughter with autism. The list is endless – structured teaching, music therapy, body brushing, visual schedules, social stories, school mainstreaming.....etc. But never have we investigated a medical approach to treatment. Recently, we wondered if medication might decrease our daughter’s anxiety and improve her attention span. Our first step was to read, “Taking the Mystery Out of Medications in Autism/Asperger Syndromes” by Luke Tsai, MD.

This book delivers what its title promises. The author writes with compassion and expertise based on over 20 years as a psychiatrist, treating over 1,000 individuals with ASD. In the beginning chapters, Tsai explains the rationale for considering medication. Used appropriately, he writes, psychotropic drugs can significantly improve the quality of life of a person with ASD. Although medication can’t address the social and language challenges that are key parts of ASD, it can be an effective treatment for disorders such as ADHD, anxiety, seizures etc. that can exist alongside. Sounds promising, but how do we know, for example, if our children are anxious because of their autism, or if their anxiety is a treatable co-existing disorder? And while we may readily accept therapies suggested by non-medical professionals, we may feel uneasy with medical interventions.

Tsai, as a parent, understands this unease and explains what a pre-medication assessment involves. First, families and professionals must complete a detailed behavioural analysis. Certain “behavioural problems” may actually be occurring because of a co-existing neuro-psychological disorder. These behaviours would likely respond to medication. But medication would not be appropriate for behaviours that serve a function, such as avoiding tasks or seeking attention.

Also guiding the decision to medicate are general principles and ethics of medication therapy, Tsai explains. Principal four, for example says “The Physician should reserve medication treatment for individuals with severe behaviour problems or emotional disturbances that fail to respond or only partially respond to nonmedical intervention.” In additional chapters Tsai covers how to monitor medication therapy and possible side effects. Medication should be managed by a physician with expertise in dealing with our individuals with ASD. But to minimize side effects, he stresses, there should be input from a team including the individual, family, teachers, occupational and physiotherapists etc. Then Tsai provides the reader with thorough, clearly written information about psychotherapeutic medications and generic drugs. One helpful chapter contains detailed explanations of neuropsychiatric disorders (such as ADHD) and possible medications.

To further empower parents, Tsai includes appendices that explain medical terms and jargon involved in pharmacology and neuropharmacology (how our bodies interact with medications.) With Tsai’s guidance, readers gain familiarity with terms such as “Half-Life” and “Post Synaptic Transmitters.” As Tsai writes in his forward, “You may need stamina, patience and determination to read through these appendices.” True – I’ll admit I bailed out on these technical chapters.

Other appendices include assessment scales used to determine if a person has a specific disorder. The last appendix is a thorough description of psychotherapeutic medications (organized alphabetically). This is a quick reference tool to research a medication your doctor may have suggested. Tsai also provides a detailed chapter on seizure disorders and treatments.

Medication is not a quick cure for emotional and behavioural issues, nor is it a substitute for a comprehensive treatment plan, Tsai reminds us. But, in order to fully advocate for our loved ones with ASD we need to learn if, why, when and how medication may help. By reading this humane and comprehensive book, parents are empowered to do exactly that.

Amy Baskin, M.Ed. (ASO Wellington County) is a freelance writer and trainer in Guelph, Ontario.
The Canadian Autism Genetics Study

(CANAGENS): Neurobiological and Genetic Studies of Autism in Toronto and Hamilton

For many years research into autism, and specifically genetic susceptibility for autism, has lagged behind studies of other serious medical disorders. There may be a number of reasons for this, such as the fact that autism is rarely seen across several generations in a family, and thus autism does not lend itself well to traditional genetic studies. Clear patterns of inheritance, such as those determined by the studies of traits in pea plants by the 19th century Hungarian monk, Gregor Mendel, are not seen. Also, autism has always been considered a rare disorder, with approximately 5 per 10,000 affected, compared to 3 in 1000 for diabetes mellitus or 1 in 100 for schizophrenia. However, recent increases in the numbers of diagnoses of autism, due mostly to a greater understanding of the spectrum of autism-related disorders, have led to a massive increase in research into genetics of autism. Researchers in Ontario are at the forefront of this genetics renaissance.

The Canadian Autism Genetics Study (CANAGENS) was established in the year 2001. We are a group of scientists and clinicians, mainly Ontario-based (Toronto and Hamilton) and from a broad range of disciplines with a common mission – to identify genetic or other biological causes of autism and autism spectrum disorders, with the further aim of discovering improved and more effective forms of treatment. In the long-term, this may ultimately result in tests that could identify children at risk of developing autism, and allow earlier treatment that may prevent onset of the disorder.

Our main focus is genetics of autism. Our genetics studies are based in the laboratory of Dr. Stephen Scherer at the Department of Genetics, HSC, Toronto, but have now expanded to include the newly established Laboratory for Molecular Studies of Child Developmental Disorders, under Dr. John Vincent, at the Centre for Addiction and Mental Health (CAMH) in Toronto. A number of recent studies have looked at patterns of inheritance of autism and DNA land marks. A number of these studies suggest that there may be a risk-gene for autism on chromosome 7. The Department of Genetics at HSC have had historic links to studies involving chromosome 7, ever since scientists here discovered the gene that causes cystic fibrosis on chromosome 7 in 1989. Since then, the HSC group have been instrumental in “mapping” this chromosome and identifying many other disease genes on chromosome 7, and in doing so, have built-up vast scientific resources for locating disease genes and hope to be in a very strong position to identify an autism gene. Dr. Scherer’s group has studied chromosomes of children with autism and identified a few who have chromosomal abnormalities. These abnormalities are either inherited from a parent, or occur spontaneously during sperm or egg development, and generally result in either a chunk of the chromosome being lost, duplicated, or exchanged with a chunk of DNA from a different chromosome. Our aim is to identify genes that are disrupted by the chromosomal abnormalities. Having identified such a gene, the next task is to show its involvement in autism in other autism families by screening for conventional mutations (for instance where a change in the genetic code has affected the function or activity of the protein which the gene encodes). Recently we reported the discovery of a gene, called RAY1, that spans the chromosome breakpoint in a patient with autism who had a piece of chromosome 7 exchanged with a piece of chromosome 13, however we have not yet been able to confirm a link between this gene and autism in other families (Vincent et al, 2000). We have now identified other candidate genes for autism using this approach. Another goal of the HSC group, in collaboration with Dr. Szatmari at McMaster University, is to look at inheritance patterns in autism families in an attempt to replicate or refute the genetic studies that have suggested the presence of a gene for autism on chromosome 7. We have also been involved in the identification of the gene for secretin (Vincent et al, 2000). The secretin protein was identified as long ago as 1903, and is an endocrine hormone that is released by the small intestine, where it stimulates the secretion of bicarbonate-rich pancreatic fluids, and has also been shown to regulate the growth and development of the stomach, small intestine, and pancreas. The gene that encodes this protein, however, remained unknown until interest in it resurfaced with the recent reports that secretin treatment was helpful in at least some autistic individuals.

The new laboratory at CAMH has been established for the specific purpose of studying genetics of autism and ASD, under the direction of Dr. John Vincent. Some of the studies that Dr. Vincent hopes to initiate at CAMH include looking for genes for autism on the X chromosome. The striking observation that males are nearly four times as likely to be affected by autism as females may implicate the sex chromosomes, and in particular the X-chromosome, having some direct or indirect effect, resulting in autism.

We have two main clinical research groups within our collective- one based at the Child Development Centre at the Hospital for Sick Children (HSC), Toronto, under the supervision of Dr. Wendy Roberts; the other based at Centre for Study of Children at Risk at McMaster University, Hamilton, Ontario, headed by Dr. Peter Szatmari. At HSC, Drs. Tamarah Kagan-Kushnir and Wendy Roberts have been investigating the incidence of gastrointestinal abnormality in autism spectrum disorder (ASD) since Wendy Roberts’ randomized controlled trial with secretin, which showed no evidence for that
secretin is effective in treating children with autism (Roberts et al, 2001). It has been noticed that symptoms such as diarrhea are more common among ASD children, and data needs to be collected so that appropriate studies of gut function can be done. In addition, low iron levels have also been noted in the last year in a very large number of our children with autism. Given that iron absorption and metabolism is a gastrointestinal function, a study is currently being developed with Dr. Stan Zlotkin, Head of Nutrition and Gastroenterology, to study response to iron therapy in autism. Another study now underway at HSC is a collaborative effort between Dr. Roberts at CDC and Dr. Liz Pang in the Division of Neurology, and involves the study of electrical impulses in the brain using event-related potentials (ERP), to investigate problems in auditory processing in ASD. Dr. Tim Roberts at the University of Toronto has been studying magnetoencephalography (MEG) – a new, non-invasive imaging technique which is able to show aberrant electrical/functional pathways in the brain, combining the temporal resolution of the electroencephalogram (EEG) and the spatial resolution of magnetic resonance imaging (MRI) – and together with Dr. Wendy Roberts and Janis Oram at CDC, he is using this state-of-the-art neuroimaging technique to study brain differences associated with language impairment in autistic children.

Dr. Sunita Vohra and Dr. Wendy Roberts are studying the effect of the selective serotonin reuptake inhibitors (SSRIs), fluvoxamine (Luvox®) and sertraline (Zoloft®) in autistic children between 3 and 10 years of age. SSRIs are believed to be effective in controlling some of the behaviours seen in autism, such as aggression, obsessive, compulsive or repetitive behaviours and anxiety or irritability. This study may help identify subgroups of autistic children who respond well to specific medications, and may indicate a role for variants in serotonin receptor genes in determining whether children are likely to respond well to SSRIs.

At the Centre for Study of Children at Risk (Chedoke Hospital, Hamilton), Dr Lonnie Zwaigenbaum and Dr. Peter Szatmari are attempting to characterize the language deficit in ASD, with the aim of identifying genes that are specifically involved in the speech and language aspects of autism. Their work also includes studies of the occurrence of birth-complications in families with autism, also studies of neurotransmitter function in brains of individuals with ASD and their families (Dr. Jeremy Goldberg). The Hamilton and HSC Toronto groups also have a joint study following infants (0-12 months old) who have an older sibling affected with autism. A small proportion of such children may themselves go on to develop autistic traits, and this study hopes to identify such children, who may benefit from early intervention.

The studies I have described represent some of the ways that scientists and clinical researchers from the CANAGEN group are trying to understand the causes of autism. Obviously, the kind of studies described here are totally dependent on the interest and enthusiasm of families of autistic children, so if you are interested in participating in any of our studies then we would welcome you to contact us either at McMaster University (autism@mcmaster.ca, or 1-888-3-AUTISM) or at HSC (Bonnie Mackinnon, 416-813-6307). For the SSRI study at HSC you can contact either Cory Baylis (416-813-6174) or Mary Hartford (416-813-7820). For the “infant sibling” study, please contact either Dr. Beth Adams in Hamilton (905-521-2100 x 74939; adamsb@mcmaster.ca or Dr Jessica Brian in Toronto (416 813 8748; jessica.brian@sickkids.on.ca. I have compiled a list of recently published papers from our studies. If you are interested in receiving copies of any of these articles, either electronically (as pdf files) or as printed copies, please contact me by email at: john_vincent@camh.net or phone (416-535-8501 x 6487).
The following people were nominated for this year’s Gerry Bloomfield Award in order to be recognized for their outstanding contribution as a Professional or Volunteer in the field of Autism. Their nomination by ASO members already indicates the high level of regard considered for each of the nominees. Autism Society Ontario is extremely grateful for the substantial contributions these people have made to improve the quality of life for all individuals with Autism Spectrum Disorders and their families in Ontario.

**Volunteer Award**

**Winners: Bonnie McPhail & Ron Harrison:** Over a year ago Bonnie McPhail (parent and ASO Durham Chapter member) actively participated in raising awareness at William Dunbar School through the Loonie day and the Walk for Autism. Funds raised through those events were then used to organize 4 successful autism training events for Durham Region. Three of those workshops were attended by 150-200 parents and professionals and Bonnie personally registered every one of them. Then she and a group of volunteers, including Ron Harrison, worked with Autism Society Ontario to develop the Toonie for Autism Day provincial campaign with great results. Ron Harrison’s interest in raising autism awareness and research funds began when he got to know his friend John Keating’s son. As a result, he volunteered to drive the vehicle that supported John’s three month CycleUSA last year. Following the completion of that event, Ron continued to look for ways to promote autism research in Canada too. As key members of the Toonie for Autism Day Committee, Ron and Bonnie have collectively and quietly volunteered over 1000 hours of time in preparing materials, contacting hundreds of people, arranging meetings, speaking with corporate and individual donors, calculating numbers of participants and dollars donated and thanking people for their support to the campaign. They have both engaged their own families and friends to assist with the campaign in tremendous ways. They opened their homes and hearts and gave more than a small piece of their lives to supporting autism research and helping to change the lives of people with autism in Ontario through what will become an annual ASO awareness campaign. Simply stated, this campaign could not have happened without their overwhelmingly valuable support.

**Short Listed Nominees**

**Heidi Kaack:** Heidi Kaack is truly dedicated to improving the quality of life for persons with autism as evidenced by her admirable and outstanding volunteering for this cause. Heidi has proven her leadership skills, commitment, and desire to educate and advocate for, and on behalf of, families in the community. Her contributions are second-to-none, and she is respected and loved by all whose lives she has touched in some very special way. Heidi was key in forming the Upper Canada Chapter of ASO which emerged from the formation of a local “Advocates for Autism and PDD” group to address the lack of available funds for developmental programming. The chapter for which she has been president for 5 years has gained an outstanding community reputation. As a result of the many and varied courses and workshops that Heidi has completed, she was able to develop a course “Teaching Children with Autism” that she has been teaching at St. Lawrence College in Cornwall since 1999. Her advocacy efforts have included work as a SEAC representative and her personal support offered to dozens of families struggling with having their voices heard in educating their children with ASD in school settings. Heidi successfully applied for and received an Ontario Works grant for the chapter which allowed them to run a summer day camp. She coordinated all aspects of this pilot program which was and continues to be a great success. She has been the driving force behind the acquisition and housing of a Snoezelen Room in their community, and has helped to raise thousands of dollars through their local Cycle for Autism annual event. Heidi has just completed her first year as a member of ASO’s provincial Board of Directors and contributes to its Fundraising and Advocacy Committees. Recently she was appointed to the Early Years Steering Committee of Eastern Ontario. Her volunteer work continues as a member representing the voice of parents on both the Rural Outreach Committee and the Steering Committee of the Child and Youth Health Network of Eastern Ontario. Heidi is a tireless volunteer who has a heart for justice and opportunities for all individuals with ASDs.

**Anita Acheson:** Anita Acheson has brought the qualities of integrity, respect, love, caring, support, and more to ASO and the membership, particularly in the Ottawa area, over a period of almost 10 years. Anita joined ASO in 1993 and by 1995 was the vice-president of the Ottawa chapter, helping to make the chapter a powerful and much-respected source of information and support for families with a member affected by ASD. She became president in 1996, and remained in this position for 2 years. She was instrumental in establishing an office for the ASO Ottawa chapter – a move which gave the chapter profile and dignity! She played a major role in setting up a summer camp for children and organized the first and second Cycles for Autism in the Ottawa area. But perhaps her greatest and most lasting achievements are with the families she has supported over the last 9 years – families who called during all hours of the day or night, and who needed help with getting services or even suggestions about how to address some problem behaviours. For the past 2 years, Anita has been involved with the Autism Spectrum Disorders – Canadian-American Research Consortium in the capacity of Project Leader for the Parent Advisory Group. This group of 15-20 parents from Ottawa, Kingston, Cornwall, Montreal and Guelph discusses current research ideas,
Winner: Bill Eleker & the staff at Parentbooks: A tiny, but packed bookstore in downtown Toronto by the name of Parentbooks is hardly a place that looks like it would be one of the most respected sources of books and materials about ASDs. They readily comment about the books and have read many of them themselves - thereby providing an invaluable service to people looking for the best resource for the best value given their identified needs. They are aware of new books and upcoming materials that might be of interest and Bill will often send a copy of new books free of charge to be included in many Autism service provider’s lending libraries. This has been a difficult year for Bill, his partner Patty and everyone else at the store but they still maintained a quality service and continued to be available to do displays at conferences and workshops all across Ontario. They have sent books to people around the world who know they can count on Parentbooks for the latest materials either by talking to them personally or through their website.

Other Nominees
Elizabeth (Liz) Cohen, Richmond Hill
John & Connie Bonekamp, Thunder Bay
Kevin Rodger, London
Marrius & Indrani Hoefman, London
Nancy Cherry, Waterloo
Natalie Whatley, Mississauga

Professional Award

Short Listed Nominees
Dr. Rebecca Ward: Becky has over 20 years of clinical experience in the developmental disabilities field and a strong commitment to working with children with autistic spectrum disorders (ASD) and their families. She is a clinical psychologist working in the Kingston area with a special interest in early intervention with children with ASD. She received her Ph.D. from the University of Toronto in 1995 while working with children with ASD at Surrey Place Centre. Her doctoral thesis was related to cognitive development in non-verbal children with ASD. She has been working in private practice for the past four years and, with speech pathologist, Marianne Becker, formed Kingston Developmental Services, a service focused on integrated developmental, behavioural and speech-language assessment and intervention with children with ASD which offered training and supervision of instructor therapists. Working with geneticist, Jeanette Holden, at Queen’s University and Ongwanada, Becky is the Clinical Research Coordinator on a five year grant, Unraveling the Mystery of Autism: From Genotyping and Phenotyping to Early Identification and Prevention. In addition to her to her position as an ASO Board member and chair of ASO’s Best Practices Committee, she is also an active member of the Kingston ASO chapter. People who know Becky know what an amazing amount of energy, enthusiasm and commitment she has for making things better for children with ASD and their families in Ontario.

Leslie Broun: Leslie has been an active ASO member for many years. She is probably most well known for her contributions to ASO’s Education Committee. Professionally she has been an Itinerant Teacher for children with special needs - especially students with autism - for the past 8 years. Prior to that she taught for 7 years in a self-contained classroom for students with ASDs in the Peel Board of Education. Also in the Peel Board she is a member of the ASD/PDD committee for direct professional development and resources. She was an active participant in the development of a training video on the use of visual schedules for students with ASD. Leslie provides public workshops across Ontario on teaching students with autism of all ages and varying levels of ability. Her emphasis has been on learning styles, the use of practical and visual strategies and how to deliver information and skills to the learner with ASD. Leslie has been appointed through ASO nominations to two Ministry of Education Committees – Educational Standards and Multiple Exceptionalities and Autism. She is the Canadian member at large for the division on developmental disabilities for the International Council for Exceptional Children. As the Member of Ontario sub-division for individuals with developmental challenges she also writes their newsletter on a volunteer basis.
Three events over the summer became wonderful opportunities to increase autism awareness while raising funds to support ASO, form new, supportive relationships and the continued growth of ASO’s Research Fund.

**ASO’s Annual Art & Entertainment Auction on May 24:**
Thanks go to the enormous team of volunteers whose efforts made this event possible. Key committee members – Al Rain, Kelly LeCouvie (chair), Ann Beauregard, Michelle Piccini, and Eleanor Ritchie worked their magic (long hours and creativity) in bringing great art, donated food, autism information, an auctioneer, other volunteers and guests together for a wonderful evening. $18,000.00 was raised while promoting the work of ASO. Special thanks to the Bank of Montreal for their donation to help offset the cost of holding this special event.

**AMR Charity Golf Classic.**
For a second year in a row Barry Goman & Suzanne Serst of AMR hosted a charity golf tournament and silent auction for ASO on June 12. In addition to raising nearly $7000.00, about one hundred guests were very moved by a dinner presentation given by Sergeant John Keating. John spoke about his family’s story in living with autism and about his amazing cycle across the U.S. in 2000 to raise funds for autism research.

**Johnson and Johnson’s 2nd Annual Walk for Hope was held at McNeil Consumer Healthcare in Guelph on June 13.**
Peter Miles and ASO worked together to promote autism awareness and the need for autism research to staff at McNeil before and during their lunchtime walk around the beautiful grounds at McNeil. Participants raised $6400.00 for ASO’s Autism Research Fund!
Dear ASO Members,

Who? There are so many issues that affect the lives of people with ASDs and their families in Ontario. Since we are primarily a parent and volunteer driven organization, we are especially interested in the wide range of opinion of our membership on matters that have an impact on your lives and the lives of people with ASDs at all age levels. In the last issue of Newslink, we published a guest editorial that provided a forum for one of our members to speak of her family’s experience and opinions about living with ASD in Ontario.

Why? It is our hope that many of you will submit thoughtfully written opinions/editorials/letters that would be considered for inclusion in upcoming issues of Newslink. Our goal is to promote dialogue among our members so that both common and unique experiences of our members are offered for public consideration and response. It will also give ASO Board members another way to link with our broader membership in order to assist them in their ongoing task of providing direction for Autism Society Ontario.

What? We are particularly interested in hearing from parents and professionals from different areas of Ontario. Topics welcomed (but not limited to) are ones that might address diagnostic issues, service and treatment issues, barriers to service or success stories, ideas about ways you have or ASO might effectively engage our provincial leaders in understanding and addressing immediate and long-term Autism and Asperger’s related concerns, unique pre-school, school-aged and adult issues, perceptions of key issues in responding to the needs of individuals with ASDs in Ontario or Canada, reactions to ASO’s activities, topics in Newslink or other hot topics presented by the media, responses to ASO or other Ontario ASDs conferences/presentations.

How? Please limit editorial opinions and/or letters to 1000 words or less. While we respect diversity of opinion, ASO reserves the right to print submissions that reflect the values and mission of ASO. Submissions may be emailed to mail@autismsociety.on.ca.

ASO has been asked to offer a written submission to the Ontario Human Rights Commission in response to its paper entitled Education and Disability: Human Rights Issues in Ontario’s Education System. Members of ASO’s Education Committee and SEAC representatives will be submitting a response prior to the October 7, 2002 deadline. This paper will be made available on ASO’s website or through the provincial office and local chapters. ASO’s Education Committee has completed the writing of the updated Education Handbook. Through support from our Trillium Grant (see Spring Newslink) this resource will be available by the end of September through the provincial office and at the ASO booth at Geneva Centre’s International Autism Symposium in October in Toronto. The handbook will also be available in both French and English.

Education Survey Results: ASO received a very favourable response of 450 resplies to its online survey in June.
We asked Kathryn Everest of the York Region Chapter to offer insights on some of the results that were gleaned from over 450 respondents to the Education Survey conducted across Ontario in June 2002. If our readers have a specific question about the survey results, we invite them to ask a specific question that may produce better/different information to inform local needs or conditions. A PowerPoint presentation of the detailed results of the survey is available to interested individuals. Contact the provincial office or your local ASO chapters for more information.

I was asked to try to publish the education survey results, but quickly realized that the survey results really created more of a database of information, and that you needed to ask a question to put it in context. So, I began to ask questions.

My first question was: What types of placements are our kids in? The following table provides both the actual number of respondents (#), as well as the percentage (%) by age group:

<table>
<thead>
<tr>
<th>Placement</th>
<th>JK – K</th>
<th>Grade 1 – 3</th>
<th>Grade 4 – 8</th>
<th>Grade 9 – 12</th>
<th>Total</th>
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<tbody>
<tr>
<td>Respondents</td>
<td>99</td>
<td>22</td>
<td>177</td>
<td>39</td>
<td>133</td>
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<tr>
<td>Regular Class Placement</td>
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<td>66</td>
<td>109</td>
<td>62</td>
<td>51</td>
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<tr>
<td>Partial Integration (+50% in integrated setting)</td>
<td>4</td>
<td>4</td>
<td>18</td>
<td>10</td>
<td>21</td>
</tr>
<tr>
<td>Partial Integration (+50% in integrated setting)</td>
<td>4</td>
<td>4</td>
<td>11</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td>Segregated Class</td>
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<td>2</td>
<td>3</td>
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<tr>
<td>Other</td>
<td>12</td>
<td>12</td>
<td>5</td>
<td>3</td>
<td>6</td>
</tr>
</tbody>
</table>

My second question was: Did the options change as the student got older? (do older kids tend to end up in more restrictive settings?) The answer was YES – however, we had a small sample size of older children (only 10 percent of respondents were in Grades 9 through 12). The following line chart allows you to compare percentage of kids in different settings by age. This finding is neither positive or negative, but just an interesting observation.

My next questions were about how satisfaction level of parents. As a SEAC rep, I don’t hear from many happy parents. Were most parents satisfied with the program they were receiving? The answer was that parents are more satisfied than I would have thought, but we still have much work to do as an organization.

Were parents of younger children more or less satisfied than parents of older children? Did parents become most satisfied as time goes on? Not really.

Happy parents did not seem to be affected by either placement of age of the student. I had theories about this, but another hypothesis proven wrong.

So what made the difference? Here were some of the top rated strengths of programs that parents reported they were very satisfied (none will come as a surprise, but are certainly worth sharing with your child’s school):

- Trained, caring, committed staff (the most important ingredient)
- Educational Assistant
- Structured yet flexible program
- Calm environment
- Individualized program
- Well defined, appropriate program goals (including academics)
- Team approach with strong home/school partnership
• Supportive peers
• Appropriate modifications and accommodations
• Inclusion of social skills, life skills and vocational programming
• Inclusion of proven good practices such as:
  – ABA
  – Occupational Therapy
  – PECS
  – Speech/Language programming
  – TEACCH method
  – Visual Supports

1. Out of the 456 surveyed, 178 (40%) reported that the child has been sent home before the end of the school day. The most common reasons were:
• Behaviour issues
• Toileting accidents
• Lack of support (EA sick or taking a course)
• Kids “looked tired, sick, etc”, but were fine at home

70% of the parents believe that their school staff has not been properly trained about autism.

Other issues that were of note were:
• Need for more staff training (83)
• More EAs (46)
• Speech/Language Services (32)
• ABA in schools (29)
• Funding (15)
• Integration (10)
• Increased classroom support (6)

As a SEAC rep, I plan to use this information to ensure I’m focused on what matters to our members.

By Karen MacKay

When I found out that my friends Sue & John had a child diagnosed with autism I decided I had to do something for them and for other children. I had three sons, and three grandchildren, and felt blessed that there had been no problems. My first ride was from Inuvik, NWT to Calgary, Alberta. Cycling down the Dempster highway made me realize that what I was doing was just physical and mental and nothing to what families and children living with autism would have to face in the future. So I dedicated my 3500-km cycle to autism and collected over $13,000 in 2000.

I contacted the Ottawa Chapter and volunteered to organize the one-day cycle in September 2001 and also to organize a leisure route from Windsor to Ottawa. I managed to convince four friends that this would be a great holiday for them, and among us all we collected over $10,000. It did turn out to be a great holiday. I believe the uniqueness of this trip was that none of the riders had relatives with autism.

This year, 2002, I am again cycling the route from Windsor to Ottawa, have lost a couple of riders and picked up a couple more. This year we will have two mothers who have children with autism. Our route is much the same as last year, but with an added feature—the fundraiser in Hockley that Doug and Sue McCreary of the Dufferin Chapter are planning. I have already reserved my space in their Tree House as my resting-place the night before the ride. I am hoping that more cyclists will join us on Saturday and cycle for one or two days. ASO’s Board of Directors and President’s Council will be celebrating with our group on Saturday, the 14th for an event-filled day!

We also have joining us Howard Pulver, who mapped our route from Windsor to Pefferlaw, for the Hockley section, and two others joining us in Cobocconk to Bancroft. Everyone and anyone else are welcome to come along.

Through the association with the ASO I have met some wonderful people who have become my friends. I admire their fortitude and determination to find a cure for autism. The business people in Ottawa have been a real help, coming on board with prizes, cash donations and support for both rides. All funds raised on this trip will support the education and awareness efforts of Autism Society Ontario. The adventure continues! Thank you for your support.

**Itinerary:**

- Leave Windsor: September 10th overnight in Chatham
- Chatham to Strathroy September 11th
- Strathroy to Shakespeare September 12th
- Shakespeare to Orangeville (Hockley) September 13th Hockley cycle back to Orangeville and ride up to Hockley with other riders on Saturday
  - Lunch with ASO
- Hockley to Pefferlaw September 14th
- Pefferlaw to Cobocconk September 15th
- Cobocconk to Haliburton (Red Stone) September 16th
- Red Stone to Bancroft September 17th
- Bancroft to Denbigh September 18th
- Denbigh to Black Donald Lake September 19th
- Black Donald Lake to Fitzroy Harbour September 20th
- Fitzroy Harbour to Ottawa September 21st
- Join one-day Cycle for Autism in Ottawa on September 22nd.
In the last edition of Newslink, ASO announced the receipt of an ACCESSability Grant through the Ministry of Citizenship. One of exciting outcomes of that grant will be an ASO publication that will feature the first hand accounts of older teens and adults in Ontario whose diagnosis falls somewhere along the Autism Spectrum (one of the PDDs). More specifically we are looking for writing that:

- promotes greater understanding of people with ASDs;
- educates community members so that barriers to effective education and employment opportunities for adults with ASDs are decreased;
- informs readers about the wide range of diagnostic expression that may be a barrier to a) gaining access to existing services and b) getting the help they need to fully participate in their communities;
- provides younger people with ASDs with greater ability to recognize their own social, communication and sensory challenges, while celebrating their strengths in a society that places demands that can be at times overwhelming for persons with ASDs.
- provides information that will be a source of hope for the increased number of people being diagnosed with ASD and their families in Ontario.
- provides information that will be a source of hope for the increased number of people being diagnosed with ASD and their families in Ontario.

The deadline for submissions is January 15, 2003. Only first-hand accounts of diagnosed persons will be considered. First hand accounts as dictated to a scribe or transferred from audio tape will also be considered. In order to include as many accounts as possible, we regret that we must restrict the length of writings to 3000 words or less. Reproducible artwork, musical compositions or other visuals that support or enhance the written material are welcomed.

Attention writers:

Although all submissions will be considered, not all of them will be included in the final publication. Submissions must include the author’s full name, age, address, phone number, email address (if available) and, if so desired by the author, contact information for a support individual to the author who may be contacted by ASO.

For more information, contact ASO’s provincial office.

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Autism Society Ontario is a registered charitable non-profit organization ( # #11924 8789 RR0001 ).

Our Vision: Acceptance and opportunities for all individuals with Autism Spectrum Disorders.

Our Mission: To ensure that each individual with Autism Spectrum Disorder is provided the means to achieve quality of life as a respected member of society. Newslink is produced 3 to 4 times per year. Subscription to Newslink is included with ASO membership. Newslink welcomes contributions from its readers.

Send your articles, reviews, letters, comments, announcements, etc. to Newslink Editor, 1179A King Street West, Suite 004, Toronto, Ontario, M6K 3C5. Phone: 416-246-9592 Fax: 416-246-9417 email: mail@autismsociety.on.ca. Inclusions of information not directly related to ASO are for your information only and individuals, events, therapies, treatments, etc. are not necessarily endorsed by ASO.