

# L'Express

**A** Quebec Federation for Autism  
and other Pervasive Development Disorders

March 2003



- ▶ *Intensive behavioral treatment of autistic children in Ontario: a presentation by Sylvie Donais*
- ▶ *Treatment of autism: research on a medical protocol*
- ▶ *When art becomes an effective factor in social integration*

## L'Express

March 2003

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### Board of Directors 2002-2003

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# Editorial

*It is now time for public authorities to act as a springboard or a catalyst in all the processes involved.*

*By Jean-Claude Marion*

Emergency! This is the word that best expresses how we feel during this holiday period.

A class action has been launched requesting services for autistic children. It mentions rights that have been ignored, discrimination based on this handicap, a disregard for the principles enumerated in the Québec Charter of Rights. It is easy to see that these recriminations are clearly justified and that the principles that serve as a basis for our action originate in highly prestigious organizations.\* The parents who are expressing themselves are many: they are better informed today than previously and thus are increasingly reluctant to accept that services are being denied to their children, which denial presents a risk of negatively affecting their lives. Nearly every day exhausted parents report on their grievances. To be convinced, one need only join a community association or attend a discussion panel. There is now increased familiarity with autism but with it a sense of powerlessness before the apparent inertia of governments and the absence of an appropriate structure for the establishment of educational methods which have an indisputable track record.

We are, in a way, victims of the success of our activities and struggles for obtaining recognition of the handicap. In fact, 25 years ago, autism and pervasive development disorders were poorly understood, often associated with a strange and unclearly defined psychoanalytic condition. Since then, a countless number of persons (scientists and others) have fought to produce changes in public perceptions and we now know that these problems may be associated with a neurological disorder or illness presenting variable symptoms. We are also aware that early stimulation properly applied by specialized educators is capable of changing the course of events and can sometimes allow children to be integrated successfully in the community. This is of inestimable value and, of course, parents know this.

Mental attitudes have changed. There are now educational methods that have won recognition. However, there remains a need to clarify the causes of the syndrome, to stem the growth of autism which is threatening to become a public

health problem, to study the environmental factors that often seem to be involved and to analyse the characteristics that are beginning to gain a consensus in the scientific community. Gastro-intestinal problems are among these characteristics and a medical treatment protocol that is being developed is the source of great hope. The clues uncovered by research add to the hope that an efficient treatment of autism may be discovered. There is one important wish: that the research remain independent and free of influences and interests that may be contradictory.

The budgets allocated to autism have been increased in other provinces. The needs are enormous. We have reached a crossroads. There is a need for action. In a difficult budgetary situation, it is imperative that we act with efficacy. The subject is too important to allow our energy and efforts to be dispersed. It is now time for our public authorities to act as a sparkplug or a catalyst in all the processes that are implicated. Detection, diagnostic resources, early stimulation, training of educators, integration, encouragement and openness by researchers, all are elements requiring a coherent and generous vision. A plan of action is therefore absolutely necessary. The Federation has submitted concrete proposals to the committee responsible for recommending solutions to our authorities and we believe that these should be very seriously considered because of the expertise that has been gained through close contact with the day-to-day problems of our clientele.

It would be intolerable for autistic children to remain prisoners of their handicap because of budget considerations. While we are conscious of the great cost and the resulting options, we consider it unacceptable that children who are already fragile should become the pawns of politics and finance. There is no doubt about the urgency that prevails. Let us try to influence the course of events. After all, we are now in the festive period when it is said that dreams can come true.

\* Commission on Human Rights and on the Rights of Youth and the Appeals Court of British Columbia

# The Immune System & Autism

By Andrew W. Zimmerman, M.D. and Susan L. Connors, M.D.

Source: Advocate third edition 2002, Volume 35, no. 3, pp.28-31.

## Does It Affect the Brain?

Several researchers have suggested that possible causes for autism may be found from investigation of the immune system in patients with this disorder. Many reliable studies have shown immune abnormalities in subsets of children with autism. Like abnormalities in the gastrointestinal (GI) tract, it is not clear how (or if) these immune findings affect the brain, the organ responsible for the most disabling symptoms in autism.

In other words, whether or not immune abnormalities are a cause or an effect of autism is unknown. The basic goal we have in this area of autism research is to find provable links between the immune system and brain function. Unfortunately, none of the immune research so far has provided evidence to support the use of immune therapies to treat autism.

We will review some of the immune findings in the following sections and will discuss several theories about how they might relate to autism.

## Immune Abnormality

For 25 years, the immune system has held the interest of researchers because of the early observation that congenital rubella (German measles infection in the mother during pregnancy) can cause autism by affecting the child's brain before birth. Might other infections of the mother during pregnancy (like rubella), or immune abnormalities in the mother or her fetus, lead to autism?

Many researchers have investigated these immune abnormalities. Certain types of immune cells (B-cells) produce antibodies after exposure to foreign substances such as bacteria and viruses. When antibodies bind to foreign molecules in an immune reaction, it will eventually clear the foreign substance. Stubbs<sup>1</sup> and others found abnormalities in antibody, or

B-cell functions, and in immune memory, or T-cell activities, in children with autism.

These observations gave rise to particular interests in maternal antibodies and immune immaturity. Subsequent studies then produced findings of low immunoglobulins (Igs), or antibodies. Treatment trials with intravenous immunoglobulin (IVIG) replacements (in an attempt to "balance" this immune system measurement), however, did not show consistently positive changes for most of the children treated.

In addition, Warren<sup>2</sup>, Torres<sup>3</sup> and their colleagues showed that unique patterns of immune system genes (HLA or human leucocyte antigens, which code for certain molecules needed to get rid of infections), located on chromosome 6, occur in some children with autism and their parents. They reasoned that this could underlie a prenatal or postnatal process where an immune reaction influences brain development.

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***"This has suggested to some researchers that the immune system in a subset of children may recognize and react against molecules in the children's brains, and produce autistic symptoms."***

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Gupta<sup>4</sup> found patterns of T-cells that shifted from T1 types (that help rid viruses and tumors from the body) to T2 types (that create immune reactions producing allergy-type antibodies). This same type of shift is similar to that found in autoimmune disorders, such as rheumatoid arthritis, and suggests that autism could be related to autoimmune problems.

Unusual patterns of cytokines (small proteins produced during immune reactions) have been described by Singh<sup>5</sup> in the blood of individuals with autism, and on stimulation of white blood

cells by Jyonouchi<sup>6</sup>. This type of research shows further differences in immune system function in autistic patients compared to normal children.

Though the clinical significance of these cytokine findings is not clear at this time, the patterns described in these studies may prove useful in the future to categorize subsets of autistic children regarding their immune system involvement.

### **Role of Antibodies Still Questioned**

Several antibodies that react with brain tissue have been described in the blood of children with autism. This has suggested to some researchers that the immune system in a subset of children may recognize and react against molecules in the children's brains, and produce autistic symptoms. Similar antibodies have also been found in lower numbers of normal controls, however.

The antibody reactions mentioned above were tested in brain tissue from non-autistic autopsied patients. Because of this, one cannot conclude that the antibodies from the blood of children with autism are reacting with their own (autistic) brain tissue and are therefore responsible for changes in brain function and autistic symptoms in those same children.

That is, it is not known whether or not autistic children are making antibodies to their own brain tissue, and if they are, what effect it has. Also, none of these antibodies has been found in the brain or cerebrospinal fluid (CSF, which is produced in the brain and bathes the brain and spinal cord) of persons with autism, and this would be necessary to demonstrate that they could directly cause the disorder.

Studies of measles and other viral antibodies, as well as immune findings in the gut, have produced much speculation, but no proof, that autism may result from an immune process (where reactions are directed against foreign molecules), or "autoimmune" disorder (in which reactions are directed against one's own tissue), in a subset of children.

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***"However strongly we might think that the immune system contributes to autism, the relationship is not like other known neuroimmune disorders."***

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### **Other Conditions and Parameters Associated with Autism**

There are many known conditions associated with the symptoms of autism (such as Fragile X and Rett syndrome), and they account for 5-10 percent of children when they present with the disorder.

With time, more causes are being described, such as mitochondrial defects (rare disorders of energy metabolism). These associated disorders can vary widely in their inheritance patterns within families, as well as in clinical presentation. A characteristic they may all have in common might be their ability to affect cells in both the brain and immune system (as well as in other tissues), and thus they may cause abnormal patterns of brain and immune system development simultaneously.

Although autism is believed to have a genetic basis, as shown in family and twin studies, the wide variability of symptoms, the potential to improve among persons affected by it, and the common occurrence of milder "traits" in relatives, all suggest that other "epigenetic" (outside the genes) factors are involved.

These may include the immune environment in the womb as well as maternal infections and other environmental exposures, and may serve to modify the expression of otherwise "normal" genes.

Comi<sup>7</sup> found a higher rate of autoimmune disorders (especially rheumatoid arthritis) in the mothers and close relatives of children with autism (although not in the children themselves), compared to families without autism. Since autoimmune disorders are typically associated with particular HLA (human leucocyte antigens) types, it is possible that these HLA types might contribute to immune effects on the developing brain of the fetus.

### **Clinical Signs of Abnormal Immune Function**

Though an immune disorder has been speculated to exist either as a cause or as a result of autism, clinical signs for this are lacking. Many children with autism have mildly abnormal immune functions on laboratory tests, have frequent illnesses (especially ear infections), and subsequently receive multiple courses of antibiotics.

They do not, however, have typical clinical signs of “immune deficiencies”. Studies have not shown clear cause and effect relationships between abnormal immune findings in autism, and the presence of unusual infections. That is, children with autism do not suffer from overwhelming infections as do children with known immune deficiencies.

### **Is Autism a “Neuroimmune” Disorder?**

However strongly we might think that the immune system contributes to autism, the relationship is not like other known neuroimmune disorders (where the nervous system is the target for immune reactions), such as multiple sclerosis (MS) or Guillain-Barré syndrome (GBS, a result of post-viral nerve damage).

In these disorders, immune reactions are directed against nervous tissue in a progressive and destructive manner. There is no current evidence of destruction in any autism autopsy report. Unlike MS and GBS, autism appears over a predictable time course in young children, many of whom improve spontaneously over time and to different degrees.

It is possible that the immune changes in autism result from the same genes that affect the brain. In fact, there are strong suggestions of this in Rett syndrome, a genetic disorder in girls that resembles autism. The immune findings in Rett syndrome (which are similar to those found in autism) result from one important abnormal gene. By analogy, the immune abnormalities in autism, like GI and brain changes, might occur in parallel to each other, all in response to the same abnormal mechanism or the same abnormal gene(s).

Unlike known immune disorders that affect the nervous system, however, there is no “smoking gun” in autism, no abnormal reaction in nervous tissue, and no antibody reaction that has been consistently demonstrated in tissue or that correlates to treatment or improvement.

### **Do Immune Treatments Work?**

There have been few studies of immune treatments in autism. Plioplys<sup>8</sup>, Gupta<sup>9</sup> and others have reported small numbers of children who responded to IVIG. However, controlled studies (comparing treatment to placebo) with well-defined outcome measures have not been published.

Prednisone<sup>Æ</sup>, an immune suppressant, has been reported to improve autism in case reports, but there have been no placebo-controlled studies of this drug. Other drug treatments that act on the immune system have been proposed but are difficult to justify at this time.

Before larger trials of immune treatments are undertaken, we need a better understanding, as well as scientific proof, for ways that the immune system and brain interact in autism.

### **Do Vaccines Cause Autism?**

Despite suggestions that vaccines may contribute to regression in autism, there are no convincing statistics that support this. It may be that immune stimulation resulting from immunizations (such as MMR) amplifies abnormal mechanisms that are already in place.

Since the vaccines are given at young ages when the brain is developing rapidly, symptoms of autism may be more severe than they would have been otherwise. These ideas are theoretical, and important research now underway should soon clarify their importance. The question of whether mercury toxicity (which could affect immune functions) may result from vaccines or other sources remains unknown.

### **What Research is Needed?**

Research on immune activity in the brain in autism might show us how (and if) the immune system affects the brain. Advanced pathological studies of microglia in autopsied brain tissue are possible, and have been carried out in schizophrenia and Alzheimer's disease. Based on these studies, clinical trials of anti-inflammatory drugs are now underway in these disorders and are showing some promise.

There are many reasons to think that the immune system is important in autism. Our information is incomplete and we do not yet know what the immune findings mean, so that immune interventions are not yet justified as treatments for autism<sup>10</sup>. Those working in this field, however, are continuing to search for answers to these important questions.

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# Intensive behavioral treatment for young autistic children: a subsidized program in Ontario

*By Dr Sylvie Donais, psychologist*

For the past two years, the author has worked as the clinical director of a centre that dispenses services in the Eastern-Central region of Ontario. In this article, she describes Ontario's intensive behavioral program for young autistic children which is subsidized by the Ministry of Services to the Community, to the Family and to Children. She traces the guidelines of the program and furnishes a good description of it based on an applied analysis of behavior. In light of her experience, she then discusses the limits of the program and formulates recommendations in order to facilitate exporting this specialized model to other provinces.

## Organization of services: a beginning

The intensive behavioral program for young autistic children is a provincial program subsidized by the Department of Services to the Community, to the Family and to Children. It was established to fulfill the need for services offered to preschool autistic children in Ontario. It is addressed to children under 6 years of age who have been diagnosed as autistic or as having non-specific pervasive development disorders (in accordance with the criteria of the DSM-IV, APA, 1994). The organization of services was prescribed by the Ministry which called upon Dr Adrienne Perry, a psychologist and researcher, also a behaviorist and autism specialist.

In March 2000, The Ministry announced that public funds would be dedicated to intensive behavioral treatment. A call for tenders was then initiated. The province was divided into nine regions and in each of them, a special service centre was given responsibility for the program. By summer 2000, the establishments were selected and the hiring process was started.

The team of intervening persons is made up of a clinical director, psychologists, senior therapists and instructor-therapists. The Ministry's guidelines state what the qualifications and roles of each are to be.

## The daily challenge of the program is to train, train, train. . .

A budget is allocated to each region for dispensing services to a predetermined number of children. In the Eastern-Central region, for the first year, the Ministry provided for approximately 90 children who had been referred for treatment. At the present time, there are more than 400 children in the program, 119 of whom receive care for an average of 30 hours a week. Families can choose one of two options: the regional program offered by the establishment or a private program. If they choose the second option, funds are allocated to the family for hiring a team of therapists who are supervised by a psychologist.

## Training of instructor-therapists and senior therapists

In September 2000, I began my new career as a clinical director. What does this position involve on a daily basis? First of all, senior therapists and instructor-therapists had already been hired when I arrived. The next step was training. Most of the senior therapists had no experience in applying the intensive treatment although a few had some experience with the behavioral approach. These were responsible for training and supervising the instructor-therapists. I asked myself how they could train therapists if they did not possess the pertinent experience. That is the daily challenge of the program, to train, train and train.

In November 2000, a two-week training session in class was given by a private clinic whose services were retained by the Ministry to complement the training of the instructor-therapists in the nine regions. At the conclusion of this training session, therapists were required to undergo a theoretic evaluation in addition to a practical evaluation involving direct interaction with a child.

No specific training is offered to senior therapists, to psychologists and to clinical directors. This can be attributed, in my opinion, to the fact that it is difficult to foresee the number of qualified supervisors required for the intensive behavioral approach for young autistic children.

To ensure better training of supervisors, the new senior therapists hired in our region are instructor-therapists who are promoted. And the promotion has a very positive effect: it increases their motivation to continue working in the program while making it more likely that they will pursue their university training.

## Description of intensive behavioral treatment

### ► IBI versus ABA

The Ministry uses the terms IBI (Intensive Behavioral Intervention) to identify this type of program, addressed specifically to autistic children.

The term ABA (Applied Behavioral Analysis) is also used to define the treatment of autistic children. However, applied behavioral analysis is a field of psychology that applies not only to autistic children, but to human beings in general.

ABA is, in fact, a scientific study of human behavior. A behaviorist observes how certain events influence the behavior of a person and asks himself these questions:

- How did a person react to an event - what verbal or non-verbal behavior did he or she present?
- What is the consequence of such behavior?

For example, a person exceeds the speed limit and sees a police car on the highway. How will he or she react? Continuing at this excessive speed could result in a speeding ticket. The person could choose to continue to ignore the speed limit or to slow down. In fact, each person has his or her own history of learning and his or her own motivations that will serve as a basis for making choices.

For the purpose of treating adults and children who present various psychological disorders such as depression, phobias, obesity, addiction to tobacco, hyperactivity or learning difficulties, a behaviorist will analyse how environmental stimuli affect a person and then will develop a program of intervention.

Intensive behavioral intervention for autistic children was developed by bringing together various behavioral techniques based on

scientific research in applied behavioral analysis carried on for the past 50 years.

## Research

Dr Ivan Lovaas (Lovaas, 1987, McEachin, Smith and Lovaas, 1993) is the pioneer in this type of treatment for young autistic children. His research, notably the 1987 study, documents in a scientific manner that a behavioral treatment lasting 40 hours a week over a period of at least two years enables young autistic children to significantly develop intellectual, language and social skills. The results are much better than those obtained by a group of children in a behavioral treatment program of 10 hours a week.

In spite of criticism on the quality of the study (Schopler, Short and Mesibov, 1989; Greshaw, Frank and MacMillan, 1997) this type of intervention has now been recognized by scientists as the treatment of choice for autistic children (Handelman and Harris, 2000; Maurice, Green and Foxx, 2001).

In Canada, Manitoba has inaugurated a program for the population of Winnipeg. British Columbia is on the point of offering this service. In the province of Québec, parents are launching a class action for the purpose of obtaining these services for their children.

How to evaluate the quality of an intensive behavioral program?

How can a parent know if the program offered to his or her child is a quality program?

Members of the Group interested in Autism from the International Association for Applied Behavior Analysis have drawn up a list of criteria to assist parents, psychologists and administrators in the development of an intensive behavioral program for young autistic children (The Association for Behavior Analysis-Autism SIG, 1998).

The guidelines proposed by the Ministry of Services to the Community, to the Family and Children are based on these criteria.

### ► Qualifications of a clinical director or a treatment supervisor

- PhD or Master's degree in applied behavioral analysis, psychology or another subject focussing on behavior analysis;
- Supervised internship or experience in applied behavioral analysis;
- Training and experience in the supervision of an intensive behavioral intervention

program addressed to a minimum of 5 autistic children;

- The equivalent of one complete year as an instructor-therapist for autistic children, supervised by a clinical director with 5 years of experience.

### ► Techniques and curriculum

The learning objectives must include the following:

- skills that precede learning (learning how to learn); responding to instructions, looking at an adult or a peer, imitating actions.
- verbal communication;
- non-verbal communication;
- pre-school skills (i.e. associating objects and pictures);
- play skills;
- social interaction;
- autonomy skills: dressing, feeding;
- gross motor skills.

Teaching methods that are used consist of discrete trial and incidental teaching encouraging the acquisition and generalization of skills.

Behavioral techniques used are: reinforcement of appropriate behavior, prompting, correcting errors, training in discrimination and promoting generalization.

Depending on the findings that are systematically gathered, the objectives and the learning program are modified.

A functional analysis is conducted for the purpose of planning interventions to reduce problems of behavior, auto-mutilation and rituals.

### ► Training offered to parent

### ► Ongoing training and supervision of implicated persons

- The therapist must be supervised for at least one hour per 10-hour period of contact with the client for the first six months.

The Ontario program is based on these criteria, with some modifications. First of all, since the program is a provincial one, it serves more than 400 autistic children. In view of the great number of clinical directors, psychologists, and therapists that are required, several years are necessary for their training.

*Integration into the school system and planning for the transition between the IBI system and*

*the school are crucial to facilitate and conserve the skills acquired by the child.*

In Ontario, the treatment of each child must be supervised by a psychologist who is a member of the Ontario Order of Psychologists. If no such psychologist has been recruited, the program may be conducted under the supervision of other professionals with at least a master's degree and many years of experience in this type of treatment. Thus, the criteria for the training of personnel proposed by the ABA-SIG (1998) are objectives to be attained over the next few years.

Furthermore, no program in applied behavioral analysis previously existed at the graduate level in Ontario, thus limiting the number of clinical directors and psychologists with this type of training. In September 2002, the University of Nevada, in collaboration with a private clinic, Behavior Institute, began to offer an ABA Master's course in Toronto. Several senior therapists and instructor-therapists are attending these courses which will allow them to earn a position as a supervisor of the treatment of certain children.

### Transition to the school system

Integration into the school system and planning for the transition between the IBI system and the school are crucial to facilitate and conserve the skills acquired by the child. The Ministry recommends that each centre develop a plan for this process before the treatment is terminated. However, practices vary by region.

One of the first difficulties encountered in the province is

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***The lack of qualified personnel at all levels: clinical directors, psychologists, senior therapists and instructor-therapists.***

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In our area, protocols are drawn up with school boards to facilitate the transition process. Some schools accept therapists in the classroom in order to provide support to the autistic child who is deemed ready to learn in this milieu. This type of collaboration enables teachers and teaching assistants to obtain a form of training on the site. However, some school boards have different policies and cannot accept our people in the classroom. In these cases, parents and the clinical director meet with the school team during the year in order to discuss the objectives to be met at home and at school. If the child does not appear to have the skills required for learning in a group, a common decision is taken so as to offer the best service to the child. For example, the child could go to school for two

mornings a week and receive behavioral intervention at home the rest of the time.

### Limitations of the program and recommendations

One of the main problems met throughout the province is the lack of qualified personnel at all levels: clinical directors, psychologists, senior therapists and instructor-therapists. The Ontario program is the only one offered on such a broad scale. Consequently, many years are required before qualified supervisors gain experience.

Another obstacle lies in the fact that subsidized establishments already have policies covering hiring and training practices as well as work hours. Our program comes up against these restrictions: no weekend service, delays in offering positions because of human resource policies, unionized personnel and a multitude of procedures to be followed before being able to get rid of a therapist who fails evaluation tests.

Also, the number of children on waiting lists is very high. The funds obtained from the Ministry are insufficient, which is frustrating for parents. Two options are therefore open to a province that seeks to inaugurate such a service. First of all, it could start on a broad scale and offer this public service to children from all parts of the province, while providing training to the staff on site. Or else, it could establish a pilot project, like in Winnipeg, providing service to a limited number of children, but offering a quality program from the start. This option allows for the development of specific expertise in one region, before eventually spreading the services to a greater number of people.

Ontario chose the first option. My recommendation would be to choose the second.

Such a program needs many years of training to develop a quality service based on the American model (Lovaas, 1987; Handleman and Harris, 2000). In the United States, many programs begin with a clinical director, supervisors and only 5-10 autistic children. According to the UCLA model, a clinical director is able to supervise a maximum of 15 autistic children if he or she hopes to offer a quality service and train the senior therapists and instructor-therapists involved. (Smith, Donahoe and Davis, 2001 in Harris and Handleman, 2001). In my region, at the end of my first year of service, I was supervising the treatment of 40 children in the regional program and 30 children receiving private funds, in addition to training more than 70 persons involved in the program, i.e., instructor-therapists or senior

therapists. Obviously, the program is expanding too quickly.

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### ***The challenge is to recruit and to train other clinical directors and psychologists who are already experienced in the intensive behavioral treatment of autistic children.***

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Currently, in Ontario, the clinical directors and psychologists, as a group, are in the process of defining standards to improve services and the training of personnel. These standards will allow the evaluation of the quality of treatment offered in each region, as soon as the Ministry invests funds for the evaluation of services.

The Ministry announced recently the allocation of an additional amount of 39 million dollars spread over the next four years. This is excellent news. However, the challenge is to recruit and to train other clinical directors and psychologists who are already experienced in the intensive behavioral treatment of autistic children.

*As behaviorists, we also learn from our successes as well as from our failures. We gain support from our successes and we learn to correct our errors.*

I have great motivation which is based on daily events. Among them: observing a senior therapist establishing an innovative intervention program to teach a child how to ask to go to the bathroom. Showing a parent how to teach his child appropriate behavior when out in public: waiting in line at the super-market without tantrums, sitting down to eat at McDonalds without yelling and finishing a meal before going to play in the park. To see a child who had no verbal skills before treatment initiate a communication with his grandfather by answering the phone.

As behaviorists, we also learn from our successes as well as from our failures. We gain support from our successes and we learn to correct our errors. This initiative by the Ontario Ministry is in its infancy. We must continue to learn, to train new people so that more autistic children can benefit from a quality IBI program.

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## Teaching Individuals with Developmental Delays : Basic Intervention Techniques

**A new book by O.I. Lovaas, soon available at the Federation.**

The long awaited sequel to the classic\* scientific text on autism has just appeared.

O.I. Lovaas, director of the Lovaas Institute for Early Intervention, outlines his own ideas and those of other renowned specialists. Based on proven practical intervention techniques, the book provides a detailed description of current programs and tackles the problems associated with pervasive development disorders. It represents an essential resource for all professionals working in the field of autism.

\* *Teaching Developmentally Disabled Children: The Me Book*

# UCD M.I.N.D. Institute Study Finds Autism Increase Is Real

Source: *Schafer Autism Report, October 18, 2002*

The unprecedented increase in autism in California is real and cannot be explained away by artificial factors, such as misclassification and criteria changes, according to the results of a large statewide epidemiological study:

"Speculation about the increase in autism in California has led some to try to explain it away as a statistical issue or with other factors that artificially inflated the numbers," said UC Davis pediatric epidemiologist Robert S. Byrd, who is the principal investigator on the study. "Instead, we found that autism is on the rise in the state and we still do not know why. The results of this study are, without a doubt, sobering."

Key findings of the study are that:

- The observed increase in autism cases cannot be explained by a loosening in the criteria used to make the diagnosis.
- Some children reported with mental retardation and not autism did meet criteria for autism, but this misclassification does not appear to have changed over time.
- Because more than 90 percent of the children in the survey are native born, major migration of children into California does not contribute to the increase.
- A diagnosis of mental retardation associated with autism had declined significantly between the two age groups.
- The percentage of parent-reported regression (loss of developmental milestones) does not differ between two age groups.
- Gastrointestinal symptoms, including constipation and vomiting, in the first 15 months

are more commonly reported by parents in the younger group.

**"While this study does not identify the cause of autism, it does verify that autism has not been over-reported in the California Regional Center System and that some children diagnosed with mental retardation are, in fact, autistic," Byrd said.**

Byrd and his research team earlier this year enrolled 684 California children who received services from one of the California Regional Centers to participate in the study. They systematically gathered information for children in two age groups - 7 to 9 years of age and 17 to 19 years of age - from families of 375 children with a diagnosis of full syndrome autism and 309 children with a diagnosis of mental retardation without full syndrome autism.

Byrd, a pediatrician with UC Davis Children's Hospital, and his colleagues, conducted the study for the M.I.N.D. Institute at UC Davis to help explain reasons behind significant increases in the number of autistic children entering the state's 21 regional centers.

A 1999 report by the California Department of Developmental Services (DDS), which operates the centers, found a 273 percent increase in autism cases between 1987 and 1998. The report was the catalyst for the state Legislature and Gov. Gray Davis to direct DDS and the M.I.N.D. Institute to identify factors responsible for the increase, funding the effort with a \$1 million appropriation.

Autism is a complex and severe developmental disorder that affects a person's ability to communicate, form relationships with others, and respond appropriately to the environment. Those affected may avoid making eye

contact and lack the ability to read faces for signs of emotion or other cues. Children typically do not engage in social play or games with their peers. Unusual behaviors such as rocking, hand-flapping or even self-injurious behavior may be present in some cases.

Commentary by Bernard Rimland\*, PhD.

The study released today by the M.I.N.D. Institute will prove to be a landmark, in that it clearly dispels many myths and misconceptions regarding the reality of the widely discussed epidemic of autism.

The report states that:

- The epidemic is very real. There has been an enormous increase in the prevalence of autism, and the increase cannot be explained by the artifacts of greater awareness of autism, looser criteria for the diagnosis of autism and immigration of families seeking services for autistic children into California.
- The cause of the increase cannot be attributed to genetic factors (there is no genetic epidemic). Therefore, the environmental causes which have been implicated by numerous researchers in the U.S. and the U.K., especially immune and autoimmune dysfunction due to exposure of the child to the mercury and viruses in childhood vaccines must be given high priority research attention.
- The recent increase in gastrointestinal symptoms in the first 15 months of life, as reported in the study, is highly consistent with the excessive vaccination theory of causation and underlines the urgency of exploring vaccine-related issues.

While I am in agreement with the major conclusions of the California Study, which support and confirm the findings of studies done elsewhere, I disagree with the statement that "recent estimations put the prevalence at 10 to 12 per 10,000 persons." In fact, a number of studies in the U.S. and the U.K. have reported figures as high as 45 to 60 cases of autism per 10,000 live births. The epidemic is not only real, but also very serious.

I also observe that while the focus of the new report is on autism, there are similarly unexplained large increases in the last 15 years in a number of other childhood disorders involving immune system dysfunction such as ADHD, asthma allergies, and juvenile diabetes. These, like autism, have increased dramatically since the 1980s while the number of vaccine doses given before age two has increased from 8 to 22.

This new report on the epidemiology of autism in California is a call for action that must not be ignored. Vaccines have never been properly evaluated for safety. The assumption of safety is not warranted. The problem must be confronted with research aimed at rational changes in vaccine policy.

\* Director of the Autism Research Institute

# Harvard - Mass Gen Hospital to Research Autism Treatment

(Source: Schafer Autism Report, November 18, 2002)

Harvard University And Massachusetts General Hospital are collaborating on a study to establish a medical protocol for the treatment of autism. They have already made significant medical observations in treating over 600 children with autism.

Even though autism has reached epidemic proportions, affecting more than 600,000 children in this country and millions of children worldwide, the medical community lacks the scientific data necessary to medically treat these children.

Without this research or similar research, autism will continue to be viewed and treated as just a neurological dysfunction. Tragically, its victims will continue to suffer, untreated, with severe, biological illnesses.

**The Harvard-Mass General study is remarkably the first major study being conducted to establish a medical basis for the treatment of autism.**

The dilemma for physicians is not having a medical care protocol based on valid research data to treat autism. Doctors are also faced with a group of children from whom it is very difficult to obtain a description of what is wrong with them. Many autistic children are nonverbal and have behavioral problems so that the physician cannot trust their response. Unless a treatment protocol is developed, many of these children will live with painful, undiagnosed medical conditions that will grow more serious as they become teenagers and adults. The success of the Harvard-Mass General study holds out hope to millions of children with autism of receiving the standard of medical care that they need.

The Harvard-Mass General researchers have already had significant findings. Dr. Tim Buie, a pediatric gastroenterologist from Harvard Mass General, has performed more than 500 gastrointestinal endoscopies with

biopsies on autistic children. His findings show that more than half of these children had treatable gastrointestinal problems that ranged from moderate to severe including esophagitis, gastritis and enterocolitis along with the presence of lymphoid nodular hyperplasia.

In a recent conference Buie echoed the opinion of a growing number of clinical researchers and practitioners treating autistic patients. "These children are ill, in distress and pain, and not just

mentally, neurologically dysfunctional," he said. After diagnosis, Dr. Buie has successfully treated his patients by replacing suspected enzyme and probiotic deficiencies. The results have been significant improvements in his patients' conditions. Left untreated these gastrointestinal problems would further complicate neurological problems and exacerbate physical problems and other symptoms of autism.

In a significant conclusion, Dr. Buie believes that many of the symptoms of autism such as self abusive behavior including self-mutilation, head-banging, unexplained outbursts, atypical sleep patterns, disrupted sleep or night awakenings, are actually symptoms of pain that a child is not able to communicate.

The Harvard team of researchers including Dr. Harlan Winter, Dr. Rafail Kushak and Dr. Buie are committed to providing the scientific evidence needed to establish gastrointestinal findings and develop successful methods of treatment. This research will be used to establish a basis for the treatment of autistic children at various medical centers.

An important component of the Harvard-Mass General proposal is to establish a network of "centers of excellence" at medical universities to treat autistic children. The centers will define and follow a standard of care. They also envision that the centers will be linked in a consortium that will collect data and statistical correlations. The collective database that will develop will become the basis for clinical treatment protocols for autism.

Initial Autism Research Findings at Harvard - Massachusetts General Research show that:

- Autistic children commonly have GI symptoms.
- All experience published so far is a laundry list of observational data.
- The brain-gut connection in autism remains to be understood.
- Evidence-based studies are necessary in order to delineate these associations.
- We must pay attention not only to the intestinal complaints of these children, but consider behaviors and actions as potential symptoms.
- We have to educate more than the families about GI issues; we must educate the professional community and involve them in the process of caring for these children.

# The link between autism and the MMR vaccine is questioned

By Sébastien Boulanger

**Editor's note: The results of this study are strongly contested\* and are currently the subject of a controversy among those implicated in the autistic community.**

A new study published in the issue of last November 7 of the *New England Journal of Medicine* repudiates the theory of a potential link between autism and the triple vaccine against measles, mumps and rubella (MMR). For several months, various organizations including the World Health Organization had been asking for more thorough research to check on the risk of developing autism and other problems of an autistic nature through a comparative study of children who had received the MMR vaccine and those who hadn't.

A Danish research team, under the direction of Dr Kreesten Meldgaard Madsen conducted a group study covering all children born in Denmark between January 1, 1991 and December 31, 1998. The group, composed of 537,303 children, was selected based on data from the Danish Civil Registration System and five other national registers. In this group, the Danish Epidemiology Science Centre identified 440,655 children who had received the MMR vaccine, of whom 316 had been diagnosed with autism and 422 with another disorder of an autistic nature.

Information on vaccination came from the Danish National Board of Health while the data on children with a diagnosis of autism or another disorder of an autistic nature came from the Danish Psychiatry Central Register. This register records information on all diagnoses made in hospitals and psychiatric departments in Denmark. In this regard, the Danish public health system has among the most complete medical data bases in the world.

"No matter what method was used to analyse the data, and taking into account various factors such as birth weight, the gender, the gestation period, the social and economic status,

or the level of education of the mother, the risk of autism was the same for vaccinated children and for those who had not been vaccinated" states Dr Madsen. In addition, it was not possible to establish a link between the age at which a child was vaccinated and the development of autism, nor between the time that elapsed between the vaccination and the appearance of symptoms.

The conclusions reached by Dr Madsen and her team confirm the results of another recent study appearing in the November 2002 issue of the *Pediatrics* magazine, published by the American Academy of Pediatrics. In a group of 535,544 children between the ages of 1 and 7 who had received the MMR vaccine between 1982 and 1986, a team of Finnish researchers were not able to discover any association between the vaccine and the incidence of neurological disorders such as autism and encephalitis.

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\* See the article entitled *Viewpoint* by Marie-Christine Destison, p. 28

# Early Stimulation

## *The exemple of Marc-Antoine*

By Sébastien Boulanger

Carole Ladouceur, Marc-Antoine's mother is a plaintiff in the class action launched by many families against the government of the province of Québec to obtain intensive early stimulation services. Her thoughts were assembled and reproduced here by Jean-Claude Marion and by the author.

Marc-Antoine was born on December 20, 1995. Today, he is in first grade in the same public school as his older sister in the Montérégie area. This statement may not seem unusual, but, in this case, it is almost miraculous according to his mother.

In fact, very early on, Marc-Antoine's parents had premonitions: the child cried and yelled almost endlessly and the slightest sound could provoke sudden yelps as though he was suffering. Carole started to be seriously worried about her son when he was about 18 months old. In December 1998, she made an appointment with a pediatric neurologist who, suspecting that Marc-Antoine may have been suffering from a disorder in the nature of autism, referred her to a clinic specializing in the assessment of pervasive development disorders at the Sainte-Justine Hospital in Montreal. On April 19, 1999 after waiting four months, Marc-Antoine was finally evaluated at the special child care centre in Sainte-Justine and was diagnosed with autism. He was three years and four months old.

### Early stimulation

Normand Giroux, at the time director of training at the Québec Autism Society, was the first who told Carole about Dr O. Ivar Lovaas' approach, an early intensive stimulation method which could help Marc-Antoine reach his full potential. Today, thanks to a number of studies,<sup>1</sup> we know that early stimulation programs applied for between 30 and 40 hours a week as soon as a diagnosis of autism or other pervasive development disorder has been made, are an obviously good influence on the future development of young autistic children.



At that time, Marc-Antoine had tremendous difficulty in understanding his environment and he had a very low tolerance to frustration. He was also prone to echoing sounds or phrases, (echolalia), and acted in what could be called "*functional echoing*". Marc-Antoine could repeat a complete sentence in its context" says Carole. For example, when we stopped our car, he would say "*we have arrived*". Taken one word at a time, he had no idea what the sentence meant. But in the context, he knew that it was

<sup>1</sup> In this respect, consult our Web site ( and more specially the bibliography for the document *L'organisation des services aux personnes autistes, à leur famille et à leurs proches. Guide de planification et d'évaluation*, pp., 101-103.

the appropriate thing to say. Carole added: "He had the ability to verbalize but it was understanding that was difficult for him."

Following the diagnosis, after many approaches and efforts made to the public health system, the family came to the conclusion that it was impossible to obtain appropriate early stimulation treatments and decided to take on the process by themselves. "We decided to proceed because, from our studies, we had discovered that the plasticity of the brain allows the child to learn and that this plasticity diminishes with time" explained Carole.

The family was referred to Dr Sylvie Donais, a psychologist with the proper qualifications, duly trained in the supervision of intensive early stimulation treatments of the behavioral type inspired by the UCLA or the Lovaas method. Carole followed a training course with Dr Donais<sup>2</sup> learned the fundamentals of the method and subsequently attended many other training sessions. She looked after hiring educators and barely a few months after his diagnosis, Marc-Antoine was able to take advantage of about ten hours of therapy a week. From the time he reached 4 years of age, the number of hours was increased to 35 a week until he was ready to enter kindergarten at the age of 5 and a half. "With four educators plus the psychologist, we had to look after schedules, salaries, purchases and the crafting of loads of material... It was like a small business with the costs involved", states Carole.

Young Marc-Antoine then succeeded in being integrated in the regular kindergarten with an accompanist, while being followed by an educator three hours a day at home, after school. "We succeeded in being financed for 10 hours a week by our rehabilitation centre only when Marc-Antoine reached the age of 5. Since we began on our own two years earlier, we had to spend about \$50,000 of our own money to be able to offer him at least part of the care he needed. We were fortunate to be able to find the money."

She states that, without a doubt, the geographic site, notably the proximity to Montreal, helped a lot. "We obtained 10 hours a week for Marc-Antoine, but there are great disparities between

regions. In certain areas, the number of hours that are financed may vary from 20 to only one depending on the establishments and the rules in the area. And in distant areas, there is not enough money nor willingness to find educators and to have access to psychologists: it is often impossible for the children to obtain the appropriate treatment because of a lack of qualified personnel."

### Ask and coordinate

Accurate and appropriate information on the needs of the child is essential for success. :We were fortunate to come across someone, in this case Dr. Giroux, who put us in contact with competent persons like Dr Donais and who pointed us in the right direction. But to get the appropriate intensity in this type of method, the salaried staff is not sufficient. Parents must have assimilated the method in order to apply it in their daily lives, to make use, at opportune moments, of the concepts taught in therapy.

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Therefore it is essential to ask the proper questions, precise questions about the areas of intervention for which parents want answers. For Marc-Antoine, the tips given by an occupational therapist were of great value with regard to holding pencils, cutting with scissors, dressing, etc. Carole said she brought the entire team of educators to meet the therapist so that they could benefit from her recommendations. These recommendations were then applied in a uniform fashion by all the educators involved in the behavioral approach with Marc-Antoine and were included in the child's program. This coordination assured the same type of monitoring for Marc-Antoine at all times, thereby aiding the learning process.

While parents have a duty to rigorously coordinate the various intervening parties, they must also act on a regular basis as veritable

<sup>2</sup> In August 2000, Dr Donais accepted the position of clinical supervisor in Ontario, a province where, since that date, the government has been offering autistic children ABA type intensive early stimulation services. Unwilling to refuse such a great professional experience, she left the province of Québec and had to cease supervising the treatment of many local children, including Marc-Antoine. She was replaced, however, by Dr Sylvie Bernard, an experienced professional, who took over her responsibilities.

coaches for the educators they hire. In fact, these educators are not taught this type of method during their education. "I personally contributed to the training of the majority of the ten educators who worked for us over the years," said Carole. "There was a lot of turnover. Our last educator left us after having been hired by the Rivières-des-Plaines hospital, specifically because of her work experience with us, work that had been supervised by Dr. Bernard. You can imagine that these organizations are very happy to be able to hire people who have been trained and who know these children well..."

### Integration

The colossal efforts made by the family did reap rewards. Today, although Marc-Antoine still has symptoms such as problems with auto-stimulation and vocabulary, he is no longer subject to echolalia, nor any behavioral problems. He is in grade one in a regular class in a regular elementary school. Significantly, Marc-Antoine is the best of his group in reading since the beginning of the year. "He understands the courses he is taking and is not there just like a potted plant!" says his mother. He is accompanied in class by an educator from the school board, and he is well integrated in spite of a diagnosis of moderate autism.

Because of the scarcity of competent resources and their unavailability, Carole deems it essential for parents to acquire for themselves an expertise on this type of method by reading a lot and, if possible, attending training sessions. "It is much more reassuring when we know how to apply the methods. We have to read and attend training sessions. It is not that complicated. Without knowing the psychological or neurological basis of everything I do with my son, I know enough to be able to act by myself, that is to recognize problems and try to find solutions. But I continue to rely on Mrs. Bernard's genius!"

With 35 hours of weekly stimulation since the age of 4, the key factor for Marc-Antoine, without any doubt, was the intensity of the intervention. "If we could start over, we would begin the 35-hour a week schedule immediately instead of 10. I would organize activities with other children whom I would invite to the house at an earlier stage. One on one relations are necessary for the development of proper interactions and conversations adapted to the age of the child."

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***Today, Marc-Antoine is no longer subject to echolalia, he has no behavioral problems and is in first grade in a regular class in a regular elementary school. Significantly, Marc-Antoine is the best in his group in reading since the beginning of the year.***

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Short term, Carole hopes that Marc-Antoine will be able to pass all his grade one courses while liking school. A psychologist is expected to visit the class shortly and to study the dynamics before issuing recommendations.

Marc-Antoine's story is an example of exceptional success, due to many factors. Obviously many families do not have the same opportunities. The absence here of free, universal intensive early stimulation services for all children diagnosed with autism or other pervasive development disorders has important repercussions on the person, on families and on society. In the case of families the investment in time required and the exorbitant financial cost may be intolerable. Collectively, it is estimated that in the province of Québec it costs approximately \$70,000 a year for every institutionalized person. It is now known that services provided systematically at an early age to all autistic children would considerably reduce the cases which would need to be institutionalized. The dignity of autistic persons cannot be measured in dollars, but in the possibilities given to each one to develop to his full potential so that he or she may be able to contribute to society.

## Another example of success

In April and May 2000, TVA's sports reporter, Guy Bolduc, and his friend Noël Burlon crossed North America on bicycle to familiarize the public and the government with the lack of resources for children suffering from severe communication problems. The 2000 Dumont Odyssey, a trek of more than 6,000 km from San Diego to Québec, succeeded in raising \$40,000 in donations and from the sale of promotional articles.

When he was 18 months old, Marc-Antoine, Guy Bolduc's son, exhibited worrying signs. He did not speak, had a wandering look and showed no signs of affection. The doctors reported a slight delay, but Guy was not convinced. After some research, he came to the conclusion that his son could be autistic. In effect, after consulting several specialists, Marc-Antoine was diagnosed as autistic at the age of two.

Guy and Sylvie, Marc-Antoine's mother, then decided to do everything to pull their child out of his black hole. After attending a daycare centre with an educator for three three-hour periods a week, Marc-Antoine started pre-kindergarten in January 2001. Every day, for 15 to 30 minutes, the child worked on his stimulation with exercises. The parents followed the Zelazo method and even adopted a gluten-free diet. Marc-Antoine's admission to the regular kindergarten this year is a major victory for him and for his parents, a victory that was the result of determination and constant efforts. Today, Marc-Antoine has emerged from his bubble. He is communicating better with people, can count, knows his letters and can read words. The child who could only say two words in June 2000 now has a vocabulary of several thousand. A real explosion!

## [www.autisme.qc.ca](http://www.autisme.qc.ca)

Almost 7000 different visitors and 90,000 pages consulted during November

The popularity of the Federation's Web site and of its discussion panel is increasing incessantly. The month of November has broken all records of hits with a total of 6,633 different visitors. Our statistics also show that, in the month, there were 10,424 hits (i.e. 1,57 per visitor) and more than 89,793 pages consulted. Since the site was launched in October 2001, it has been consulted by people from more than 50 countries.



*Many parents met for a festive evening in a Montreal restaurant last September.*

More and more parents, intervening parties and even students, who formerly merely read the text on the discussion panel, have recently entered the fray, sharing their questions, viewpoints and valuable advice with the entire community. At the suggestion of a few parents, several assiduous visitors to the forum agreed to meet in a Montreal restaurant on Saturday, September 21<sup>st</sup>. The evening, that for once was not just virtual, was an occasion to discuss in a friendly atmosphere and to discover the faces that went with the names. Will there be another meeting soon? We wish to thank one and all for your constant attention and your valuable support

## Abitibi-Témiscamingue

# A socio-dynamic approach to integration through art

## When art becomes a factor in social integration

By Sébastien Boulanger

For several months, a small group of young autistic adults from the Abitibi-Témiscamingue region have been enjoying an original experience in social integration thanks to a special approach known as a *socio-dynamic approach to integration through art*. A few young people between 21 and 35 years of age are currently working on the recording of a music CD, and a roving painting exhibition is already in the planning stage. Developed by Mohamed Ghoul and offered by the Percu-en-Arts artistic expression centre which he directs, this approach is part of a broader program of socio-cultural integration coordinated by the regional autism society of Abitibi-Témiscamingue (SARAT) and the La Maison de Rouyn-Noranda rehabilitation centre.

The idea for such a project had been germinating for some time, following a succession of fortuitous meetings. In 1998, on an invitation by the La Maison centre, Mrs Doris Dubé, SARAT coordinator, went to France and met Mohamed Ghoul, a musician and educator for a group of centres for autistic individuals in the Paris region. At the time, Mohamed was collaborating with Turbulence, an ensemble composed of young autistic persons, with whom he did some theatrical work. His experience in France with the autistic world, led him to come across a number of people, including the American psychologist Howard Buten who had devised therapeutic methods for autism and who was the author of several books including *Quand j'avais cinq ans, je m'ai tué (When I was five years old, I killed myself)*. Interested parties in Québec then invited Mohamed to come and establish percussion centres in Abitibi, where he finally settled down in January 2001. In collaboration with SARAT and with Raymonde Gagnon, educator, and the coordinator of autism services, Ronald Huard, both from the La Mai-



son rehabilitation Centre, the project was developed.

This program which is unique in the province of Québec is a work of synthesis involving several fields of intervention. It brings together music, painting, leisure activities of all kinds and traditional rehabilitation services such as speech therapy, psychomotor skills, psychology and therapy through music. Lasting four days a week, the program schedules these activities more or less strictly, allowing room for and encouraging spontaneity, change and communication. The program is usually continued at home with parents beyond the number of hours at the centre.

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***The objective of the artistic integration workshops is to give people with a handicap a sense of autonomy, of competence, of success and of self-realization.***

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According to Doris Dubé, whose 21-year old son, Joffrey, participates in the program, "It is above all a way of creating bonds between pa-

rents, intervening parties and autistic persons and to understand the sense of their language. The atmosphere created by the program is just as important as the range of activities offered. The more we understand, the more we give them the tools to express themselves. Autistic people communicate a lot, but their method is not adequate. It takes people who know how to listen and who try to understand these persons”, she says.

Art represents an important part of the overall program, with about fifteen hours a week devoted to workshops. “The objective of the artistic integration workshops is to give people with a handicap a sense of autonomy, of competence, of success and of self-realization” explains Mohamed. “We hope to lessen the frequency of adverse behavior, to increase the ability to tolerate change and frustration and especially to improve the social skills of autistic persons.”

With his workshops on percussion, painting, singing, written composition and oral creativity, the socio-dynamic approach to integration through art recommended by Percu-en-Arts allows musicians to interiorize and integrate values, to accept social norms and regulations. The musical instruments, particularly the African djamba, take on a mediating role among participants and allow the group to interact thanks to an original means of artistic communication. The structure provides these young musicians with a reassuring framework facilitating their acceptance of new people in their group, who, in turn, will accept others.

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***The idea is definitely not to create closure. The approach requires the participation of society as a whole, making it aware of differences and promoting interaction.***

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Mohamed declares: “Nothing is ever rigid and spontaneity is very important, even during the shows given by these young people. We do not want to incite too much change, but autistic persons who participate in our workshops nevertheless experience a lot of change. We are open to the outside world and our aim is definitely not to recreate closure. Our approach requires the participation of society as a whole, making it aware of differences and promoting interaction. For example, our rooms are located in an open area, in a downtown building where several other organizations have their offices. This allows us, for example, to invite musicians

who may not know the autistic persons, and even to have parents participate. The golden rule is: You come into the room, you take an instrument and you play. A *sine qua non* condition is participation and close contact with the young people.

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**By tackling head-on the development of social skills, communication, imagination, this method multiplies exponentially the learning possibilities.**

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Along with our art workshops, young people are offered rehabilitation services including speech therapy and exercises for the development of psychomotor skills. There are also communication workshops provided by the La Maison rehabilitation centre. “Mohamed’s project fits in perfectly with our approach”, explains Doris. In addition to the art workshops and the classic rehabilitation services offered by La Maison, the program proposes, through SARAT, a full range of leisure activities, such as visits to animal shelters and to amusement parks, handicrafts, bowling on Friday afternoon, and even 5 to 7 parties with parents a few times a year. “These activities are tools for the development of communication”, says Doris.

By tackling head-on the development of social skills, communication, imagination, this method multiplies exponentially the learning possibilities. “Music and performing put the young people in positions where they are admired. Art provides an opening on to the world and allows autistic individuals to develop self-confidence that they would not gain through other activities”, states Doris. Thus, music has allowed her son Joffrey to attempt things which he had renounced until then, and to evolve in an extraordinary fashion in areas of communication and social interactions.

After having given several public concerts to very favourable reactions from parents and other interested parties, the group, recently given the name of La Bohème, is preparing an album which should be released in the spring of 2003. The group is supported by Yves Mercier, a musician who masters several instruments, and who assists by putting his studio at the disposal of the young people. Mohamed hopes to bring the group to France for a performance and to invite a group of young autistic artists from France to perform in Québec. A painting exhibition organized with the collaboration of painter Luc Lafrenière is to be inaugurated at the same

time as the launching of the album. The exhibition is expected to travel to a few cities in the province, probably during the summer or autumn of 2003.

Although it needs to be synthesized, the program developed by Mohamed Ghouli and by the SARAT staff and the La Maison rehabilitation centre looks promising. "We had thought that we would achieve something of interest in 5 years...But in only 1 year and a half, we are already working in the art field 15 hours a week and everything is progressing well. It's unbelievable how things are advancing here" states Mohamed. "We are open to a lot of things", he adds. In fact a document involving all those concerned in any way is being produced under the direction of Etienne Rouleau, producer of videos. Furthermore, a research project to be conducted with the Unité d'enseignement et de recherche en développement humain et social (Teaching and research unit on human and social development) from the Université du Québec in Abitibi-Témiscamingue has just been authorized. The object of the research is to verify the hypotheses and results of the program by scientific measurements.

"We needed to prove that our approach works, to demonstrate the potential for learning and the ability to relate to autistic persons", declares Doris Dubé. "Furthermore, we believe that this type of program could be exported to the rest of Québec where other autistic persons need it and to other kinds of clientele. We put great emphasis on the quality of life of autistic persons and on their finding a place in society. We would like to try this experience with pre-teenagers before they reach the critical stage of adolescence."

*For further information, for training workshops\**, to reserve the album or simply to visit the site, you can reach Mohamed Ghouli by phone at (819) 797-0953, extension 1, or by e-mail at the following address: To receive documentation on the program in its entirety, phone SARAT at (819) 762-6592, extension 7230.

## A communiqué from the Québec Federation of Rehabilitation centres for intellectual deficiency

A crying need in the matter of autism!

**Longueuil, December 11, 2002.** Even though the plan issued by the Ministry of Health and Social Services *Pour faire les bons choix (To make the proper choices)* by François Legault recognizes the needs of those with autism or pervasive development disorders, and that an investment of 40M\$ is to be provided for this sector, in the short term, the **addition of financial resources from the Ministry of Health and Social Services is absolutely necessary.**

At the present time, in order to fulfill the needs with regard to autism, the public network of rehabilitation centres for intellectual deficiency, (Centres de réadaptation en déficience intellectuelle - CRDI) responsible for offering specialized services to autistic persons or those with other pervasive development disorders have only been able to count on an investment of 2M\$ for the year 2002. An amount of 2M\$ is also budgeted for the year 2003.

Even if 1,600 persons are already being served by these centres, 500 persons with autism or other pervasive development disorders are still waiting for services. This lack of services has important consequences on their development and on their ability to be integrated in the community. Recent research and studies conducted on autism and other pervasive development disorders provide a clear indication that it is necessary to act as early as possible in the life of an autistic child and that the time devoted to treatment is of prime importance. In this regard, last October, the Fédération québécoise des Centres de réadaptation en déficience intellectuelle submitted a brief to the Ministry of Health and Social Services outlining the organization of services offered for persons with autism or other pervasive development disorders.

In spite of all their efforts to increase services to those with autism or other pervasive development disorders, and to improve accessibility to services for those suffering from intellectual deficiencies, the rehabilitation centres are unable to respond to the different requests for services with the budgets they have at present.

Source: France Pomerleau, Communication Consultant (450 646-7540 extension 224)

\* For organizations mandated to look after handicapped persons or those experiencing problems in social integration.

## ***Class action: The Federation supports the steps taken by parents***

*By Lucille Bargiel*

In the spring of the year 2000, a group of parents took legal action against the government of the Province of Québec and its implicated organizations to obtain for all children with autism or pervasive development disorders, free of charge, the intensive early stimulation services to which they are entitled. At a press conference held in Montreal last October 21<sup>st</sup>, representatives of the parents involved in this class action stated that they had received the support of the Québec Commission on Human Rights and on the Rights of Youth (Commission des droits de la personne et des droits de la jeunesse). During this press conference, the attorney for the families, Jean-Pierre Ménard, pointed out the interest raised by a recent decision rendered by the Court of Appeals of British Columbia. In a suit similar to the one submitted here, the Appeals Court of British Columbia concluded that the government of that province had violated the Canadian Charter of Rights and Freedoms by refusing to offer on a universal and free basis intensive early stimulation services to autistic children.

You will find below a text by Lucille Bargiel reiterating the backing of the Federation for parents and their undertakings. You will find the complete file on the class action in the Federation's Web site in the *Communiqués* section, or in the section on recourse at the following address: <http://beaudincom.com/autisme>.

On behalf of the Fédération québécoise de l'autisme et des autres troubles envahissants du développement (Québec Federation on Autism and other Pervasive Development Disorders) I reiterate that this organization is backing the parents who are claiming for their children intensive early stimulation services and who have taken a class action for this purpose.

For more than 25 years, until recently under the name of *Société québécoise de l'autisme (Québec Autism Society)*, the Federation has been working for recognition of the needs of autistic persons and their families. It has been requesting for a long time stimulation services for the children, with the conviction that such services would have a tremendous impact on the future of these children and on the long-term reduction of the social costs caused by autism.

It is high time that these children get the help they need, so that they are not compelled to join the many who preceded them and who were deprived of the appropriate rehabilitation and schooling, forcing their families to fulfill, with little or no assistance, the requirements of their education. At the present time, many of these persons, still without services, have had to be hospitalized due to the lack of special residences and daytime activities, and are often kept under physical and chemical restraints because of the absence of the proper approaches for their particularities. Their families continue to be exhausted while trying to get help and live in fear of the future, not knowing what will happen to their sons or daughters.

Over the course of the last quarter century, the Federation has defended in every way possible the interests of autistic persons and their families, demanding stimulation, education and rehabilitation

services as well the necessary support for families in distress, for parents as well as brothers and sisters. That is why it is joining the parents who have got together to take a class action with a view to ensuring a better future for their children.



*Representatives of families at the press conference held in Montréal last October.*

Members of the Federation are anxiously waiting for concrete action on the part of the Ministry of Health and Social Services following the submission last February of the report from the provincial consulting committee on autism. This time, we expect from the government more than guidelines and recommendations: we are pressing it to establish without delay a plan of action for persons with autism or with other pervasive development disorders and for their families, together with the necessary financial resources to really make a difference.

# AN APPEAL TO ALL!

## Survey on the reactions to vaccination

Editor's Note: For the purpose of providing research material on the possible side effects of vaccination and the potential for triggering autism, Autisme et troubles envahissants du développement Montréal (ATEDM) (Montreal Society on Autism and Pervasive Development Disorders) wishes to prepare a file on the provincial scale on this subject. In order to do this, we are asking parents to answer the survey below if they have observed any noticeable changes in the health (digestive problems, diarrhea, infections, etc) or the behavior of their child in the days or weeks following vaccination. Your testimony will be treated in full confidentiality. Several parents have already shared their experiences with us and we hope to be able to make a more accurate compilation of affected children and the symptoms observed.

Thank you for your collaboration.

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1.1 Sex of the child: \_\_\_\_\_

1.2 Date of birth of the child: \_\_\_\_\_

1.3 Diagnosis received: \_\_\_\_\_

1.4 Did your child have a period of normal development? \_\_\_\_\_

If so, until what age? \_\_\_\_\_

2.1 Did your child receive all the vaccinations recommended by the public health system? \_\_\_\_\_

2.2 Did you note any reactions following any of these vaccinations? \_\_\_\_\_

2.3 Do you know the name of the vaccine or vaccines that caused a reaction?

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2.4 How old was your child when the vaccine or vaccines was (were) administered? \_\_\_\_\_

2.5 How long after vaccination did you note any reactions? (Hours, days, weeks) \_\_\_\_\_

2.6 City/Province/Country in which your child was vaccinated:

---

3.1 Describe the physical symptoms observed after the vaccination (redness or swelling at the injection site, fever, diarrhea, constipation, vomiting, red cheeks or ears, excessive tears, epileptic seizure, etc.);

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3.2 Did your child have gastro-enteritis before his or her loss of skills? \_\_\_\_\_

3.3 Did your child have any other viral sicknesses that you think may be consecutive to the vaccine (ear infections, bronchitis, asthma, pneumonia, etc.)? Which ones?

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4.1 Describe any changes observed in the child's behavior following the vaccine, balance, mood swings, sleep problems, auto-mutilation, aggression, diminished social or neuro-sensorial skills, etc.):

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4.2 Did your child exhibit a sudden loss of language skills after vaccination (ex.: a child who speaks normally at the age of 18 months, suddenly stops talking)? \_\_\_\_\_

5.1 Physical symptoms currently exhibited by your child that are a source of concern :

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5.2 Behavior problems that are a source of concern:

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6.1 Did the father or the mother receive dental treatments: replacement, application or polishing of amalgams\* in the 3-month period before pregnancy. Describe:

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6.2 Did the mother have dental amalgams\*? \_\_\_\_\_

6.3 Does one of the parents work in a dental clinic? \_\_\_\_\_

7.1 Was the mother vaccinated during her pregnancy? \_\_\_\_\_

7.2 Was the mother vaccinated during the year that preceded her pregnancy? \_\_\_\_\_

8. Are there any disorders of an auto-immune type in the families of the parents (Asthma, allergies, multiple sclerosis, lupus, chronic fatigue, Crohn's disease, etc.)?

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9.1 Postal code (optional) \_\_\_\_\_

9.2 If you would like us to communicate with you for other studies or endeavours, please include your coordinates (optional)

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Telephone: \_\_\_\_\_ E-Mail: \_\_\_\_\_

Thank you for completing this form. The information obtained will be used only for statistical purposes.- Confidentiality assured.

Autisme et troubles envahissants du développement Montréal

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\* Alloy of mercury and other metals. Amalgam or silver and tin for fillings.

# Bring the **child** back to the centre of our concerns

By Jean-Marie Berthelot, president of *Autisme et Troubles envahissants du développement Outaouais (Autism and Pervasive Development Disorders for the Ottawa region)*

*Editor's Note: With this letter, the author comments on a controversy that took place in the Ottawa region. The newspaper, Le Droit, had reported on an incident involving an autistic child in a school. There had been an altercation with another student, in which an educator intervened, then filed a complaint about violence resulting in the suspension of the autistic child. The following letter attempts to calm things down while affording some support to the mother of the autistic child.*

Source: *Le Droit*, in the issue of Monday, November 18, 2002, p. 17

It is with sadness that I read in the *Droit* of November 9 the story about a young autistic person from Gatineau who was expelled from the Carrefour school and who is threatened with criminal procedures resulting from alleged violent behavior during a conflict.

I, myself, have an autistic boy and, although he is not violent, he could find himself in a similar situation. The article describes an unfortunate situation which often confronts autistic children: persecution by other children because of their difference, as well as a lack of support adapted to their needs. Autistic children are very sensitive to insults and abusive behavior, and for many of them verbal violence hurts more than physical violence. In such situations, the autistic child is always the loser.

Autism and pervasive development disorders are neurological illnesses (and not mental illnesses) with serious effects on the child's development particularly on their communication and social skills.

## Viewed as eccentric and odd

These children are generally viewed as eccentric and odd by their schoolmates. Their social ineptness often makes them scapegoats. They lack a comprehension of human relations and of the rules and conventions of socializing. They are often rigid, due to problems in managing change. All this makes them anxious and vulnerable. However, violent behavior is not part of the disorder, but is a manner of expressing the child's inability to control an environment in which the stress level is too intense.

## What to do?

To begin with, it is important to bring the child back to the centre of the preoccupations of all the intervening parties, to ensure a positive evolution of any situation. There has to be a setting that meets the needs of an autistic child.

These needs differ from those of a child with mental retardation or behavioral problems. First of all, the school must protect the child and refuse to tolerate any ridicule on the part of his peers. No school must allow a handicapped child to be harassed or ridiculed; respect of human dignity must be instilled.

Other pupils must be taught what autism is and empathy and tolerance must be promoted. People must work with the autistic child in order to help him manage his stress and eliminate violent reactions. Contrary to the general stereotype, many autistic children want friends, but do not know how to interact. They must therefore be taught to react to social indications.

It is possible to provide a proper setting for autistic children in order to ensure that situations such as this are not repeated.

If the school does not have resources that are thoroughly familiar with autism

and therefore able to counter such situations, there is a specialist at the Ottawa regional office of the Department of Education who is responsible for facilitating the integration of autistic children into the school system.

Furthermore, specialized resources from the private sector can help schools and school boards establish a framework that is appropriate for the needs of autistic children. At the elementary level, a class for autistic children already exists at the Dôme school in Hull. Those involved in the field of education in the Ottawa region should study the possibility of establishing special programs for autistic children at the high school level. These already exist in some areas of Québec with some success.

I would like to repeat the essential point: never lose sight of the well-being of the child.

# Politics and Research

*A synthesis with comments by Marie-Christine Destison*

*“NO SECRET CAN RESIST TIME”,  
JEAN RACINE*

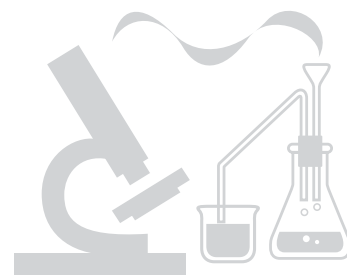
## ► **United States, August 2002**

SCANDAL: At a press conference, the **firm of attorneys Waters and Kraus**, the main instigators of a lawsuit relative to the presence of thimerosal in vaccines and the associated neurological problems that could trigger autism, revealed some news that fell like a bombshell on the pharmaceutical industry and government health institutions: Eli Lilly, one of the world leaders in the field of pharmaceuticals, apparently was aware of the dangers that could result from the presence of thimerosal in vaccines, as early as in the 1930s. Waters and Kraus also revealed that the Centers for Disease Control and Prevention (CDC) had hidden critical pieces of evidence in this regard from the Institute of Medicine (IOM). These revelations were made in the course of the lawsuit and would never have been made public if the ongoing judicial inquiries had not been undertaken.

This evidence consists of a confidential report, which was **never published**, produced by the CDC, that considers autism as a neurological disorder possibly caused by the mercury found in pediatric vaccines. A different version of the report was published and cited by the IOM as an inconclusive study relative to the fact that thimerosal may have contributed to the national epidemic of regressive autism and other neurological disorders in children (an epidemic which is now acknowledged: see section below).

The confidential version shows clearly that exposure to more than 62.5 micrograms of mercury during the first three months of life results in a significant increase in the risk of developing infantile autism. To be more precise, the study shows a risk which is two and a half times greater for children exposed to this source of mercury than for children who have not been exposed.

Remember that in the United States, the courts have generally admitted that a risk multiplied by 2 and more is sufficient to consider that such exposure be considered as a cause of sickness. In the case of *Cook vs US* 545 F. Supp. 306 at 308 (Northern District California 1982), the Court stated: “in the case of a vaccine, a relative risk greater than twice establishes that there is a



greater than 50% chance of damage being provoked by the vaccine.”

The confidential report obtained by the Safe Minds association specifies: “For exposure assessed at the age of three months, we have found increased risks of neurological development problems relating to numerous cumulative exposures to thimerosal within the group of “pervasive development disorders” for the sub-group labelled “particular delays” and within this sub-group for specific problems such as “language disorders”, “stuttering”, “autism”, and “attention deficit disorders”.

These facts are shocking but not surprising when we take into account the political influence wielded by pharmaceutical giants and the tremendous responsibility which would fall on them if they were forced to compensate thousands of families.

Subsequent to these revelations, senator Dan Burton, the grandfather of an autistic child and head of the Government Reform Committee, has claimed indemnities under criminal law from government officials who hid the danger of mercury in vaccines.

A hypocritical and disguised response is found in **the new Homeland Security Bill, HR 5710**, more commonly known as the Frist Bill after its main author. Through a last-minute amendment, which was not debated in the assembly, it aims to immunize retroactively (i.e. the ongoing lawsuits would be null) the pharmaceutical industry from any lawsuit in order, supposedly, to give its members a free hand in the fabrication of all vaccines or antidotes against chemical weapons. This bill passed before the Senate on the 19<sup>th</sup> of November, but many Republican and more especially Democrat senators, who had been made aware of the problem and who had received more than 50,000 messages from the parents of autistic children, have become active in an effort to have this amendment revised next January.

Can anyone tell me how the bio-terrorism alluded to in this bill is in any way related to the right of parents to sue makers of vaccines who are

fully aware that their products are contentious and responsible for neurological disorders in children? Once again the power of money and economic interests supersedes the rights of man.

As a matter of interest, former president Bush was, during the 70s, a member of the Board of Directors of Eli Lilly; Mitchell Daniels who is a member of the committee that worked on the new Homeland Security Law was vice-president, strategy and policies, for Eli Lilly. As for Mr. Rumsfeld, he was chief of Searle Pharmaceuticals, also involved in the Bush administration, and there are also of course a great number of lobbyists from the pharmaceutical industry. The most recent data from the Center for Responsive Politics indicate that Eli Lilly provided more financing than any other pharmaceutical firm, in the amount of approximately 1.26M\$, to Republican congressional candidates.

On November 22, Senator Burton, in a letter to president Bush, requested that a conference on autism be held at the White House.

## ► **October 22**

### **An expert on vaccines comments on the uselessness of studies**

Dr Thomas Jefferson, whose work on the safety of vaccines was financed by the European Commission, states that the problem raised is treated like a poor relation by public health systems and that government authorities have never given it any priority. Dr Jefferson is the head of the vaccination department of Cochrane Collaboration, an organization made up of scientists whose aim is to provide true and accurate information on the effects of treatments available throughout the world and to promote the highest standards of quality in the research community. He is also a member of the European program's committee for better monitoring of vaccine safety.

Dr Jefferson states: "There are some good research papers but they are submerged in a sea of faulty ones. The public has been abandoned and is not aware that appropriate studies are not being conducted." Concretely, with regard to the MMR vaccine, only 20 studies out of 3,500 are capable of helping determine whether this vaccine contributes to the development of certain conditions, including autism.

Even though Jefferson suggests that there is no proof to affirm that any vaccine in current use is dangerous, he insists that there is a lack of efficacious studies on the risks and on the advantages of these vaccines. The objectives

and the criteria used in the research on the safety of vaccines are open to serious criticism.

<http://www.telegraph.co.uk/news/main.jhtml?xml=/news/2002/10/27/nvacc27.xml&>

### **Study by the University of California: the autistic epidemic is real**

A team of researchers from the University of California, under the leadership by Dr Robert Byrd, confirms that there is a dramatic increase in the number of autistic persons in California. The numbers tripled over the last 15 years. The factors leading to this increase are unknown but, **the argument which has often been advanced that the disorder is better recognized, has definitely been swept aside in this study.** Dr Byrd declares that it has become urgent to look for the causes, including the possible involvement of the MMR triple vaccine. Concerning vaccines and thimerosal, Byrd is pleased that last year the addition of a small quantity of mercury as a conservation agent was forbidden (mercury was used since the beginning of the 90s) in the vaccine against hepatitis B. He adds: **"combining any dangerous toxin to a product that is supposed to be beneficial is a bad mix."**

Below is an extract from the written reaction of Dr Martha Hebert, pediatric neurologist at the Massachusetts General Hospital and at the Harvard Medical University, member of the Council for Responsible Genetics:

"In the field of research on autism, we must reconsider the emphasis we have put on genetics. As Dr Byrd has stated: Genes do not provoke epidemics. Dollars flow for genetic research in order to find the causative genes, but the only effective treatments today are those involving intensive reeducation. This new study is a strong indication that other factors are involved, because stated simply, the human genome does not change this quickly. Where and when can such a change occur so rapidly? Only in the environment. Environmental influences include chemical products, metals, vaccines and viruses. Since the genes that affect the brain also affect the body, environmental triggers would also have an effect on these two systems. In fact the behavioral disorder that defines autism is often accompanied by intestinal disorders, problems with the immune system and other ailments.

We must focus our attention and our budgets on research on the environment, not only on genes. Failure to do so will lead to a great number of new epidemics of unexplained disorders...

Extract from the reaction of senator **Hillary Clinton** to this research:

"Today, chronic sicknesses like autism, cancer, asthma, Parkinson's, Alzheimer and diabetes affect more than a third of the American public and cost our country more than 325 billion dollars a year... To reverse this trend, we must find a way of tracking down the causes of these sicknesses and identifying the environmental factors that may be contributing to their existence..."

Letter published in the readers' column of the October 29, 2002 issue of the Schafer Autism Report.

## November 2002

### ► The Danish study

A Danish study on epidemiology provides strong evidence against the hypothesis of a link between the MMR vaccine and autism (NEJM vol. 347, November 7, 2002, no 19).

There have been many responses including those of Sally Bernard (Safe Minds), Dr Ed Yazbak and Dr Wakefield:

#### **Sally Bernard Executive Director Safe Minds**

Safe Minds emphasizes that other vaccines besides the MMR could be involved in the cause of autism and that only **biological studies and not epidemiologic ones** can provide answers.

Sally Bernard declares: "It is important to note that the Danish study covers only the MMR vaccine and not other vaccines containing thimerosal also targeted in autism. The possible interaction between the MMR vaccine and others was not tackled; the study did not distinguish between the cases of regressive autism which may be linked to MMR and the cases of autism acquired at birth linked to thimerosal."

Mrs Bernard reminds us that thimerosal contains 50% of ethyl of mercury and has been used in most pediatric vaccines like DTP (diphtheria, tetanus, polio), the flu vaccine and the hepatitis B vaccine. Concrete researches have indicated that exposure to mercury *in utero* and during the first months of life (the time when these vaccines are administered) may cause the immune system to dysfunction, predisposing a child to viral infections. It is biologically possible and plausible that this dysfunctional immune system could allow the live portion of the measles virus in the MMR vaccine to persist in children who are susceptible to becoming autistic, making the

symptoms of the disease much worse. This connection can in no way be detected by an epidemiological study like the Danish one. "However, says Mrs Bernard, these faulty conclusions should not mask the important discoveries brought to light by the vast well-planned Danish analysis. The authors report an increase in the prevalence of autism in their country and therefore confirm the trend observed in other recent studies. This increase is an indication that the environmental factors prevail throughout the world. Considering that the vaccination policy in Denmark uses a lesser exposure to thimerosal, it is normal that the prevalence of autism is also less than in the United States, which reinforces the hypothesis of a link with thimerosal."

#### **Edward Yazbak MD, FAAP, TL Autism Research, Falmouth MA**

In a response that you can read in its entirety on the following Web site Dr Yazbak, who was present in Québec in 2001 at our conference, expounds on the various conflicts of interest that prevail in all research financed by the pharmaceutical industry or by government health authorities, who have no interest in bringing changes to the current policy in this field... He states: "Special pathological findings in the intestines, the evidence of the measles virus strain from the vaccine, a high rate of IAG and urinary polypeptides, as well as the presence of anti-myeline antibodies represent discoveries that are both objective and of crucial importance. Honest scientific studies that are completely unbiased and that effectively EXAMINE the children and study the biological, cellular, molecular, toxic and immune aspects are urgently needed. Talking to parents is also an excellent idea! Finally, only this type of study is worth the money required."

#### **Andrew Wakefield MD**

The letter which you can read in its entirety in the attached link is extremely scientific, Fortunately so! What is important for us as parents, is that it is consistent with our previous reactions, that is that this new epidemiologic study, like earlier ones, is inadequate for evaluating the problem raised by Dr Wakefield's team that addressed NEJM. He concludes that the foundation of his hypothesis has not been shaken nor has it changed in any way; briefly, he says: Examine the children and stop congratulating yourselves with these useless and costly studies...

[www.freewebz.com/schafer/wakefield.htm](http://www.freewebz.com/schafer/wakefield.htm)

## Development of a medical protocol

A biological study by Harvard University and the Massachusetts General Hospital in collaboration with Oregon through the Northwest Autism Foundation has been announced.

These three partners aim to develop a medical protocol for the treatment of autism. They have already made important medical observations, having treated more than 600 children suffering from autism. Although autism has reached epidemic proportions affecting more than 600,000 children in the United States and millions of others throughout the world, the medical community is lacking important scientific data for the medical treatment of these children. Without this research, autism will continue to be viewed and treated solely as a neurological dysfunction.

Tragically, the untreated victims will continue to suffer from serious biological ailments. This research is to be noted because it is the first major undertaking with the goal of establishing a medical basis for the treatment of autism. Dr Tim Buie, a pediatric gastro-enterologist and a member of this team, has already conducted more than 500 gastro-intestinal endoscopic examinations with biopsies. More than half the children examined in this manner had gastro-intestinal disorders that were treatable and that ranged from moderate to grave, including oesophagitis, gastritis, entero-colitis with nodular lymphoid hyperplasia. Dr Buie is echoing numerous other clinical observations made by researchers and practitioners who have treated autistic patients (does the name of *Dr Wakefield* come to mind?)

He states: "These children are sick, in great distress and suffering; they are not merely mentally and neurologically dysfunctional." Dr Buie has successfully treated his patients by administering enzymes and probiotics which appeared to be lacking. The results showed great improvement in the condition of these children. Had the gastro-intestinal problems been ignored and not treated, the physical behavior and other symptoms associated with autism would have been exacerbated.

In conclusion, Dr Buie thinks that a number of symptoms such as auto-mutilation, head banging, sudden unexplained tantrums, abnormal sleep cycles, nighttime waking, are in fact symptoms of pain that the child is unable to express verbally. An important feature of this study is to propose the establishment of a network of centres of excellence within medical universities for the treatment of autistic individuals. These centres would be linked

together as a consortium that would gather all the data and statistics from the research.

Among the recommendations following the initial phase of this study, I especially recall this one, which I am dedicating, as a conclusion, to the Québec physicians and more particularly to the pediatric gastro-enterologists from the CHUL whom I contacted two years ago. (They will probably be more attentive now because of the prestige of the authors of this new study than they were to my unimportant person!). These doctors acknowledged that they had two autistic patients whose medical examinations produced results that were problematic.

"We must educate more than the families concerning these gastro-intestinal problems; we must educate the professional community and involve them in the whole treatment process and in the special care for these children."

[www.autismnwaf.com/harvardproject2.htm](http://www.autismnwaf.com/harvardproject2.htm)

**Fédération québécoise de l'autisme et des autres  
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