

Express

A Quebec Federation for Autism
and other Pervasive Development Disorders

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- ▶ *The most recent **DAN conference** held in San Diego in October 2001*
- ▶ *An in-depth look at the **Wakefield** controversy*
- ▶ ***FILE:** A comparison of **educational methods***

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The Québec Federation on Autism and
Other Pervasive Development Disorders
(formerly Quebec Society for Autism)
was founded in 1976. It encompasses
14 regional associations and has more
than one thousand members. For infor-
mation on the association in your area,
consult our Web site or dial (514) 270-
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Visit our web site :
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A new name, a mission to bring people together

It has been official since the start of the year 2002: the Québec Autism Society has become the Québec Federation for Autism and Other Pervasive Development Disorders.

This change is an important step in the reorganization process that was adopted at the annual general meeting held last June. It is to be remembered that in 1998, the Association, together with the regional societies, had initiated a brainstorming process to redefine their respective roles. For example, **by consensus**, we agreed on each one's roles: notably, the leadership and assembler role for the Society and the role of dispenser of direct services for the regions.

The **Québec Federation for Autism and Other Pervasive Development Disorders** now considers itself a group of organizations with a common mission to defend the rights and interests of autistic persons, of those suffering from pervasive development disorders and their families. Individual members will now be members of the Federation through their regional organization, since membership status is now attributed to these organizations.

Even though a person is first of all a member of a regional association, it goes without saying that we will continue to respond to all requests for information that may be addressed to us on a daily basis.

The Federation is committed to pursue its important roles: coordinating provincial undertakings; backing regional associations; making autism known by organizing familiarization, information and training programs and by promoting the integration of autistic persons.

Please do not hesitate to communicate with us at any time.

Director General, Jo-Ann Lauzon

Editorial

By Jean-Claude Marion

Attacks, indictments, conflicting strategies, these are just a few of the words that describe the climate of the more or less elegant controversy that prevails in the world of autism as we go to press. We have just witnessed the dismissal for “a dissident view” of a respected researcher in the person of Dr Wakefield who was asked to leave the Royal Free Hospital in London after thirteen years of good and loyal services. His fault: raising the question of a possible link between the triggering of autism and the MMR vaccine (vaccination against measles, rubella and mumps). We do not propose to pass judgment on Dr Wakefield nor to dwell on the ups and downs of his career¹, which in our opinion should continue to be brilliant, although it will be pursued in different climes. What we hope to do here, and it is very important, is to reflect on what this doctor’s work has brought to light.

Listening to the complaints of parents who noted that after MMR vaccination, their children demonstrated regression simultaneously with intestinal problems, Dr Wakefield initiated a response which is all too rare. He **listened** to parents, treated them as **essential partners** and concluded that their judgment merited investigation. His discovery of symptoms of intestinal inflammation, unknown until then, and the finding that the measles virus was present in infected tissues, merited, at the very least, that questions be asked and that the scientific community be alerted. The link between vaccination and autism has not been scientifically established. It has only been questioned. We do not wish to enter into this debate with its countless traps, but simply to state that the steps taken are good and worthy of serving as an example! In our opinion, humility, open-mindedness, the quality of listening without demagoguery could only serve the cause of autism.

This leads us to question the innocuousness of vaccinations in general. These should, we think, be removed from financial monopolies and be subjected to stricter controls. Nobody can deny the important breakthrough vaccinations have had in the fight against contagious diseases. It would be wise, however, to verify their harmlessness over longer periods than those that are standard today. Side effects cannot always be detected within a few weeks. A genetic predisposition may lead to a longer and more insidious period of regression, spreading out over several months. Furthermore, the mercury-based preservatives, such as thimerosal, even though they are now being replaced, should be absolutely banned. The “secret” study of the CDC (consult following pages) on the negative effects of mercury in the triggering of symptoms of autism is revealing.

To conclude on a more positive note, it has been proved scientifically that educational methods (and more specifically, behavioural methods like ABA²) give very encouraging results. Their uncontested recognition by the scientific community is sufficient reason for giving you the opportunity to see, in a synthetic chart appearing in the following pages, the characteristics of the various educational interventions that could help your child. And their effectiveness also gives more than a glimmer of hope.

¹ You can form a better opinion on the debate by reading the reactions, testimonies, new, disturbing or contradictory studies in the pages that follow.

² A recent study has confirmed these facts. It proved that children between the ages of 4 and 7 who received, either at home or in school, intensive early ABA-type stimulation (28 hours a week) for a year, showed very appreciable progress which could not be contested scientifically.

The most recent DAN conference

*A summary from notes taken during the conference
by James Adams, father of an autistic child*

This summary is not to take the place of a doctor's opinion.

The most recent DAN conference took place from October 5 to 7 in San Diego, California. Many consider it to be the best of those held during recent years, undoubtedly because of the impression of coherence that was delivered by the different speakers. They definitely gave the impression that they have come to similar conclusions. We can see that a common vision of autism is forming and this should lead to a better understanding of the disorder and to increasingly effective treatments.

Opio-peptides

Dr Karl Reichelt's work deals with the role of **opio-peptides** in autism. The researcher has published a number of scientific articles dealing with the presence of unusual proteins and peptides in the urine of autistic persons. These proteins and peptides come from casein (milk products) and gluten (wheat and related grains). Their effects on the brain are similar to those of opium products and may even exceed the power of morphine. The peptides enter the blood stream because of two major biological defects:

- the inability of the digestive tract to digest or to completely decompose the casein or gluten molecules into amino acids;
- a porous intestine that allows undigested proteins or peptides to penetrate the blood stream.

The inability of the intestine to digest proteins properly seems to be due to a lack of peptidases (digestive enzymes) that may be caused, according to Dr Reichelt's hypothesis, to genetic deficiencies. Dr Cade, during research conducted in 1999, found antibodies (IgA) to gluten and to casein in the intestinal mucous membranes of 12 out of 44 autistic persons. These opio-peptides can lead to a number of behavioural and physical reactions and could be the cause of many autistic symptoms.

A two-year blind study led to the discovery that **the condition of autistic children improved when on a gluten and casein-free diet but regressed upon cessation of the diet**. In a recent research project conducted in 2001, DrCade succeeded in demonstrating that treatments with digestive enzymes can also be beneficial, but their effectiveness is inferior by 50% to the gluten and casein-free diet. He therefore recommends that all autistic persons try a gluten and casein-free diet.

Opio-peptides can lead to a number of behavioural and physical reactions and could be the cause of numerous autistic symptoms.

Briefly, gluten and casein, originating respectively in wheat and milk products, seem to create in autistic persons effects similar to opium-related substances. It is highly recommended that they try a diet that excludes gluten and casein.

Abnormal immune system

Dr Gupta tackles the subject of abnormalities in the immune system linked to autism. The immune system is essentially composed of T cells, B cells, and natural killing cells (NK). The T cells (or T lymphocytes) include TH1 cells (acting against viruses and fungi) and TH2 cells (immune and inflammatory reactions, production of antibodies).

In cases of autism, there is often a major change in the proportion of the normally well-balanced ratio of TH1 and TH2 cells: **fewer TH1 cells and more TH2**. The **reduction of TH1 cells** could explain the increased predisposition to **viral and fungal infections** seen in autistic persons. **An increase in TH2 cells** could explain the **increased auto-immunity**, as shown in his treatises on the discovery of antibodies against the basic protein (MBP) and against the neuronal filaments of the axon in the brain.

In autistic persons an increase in the tumour necrosis factor (TNF) is observed. This increase

could lead to a decrease in blood flow to the brain, to the loss of Purkinje cells (often noted in autopsies), to changes in neurotransmitters and neuro-peptides, and could provoke myelin damage similar to that observed in multiple sclerosis.

Even rudimentary methods were sufficient to demonstrate that very small concentrations (micromoles) of thimerosal (compound with mercury sometimes used as a preservative in vaccines) can lead to the destruction of cells.

The small proportion of TH1 cells could also explain the **intestinal porousness** associated with autism. This could be provoked by an increase in the number of viruses, that would cause a more rapid multiplication of lymphoid cells. These peculiarities, which were also noted in several cases by **Dr Wakefield**, could lead to the absorption of greater quantities of non-decomposed peptides, as observed by **Dr Reichelt** and others. A possible treatment for autism could therefore consist in an intravenous injection of immunoglobulin to neutralize bacteria and viruses and stimulate an attack by the phagocytes on bacteria and fungi.

Mercury could also play an important role in autism. It can, in fact, poison mitochondrions (the section of each cell that produces energy), distort DNA, alter the permeability of the membrane, leading to auto-immunity and causing cellular death. Even rudimentary methods were sufficient to demonstrate that very small concentrations (micromoles) of thimerosal (compound with mercury sometimes used as a preservative in vaccines) can lead to the destruction of cells.

To summarize, in cases of autism, a **major disturbance in the immune system** has been observed, rendering affected persons very susceptible to bacteria, fungi and viruses. This disruption could provoke an attack by the body through its own immune system (or auto-immunity). Mercury figures among the possible causes of this phenomenon.

Problems linked to sulphur

Substituting for **Dr Rosemarie Waring**, **Dr Susan Owens** presented her data on the role of sulfates in autism. It is recognized that autistic persons excrete in their urine about twice as many sulfates as others, leaving in their bodies only one fifth of the normal rate of sulphur, and it is known that sulphur is a mineral which is essential for several bodily functions.

A loss of sulphur has also been noted in the urine of AIDs patients, leading to a lack of sulfated extracellular structures in the brain. This phenomenon has not yet been studied in autistic persons, but it could be similar. In men suffering from AIDs, a treatment with N-acetyl cysteine has proved beneficial. In autism, the tumour necrosis factor (TNF) is high and could inhibit the conversion of cysteine to sulfate.

Low levels of sulphur may cause a number of problems.

- A lack of sulphur could explain the low level of oxytoxins, important for socialization, found in autistic persons. In fact, sulphur is necessary to sulfurize the CCK hormone which stimulates the oxytocynergic neurons to release oxytoxins.

Sulfates are important for detoxicating metals and other toxins.

- Sulfating requires activated sulphur, which in turn requires magnesium.
- Boys excrete more sulphur than girls and may therefore be more susceptible to problems associated with sulfating.
- **Dr Wakefield's** team has discovered a sulphur deficiency in the intestinal ileum that could possibly lead to intestinal porousness.
- Sulfates are necessary for releasing digestive enzymes from the pancreas.
- Low levels of sulphur could contribute to the weakening of several enzymes.
- Weak levels of sulphur could result in limiting the adjustment of neurons since the peri-neural network surrounding the neurons that controls their operation, is principally composed of chondroid sulfate.
- The hepatitis B vaccine may inhibit the sulfating chemistry for one week in a healthy person.

Briefly, almost all autistic persons have **very low levels of sulphur** in their blood, which could be the cause of **many of the problems associated with autism**. The lack of sulphur could be compensated for by Epsom salt baths, sulfuretted creams (now available from Kirkman laboratories) or perhaps by products such as cysteine or the N-acetyl cysteine (**Dr Pangborn**, however, is somewhat reticent about the use of cysteine or N-acetyl cysteine). Since sulphur

takes between 4 and 8 hours to be eliminated from the bloodstream, these products should be used at least once a day and perhaps even more often.

Problems associated with mercury

Dr Jim Laidler tackles the most recent statistics from the *US Dept of Education* dealing with the number of autistic persons, showing that the number of cases of autism has grown tenfold during the past seven years. In addition, these statistics indicate that, contrary to what occurs in other problem cases, the sharp increase is occurring mainly in young people (there are twice as many new cases in the 6-11 year old category than in the 11-17 year old category). This phenomenon could depend on environmental factors. **There are similarities between autism and signs of mercury poisoning** with regard to limitations in the field of vision (limited sight of things) as well as to autoimmune abnormalities and many other symptoms.

According to **Dr Laidler**, at the present time, DMSA is the most effective product for mercury detoxification. We should avoid having recourse to Chlorella and cilantro, because although they succeed in holding mercury in the environment, they do not retain enough in human tissues and tend to allow it to be released into the body.

DMSA can be used effectively in a cycle of 3 active days and 11 inactive days, with a dose every 8 hours (taking it every 4 hours or every 8 hours does not seem to make much difference). DMSA may cause fatigue or irritability as it seems to provoke temporary gastro-intestinal dysbiosis. It does not carry mercury to the brain.

Once the DMSA has reduced the level of heavy metal, alpha lipoic acid can be added to increase the excretion of mercury. Doses of alpha lipoic acid of 1-3 mg/kg per day can be introduced and gradually increased to 10 mg/kg a day.

Chelation should be stopped as soon as the excretion of mercury becomes undetectable or if no new improvement is observed. Since the condition of some autistic persons improves with DMSA, even when only small quantities of metal are excreted, DMSA could have other effects: it could act as a powerful antioxidant, eliminate cysteine or bind with gliotoxin (a toxin derived from yeasts that affects the neurons).

Dr Laidler also attacks the question of a possible link between NMDA receptors (n-methyl

d-aspartate) and autism. A blocking of this receptor could lead to a lessening of pain, and to a limitation of the field of vision, as well as to attention problems, hearing difficulties, repetitive behaviour, dilated pupils and language disorders. The reason for this phenomenon is due to the fact that this receptor controls the destruction of brain cells during development and that it adjusts pain thresholds and has an influence on both dopamine and serotonin.

The number of cases of autism has grown tenfold over the past seven years.

In brief, the increased number of autistic persons could be explained by the presence of mercury in vaccines and other products. Many symptoms associated with this problem could ensue from mercury poisoning. The use of DMSA initially, followed by the use of this same product with the addition of alpha lipoic acid is effective in reducing the levels of mercury and could even lessen the symptoms of autism in certain cases.

Biochemical tests

Dr Jon Pangborn shows how each of the biochemical types of autism can affect the metabolism. He also draws up a list of specific laboratory tests for each type: hyperphenylalaninemia/urea, histidinemia, Fragile-X, Rett's Syndrome, Lesch-Nyhan Syndrome and purine autism.

He briefly discusses the numerous factors that can weaken the enzyme required for digesting gluten and casein, i.e., the DPPIV, while mentioning the existence of a study on the *EnZymAid* which could help determine how to reduce a number of symptoms of autism.

Finally, he presents examples of the typical results of **analyses** conducted on hair and red blood cells. Other results of tests on amino acids, detoxification protocols, stool analyses, sensitivity to yeast and to bacteria, analyses of fatty acids have enabled him to illustrate these theories.

All these subjects are covered in greater detail in the new *DAN! Protocol* (Biomedical assessment options for children with autism and related problems) co-authored by **Dr Pangborn** and **Dr Baker**.

Treatments

Dr Woody McGinnis

Autism, and the attention deficit and hyperactivity disorder (ADHD) are quite similar because

of the many problems associated with them. In both cases, the intestine and nutrition play very important roles. In fact, in-depth reports on gastro-intestinal problems indicate that 85% of children subject to night waking suffer from gastric reflux. Researchers explain this situation by the fact that in the prone position, gastric acid moves up through the oesophagus and causes a burning sensation.

Gastro-intestinal problems may lead to poor digestion, faulty absorption of nutrients, porousness of the intestine, a proliferation of microbes and also perhaps to a modification of signals being sent to the brain (80% of vagus nerves go from the intestinal tract to the head)

A zinc deficiency can lead to diminished gastric acid which is a determining factor in the process of digestion. It has been observed that 45% of persons with attention deficit and hyperactivity have low levels of gastric acid. The same probably applies to autistic persons.

Furthermore, it seems that it is not rare to note a greater need for oxidants. In these cases, it would be appropriate to give vitamins C, E and A, zinc, selenium and taurine. The intestine and the brain are very sensitive to oxidating stress.

To help with detoxification, it is necessary to take vitamins B6 and B12, with folic acid, magnesium, zinc, selenium, lipoic acid and methionine.

Among possible treatments, there are: diets (gluten and casein-free, light sugar content, without artificial sweeteners,) digestive enzymes, probiotics, vitamin/mineral supplements - particularly zinc and vitamin C - cod liver oil (for vitamins A and D), fish oil and oil of evening primrose (for omega 3 and omega 6 acids) antiviral medications, secretin, DMSA/alpha-lipoic acid (to eliminate heavy metals) and bethanecol (to improve the condition of the intestinal mucous membrane and to stimulate digestive enzymes).

It is recommended that nutrition tests be performed. These include checking the pH factor in stools (easily done at home), IgE or IgG measures to test for food allergies and the dosing of urinary puroles (25% of autistic persons have these toxins). One of the laboratories suggested is *Vitamin Diagnostics*.

Constipation problems may be fought by the intake of magnesium, citrate, fibres, vitamin C and bethanecol.

Glutamine may prove effective for the intestine but should be avoided if the level of ammonia in the blood is high.

Additional information: Jeff Bradstreet

Dr Jeff Bradstreet outlined his plans for the infrastructure of a centre designed to fulfill the biological, behavioural and nutritional needs of autistic persons. He hopes to raise between 20 and 30 million dollars from the private sector for its creation.

He then proceeded to discuss the biological problems associated with autism and the way to treat them. He explained that vaccines and the additives found in vaccines may disrupt the immune system by transforming TH1 cells into TH2 cells. In some cases, the additives found in vaccines are introduced with a view to stimulating the production of antibodies. In the case of autism, however, the production of antibodies may have already been over-stimulated, resulting in auto-immune problems.

Dr Bradstreet then discussed the question of the causes of autism. He dwelt particularly on the following points.

- Autistic entero-colitis creates an abnormal environment for harmful bacteria, yeasts and dangerous parasites.
- Exposure to mercury alters the type of micro-organisms lodged in the intestine (this also occurs when DMSA is used to eliminate the mercury).
- His study on the influence of mercury has enabled him to discover that, during a DMSA test, autistic children excrete 5 times more mercury than normal children (8.63 mcg/24h compared to 1.48 mcg/24h). He concludes that either autistic children were exposed to higher levels of mercury, or else they have a limited capacity for eliminating it. Mercury can have several effects, including the complete inhibition of the DPPIV required for digesting gluten and casein.
- In terms of abnormalities to the digestive system:
 - 90% of autistic children exhibit a zinc deficiency;
 - 90% of autistic children exhibit an excess of copper;
 - Calcium and magnesium deficiencies are common;

- Almost 100% of autistic persons exhibit a deficiency in Omega 3 fatty acids.
 - Almost 100% of autistic persons exhibit a fibre deficiency;
 - Almost 100% of autistic persons exhibit a deficiency in antioxidants.
- A damaged gastro-intestinal tract leads to poor digestion of proteins which results in:
 - a deficiency in essential amino acids;
 - added nourishment for dangerous bacteria, leading to high rates of ammonia (which is toxic). Substances that reduce ammonia can also lessen mental confusion (alpha-cetoglutaric acid is an option);
 - gluten and casein peptides which act as opiodes;
 - undigested proteins provoking allergic reactions in the intestine and in the blood.

Dr Bradstreet also enumerated treatment options for different disorders. A summary of these treatments can be found on the Web site of the Québec Autism Society (under the title - " conférence", Dan! 2001.

Omega 3 fatty acids General principles, by Dr Andrew Stoll

The principal fatty acids in the Omega 3 family are formed by DHA (docosahexanoic acid) found in linseed - and by EPA (eicosapentanoic acid) found in fish oil.

Because of their effects on certain psychiatric disorders, fatty acids of the Omega 3 type contained in fish oil (EPA) are increasingly attracting the interest of researchers.

Animals are unable to synthesize these Omega 3 fatty acids which are mainly produced by phytoplankton (algae) and are introduced into the food chain by fish who eat them. The main sources of Omega 3 oils are therefore linseed, algae, fish oil and some eggs from hens or birds who feed on linseed or fish.

Because of their effects on certain psychiatric disorders, fatty acids of the Omega 3 type contained in fish oil (EPA) are increasingly attracting the interest of researchers. They have been tested in treatments for schizophrenia, depression, postpartum depression and bipolar disorders and have proved to be effective. In an earlier study on bipolar disorders, **Dr Andrew Stoll**

found that taking 10g/day of fish oil was beneficial. It is to be noted that residents of the United States consume less than 1 g/day of Omega 3 fatty acids (EPA and DHA), a quantity which is probably much less than what is needed, and that the Inuit, on the other hand, consume between 15 and 19 g/day.

Although they eat a great quantity of fish, Japanese people do not seem to be affected by the high levels of mercury found in their diet. The majority of commercial fish oils are of poor quality, and we recommend those that do not have a rancid taste. One of the options is *Omega Brite*, which is highly concentrated. In addition, a study conducted on more than 15,000 patients taking Omega 3 did not reveal any harmful side effects.

Dose: **Dr Stoll** recommends 2-5 g of Omega 3, once or twice a day, with a higher level of EPA than DHA (except perhaps for young children who have a greater need of DHA for brain development.) Further information can be found in his book *The Omega 3 Connection*.

Briefly, it has been proven that EPA is beneficial in the treatment of certain psychiatric disorders, whereas DHA is not. There is no formal study on its usefulness in cases of autism, but it does seem to provide some benefits. A high quality fish oil is a good source of Omega 3 fatty acids.

Omega 3 fatty acids Treatments, by Dr Paul Hardy

Dr Hardy tells of his experience in treating several autistic persons using Omega 3 fatty acids and other food supplements. He submits the hypothesis that some people diagnosed with autistic spectrum disorders (ASD) may actually be suffering from a bipolar problem. Over the past 100 years, the size of the brain has diminished by 10%, probably because of a lack of Omega 3 fatty acids that make up more than 60% of the brain. The consumption of Omega 3 fatty acids has considerably lessened in American diets. Fish from fish farms are usually fed corn and, therefore, have very little of the Omega 3 fatty acids that are found in algae. Furthermore, cod liver oil has been used much less frequently as a medicine since the 1960s, without apparent reason. Finally, baby food does not contain any essential fatty acids.

In his clinical practice, Dr Hardy observed a deficiency of Omega 3 fatty acids in a number of autistic persons, as well as an unhealthy high level of acid from peanut oil (a bad fatty

acid). In his opinion, the deficiency is probably under-assessed, since the levels of Omega 3 are very low in the United States and since the scales of reference used by laboratories may also follow this trend. **Dr Hardy** estimates that 90% of people with ASD lack Omega 3 fatty acids. He therefore recommends 2-5 g/day or a combination of DHA and EPA, beginning with low doses and gradually increasing them.

Potential consequences of mercury, by Dr Jane El Dahr

Dr El Dahr believes that in some genetically predisposed subjects, prenatal exposure to mercury and exposure in infancy could cause some neurological damage leading to autism. This hypothesis is supported by a comparison of symptoms, toxicity studies, case studies and epidemiology. The most probable sources of mercury are fillings in the mother's teeth, the consumption by her of contaminated fish, certain other consumer products (eye drops, nasal vaporizer, and others), rho-gam, flu shots given during pregnancy, as well as vaccinations given during childhood.

There are, in fact, several similarities between the symptoms of mercury poisoning and autism.

The increase in the number of cases of autism seems to correlate with increased vaccination. Babies who have been given all their vaccines during the first six months of their lives have absorbed more mercury, through the vaccines, than the norm recommended by the FDA. There are, in fact, several similarities between the symptoms of mercury poisoning and autism. To mention a few: poor socializing skills, language problems, repetitive behaviour, sensorial abnormalities, poor cognitive and motor skills, behavioural problems. There are also similar physical symptoms at the biochemical and gastro-intestinal levels, as well as in muscle tone, neuro-chemistry, neurophysiology, EEG readings (electro-encephalograms) and in the immune or auto-immune system.

From data taken from the *Vaccine Safety Database* covering 110,000 children born between 1992 and 1997, statistically significant associations were observed between cumulative exposures to thimerosal contained in vaccines and the risk of later development of tics, of attention deficit problems (ADD), of delayed language and speech skills as well as delayed neuronal development. The sample study was, however, too small to determine specific risks for autism.

In conclusion, mercury may be the cause of certain cases of autism. Children are exposed to high levels of mercury via childhood vaccinations, and a strong similarity between symptoms of mercury poisoning and autism has been observed.

Dr El Dahr recommends a new book *What your Doctor May Not Tell You About Children's Vaccinations*, by Stephanie Cave, (recently put on sale).

Treatment for mercury poisoning, by Dr Amy Holmes

Dr Holmes tackles the question of a treatment for mercury poisoning, initially using DMSA alone and later adding alpha lipoic acid. It is very difficult to measure mercury toxicity, as it is rapidly eliminated from the bloodstream, the urine and hair (within a few months or less) and remains lodged in the tissues. **Dr Holmes** recommends that instead of assessing the effects of mercury by testing for organic acids in urine, it would be better to break down the porphyrins in the blood. She also recommends the evaluation of the immune system and other blood tests. She is highly in favour of the observation of the quantity of sulfates excreted in the urine, a possible indication of kidney dysfunction, and the presence of mercury associated with the kidneys. (It is to be noted that **Dr Waring** found that sulfates were excreted in the urine of the majority of autistic children.)

Before starting the mercury detoxification process, the intestine has first to be cleared of bacteria and yeasts, and must be kept in this condition. Furthermore, all sources of mercury must be eliminated, which implies the removal of mercury-silver fillings from teeth, the elimination of sea food, and the suppression of thimerosal.

Initially, DMSA alone should be used to eliminate mercury from the body. A maximum dose of 10 mg/dm, 3 times a day for 3 days, should be followed by 11 days without any dose. Repeat several times. Glycine can help, but it has a very weak effect of the excretion of mercury (5%). Test the urine after 2-5 cycles, since metals are mostly excreted in this fashion. Continue until a small quantity of mercury and heavy metals has been eliminated. Then, as a second step, administer the DMSA with alpha lipoic acid (AL) in the following ratio: DMSA:AL from 2 :1, increasing to 6:1. Even though DMSA cannot cross the blood/brain barrier, the AL can, and it allows mercury to be excreted, mainly in the stools. Also, the addition of AL will lead to a

further excretion of mercury, possibly mercury from the brain. The stools must be tested every 4 to 6 months to determine the quantity of mercury that is eliminated and must be repeated until the quantity found is in the normal range. If stools are too difficult to obtain, an analysis of the hair can be performed. Step 2 will be delayed considerably if lead and tin are still present. It is important to eliminate them completely before adding AL to the DMSA. During step 2, the usual side effects are the following: initial deterioration (worsening of behaviour, diarrhea, headaches, fatigue and excessive growth of intestinal yeasts and harmful bacteria). This whole procedure must be subjected to checks (analyses of blood, liver enzymes, and a verification of problems associated with minerals). Side effects are rare and affect only 0.5% of patients.

Age	IMPROVEMENT*			
	Marked	Moderate	Slight	None
1-5 years	36%	39%	15%	9%
6-12 years	15%	35%	36%	15%
13-17 years	0%	17%	54%	29%
18+ years	0%	14%	14%	71%

* Subsequent to the elimination of mercury

By marked improvement is meant few or no autistic symptoms. The degree of improvement corresponds to the quantity of metal excreted with DMSA + AL. Children who responded the most quickly to the treatment are those who had normal development followed by a regression. Other children may need more time to respond to the treatment. Further research is necessary.

In conclusion, DMSA followed by DMSA with alpha lipoic acid is effective in eliminating mercury and other heavy metals. Results show significant improvement, mainly in the youngest children and in those who had been developing normally before regressing.

The measles virus and autism, by Dr Andrew Wakefield

Dr Wakefield submits a summary of the researches conducted on autistic enterocolitis. He provides proof that there is a persistent viral infection in the blood of many autistic children, based on the reduction of CD3 lymphocytes, an increase of IgG1 and a reduction of IgG4 and IgG2. In addition, biopsies done on autistic children reveal inflammation of the mucous mem-

branes (epithelial tissues) of the entire intestine. The live measles virus was found in 76 of the 83 children in the control group, as compared to 1 out of 35 in the control group. Genetic testing showed that the source of the virus was the vaccine and not an errant source.

“The live measles virus was found in 76 of the 83 children in the control group, as compared to 1 out of 35 in the control group.”

In tests performed on autistic children, **Dr Singh** noted that they tended to have high levels of antibodies for measles but not for other viruses. This information suggests that the MRM vaccine could be linked to one of the causes of autism. To test this hypothesis, **Dr Singh** studied autistic children who seemed to have regressed after their first MRM vaccine. He then monitored these children to see what would happen when they received a second MRM vaccine as compared to those who did not get the second vaccine. To do so, he studied behaviour patterns, physical symptoms, macroscopic and microscopic pathology as well as growth charts. Children who received the second MRM vaccine, had a second regression shortly after the injection, as compared to children who did not receive the second MRM and who suffered little or no additional regression. These results are a strong proof that the MRM vaccine can cause autism.

ANOTHER TESTIMONY CRYING OUT TO BE HEARD

A testimony by Lucie Lejeune

I am the mother of an autistic boy of 12 and it is as an absolute non-professional that I heard about biomedical research; about gluten and casein-free diets, vitamin supplements, fatty acids, secretin, heavy metal poisoning, vaccinations and all the rest!!!! It was all Greek to me and difficult to understand. I had read a lot in various papers from our associations, but it seemed to me that the literature was addressed to people with a solid medical background and that it could bring me no concrete help. I was struck by the conviction of doctors at the conference and especially by their desire to act by attacking the medical causes and by finding concrete treatments such as a modification in the diet of autistic persons. I found in their convictions a real hope that differed from the traditional talks leading to despair. It is in this first conference that I attended that I found a great source of motivation to work for this cause that has become so important to me. It is essential that something be done for very young children, that is sure. But even though my son has already passed this critical stage, I have chosen not to quit and to work for the generations to come. It is never too late and I will do all I can for him now. The rest, I am doing for those who will need help in the future.

While talking to various people, I became aware that the DAN is open to everybody. It suffices to have an autistic child (and that is something!!!), willpower, curiosity, a little courage and especially the will to cause the autism issue to move forward so that the same errors are not repeated. Your child is not a mental patient, it is his body that is sick. My testimony is not scientific but descriptive. I do not propose to get into the worldwide controversy of "for or against" vaccination, since it does not really exist as formulated in this way. **It is important to note that the DAN doctors do not recommend a campaign for or against vaccination, but that they hope rather to discover the best way to administer vaccines so as to protect children from serious illnesses that still exist today.** It is sad to note that some professionals in the health field still view the discussion as a threat instead of seeing it as an opportunity for a dialogue leading to the advance of science.

I therefore took the opportunity last October to go to the semi-annual convention of the group called DAN or "Defeat Autism Now." I will leave to more

* « Biomedical Assessment Options for Children with Autism and Related Problems »

A consensus Report of the DAN! scientific effort by J.B.Pangborn, Ph. D. and S.M. Baker, september 2001, Autism Research Institute, San Diego.

knowledgeable people the task of explaining in greater detail the scientific content and results of research as they were presented at the conference.

In conclusion, I would like to tell you what really impressed me: I felt that all these doctors had reached some kind of consensus in their conclusions, that they had attained a high level of comprehension of the symptoms of autism, that in other words, we could look forward to happier futures. In addition, their theories open up the possibility of treatments that can improve the condition of our children. I must insist on recommending that interested parents consult the new protocol* I published by DAN!. This protocol provides a look at a plethora of analyses and treatment possibilities (simple or more complicated) that can help combat the autistic "sickness".

An exceptionally moving moment during the convention : the concert by young Matthew Savage



I had never had the opportunity of attending in person such a phenomenal experience until I went to the benefit concert given by young Matthew Savage, during the "Poolside Dinner" evening. Matthew is a high level 9-year old autistic child, if I may be allowed to use this somewhat controversial expression.

Matthew has an extraordinary talent as a jazz pianist. He charmed the whole room with his spontaneity and his incredible interpretation of a type of music that requires so much life experience.

I was fortunate to be able to eat with him and his mother who explained that her son is a product of DAN!!! He continues to follow a strict gluten and casein-free diet.

An overview of educational interventions now used in autism

By Polly A. Yarnall, M. Ed.

Adaptation authorized by the author and carried out by the Web site team of the Québec Federation for Autism and Other Pervasive Development Disorders and François Gignac, psychologist with the CRDI of Québec

It is justifiable to assert that, at the present time, educational approaches provide the greatest support, practical help and results in the evolution of autistic persons and those with related problems. But what approaches are most commonly used? How can we get a clear and synthetic idea of what they are? What results do they give? How are they used? What are their advantages and disadvantages? What errors are to be avoided in applying these programs?

Mrs. Polly A. Yarnall, M. Ed. gives direct, clear and precise answers that will satisfy parents as well as educators and other parties involved with autistic persons. A synthetic chart appears below.

Read on!
François Gignac

About Mrs. Polly A. Yarnall

Polly Yarnall is an internationally renowned educator known for her expertise in educational approaches for persons with autism. Her 23 years of experience in the field are obvious in her writing, presentation and training sessions. After earning her bachelor's degree from Duke University and a masters in education from Villanova, she has worked with children and adults in the fields of academia, residential services and also in day centres for adults, as well as in private practice.

She was the guest presenter at four conventions of the *Autism Society of America* and was the presenter at regional and state seminars throughout the United States. Furthermore, requests for consultations, presentations and workshops have brought her to Japan, Australia and England.

She has certifications and other recognitions from the Department of Education for the State of California, where she lives. Her exposé *Behaviour modification - What is missing?* presented at the national level, was translated into Chinese for a course addressed to Hong Kong parents.

Mrs. Yarnall graciously offered François Gignac the rights to the translation, adaptation and publication on the Web site of the Québec Federation on Autism and Other Pervasive Development Disorders (FOATED) of the following chart. She can be reached at payarnall@juno.com.

Comparative table

	LOVAAS	TEACCH	PECS
Basic principles of the approach	Also known as Intensive Behaviour Intervention (IBI) or Applied Behaviour Analysis (ABA), Intensive Behaviour Intervention was one of the first forms of behaviour modification. The present program was validated in 1987 with the initial intention of integrating the child in a day care centre. The Lovaas approach has evolved and is now known as IBI and ABA	Signifies: Treatment and Education of Autistic and related Communication Handicapped Children. More than 32 years of empirical data on the effectiveness of the TEACCH approach. Includes parents as therapists. Recognizes the need for support from childhood to adulthood. Pays attention as much to the way autism affects a person as to behaviour.	Signifies: Picture Exchange Communication System. Is derived from the need to distinguish between speaking and communicating. Combines in-depth knowledge of speech and language therapies adapted for an understanding of communication when students attach no importance to the meaning of words. Very compatible with TEACCH
Objectives	Teaching the child how to learn while paying attention to the following skills: being attentive, imitating, developing the ability to receive and to express language, pre-school skills and personal autonomy.	Providing strategies to help support the person throughout his life. Encourages autonomy in all levels of behaviour. Adapts to individual needs of autistic persons.	Helps the child initiate communicative interactions spontaneously. Helps the child to understand the functions of communication. Develops communication skills.
Implementation and application	Uses the ABC model. Each attempt or task asked of the child consists in: A request (A= antecedent) - a directive given to the child to perform an act. Behaviour (B) - an answer from the child, i.e., what can be interpreted as a good answer, a poor answer, or no answer. A Consequence (C) - a reaction by the intervening party, i.e., a range of responses that could range from strong positive reinforcement, slight congratulations, no response, or a slightly negative reaction (ex. a No). A pause to separate the trials from one another (interval between trials)	Organizes properly, structures and modifies the environment and activities. Puts emphasis on visual models of learning. Uses functional contexts to teach concepts. The program is based on individual evaluations. Uses foreseeable structures to promote spontaneous communication.	Recognizes that young autistic children are not really influenced by social rewards. Starts the learning process by functional acts that put the child in contact with significant rewards. Begins with assisted exchanges and proceeds according to an eight-step hierarchy. Requires an initial ratio of two trainers per autistic person (2:1).

	LOVAAS	TEACCH	PECS
Results reported	Initial research shows improvements in IQ, comprehension and spoken language as well as social and adaptation skills. The original LOVAAS study gave spectacular results with 45% of children that could not be distinguished from normal children. Studies attempting to replicate these results are now being conducted. Although no study has as yet reproduced the same results as the original ones obtained by Lovaas, preliminary results of the replications are encouraging.	Gains in functioning and development. Increase in functional and adaptation skills. Skills acquired are generalized and applicable to other environments. A report from North Carolina shows a reduction in the stress levels of parents and fewer requests for placing children outside the home. Higher level of success reported.	PYRAMID Educational Consultants report empirical data supporting the approach. Increased capacity for communication in most of the users of the method (the children understand the function of communication) and initiation of spontaneous use of speech.
Advantages of the approach	Recognizes the need for teaching one-on-one. Uses repetition of answers that are understood until complete assimilated. The child is kept listening for longer periods of time. Success in obtaining verbal presentations from some children. Allows them to integrate sooner with others. More effective for mild to moderate autistic persons in the higher IQ range.	Dynamic model that takes advantage of and uses several fields of research. Non static model. Anticipates and supports integration strategies. Compatible with PECS, floor-time, occupational therapy and other selected strategies. Is addressed to sub-groups of autism, uses personalized evaluations and approaches. Identifies emerging skills that are most likely to succeed. Flexible, thus reducing stress felt by the child and the family.	PECS method helps initiate speech. It focusses on the social and communication deficiencies of autism. Is appropriate for non-verbal or pre-verbal children and for those whose non-verbal IQ is higher than their verbal IQ. Semantics of the PECS method resembles spoken language more than sign language.
Questions about the approach	In the absence of a comparative analysis on the effectiveness of the various methods, Lovaas is often presented as the approach to use. No differentiation between types of autism in creating programs. Insists on obedience and dependence on those giving incitements and reinforcements. Purely behavioural approach that may ignore the neurological components of autism which could be the cause of problems in execution and attention. May add stress to the family and the child. High cost: \$50,000 per year per child. Prevents equal access for all.	The perception that TEACCH is giving up in the face of autism rather than fighting it. Seems to be an exclusive method separating autistic children from others. It may appear that TEACCH isolates children in independent work places when they need to develop their social skills in the company of other children. Beliefs based on a faulty or superficial knowledge of the approach.	May suppress spoken language. (Actual experience proves the contrary, however).

	LOVAAS	TEACCH	PECS
Errors to be avoided	<p>Creating a dependence on one-to-one teaching.</p> <p>Increasing stress for the family and the child.</p> <p>Interpreting all behaviour as voluntary and stubborn rather than as manifestations of neurological problems.</p> <p>Ignoring sensory problems and functional difficulties.</p> <p>Failure to recognize when it is time to move on to another approach.</p>	<p>Failure to provide sufficient training, consultation and follow-up for the educators to implement the program properly. Seeing TEACCH as a simple school program rather than as a continuum of general support and strategy.</p> <p>Providing only minimum training to educators who are meant to train or advise the rest of the personnel. Failure to establish real collaboration with parents.</p>	<p>Failure to adhere strictly to the teaching principles of phase I. To have a tendency to work only on step 1 or to use only one educator. To provide inadequate support and follow-up to workers who have only been given a two-day training session. Training only one person in the method rather than the entire personnel involved.</p> <p>An inconsistent implementation in the milieu.</p>

	GREENSPAN	INTEGRATION	SOCIAL SCENARIOS
Basic principles of the approach	<p>Also known as Floor-Time, or as the DIR (Developmental Individual-Difference, Relationship-Base) model. Aim is for emotional development through a developmental model. Is based on perspicacious and precise observations of the child in order to determine his actual functional level. Centered on the child and built in accordance with his state.</p> <p>Floor-Time is only one part of a series of 3 including spontaneity through semi-structured games, in addition to games for motor and sensory skills.</p>	<p>Initially focussing on children with mental retardation and problems other than autism. Backed by sociological, political and educational fields, unlike other approaches based on psychological data.</p> <p>Integration is defined by three federal laws: PL 91-142, REI and IDEA (USA)</p>	<p>Method also known as social stories. Initially developed by Carol Gray in 1991 to help autistic persons understand the rules of a game. Further developed for the understanding of more subtle social rules in our neurotypical culture. It tackles the deficiencies in the Theory of the Spirit (the ability to understand another person's perceptions).</p>
Objectives	<p>Aims for personal interactions to facilitate the mastery of developmental skills. Helps professionals to view the child as a functionally integrated and connected person. Does not deal separately with speech development, motor development, etc.</p>	<p>To educate whenever possible handicapped individuals in classes and environments with normal children. To educate handicapped children with their age group. To avoid applying separate teaching methods except in special circumstances.</p>	<p>To clarify social expectations for persons affected with a problem in the spectre of autism. To identify problems in the perspective of the autistic person. To redefine faulty social interpretations. To furnish a guide for behaviour and individual management tools for social situations which autistic persons will eventually have to face.</p>

	GREENSPAN	INTEGRATION	SOCIAL SCENARIOS
Implementation and application	Teaching in interactive contexts. Addresses retardation in development through sensory modulation, planning, organization, motor involvement and the process of perception. Is usually carried out in 20-minute sessions followed by 20-minute breaks. Each session is addressed to one of the aspects of the developmental retardation mentioned above.	Autistic children are usually placed in one-on-one settings. Curriculum is modified to promote learning based on the strengths and weaknesses of the autistic child. Requires a team approach for planning. The approach may consist in selective integration (by subject or class), partial integration (half day of integration, half day of teaching) or else radical and complete integration without exception.	The scenarios are specifically designed for each person and adapted to the problem situations of each one. They generally include three typical sentences: for opinions, for descriptions and for directives. The various types of sentences appear in the social scenarios and are repeated in turn. The scenarios may be read BY or TO the autistic person. They are presented far in advance in order to allow time for several readings, but particularly just before a situation is to present itself.
Results reported	Shows parents how to talk with their child in a happier, more relaxed way. Introduces (hypothetically) a solid structure for future neurological/cognitive development.	In certain circumstances, autistic children can succeed in functioning properly and in becoming more sociable in classes of normal children or in non-autistic environments. Is good for students who share the intellectual capacities of their fellow students.	Stabilizes the behaviour required for a specific situation. Reduces frustration and anxiety in autistic persons called upon to act in a given situation. Behaviour improves in the course of a given situation when the social scenario is applied coherently.
Advantages of the approach	Addresses emotional development, unlike the other methods that concentrate on cognitive or behaviour problems. Avoids the concentration of exercises in fields where the child presents deficits (which could increase frustration and emphasize that he is not capable). It is not an intimidating approach. Helps convert the child's actions into interactions.	Increased possibilities of social interaction and the ability to follow models. Greater exposure to verbal communication. Opportunities for others to acquire a better understanding and greater tolerance for differences. Greater possibilities of developing friendships with children who develop normally.	Developed specifically for the social deficiencies of autistic persons. Adapted to specific and individual needs. Time and cost are flexible.

	GREENSPAN	INTEGRATION	SOCIAL SCENARIOS
Questions about the approach	Does not address specific fields of competence. No study has shown its effectiveness for autistic children. Based more on hypotheses than on research. Is more of a passive method.	Automatic integration goes against the spirit of the guidelines and laws that are at its base. The odds of successful integration begin to level off by the end of third grade when work becomes more abstract and the rate of learning is more rapid. An increase in the use of oral teaching is a great disadvantage for autistic persons. Sensory problems and difficulties in processing information tend to be either incorrectly or insufficiently corrected. The regular school system is not necessarily the best learning environment for autistic children. Teacher and students in the integrated classes are usually poorly prepared for dealing with autistic students.	The data on the approach are more often anecdotal than empirical. The benefits depend on the competence of the author of the scenarios, on his comprehension of autism and on his ability to put himself in the autistic person's place.
Errors to be avoided	Attempting to implement the approach without training or professional supervision. Loss of control. Trying to have the child do what YOU think he should do. Allowing him insufficient time. Attempting to apply the method during activities already going on with other children.	Providing insufficient training, preparation, information and support to the personnel. Placing students in settings where the levels of auditory and visual stimulation are too intense. Assigning to the student work with cognitive requirements beyond his comprehension. Depending on one-on-one individual support. Focussing on academic skills to the detriment of functional skills. Failure to offer multiple opportunities for applying functional skills.	Using too many sentences linked to goals in relation to the number of sentences dealing with perception and description. Starting sentences associated with goals, with overly rigid terms (i.e., I will do, instead of I will try to do, etc.) Drawing up a scenario too complicated for the age and/or the cognitive development of the person. Using overly complex language. Failure to be specific enough in describing the situation for the anticipated behaviour response.

More about the *Greenspan method*, or play therapy

Extracts from *Trousse d'information sur l'autisme* *

By Rémi Pouliot and Isabel Thibault

General principles

Among the many educational methods addressed to autistic children, the method proposed by Dr Stanley Greenspan stands out because of its originality and its philosophy. Floor time or play therapy allows the child to interact with his surroundings while performing his activities. To a certain extent, the child takes control of his daily activities and his parents, or educators, become integrated into his world without imposing on him a set program or schedule.

Contrary to some teaching methods, the Greenspan method is not based on structures, teachings and programs that are imposed on the child. Neither does it try to specifically repress negative behaviour, although it eventually arrives at these results. In fact, the Greenspan approach has as its primary objective the creation of reciprocal communication directed by the child rather than by the other party involved. It helps the child to become more attentive to his surroundings, to be more flexible to imposed change, to take more initiatives in his interactions, to better tolerate frustration and to take pleasure in learning.

The originality of his method is in keeping with the well known fact that children learn through play and that they will allow you to enter their world when they feel like it. This affirmation applies equally well to an autistic child. The method advances the notion that well led games can give just as good results as those obtained from conventional teaching methods. In addition, the method can apply to all autistic persons no matter what their symptoms are or how serious their condition is. Language is not a prerequisite since oral communication is not required. Floor time must be made up of several short sessions of about twenty minutes. The more the child gets used to the method, the longer the sessions can be.

Its operation can be broken down into five major steps:

The first **observation** step consists in noting the child's facial expressions, his posture, the words he uses, his interest at the time, etc., in order to determine the best way to enter into his world. For example, your child plays with cars. Observe his behaviour. Does he simply look at them? Does he make them move? Does he make them collide? Does he appear to be absorbed in his game?

Next the best **approach** is to be decided on so as to succeed in the undertaking. You must succeed in creating some communication with your child. If you see that he is making his miniature cars have accidents, sit down with him and do the same thing.

The third step involves **letting yourself be led** by your child. You should become his playmate, leaving the choice of activity up to him. This will strengthen his self-esteem and he will have the impression that he is being understood. Ask him what to do, what car to take, etc.

In the fourth step of the method, **push the game a little farther** by asking questions, by making comments, by placing obstacles and problems, etc. You could invent a mountain that blocks the road for the cars, you could ask him where the cars are going, etc. Your child will then have to find a solution to your questions or to the problems that you have created.

Finally, your child must **close the communication circle** that you opened by answering your questions, by making comments or by solving problems that you have put before him. Your child could invent another road to get around the mountain or make a tunnel to go through it; he could answer that the cars are going to his grandmother's, etc.

* Soon to be available on the Web site : www.autisme.qc.ca

Handy tips

Below are several pieces of advice and ideas to help you introduce, on a daily basis, the best Greenspan approach for your child. Please note that the toys and the ideas must be **adapted to the age, capacity and personality of the child** and that you need not own all the material mentioned or to work on all the suggestions for the method to function.

► Useful tools (you can store the material by themes in transparent boxes)

- Plastic foods, utensils and dishes;
- miniature transportation equipment, road signs, roads;
- dolls (a girl and a boy) and accessories;
- plastic animals;
- toy phones, blackboard and chalk (white and coloured);
- picture books, plastic letters and numbers;
- Lego blocks;
- construction paper and colouring pencils;
- balloons and balls;
- outdoor playthings, sand box and accessories, swings.

► Applying the method at home

- For dressing and undressing;
- at meal time;
- when travelling by car;
- at bath time;
- at bed time.

► To develop reciprocal communication

- Play verbal “ping-pong”, i.e. respond to all sounds or words expressed by your child. If your child makes a sound, repeat it and make another. Ex. cat / cat, dog / dog, pig;
- play children’s games such as tag, cat and mouse, “Simon says”;
- give new meanings to acts besides the usual ones;
- do not interrupt any positive behaviour or any pleasant occupation.

► To develop motor skills

- Put a piece of a jigsaw puzzle in the wrong place;

- hide an object that he wants or put it in another place;
- provide destinations that correspond to certain actions (if your child is throwing things, bring him close to a basketball net; if he hits, bring him toward some drums, etc.);
- create problems that your child will have to solve;
- make frequent changes in his environment to stimulate flexibility;
- encourage your child to initiate and to pursue actions;
- show symbolic consequences to actions (if a doll falls, ask your child to take care of it; etc.);
- make up a treasure hunt with cards;
- encourage sporting activities.

► Creating a symbolic world and encouraging abstract thinking

- Have your child discover what is real and what is a game;
- hand him symbolic objects corresponding to his feelings (if he want to leave, give him car keys and a miniature car, etc.);
- use plastic figures, giving them the names of your family members;
- give a symbolic meaning to objects (a carpet could become a river, a chair a podium, etc.);
- talk directly to dolls;
- ask abstract questions (Why? What do you think?);
- accept and understand all your child’s feelings and encourage empathy;
- perform visualization activities;
- encourage role playing with costumes and stuffed animals;
- be creative.

► Creating problems

- Trying to pour juice without lifting the cover;
- asking your child to take his bath when the bath is empty;
- changing the location of his favourite things;
- putting two stockings on the same foot;

- reading a book beginning at the end;
- giving him pencils that do not work;
- giving him your shoe instead of his.

▶ **A few questions to ask yourself to make the method work**

- Do I understand my child's needs and feelings?
- Am I imposing my actions on him?
- Am I using encouraging gestures?
- Am I approaching my child slowly and with respect?
- Do I recognize when it is appropriate to respond with a gesture or a sentence?
- Do I keep my voice calm?

▶ **General advice to be followed**

- Allow yourself to be guided by your child;
- insist on getting an answer;
- always try to push the activity as far as possible;
- do not interrupt an activity as long as there is some interaction;
- put emphasis on the progress of the game;
- get involved in activities;
- do not transform a game into a lesson.

Following is a list of documents that could prove useful for applying the Greenspan method in the home:

GREENSPAN, I. Stanley, WIEDER, Serena and WESLEY, Addison. *The Child with Special Needs: Encouraging Intellectual and Emotional Growth*, 1998.

GREENSPAN, I. Stanley, *Infancy and Early Childhood - The Practice of Clinical Assessment and Intervention with Emotional and Developmental Challenges*, International Universities Press Inc., 3rd Edition, 1997.

The *Developmental - Individual Difference - Relationship Based (DIR)* model and various strategies on the floor-time method featuring Dr Stanley Greenspan and Serena Wieder, Ph.D are available on videocassettes. Dial (301) 656-2667 to order them.

Dial 1-800-325-6149 to order the film *Floor Time - Tuning in to Each Child* (Scholastic Inc. New York, 1990).

We also recommend that you visit the following Web sites:

www.stanleygreenspan.com

www.mindspring.com/~dgn/

www.coping.org/earlyin/floortm.htm

In brief

The Greenspan method, although not designed solely for them, can give excellent results for autistic children. The results can vary, however, from one child to another, and the method must be accompanied by a well balanced educational program (ABA, TEACCH, etc.). One of the important advantages of the floor-time approach is that **it does not require the intervention of special educators**. It can therefore be carried out easily by parents. Certain errors should however be definitely avoided:

- controlling the game and trying to bring the child to do what YOU want;
- not allowing sufficient time for the activities;
- transforming the game into a teaching experience;
- holding expectations based on the behaviour and skills of children who are not autistic.

In fact, if the method is properly executed, your child will be motivated to continue to communicate just for pleasure. That is why the most important ideal of the Greenspan method is shared pleasure.

A Visit to TEACCH

By Gilbert Leroux, psychologist at the Saint-Étienne de Montréal school.

Every year the University of North Carolina holds an intensive week of conferences. During the first two days, organizations and individuals representing the international portion of the event act as spokesmen or simply attend the conferences. Numbering about one hundred, they are parents and other interested parties from England, France, Sweden, Japan, Ireland, Scotland, Belgium, Spain and Italy. For the next two days, all international participants get together with parents and involved parties from North Carolina (numbering about six hundred).

The main trends are tackled in a spirit of openness and it is obvious that a real attempt is being made to plan and to find the best methods of acting in favour of autistic persons and their families. Dr Gary Mesibov, director of the TEACCH division (succeeding Eric Schopler) reminds the audience of the TEACCH mission and the values attached to it.

TEACCH is a state service set up to see that social, scholastic and work integration services respect the needs of all autistic persons in the State. One of the main advantages of the TEACCH Division is that it is based at the University and therefore enjoys a neutral position in the face of various State bodies, both public and private. In addition, the University obtains grants for research in the field.

Dr Mesibov passes judgment on medical research deploring the fact that several recent research activities did not include three groups in their studies, i.e., a control group without a placebo, a group with a placebo, in addition to the experimental group. He warns against the placebo effect that could show better results than those observed in the experimental group. He underlines the fact that medical research shows no correlation between vaccinations and an increase in the diagnosis of autism. While acknowledging the harmful effects of a possible cessation of vaccination, he suggests research



From left to right: Gilbert Leroux, psychologist, Gary Mesibov, director general of TEACCH and François Gignac psychologist.

be continued on the method of administering vaccines and the age at which they should be given. He questions the administration of three vaccines at one time. He also brings up the question that, at the present time, groups who have been given secretin do not show better results than those being given a placebo. He also questions the research done in the areas of nutrition, allergy, immunology and genetics.

In spite of the lack of conclusive results, he encourages the pursuit and the funding of serious research. He suggests that research be conducted on one element at a time, without upsetting everything at once.

Dr Mesibov deplores the fact that many people merely reduce TEACCH to "baskets", "schedules" or repetitive activities. Although structured teaching is one of the forces of TEACCH, Dr Mesibov conducted a survey to check with State personnel to find out which fundamental values of TEACCH are recognized and form a consensus.

He notes five major themes, listed by order of importance:

1. He accords equal importance to the commitment, appreciation and respect shown to autistic persons. The main point that is recognized is the fact that the people responsible LOVE the autistic person.

2. The people responsible are always in search of excellence. In this regard, they recognize affinities and persevere in their work, always trying to do better.
3. The responsible persons are enthusiastic and always try to get to work without necessarily knowing the answer to everything. In this regard, he mentions an exhaustive study on toilet training which ended with about 20 recommendations, none of which dealt really with the subject itself. It would be utopian to try to please everyone and never displease anyone; and to attempt to do a little of everything and do it well is impossible since no single person can be good in all fields; it is therefore preferable to act in teams and to make concerted efforts.
4. Collaboration and cooperation are obvious and well received by parents, schools and rehabilitation centres. There ensues a sort of allegiance, fidelity and loyalty to the autistic person. Dr. Mesibov does not accept the fact that in the United States, so many millions of dollars end up in the pockets of lawyers. There are few if any of this type of lawsuits in the state of North Carolina.
5. Finally, there is a lot of positive and optimistic feeling ensuing from this inquiry; realistic thought without an excess of idealism.

Dr Mesibov and Dr Roger Cox suggest that it is high time that proven approaches join forces.

Since there are no miracle recipes, and since no single approach suits everybody, there has to be a wide range of interventions which, depending on the type of handicap, give positive results.

Structured personalized teaching, applied behaviour analysis (ABA), visual communication aids (PECS), social scenarios, work with parents, stimulation of the senses, etc., must be adapted to each autistic person, after a thorough analysis of his functional ability.

For all these reasons, the University of North Carolina is committed to providing the most pertinent information possible:

Dr Cathy Pratt, of the Indiana Resource Centre, University of Indiana: *The integration and inclusion of autistic persons or those suffering from pervasive development disorders into the community and paired with so-called normal subjects*. This is based on the needs of each indi-

vidual. Regular schools are solicited and they may have special classes; there are no special schools, however. The presence of normal students and other involved parties is turned to good account with one and the same objective: quality education for all.

Dr Sally Rogers from the University of Colorado Special attention is directed to the most important objectives to be met in autism: imitation, learning social skills, developing communication ability and symbolic play. It is important to adjust our type of involvement to the needs of the person and not to expect the contrary.

Kathleen Ann Quill: the Autism Institute, Mass A speaker whom we know well since she was a guest in Québec several times. She presented her new book brilliantly: *DO-WATCH-LISTEN-SAY: SOCIAL AND COMMUNICATION INTERVENTION FOR CHILDREN WITH AUTISM* (2000)

Mary Beth Van Bourgondien She presented an overall intervention plan for behaviour modification in autistic adolescents. She takes into account the biological, psychological, emotional and social aspects.

Robert and Lynn Koegel from the University of California in Santa Barbara Well-known behaviorists, they founded the *Journal of Positive Behaviour Interventions*

Therese Pawleck This psychologist introduced us to the work she has done for sightless and sight impaired autistic persons. This represents a particularly difficult challenge.

Joining forces and combining resources and skills to serve autistic persons and their families exemplify the spirit of TEACCH. And, here in Québec, we also have a group of people who have come together to work in the same spirit, the Québec Society and its chapters, that have greatly contributed to updating our knowledge and practices. They have invited renowned speakers on various subjects and some of us have been able to travel elsewhere to see how autistic persons are treated in their daily lives.

This year, in North Carolina I had the opportunity to become acquainted with François Gignac, a psychologist with offices in Québec, who was also thrilled with the week of conferences.

We hope that these few ideas will contribute to advancing the cause.

Living with the *Asperger Syndrome*

Source: Huard, Georges, "Living with the Asperger Syndrome" *Prism no 34* (An approach to the autism enigma). Les Éditions de l'Hôpital Sainte-Justine, Montréal, 2001, pp. 75-79

I am 41 years old and I work as a technician at the University of Québec in Montreal. In this document, I will explain what it is like to grow up with the Asperger syndrome. I lived in a single parent family with my two brothers (one of whom suffers from Kanner's autism) and a sister. I am the oldest of the four children. The difficulties presented by the Asperger syndrome are hard to pin down. Parents wonder what is wrong. They can't figure out how a person as intelligent as I can be lacking in common sense and be unable to know what shouldn't be said.

Early childhood

I remember that at the age of two, I was more interested in newspaper texts than in the pictures, to the immense satisfaction of my mother. This encouraged her to teach me to read before I started school. In grade one, I was seen as a reading "champion." On the other hand my behaviour did not go along with my knowledge. I was interested in insects and other subjects such as the metro (which had opened in 1966), tornadoes, clouds, etc., but I showed no interest in people. I found my younger brother (the one not suffering from Kanner's autism) tiresome. He teased me, but my behaviour fit into the normal range for a child.

Elementary school

I remember that my mother scolded me for asking questions at the wrong time (while she was busy, for example). My younger brother was scolded less often than I for similar behaviour, but he could be punished for having lied, for example. In school, I had trouble making friends, and when I did have some, I preferred to interact with one rather than to play in a group. I



was seen as a loner. I loved to spend hours in the library reading all the books I could find on insects.

I felt frustrated when people did not seem to share my interest. I found that they gave up too easily on everything I persevered in. I found people were too quick and everything seemed disconnected. I loved speaking to grownups because they seemed more inclined to listen to me. My mother could visualize me making progress in science, but she worried about my lack of social skills.

With the Asperger syndrome you also have a naive view of your surroundings. My neurotypical (not autistic) brother often used to make up stories and I bit every time. Once, he took advantage of my passion for insects to make me believe that a ladybug measuring 3 inches in diameter (very big) was crawling on the kitchen window. He told me to ask my mother to take down the window to attack it. Of course, I asked my mother and she rebuked me saying "Do you think I am going to take down

a window just to chase a little ladybug?" Gilbert, my brother, laughed when he saw me being scolded.

Another time, I dropped 5 cents too many in the cash box of bus 125 in the city of Montreal. The driver wrote out a receipt asking for my name and address so that I could make a claim from the head office of the Transportation Company (in 1971, 5 cents were worth a lot more than today). My brother made me believe that I would be arrested and fined \$25 for not having paid attention. I panicked and he enjoyed my panic. I could not detect from his expression that he was joking.

At about grade 6 of elementary school, my teachers were concerned by my social interaction problems and they enrolled me in a drama course where we were taught how to express sentiments and emotions and I learned to view social relations in a new light. There was even a show presented to parents at the end of the school year. That helped me a lot in understanding others, but life does not follow a script.

Adolescence

Special interests are a characteristic of the Asperger syndrome and I was no exception. After insects, I became increasingly interested in calculators and in instruments to measure the passage of time: chronometers, and mechanical timers, as well as digital timepieces. To others, I was an idiot-savant, an eccentric person because I showed no interest in the opposite sex and because all my free time (recess and lunch) was spent in the library. I kept contact with other teens to a minimum, as they all seemed hostile. Periods of depression increased and my relations with my brothers and sister became tense, as I was not growing up like they were and I seemed to take up too much space in the family.

My mother, concerned about my social relations, used to bring me to places like the Planetarium, the Mont-Royal or the Botanical Gardens. We used to go out on Sundays with my other autistic brother, while my "normal" brother and sister socialized with their friends near the house. I thought they must be bored staying there without ever discovering things like I did. On the other hand, I found the subjects of conversation of people in the area boring and I enjoyed structured outings with interesting things to see.

For my mother, it was a lot to ask of her to take me out on a regular basis since she had a full-time job in addition to the household chores.

Furthermore, a teenager who had to depend on his mother to go out seemed odd. One day, my mother helped me enroll in a youth club. It was a club of nature lovers with excursions every two weeks and evenings in a laboratory to analyse plant specimens. The excursions were outside the city in woods, mountains or nature parks. We did bird watching, studied herbs and insects. These outings made me breathe in some fresh air and my behaviour improved while my depression diminished. Even my "normal" brother and sister came along on a few excursions. What an Asperger person likes is to have the entire family join in his interests, and to feel some harmony. Sharing an Asperger's interests is a sign of approval just like a hug for a normal person. The entire period of adolescence when others viewed my interests as fuddy-duddy, dumb or not cool was the most difficult one to put up with.

Routine was very important to me and organized excursions provided a reassuring routine, as I was unable to put up with people who were always changing their mind.

In 11th grade, I received a small Hewlett Packard calculator with a chronometer exact to the hundredth of a second.

I loved seeing the fractions of a second scroll by. The calculator could also be programmed, and that aroused in me an interest in computers. In my last year of high school, I followed an introduction to computer science course. I studied BASIC on an HP 2000 computer. With my obsession on the passage of time, I devised programs that counted the number of days until the end of the term. Another program counted the days between two dates. The computer was a fascinating machine, non-judgmental and infinitely patient. I spent hours on the Decwriter II keyboard installed in a small room of my school. Eventually, this passion led me to a career in computers.

Adult life

At the college level, the tension of adolescence diminished, and it was a period where life seemed easier. I graduated with high marks and the three years were pleasant on the whole. However, the time came for facing the workplace. Thanks to my high marks, I got a first job which I lost eight months later. The reason: problems in communicating with others. It was as though the difficulties that seemed to have disappeared after adolescence were coming back to haunt me.

In the workplace, there is even less forgiveness than among teenagers. The tone of voice of other people makes no impact on me, and I can't distinguish between what is serious and what is a joke. An inability to manage priorities, time limits, etc., cost me some jobs. For nine years I worked as a messenger on bicycle in Montreal, a job that required very little decision making but a lot of physical effort.

In the early 90s, messengers earned good money and I bought a programmable electronic agenda, a PSIONLZ. I wrote a program to count the seconds in a week-end: a two-day week-end lasts 172,800 seconds (3,600 x 48h), and a three-day holiday lasts 259,200 seconds. My exotic habits attracted the attention of a colleague who compared me to Raymond Babbit in the film *Rain Man*, which had just been released. This inspired me to read more on the subject starting with a text by Uta Frith entitled *L'énigme de l'autisme* (The autism enigma). Upon reading, I learned why I needed routine and to know what lay ahead, even though the majority of people find this boring.

In 1995, the steps I had taken led me (with the help of *Autism and Pervasive Development Disorders Montreal* and the *Québec Autism Society*) to a diagnosis made by Dr Laurent Mottron. This helped me understand my past and showed me how to help my autistic brother. In 1996, I worked 35 days at the University of Québec. I learned how to do a Web page and in 1997 I went back for good. I help people solve computer problems, making up safe copies of data. I adore this work because I am able to try all the new generations of computers, such as the Macintosh G4, Pentiums, scanner, digital cameras. My boss tells me I am the most important person in the department.

The university milieu is more forgiving of social lapses and differences than the business world where image is more important. A person can be judged because his tone of voice does not please, and all attempts at explaining are useless. At the UQAM, these things are overlooked in favour of results. At the UQAM, I succeeded in saving a few hard drives from catastrophe. I have responsibilities including making backups and recuperating data, seeing that all goes well.

As an adult, I have learned to navigate in society. However close relationships are still difficult for me. I cannot pay attention to subtle changes in an emotional context, and I have to disconnect from the world from time to time. I cannot say I am cured, but rather that I have succeeded in integrating. When I buy clothes, I pay very little attention to cut or style. For example, I went to a meeting of the Alumni of my high school in jeans. I was not refused entry. A former teacher with hippie tendencies was very pleased to see me and told me that in 1975 everyone was a little eccentric and that my Asperger syndrome did not stand out too much.

Georges Huard

Web site: http://people.sca.uqam.ca/_huard/Asperger_introduction.html

A casein-free diet changed my life

By Blouf

I want to tell you about my gluten and casein-free diet because it changed my life. I am not autistic but the symptoms associated with the foods in question are strangely similar. When I was little, there were times when I told my mother: "I'm bored". She tried to list all the activities that I normally enjoyed, but, oddly, nothing seemed to interest me or to attract me. I used to then sit before my computer and think about what program I could get involved in. But everything seemed too long, too complicated, or useless.

Growing up, the nightmare continued, but how was I to know that it wasn't normal? I suffered regularly from insomnia. I was told that it was because I worried too much or that I paid too much attention to my thoughts. I often used to go downstairs for a glass of milk during these bouts. I sometimes had headaches, but I refused to take pills. I always had a look of sadness even when I was supposed to be happy.

The more I advanced in my studies the more pressure I felt. I never had the courage to do my homework and I was always afraid of going to school. Small details seemed insurmountable. In my worst moments, just smiling seemed to require too much energy. I remember having spent my first week of holidays without my parents in a complete fog. I ate anything (yogurt, evaporated milk). I spent sleepless nights watching television. I was like a zombie.

For a long time, I was thought to have psychological problems or to be suffering from depression. I searched within myself for a long time to find out why I felt so awful. After having tried psychology, meditation, sports, holidays, etc., I finally heard about a gluten and casein-free diet. The list of foods corresponded exactly to those I loved. I remembered that when I had followed a diet for losing weight, I had felt abnormally



well, in spite of mild headaches. These small signs convinced me to try the diet for at least one week. In any case, from a logical point of view, there was really nothing besides food that could have caused me harm. After only three days, I began to feel some incredible effects. You have to understand that for me this was a revelation about how others saw life. How could I have known that life could be pleasant?

Before this I was unable to be happy. I could only feel a little less bad while being tossed from one pressure to another. I endured life. No, I was not lazy although that was what people thought and so did I. The reality was that I exerted superhuman efforts just to be considered a "do nothing that needs to be shaken up a bit."

The course of the diet

Within a week I did not recognize myself. I sorted out my room, which I hadn't touched for months. I sang in the shower. I smiled more. I answered willingly when I was asked a question, whereas previously words had to be pulled from me. It was a new me. I still felt a few reflexes of fear over a lot of things, but I realized that these feelings were not called for. I suddenly had the urge to go out and to move.

At the start of the diet, I tended to eat nothing. Often, I had hunger pangs, but when I glanced at what I was allowed to eat, oddly, I was no longer hungry. I call these hunger pangs selective. Clearly I was not suffering from hunger, but from withdrawal. My hunger feelings were completely smothered. I had to rely on gurgling sounds in my abdomen to know if I was really hungry. It took all of five days before the feeling of hunger reappeared. When you are really hungry, you eat anything; everything tastes good.

As I grew to respect the diet, my taste buds came to appreciate other foods. I was able to enjoy the flavour of these foods, while milk products seemed less important or vital. Previously, food was about the only pleasure I had in a day.

Now, this is not the case at all. However, one very slight lapse in the diet had catastrophic results. I stayed in bed for three full days. I had never experienced such a severe crisis before, in spite all I used to eat.

It must be understood that the diet has a somewhat magical aspect. I could not come to the realization that the food which had always faithfully sustained me during my moments of depression and that I had always eaten since early childhood could have such a disastrous effect. I did fall by the wayside at times, and sometimes thought I would never succeed, a little like people on a weight-loss diet. Alas, the verdict was without appeal. Dizziness within twenty minutes somewhat as though I had abused alcohol. Strong muscular contractions. And BOOM, I reverted to a lamentable state incapable of thinking or remembering anything without superhuman efforts.

During the course of the first few weeks, my state oscillated between good times and a return to hell. In any case, I had to relearn everything about myself. All my guidelines were faulty.

After being knocked out for three days for minuscule lapses (a café latte) I started to be afraid of forbidden foods. Then, I gradually stopped missing them. The diet is not as frustrating as a weight-loss diet, where one has to do without one's favourite treats. Here, it was obviously a question of poisoning my body. What is really the most difficult is being unable to eat like other people in a restaurant or even being unable to share a pizza with friends. But I am so much better now, that I really regret nothing.

Similar symptoms associated with Gluten and Casein

During the period of implementing my diet, I was able to draw up a list of symptoms associated with ingesting gluten or casein. In fact, even though self-observation is difficult, the obvious and important contrasts made it possible to make comparisons especially since I had more energy to do so.

REST

Previously: insomnia, no effect of a sleepless night on my general condition, perpetual disorientation. Sleep is not healing at all and can be interrupted at any time. It was as though I was waiting to do nothing. Careful though, I kept my eyes shut and looked as though I was asleep.

ACTION

Previously: everything is a struggle, even serving a drink or performing a favourite activity. I could only act under pressure or when threatened. Total lack of energy.

MENTAL

Previously: difficulty in thinking during my worst moments (I had to write everything down systematically to be able to think), slow thought processes. I had to force myself to remember an event. The fact was memorized but recalling it was too tiring. Difficulty in ordering my thoughts. Limited field of vision. Faulty hearing. Now images appear clearer, as though previously I only had approximations. They are now brighter and more subtle. Previously: everything that called upon my brain was bad. Everything was a bother. . .

PHYSICAL

Previously: permanently contracted muscles. Impossible to relax muscles. All movement was difficult and painful. Hunched shoulders. **I only realized it with the diet. After three days, all my muscles started to relax all at once. I felt as though I had just done 80 km of cycling.** I still tended to bring my elbows up along my sides, leaving my arm hanging like before. To sleep I instinctively put my pillow on my head so that its weight could cause my neck to relax somewhat when I was lying down. Otherwise I had a tendency to straighten it out a bit. It is the main symptom that is not psychic and that can be detected objectively. A blank, expressionless look on my face. Eyes often cast downward. Difference in sensitivity to pain between the body and the face. If I set the shower temperature at warm for my body, it seemed overly hot and burning on my face. Putting my glasses on my nose was highly disagreeable and required a lot of willpower. Difficulty in putting on clothes because of the unpleasant tactile sensation (I used to open the window so that I could feel cold and be better prepared to dress more quickly).

I never had stomach aches or major digestive problems while eating the harmful foods. If these ailments had affected me, I would undoubtedly have noticed the problem sooner.

PLEASURE

Generally speaking, the perception of fun was absolutely absent. It was as though I felt only neutral or negative about everything.

I was unable to read feelings from facial expressions. A smile seemed hypocritical to me. I de-

rived no pleasure from taking a hot shower, or from sleeping or from sinking into a comfortable chair after physical exertions. There was no pleasure in speaking, thinking, in doing things, in cooking a good meal. Everything was a chore. At the fun level, I only got crumbs and never felt the way I should have about the good things that happened in my life.

PAIN

Important lowering of the pain threshold.

CRISES

I sometimes had incredible attacks of anxiety and of hatred. At the time, they seemed to me to be justified, but, in reality they were for ridiculous details or unimportant reproaches. It sometimes happened that I became completely disconnected from reality. I reacted to nothing, with disastrous effects on those who loved me (seeing a loved one completely cold and ignoring you). My mother started to cry once, and I felt nothing at all. I felt nothing even though I was conscious of what was happening. That condition could last several hours. Afterward, things came gradually back to normal and I realized all the horror of what had just happened. I felt extremely bad, because I remembered everything. Then my emotions were present, but things had degenerated beyond what I could stand.

Cold could trigger a sort of attack before I even noticed that I was uncomfortable. I became incapable of taking a decision or of finding a solution to get warm. I couldn't even talk. If I was asked what was wrong, the question was enough to force me to think and to suffer. I began to get nervous if someone didn't immediately lead me to a shelter, but nervousness and the effort of talking made my condition worse. I became completely tongue-tied and felt a strong dislike for the person with me especially if I was asked to help or to hold something. And then I became completely disconnected and felt nothing. Once I kept walking because I could not bring myself to stop or to look at a map, or to think about how I could find my way. I could even have asked for instructions from someone. But, the person would have had to guess without asking me anything. I felt that he would have harassed me with questions, which I would have found unbearable at the time.

How did I not realize that something was wrong, you may ask?

In fact, it is because my thought processes were transformed in an insidious manner. At every moment, I had the impression that I was myself and that I was thinking rationally. For example, I didn't say: "I lack enough energy to do this" but rather "I don't feel like doing this". An example which illustrates the problem of altered judgment is this: during the implementation phase of the diet, I wanted to note the effect that a lapse would have on me. This was transformed in my thoughts from "I must identify my symptoms" to "I must identify my symptoms and I'm tired of this." Often, effects are felt within one hour, but I wasn't able to notice them until five hours later. Oddly, my level of activity had diminished and I once again wanted to look at TV!

I want to point out that it wasn't of things themselves that I was afraid, but I was afraid to have to do them. There is a nuance. I loved people, but I avoided social contact. That made me very unhappy, but, on the other hand, discussions were too difficult for me. There is a nuance there too.

My life was not all as dark as I have described it. I have spoken mostly about the worst moments. **Now I am doing much better thanks to the diet. I am almost never afraid. I am relaxed. I like to laugh in the company of others.** I am no longer afraid of the trip to visit a friend or to ask for a train ticket. I eat much less than before without having to pay special attention. I enjoy life better and am much more available to my friends. Services rendered are no longer one-way, and I know how to return them. I have the impression of having a past, because memories return to me spontaneously. I hardly ever get stressed before problems occur and have learned to manage them when they present themselves instead of always anticipating the worst. A whole lot of tiny details that are not visible from the outside but that, for me, change everything. It is not a question of intellectual capacity. I succeeded in all my courses even without the diet. I think this should not be overlooked.

It simply has to with happiness.

Blouf

At this time when diagnostic criteria have remained stable for several years in California and when the credibility of the diagnostic system with regard to autism has been conclusive since

Autism Epidemic

Records continue to be broken in California and no one knows when the epidemic will stop.

Source FEAT (R. Rollens), January 2002



1970, the Department of Developmental Services (DDS) recently released its latest statistics for the year 2001. These deal with the number of new cases of autism diagnosed in accordance with the criteria established by the DSM IV*

1. If we consider the period covering the years 1970 to 2001, we note that on an annual basis, the 2001 figures represent an all-time record. About 2,725 new autistic children were integrated into the California school system during the year, representing an increase of 20% over the year 2000. The final quarter of 2001 (i.e. from October 4, 2001 to January 3, 2002) also broke all historical records for any year's last quarter year, as did the statistics for the four quarters each of which reached record proportions. There were more cases of autism in 2001 than in the years 1994, 1995, and 1996 combined.
2. In 2001, for the first time in the history of California, autism has become the most important disorder and now accounts for a surprising 35% of all development retardation. Things have gone far beyond the now historical levels of 3%. Autism has surpassed in numerical importance mental deficiency, cerebral palsy, epilepsy and other diseases similar to mental retardation.
3. In California there are now 16,802 autistic

persons in the school system. It took 25 years (from 1970 to 1995) for the number to reach 6,527, and only 3 years (from 1999

About 2,725 new autistic children were integrated into the Californian school system during the year, representing an increase of 20% over the year 2000.

to 2001) for 6,596 new cases to emerge. In other words, the levels that were reached in 25 years doubled in 3 years.

4. According to the DDS, out of the 16,802 autistic persons introduced in the school system in California, 82% are male, 56% have no mental deficiency and 80% were born after 1980, the year that marked the beginning of the autism epidemic. It is important to note that 11,104 of them or 2/3rds (66%) are children aged 0 to 13 years.

* It is to be noted that, according to the DSM IV, autism shares the title of prime category of pervasive development disorders with four other PDDs, i.e., Rett's syndrome, disintegrating childhood disorders, the Asperger syndrome and non-specific PDDs. These statistics apply to autism proper which is the only type considered. The four other categories of PDDs (including Asperger) are not considered.

The *Wakefield* Controversy

An overview

*Autism and intestinal problems:
A New Study*

Source: Autism Research Review International, vol. 15, no. 4, 2001, p.2

A recent discovery by **Dr Timothy Buies**, researcher at Harvard University, confirms the theories of **Dr Wakefield** who first noted the presence of a particular type of inflammation of the intestinal mucous membranes in a number of autistic children. As you know, Dr Wakefield was recently dismissed from the Royal Free and University College Medical School in London after hypothesizing that abnormalities in the digestive system of autistic children could be linked to the MRM vaccine.

Dr. Buies also states that biopsies performed on 15 of the 89 autistic children that he examined had abnormalities in their digestive tract (inflammation of the oesophagus, gastritis, enterocolitis and also nodular lymphoid hyperplasia). The study also reveals that many of these

children suffer from a deficiency in lactase (lactase is the enzyme needed to decompose lactose) and in sucrase (invertase) required for the digestion of sugar. This discovery could explain why the condition of certain children shows considerable improvement when they are put on a milk and sugar-free diet. In addition, researchers have been able to demonstrate that these children had low levels of the disaccharidase/glucoamylase enzyme, thereby confirming certain studies indicating that the addition of certain enzyme supplements could improve the condition of many autistic persons.

Dr. Buies' conclusion is clear: "These children are ill and suffer. They are not merely mentally or neurologically afflicted."

A secret study questioning the role of mercury

Source: Autism Research Review International, vol. 15, no.4, 2001, p.2

A study which has not been made public and which remains confidential, conducted by CDC (Center for Disease Control) scientists in the United States, shows that exposure to significant quantities of mercury during the first three months of life greatly increases the risk that a child will be autistic.

This disclosure was made by a lawyer in the Waters & Kraus firm of legal consultants, members of a group of law offices mandated to represent families of autistic children in at least 25 American states. Lawsuits have been instituted throughout the country in the hope of inciting pharmaceutical companies to look for possible links between vaccines containing mercury and the triggering of some development disorders.

Lawyer Andy Waters states that the CDC report which was not made public, was picked up by the SAFEMINDS group and discloses that the risks of autism are 2.48 times greater in children who have been exposed to more than 62.5 micrograms of mercury in the first three months of their lives. In a press release, the firm of Wa-

ters & Kraus explains "that in the United States, tribunals consider that any risk multiplied by 2 is sufficient to prove that any exposure of this kind provokes the sickness". Waters adds that in the majority of cases assessed by his firm, the autistic children had received more than 62.5 micrograms of mercury through pediatric vaccinations.

Last autumn, a report made public by the same CDC stated that thimerosal, an agent of preservation containing mercury used in many vaccines, was not directly associated to autism. It recommended, however, that doctors avoid, whenever possible, the use of vaccines containing this product. According to Waters & Kraus, the confidential report of the CDC contains different information. Here is a sample: "Concerning the exposure to mercury assessed in children at the age of three months, we have discovered an increase in the risk of neurological development disorders that are associated with a cumulative and growing exposure to thimerosal by a whole category of children suffering from development disorders, in the sub-group

called “specific delays”, and more particularly, in those with “problems related to speech” “autism”, “stuttering”, and “attention deficits”” According to Waters, the content of the report, as well as the fact that it was kept secret, is shocking, but unfortunately not surprising, in view of

the political influence of pharmaceutical companies and the enormous responsibility they would have to assume if they had to reimburse the thousands of families for the care needed by these children.”

Dr Andrew Wakefield forced to leave his position

Andrew Wakefield, the doctor who first made the association between the MMR vaccine (measles, rubella and mumps), autism and intestinal abnormalities, had to leave his position at the Royal Free Hospital in London.

Mrs. Rosemary Kessick, whose autistic son was one of Dr Wakefield’s first patients told of the revulsion felt by parents: “What people fail to realize is that Andrew Wakefield did not need us. We are the ones who needed him, since we were convinced, and rightly so, that our children had intestinal problems which were, in some way, related to autism. Dr Wakefield supported us and because of this he has been treated in a deplorable manner. Barbara Loe Fisher president of the National Vaccine Information Centre agreed with this viewpoint and stated that Wakefield “chose to do what he had to do instead of looking for an easy way out”.

Dr Wakefield has declared that, although he regrets having to leave his work, he does not regret his decision to pursue his research against the advice of the establishment. “Losing my professorship at the Royal Free Hospital of London does not look very good on my résumé”, he says, “ but there are some issues that are important to me. What is most important now is what will happen to these children.”

Ironically, shortly after Dr Wakefield’s departure from the Royal Free Hospital, the British government published a report stating that, with what is known at present, there is no proof that the MMR vaccine could cause autism in certain children. It is to be noted, however, that Timothy Buies, a researcher at Harvard, has just published the results of research that support Wakefield’s theory on the association between autism and certain intestinal abnormalities.

A call to all!

ATEDM is seeking to draw up a file on the possible side effects of vaccination. For this purpose, we are asking parents who noted after-effects or consequences in their children after their vaccination, to tell us about them. Thus, if you noted appreciable changes in the health (for example, digestive problems, diarrhea, infections, etc.) or behaviour of your child in the days or weeks following a vaccination, please phone us at the number shown below, and try to remember the vaccines your child received and

the type of symptoms he is exhibiting as well as the moment they appeared. Your testimony will be treated in complete confidentiality. Several parents have already shared their experiences with us and we hope to compile a more accurate account of children affected and the symptoms observed.

Joanne Lefèbvre,
tél.: (514) 524-6114, ext. 3058
Autisme et troubles envahissants du développement Montréal

My position on the MRM vaccine cost me my job... But I will fight on so that the truth can triumph

by *Dr Andrew Wakefield*
Source FEAT, January 2002



Last year, after 13 years, I left my job as a gastroenterologist at the Royal Free Hospital and University College in London, largely as a result of the measles, mumps rubella vaccine controversy.

Now that I have left, there is one overriding priority: to ensure that children with autism and bowel disease get the investigation and treatment they need and deserve. Prior to my departure, the situation had become very difficult. During the course of our investigations, my colleagues and I had at all times followed the rules of scientific hypothesis testing, peer review and publication.

Despite this, not only was our research programme under threat, but also the provision of clinical care for these children was under increasing pressure, in large part because of the political baggage that the MMR issue brought with it.

However, I have made it clear that I have no intention of stopping the work. Parents should be reassured that the current research programme will be completed. Thereafter, I will go wherever I have to go to continue it. There are other people in the United States doing this work and one possibility is to continue there.

One problem for such work, however, is that within the conventional university structure it is vulnerable. Universities are susceptible to external pressures because they are increasingly financially dependent upon the pharmaceutical industry.

The clinical issue - autism, bowel disease, and possible links with MMR - is a relatively simple story that has become obscured by layers of personal, political, financial and other imperatives that threaten to subvert the issue of how to help these children. This must be resisted if we are to separate fact from wishful thinking.

From the outset, parents have, in good faith, reported their children's symptoms linking bowel symptoms to developmental and behavioural regression. Their concerns have been almost universally dismissed by health care professionals. Some had to wait many years before getting their child investigated.

As doctors we must first listen and then act upon what we have heard. This is one of the tenets of conventional clinical medicine. I was fortunate enough to work with paediatricians who share this belief and are also world leaders in the field of childhood intestinal diseases. Early in our investigations it became clear that the parents were right. They have helped us to identify what appears to be a new bowel disease in a group of children with autism. Since our first report came out in 1998, we have investigated more than 200 children with autism, the majority of whom have a strikingly consistent pattern of intestinal inflammation. There is also growing support from other doctors. People are coming off the fence and acknowledging that genuine questions need to be answered.

Unfortunately, the Government's determination to exonerate the MMR vaccine has led to research data being used inappropriately. Conflicts of interest abound, scientific arguments have been misconstrued, and what remains amounts to little more than propaganda.

Latterly the spotlight has fallen on Leo Blair, the son of the prime minister*. I entirely respect the Blairs' right to privacy. Nonetheless, Tony Blair's response to media questions, while full of sound and fury, was neither convincing nor very helpful. To the more cynical it was reminiscent of the ambiguity of other Presidential denials, such as when Bill Clinton made the infamous remark: "I did not have sexual relations with that woman".

I believe that the Government's response has been inadequate, at times inappropriate, and will ultimately be deemed irresponsible. This is, in my opinion, made inevitable by a structure where politicians, in the face of a controversial medical issue, are dependent on their mandarins at the Department of Health. The latter represent a polarised and rarefied view point, making politicians extremely vulnerable. The Government and its representatives in the Department of Health rely upon epidemiological studies that, among many flaws, have tested hypotheses that have little or no bearing upon the children we have investigated.

Meanwhile, the tragedy for these children continues. Denied appropriate health care already, they continue to be ignored because acknowledgement of their plight could raise the spectre of an association between their disease and the vaccine.

Until we have sufficient evidence, parents should be in a position to choose how they protect their children from these diseases.

The parents' dilemma is shared by my wife Carmel and me. Two of my four children, now four and seven, have not received the MMR vaccine and have yet to receive the single vaccines. When we were trying to work out what to do for the best, the data were only just coming to light. Now, they are beyond the age where measles is really an issue. It is children under two years of age who are at greatest risk if they get measles, and for this reason I would strongly recommend protection with the single vaccine at the recommended age of 15 months.

At times, the criticism over my work has been fierce. My wife has been very supportive. It would have been impossible to continue if she hadn't. We are of a like mind. She reminds me that we have four healthy children and that one can't walk away from the issue saying: 'This is uncomfortable for me so I'm off to a career in liposuction and removing ingrowing toenails.'

The debate should not be polarised into pro or anti-vaccine. The issue is one of how best to protect children. Clearly, if children were to die because there was a measles epidemic and there was no available effective alternative to the MMR jab, that would be enormously regrettable. For this to happen when an effective alternative has been denied would be completely unacceptable.

There should be no reason to raise fears about complications of measles epidemics and measles deaths because the alternative - the single measles vaccine - is there. I regret the message has been distorted and that we have been unable to establish the kind of dialogue that we sought with the Department of Health.

I have no personal regrets; rather it has been a privilege to be involved. Any gratification is however tempered by a knowledge that precious time has been lost for these children to territorial and political imperative.

In the end, for doctors, it may stand as a lesson in humility, reinforcing the roots of clinical medicine. And also humility in deference to the powerful evolutionary forces of parental instinct and recidivist micro-organisms like measles that will return to haunt you if you fail to accord them the greatest respect.

It is also a lesson that there is no substitute for listening.

* It appears, according to some sources in the press, that the Prime Minister's son was not given the measles vaccine in the combined form as recommended by the policy on vaccination existing in Great Britain, but rather through a single vaccine. Rumour has it that the Prime Minister chose this solution because of the possibility of cases of autism.

A new position for Dr Wakefield

We have learned at the start of this new year that Dr Wakefield has accepted the position of scientific director at the ICDRD (International Child Development Resource Centre) in Palm Bay, Florida. The Centre's director, Dr Jeff Bradstreet, is happy with this decision and feels confident that the arrival of Dr Wakefield will contribute to giving worldwide renown to the team of specialists working there. Dr Wakefield will continue his research on the possible link between MMR (measles, rubella, mumps vaccine) and the triggering of autism. He will also study the role of the intestinal tract in the developmental problems observed in the child as well as the causes of certain inflammatory disorders of the intestine such as Crohn's disease and ulcerative colitis. He will be working in collaboration with doctors from various parts of the world.

The Centre now treats more than 1,700 autistic children from all corners of the planet. The cost of its development over three years is estimated to be 25 million dollars. **While clearly affirming its commitment to scientific independence, the ICDRC retains the aim to share the latest research, clinical treatments and therapies, to evaluate the effectiveness of interventions and to develop new protocols oriented directly on the progress of the child.** Its "Open Windows Essential Training" provides training for parents seeking to improve their comprehension of autism and to better direct their interventions. Further information can be obtained on the following Web site: www.icdrc.org

This new occupation seems to satisfy Dr Wakefield: "The world of autism is in a state of crisis," he says. "The number of afflicted children is growing in leaps and bounds. Traditional medicine seems incapable of finding satisfactory responses and even avoids raising the proper questions. The ICDRC breaks with tradition and offers great potential. It will be an honour for my team, as well as for me, to contribute to its realization.

Confirmation of concerns about the measles virus

A new study to be published in April in the *Molecular Pathology* magazine, demonstrates that the measles vaccine is found in the intestinal tissues of a large proportion of children suffering both from development disorders and intestinal inflammation. An Irish team under the leadership of professor John O'Leary, and working in collaboration with Dr Wakefield, arrived at this conclusion after analysing 91 children who exhibited these characteristics. The measles vaccine was detected in 75 of these children, whereas it was found in only 5 children from a control group made up of 70 healthy children. This new study has just relaunched the thesis that the measles vaccine could play a role in triggering autism.

EDITORIAL COMMENT: More than ever, it seems that a complementary study is indispensable.

The usefulness of research groups like the one set up in Montréal by **Dr Spitzer** becomes very important. Remember that the aim of his project is to draw up a protocol based on the epidemiology of autism and to study the influence of environmental factors, including the MMR vaccine, in triggering it. The research which is to be conducted on 3,000 autistic children from 8 countries is backed by the "Foundation for Biomedical Sciences Integrity" under the presidency of Dr Victor Goldbloom.

Reactions of a less alarmist nature . . .

In a climate of controversy pushed to the heights of paroxysm, another study (circulated on the Web, and soon to be published in the *British Medical Journal*) states that there is no link between the MMR vaccine and the presence of "autistic enterocolitis" or the triggering of autism. This British study covered 473 autistic children and was directed by Professor Brent Taylor (who was the first to oppose Dr Wakefield's theories in 1999).

Class action for care adapted to autistic persons

The struggle goes on

Statements obtained from Jean-Marie Berthelot, spokesman for families

Steps taken in 2001

In June 2000, on the initiative of a group of parents, legal steps were initiated to obtain the recognition of the right of all young children with autism of pervasive development disorders to receive early intensive stimulation. The class action is necessary to force the Québec government to offer these children the health services to which they are entitled. One hundred and forty-four children are enrolled at the present time and registrations are continually increasing.

The group of parents obtained financial aid from the *Fond d'aide aux recours collectifs (Financial aid for Class Actions)* enabling them to pursue their struggle without having to organize a major fund raising campaign.

To maintain pressure on the government and to denounce the discrimination which the children have to endure, a letter signed by more than 100 persons and 10 organizations for the defence of the rights of persons afflicted with autism was addressed to Mr Bernard Landry, premier of Québec, and to Rémy Trudel, Minister of Health and Social Services.

This led to a meeting with the premier and the junior minister of Health and Social Services, Mrs Agnès Maltais. The meeting, in turn, led to a request by Mr Landry to Mrs Maltais to the effect that she prepare a presentation on autism to be submitted to the next council of ministers. The premier claimed to be astonished at the lack of services provided to these children.

The organizing committee of the class action subsequently held press conferences in Montréal, Hull and Chicoutimi to confirm that funding had been granted by the *Fonds d'aide* and to announce that the "Request for authorization for a class action" had been deposited.



These press conferences received excellent media attention, both on television and in print.

After this coverage, the head of the opposition party at the National Assembly, Mr Jean Charest questioned the Premier about the reasons that forced parents to pursue the government in order to obtain services to which they are entitled. It is clear that this is a good way to keep up the pressure on the government. The struggle goes on.

The web site is accessible to interested parents and will probably answer any questions they may have on the subject.

www.beaudincom.com/autisme

Zoo-therapy for the autistic child

by Annie Bernatchez, M.A. Ps.

In several special schools in the great metropolis, there are regular zoo-therapy sessions for autistic children. Zoo-therapy can be an individual or group intervention in which a chosen, trained animal is introduced by a qualified party to a person with the hope of developing possible affective, motor, cognitive and social skills. It is a method that supplements the regular services provided to autistic children.

The positive impact of animals on children who find it difficult to establish social relations and who are withdrawn from society is documented in scientific literature. The animal, most often a dog, serves as an effective tool to reduce the child's tendency to withdraw, while enhancing his ability to pay attention and to respond to exterior stimuli, to become better oriented in space and time and promoting social interactions. The use of an animal arouses interesting reactions in a child. Thus, a dog, because of the texture of its fur, its odour, its bark and its warmth allows a child who is withdrawn to turn more to the outside world, and thus to lessen some forms of inappropriate behaviour (self mutilation, stereotypical movements) while increasing appropriate social behaviour (visual contact with the animal, imitating the acts of the trainer). For example, by licking the hand of an autistic child, the dog allows the child to become conscious of another being and of the environment while gradually edging toward physical contact. The dog thus acts as a mediator to counteract the rejection of interpersonal relations. Once he has attracted the attention of the child, the zoo-therapist can pursue other objectives, working with the child through a whole range of activities directly associated with the dog, such as holding it on a leash and walking around with it or throwing it a ball.

A personalized plan of zoo-therapy is devised for each child, taking into account an analysis of the needs of the child and his surroundings, the formulation of objectives to be met and the most appropriate strategies to be followed with the animal. The elaboration of such a plan requires the close collaboration of the zoo-therapist, the special educator and the teacher. An observation grid showing the behaviour of the child during zoo-therapy sessions should be filled in to monitor the progress of the child. It is to be noted that regularity and consistency are important to ensure the child's stability and the results.

In short, because it can bring a number of beneficial services to the child, the animal may turn out to be an ally for a therapist working in a structured manner. The reassuring and encouraging climate introduced during a zoo-therapy session opens up the possibility of all kinds of achievements. Entering into a multifaceted undertaking, zoo-therapy contributes to the improvement of the quality of life of numerous autistic children.



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New of our Web site

autisme.qc.ca

Regular visitors to the Web site of the Québec Federation on Autism and Other Pervasive Development Disorders must have noticed important modifications, since last October, with regard to the presentation of contents and to the structure of the site. In consideration of the new avenues offered through the Internet, we had decided to improve and to make public the enormous work undertaken since the creation of the site in October 1999. We have given our port a more attractive structure that makes room for 14 regional association sites, a chat room, a search engine allowing for a new discussion forum, which is more dynamic and presents more interactive possibilities.

Almost 6,500 visits during the month of January and more than 70,000 pages consulted.

This step is just one in a more complete transformation which, in addition to changing the organizational structure, elicits greater participation from regional associations and other parties in the field. As shown by the frequent requests for collaboration from Quebec and Europe especially, the reputation of the site in the French speaking world, among community organizations, the scientific community and the professionals working for the Department of Health and Social Services is constantly growing, thus meeting our fundamental objectives of discussion and partnership.

In addition to regular reports on scientific news, to monitoring the media, to communiques, to the column entitled *Comprendre l'autisme* (Un-

derstanding autism) and to the notices of conferences, regional events and training sessions, there is on the site the electronic version of *Express*. We will soon be putting on line the new information kit on autism¹ as well as an electronic version of the news bulletin sent to our subscribers on a regular basis.

All these efforts are rewarded on a daily basis by parents who visit the site and to whom, in reality, it is addressed: Almost 6,500 visits during the month of January and more than 70,000 pages consulted. The discussion forum is being used more and more as a means of exchanging opinions, of sharing, advising and comforting. Chat evenings with *Chips and Port* are even being organized - and participation as well as simple curiosity are constantly growing. These data encourage us to continue to produce and publish quality documents in French, with data given in layman's terms, and regular reports on medical research on autism. For a good quality of life and a smoother social integration of autistic children!

¹ List of practical information on the various aspects of the life of an autistic person.

Late breaking news . . .

The Wakefield controversy attracted extraordinary media coverage* during the month of February. We have chosen to reproduce two articles that confirm the need to continue research on MMR vaccines.

A reader's opinion following an article by Isabelle Hachey that appeared in La Presse on February 18, 2002

Madam,

I do not know if you are involved directly in the problems of autism, but it appears that you are not aware of all the studies on the very controversial subject of the association between the MMR vaccine and autism. Allowing yourself to pass judgment on Dr Wakefield's work and to say that it is a botched job is absolutely unacceptable. I wish to remind you that his studies have been published in *Lancet*, *The American Gastroenterology Report* and, more recently, in the *Journal of Clinical Pathology*. It can therefore be assumed that at least his methodology is good enough for these medical journals! Should your spirit of criticism persist, you would be advised to doubt the studies of Taylor and Peltola as well.

You should remember that Peltola's study, financed by the Merck pharmaceutical group, took 14 years and ended in 1996 at a time when no one had yet heard of a link between the MMR vaccine and autism. The word autism does not appear a single time in the study. Peltola himself admitted that the study did not have cases of autism as one of its objectives and that this criterion was not even mentioned. This just to mention one of the most flagrant irregularities concerning the pertinence of such a study in the matter of autism.

As for the Taylor study, it is only a retrospective epidemiologic study that contents itself with analysing data and numbers and verifying the prevalence of gastro-intestinal disorders in autistic children. Dr Wakefield could retort that he checked the medical reports of many children concerned and that the quality of these reports is deplorable, the majority of gastro-enterological symptoms not being listed by the psychiatrists who drew up the reports.

In addition, professor Vijendra K. Singh, biologist at the Department of Biology and Technology Centre, Utah State University, has confirmed Dr Wakefield's works while addressing the problem from another angle, i.e., by looking for the presence of anti-measles antibodies as well as antibodies against neuronal proteins such as myelin in autistic children. More than 60% of autistic children have these antibodies as compared to 0 in the control group. He produced a number of studies on the subject, the most recent of which I urge you to read. *Journal of Allergy Clin. Immunol.* 109 (1) S232, 2002

It is certainly more comfortable to adopt the "medically correct" opinion than to assume the result of these researches, especially when they put into question an institution like vaccination. **The only proper attitude in the face of these results is to demand further research.**

Marie-Christine Destison
Mother of Adrien, autistic person aged 18.

Dr Walter Spitzer asks for a public debate

Over the past few days, *La Presse* has published very definite viewpoints concerning a possible association between the triple vaccine for measles, rubella and mumps and the incidence of autism. It has been suggested by at least one member of the Department of Health and Social Services of the Québec government that my epidemiologic opinions are without proof or scientific foundation. Nobody has approached me to ask for my opinion on this international controversy. It is important that a fair picture be given to the public and especially to parents of autistic children.

Dr Yves Robert rejects the hypothesis that the MMR vaccine could be a risk factor for autism, citing recent articles in this regard. In my opinion, the evidence that we now have does not allow us to involve or to exonerate the triple vaccine as an element in the causality of the disorder. I am convinced that two definitive studies must be undertaken or completed, one on epidemiology and the other a clinical one with laboratory tests. My concern is open minded.

I challenge Dr Robert and I invite him to a public debate anywhere in the province of Québec at any time after May 1st, 2002. My only condition is that the general public, and more particularly the media, be invited to attend. I suggest that the debate be presided by a dean or former dean of a faculty of medicine and that it be coordinated by Dr Victor Goldbloom, pediatric specialist and former minister in the Québec government. All conflicts of interest must be disclosed as well as the proper credentials in epidemiology. I suggest that the debate take place at the University of Montréal.

If the MMR vaccine is harmless, let it be confirmed once and for all. Working in the field of public health, I have a passionate desire to see that proof is obtained - but I respectfully submit that we cannot consider that we have it. I hope Dr Robert accepts the open process that I propose, in order that our short and long term policies may be based on valid and comprehensible scientific data and that they may be accepted and understood by the general public.

Walter O. Spitzer, M.D., M. P.H., F.R.C.P.C.
Professor emeritus in epidemiology
McGill University

* We invite you to consult the section "revue de presse" (Media review) on our Web site to get an idea of the debate.

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