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# Practice

EXPLORING MEMBERS' PRACTICE ISSUES

*Practice* is a quarterly update service from Dietitians of Canada. *Practice* includes information on scientific and clinical developments and Canadian dietitians' experiences and challenges in practice. Opinions expressed in articles are those of the authors and do not imply policy of the Association unless so stated. Articles are not peer-reviewed.

**Submissions** – Submissions are welcome from Dietitians of Canada members. Guidelines for writing reflective articles are available from the Coordinator. Submission deadlines for each issue are:

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**Please forward submissions, suggestions and comments to the Coordinator:**

Catherine Morley, PhD, RD, FDC  
Phone: (604) 925-1209  
E-mail: kikimorley@shaw.ca

**Dietitians of Canada  
Central Information**

480 University Avenue, #604  
Toronto, ON M5G 1V2  
Phone: (416) 596-0857  
Fax: (416) 596-0603  
E-mail: centralinfo@dietitians.ca  
Web site: www.dietitians.ca

## Going Against the Grain – A Look at Autism

When I started my career a few years ago, I knew that the responsible approach to dietetic practice required ongoing access to and use of current reliable information. I assumed that keeping up to date in several well established areas of nutrition would be plenty. Then a chance encounter, coupled with professional curiosity, helped me discover an unexplored path.

I am presently living and working in Switzerland. One day my husband introduced me to a couple whose 25-year-old son is autistic and lives in a home for mentally disabled individuals. I knew next to nothing about this condition and to my surprise, the family told me about the importance of diet in their son's life. I was at a loss. I expressed surprise and interest in learning about what is known as autistic spectrum disorders (ASD). Over time, I got to know this family better and understand their son's difficult life, and also to appreciate their relentless efforts to promote a better understanding of the disorder, to build support/information networks for parents of autistic children, and to establish a parental cooperative to do their volunteer work efficiently.

Here is a simplified summary of what I have learned about diet therapy and autism, a complex condition not yet fully explored and understood, with a much debated etiology, and several therapy options, not all of which are endorsed by the scientific community at large. The numbers of children diagnosed with autism are skyrocketing in several western countries, including Canada. The disorder has many faces. Its etiology comprises several possibilities, some presently controversial: metabolic aberrations, heavy metal toxicity, dietary chemical toxins, antibiotics, opportunistic pathogens, thimerosal in vaccines, and viral damage from vaccines, particularly measles, mumps, rubella (MMR). An already fragile autoimmune system would

lead to an inappropriate defence against or reaction towards one or several of these insults in early life. Multi-organ dysfunction is then suspected, i.e., gut imbalance (bowel inflammation, presence of opioids, dysmotility, leaky gut, dysbiosis), gastric abnormalities (upper and lower reflux, gastritis, disturbed digestive enzyme activity), immune dysfunctions, and brain dysfunctions. On the broad understanding that organs are interconnected, biological and immunological problems would eventually affect brain function and influence behaviour.

A simplified explanation of the leaky gut syndrome illustrates this well. Following an insult to the gastrointestinal (GI) mucosal lining, inflammation would occur; more damage to the membrane would take place; the inflammation would become greater and GI lining permeability would increase, allowing access to a host of unwelcome particles otherwise not able to cross this barrier. If such proteins as gluten or casein, known to have opioid-like properties, enter the blood they could potentially cross the blood-brain barrier and reach the brain. This is suspected to alter brain activity and result in abnormal

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behaviour, such as that observed in many autistic children.

Despite the complex nature of ASD, autism was until quite recently mainly classified as a psychiatric disorder needing strong medication. As many dissatisfied and desperate parents sought alternative solutions, parental associations emerged. They encouraged some physicians and researchers to investigate and support alternative therapies including Applied Behavioural Analysis/Intensive Behavioural Intervention (ABA/IBI), sensory integration, speech therapy, occupational therapy, physical therapy, auditory interventions, Relationship Development Intervention (RDI), and diet therapy.

IBI is now considered an evidence-based therapy, endorsed by behavioural psychologists. This therapy is becoming accessible at no cost to autistic children due to families' class action suits against several provincial governments in Canada. Times are changing; funding for autism research, studies and medical care may be substantially increased. We have only to consider the example of the Charest Government in Quebec and its recent generous budgetary promises.

It may be time for the dietetic community to pay more attention as well. For many years, thousands of parents have used the gluten-free casein-free diet (GFCF) to alleviate symptoms in their autistic children: gut inflammation, diarrhea, constipation, self-abusive behaviour and rage, seizures, hyperactivity and inattention, speech impairment. In some cases, symptoms had completely disappeared using diet alone or in conjunction with other therapies. And that is not all. The diet therapy has become more complex based on research findings. The times of anecdotal trials are over. We are now looking at detailed dietary protocols including GFCF, multiple-food allergy management sometimes involving rotary diversified diets, and dietary supplements for many potential deficiencies. Some medical laboratories offer formulas containing omega-3 fatty acids, digestive enzymes, vitamin B12, vitamin C, vitamin B6, probiotics, folic acid, bovine colostrum, calcium, magnesium, zinc, antioxidants,

cranberry extract, aloe vera, marine derived alginates, beta glucan, lactoferrin, glutathione, and others.

For physicians confronted with the complexity of autism, providing adequate care is a tremendous challenge, often intimidating and discouraging. My inquiries about dietary interventions in autism, whether in conversation with dietitians or on the DC Discussion Area network, remained unanswered. A couple of parents' associations, one in Montreal and another in England, conveyed their observations about dietitians' reluctance to cooperate and provide assistance with the GFCF diet or other 'food eviction' diets. For example, the British parents' association worked for three years for the British Dietetic Association (BDA) to acknowledge the existence of biological symptoms in autism (e.g., inflammatory bowel disease, upper GI abnormalities).

Over time, parents of autistic children seeking medical guidance have gradually lost their trust in doctors and dietitians, who knew less than they did, would not take the time to listen, and refused to consider alternative options for diagnosis and treatment. They struggled on their own and learned about dietary management through trial and error with their own children. Hopefully, there are health care professionals who are taking interest and starting to make a difference. I would like to think I am becoming one of them.

My understanding of the dietary implications in autism is still modest. While there are many pieces of the puzzle missing and treatment approaches being used that future research will resolve or refute, it is essential to give parents of children living with autism professional guidance and follow-up. While listening to parents' stories and comments at conferences on autism, I realized that many are hesitant about the various therapy options available, often quite confused, and very much concerned with their adequacy and safety. At times I felt unwelcome, almost an intruder, hesitating to reveal my profession. I think dietitians can build connections with families living with autism and prove they can help.

We can start by showing that we

are interested to know and do more, especially those of us already dealing with patients suffering from ASD. While we may not necessarily agree with the choices parents make for their children, such as GFCF or nutritional supplements, we can certainly agree on ways to ensure that the diet is calorically and nutritionally adequate for these children, based on their growth and developmental stage, and their individual health and nutritional status. To gain more pertinent knowledge, we can consult many interesting sources containing scientific references, information about therapy programs and upcoming conferences, and practical advice to parents and professionals. Hopefully, nutrition scientists will also become involved in autism research and accelerate the progress made in the nutritional aspects of this condition. With more dietitians and physicians, especially gastroenterologists and pediatricians, becoming more knowledgeable and open to the new medical approaches for autism, autistic individuals will get much improved health care and experience better quality of life.

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### Contact Information:

*Gilda Corpadean Delaunay, PDt  
La Tour Hospital  
Geneva, Switzerland  
[gcorpadean@yahoo.ca](mailto:gcorpadean@yahoo.ca)*