Janice Joneja, born and brought up in England, now has her home in Canada and is internationally renowned for her work on dietary management of food allergy and intolerances. She makes return visits to the UK for teaching at Surrey University and on several such occasions she has presented seminars for Action Against Allergy attended by dieticians and GPs. In 2001 she accepted an invitation to become a patron of AAA.

THIRTY YEARS IN FOOD ALLERGY

My Life as a Scientist, Clinical Dietitian, and Mother

Janice Vickerstaff Joneja Ph.D., RD

Thirty years ago I found myself in a strange dilemma. My training as a scientist and my thinking and emotional response as a mother landed me in a situation where I felt helpless in both roles. My infant son had been diagnosed with severe asthma. He had suffered with eczema almost from birth, first on his face, hands and legs, and later on just about every area of his skin. By the time he was five years old he was dependent on oral steroids for control of both conditions. Whenever we tried to reduce his intake of Prednisone below about 10 mg per day, he would develop severe, and on more than one occasion, life-threatening asthma, which his paediatrician diagnosed as *status asthmaticus*. At the lower dosages of Prednisone the eczema on his hands became extreme; frequently the eczematous patches became infected with common skin bacteria, and his fingers swelled to double their normal size. He would often go to kindergarten wearing little white cotton gloves to cover the oozing sores and to keep in place the steroid-containing ointment that I liberally applied to his hands on the advice of his doctor (I now know that that was actually the wrong thing to do in the circumstances![1])

I had first noticed that he seemed to react to specific foods when he was about two years old. Orange juice would result in him running through the house, screaming. When I tried to hold him to stop the rampage, I felt his whole body quivering and shaking, and it was clear that he had no control over this reaction. Such behaviour could be triggered predictably and consistently by his drinking a glass of orange juice, but occurred at no other time. By the age of about four, this response had

thankfully stopped, but whenever he drank orange, or any other citrus juice for many years, he would start scratching, particularly his hands - a clear indication that it was a likely exacerbating factor for his eczema, which often starts with itching. Another food that would consistently cause similar scratching was chocolate. Hallowe'en and birthday parties were occasions for bartering – all the chocolates, chocolate cake and sweets were assessed, and exchanged for a toy or other desired treasure of equal value. It became a game that finally the whole family enjoyed.

However, whenever I mentioned these "food allergies" to my son's doctors, the response was polite dismissal. It is likely that, because his father was also a physician, they were reluctant to openly label his mother "neurotic" and "over-protective" as so many parents of allergic children were in those days (the mid-1970s). Only one doctor, his respirologist, was frank enough to declare, "There's no such thing as food allergy!" In those days the idea that asthma and eczema have an allergic aetiology, especially the idea that *food* allergy might be involved, was categorically denied by too many medical practitioners. It was not until he was proven to be anaphylactic to peanuts that his medical advisors would entertain the idea that my son might *also* have food allergy, *in addition* to his other problems.

What made the whole situation so bizarre for me was the fact that my early training in immunology took place in the university department where the chairman was none other than Professor Philip Gell, one of the co-discoverers of the antibody responsible for allergy (IgE), and who, with Professor Robin Coombs, developed the classification of the hypersensitivity reactions responsible for allergy, a system that is still recognized today. In essence I learned the immunology of allergy from the undoubted "masters" of the subject, and followed this with research in medical microbiology and immunology, gaining a Ph.D. in the field, and later an appointment as Assistant Professor in Microbiology at the University of British Columbia. I then taught and carried out research in the immunology of mucosal surfaces of the mouth and digestive tract at the University of Colorado Medical School in Denver. I knew the science all right – but when it came to managing my own son's allergies I was helpless.

My concern and confusion were increased to an alarming extent with the events that occurred in my son's thirteenth year. For several months he had been experiencing severe migraines. At their worst they happened three or four times a week with severe headache and vomiting. He would spend twenty-four hours in his darkened bedroom with each episode. Finally he was hospitalized, and every appropriate test was conducted. Special care was taken with these tests, since his own father was the only neurologist (and, incidentally, the only psychiatrist – he is, and was, a Fellow of the Royal College of Physicians and Surgeons of Canada in both specialties) in the town at the time. No pathology was detected that could account for the migraines. His paediatrician prescribed a "parentectomy": she had reached the conclusion that stress within the family home was responsible for our son's problems, and suggested that we should consider making arrangements for his

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living elsewhere. {As an aside, when he did go to boarding school his allergies became even worse than they had been at home!}. Fortunately for us, his parents, who were in danger of living the rest of our lives in the shadow of the guilt engendered by the thought that we alone were responsible for the debilitating ill-health of our only son, a cause for the migraines was discovered. Once again it was related to food.

Based on his observation that he felt nauseated and ill after eating meat, my son decided to become a strict vegetarian. In accordance with his request, when he returned home from his two-week stay in the hospital, with symptoms unchanged in severity and frequency, I provided meals completely free from food derived from any animal source. The most amazing and gratifying result of this drastic change in diet was that he became free from migraines, immediately and completely! For several years he remained a strict vegan in his food choices. He did not eat any meat, poultry, fish, egg, milk, or milk products. He found that ice cream, milk, cheese or other milk-based food caused immediate vomiting. In spite of his continuing anaphylactic reaction to peanuts (even the smallest quantity of peanut as a "hidden ingredient" in a food, accidentally eaten, resulted in immediate throat swelling and the onset of anaphylaxis, requiring prompt medical intervention) he was able to eat any other legume with impunity. This was fortunate, since his main sources of protein were dried peas, beans, lentils, and soy. I became an expert in bean-based gourmet cooking! Years later, as a result of careful food challenges, I discovered that the primary cause of his migraines was pork, followed to a lesser extent by beef. Although he is not now vegetarian, as long as he avoids pork, beef, and foods containing these meats he remains free from those distressing migraine headaches. Interestingly, again as a result of careful food challenges, I discovered that he is also highly sensitive to sulphites – a situation that I now know to be quite common in steroid-dependent asthmatics.

The most important outcome of the experiences with my son's allergic conditions (and later my daughter's) was, for me, the realization that in spite of my specialized knowledge about the scientific bases of the clinical signs I was witnessing at first hand, I, and the medical specialists involved in their care, were unable to be of any real assistance in addressing the causes of my children's allergic diseases. The recognition of the limited resources available to my children, to me, and to the untold numbers of people in similar situations has prompted me to pursue what has been my primary objective in the past twenty years. In 1989 I went back to university to take all the courses and internship required to become a registered dietitian (RD) so that I would be in a position to apply my scientific knowledge of allergy in a clinical setting. Whereas previously I was a laboratory scientist, conducting research into the *mechanisms* responsible for microbial and immunological diseases, now I am focused on the clinical application of the knowledge gained from laboratory

science for the benefit of people experiencing the results of such diseases. This type of "evidence-based" research is becoming increasingly important in medicine, and in no context is it more valid than in the pursuit of understanding and controlling the different ways in which our bodies interact with the food we eat – especially when the food that should nurture becomes a cause of distress.

A unique research program

In 1991, I was instrumental in the establishment of a unique service – the Allergy Nutrition Research Program at Vancouver Hospital and Health Sciences Centre in Vancouver, British Columbia. The program comprised three components:

1. An outpatient clinic where patients could obtain help in the identification and management of their adverse reactions to foods.
2. An information resource, providing information on current research in food allergy for health care professionals such as physicians, public health nurses and dietitians. The dissemination of this material was achieved through numerous seminars, lectures, workshops, radio and television interviews, the publication of books, manuals, audio and video resources, and articles in peer-reviewed medical and scientific journals.
3. Research in adverse reactions to foods, both in the laboratory, and in the clinical setting.

Gradually, with strong lobbying and untiring pressure from allergic patients, parents and the support groups that they formed, such as the AAA, traditional doctors and scientists were forced to look at food allergy more carefully. During the past thirty years there has been a dramatic change from the dismissive attitudes of the 70s, in which at least one paper in a respected medical journal labelled food allergy as "an epidemic of nonsense". Today I am faced with at least one new paper per day on food allergy, which I access on my computer listserve. The amount of information is often overwhelming, and it is a major task to sift through the often conflicting results of thousands of research studies on allergy which currently are being conducted throughout the world.

However, the increasing awareness of food allergy, and the frightening potential for a life-threatening anaphylactic reaction is not without its down-side. As in all aspects of life, there are the extremes where the lack of common sense and moderation pose threats to an almost equal degree. Some years ago I was invited to give a lecture at a conference organized by a food allergy support group in Ontario, Canada. As I made my way to the lecture theatre I was confronted by a distressingly macabre scene – emergency health professionals in full uniform, with ambulance stretchers and hospital gurneys, displaying resuscitation equipment complete with face masks, IV tubing, oxygen cylinders, and syringes ready for injections. Of

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course, such a scenario is not unusual when a patient is at risk of anaphylactic shock, but as an exhibit the message was too stark and frightening for a conference on food allergy in children, and unfortunately, set the tone for the whole of the meeting. Hair-raising stories of fatal and near-fatal anaphylactic reactions, frantic emergency calls, and terrifying races to the hospital by car and ambulance were recounted with relish. The attendees for the most part were parents whose children had been diagnosed with food allergy, and those new to the allergy scene were clearly distressed and upset. While it is always important for anyone associated with food allergy, especially parents and care-givers of atopic infants and children, to be aware of all potential dangers, to present the rare threat of anaphylaxis in such frightening and uncompromising terms amounts to quite unnecessary fear-mongering. Anaphylactic resuscitation is rarely required in the day-to-day management of food allergy, and to generate such fear and anxiety at the outset of a conference designed to equip parents to handle food allergy in their children has the potential to put the well-being of not only the atopic child, but the whole family and its support network, in jeopardy. A story from my years as head of the Allergy Nutrition Program at Vancouver Hospital and Health Sciences Centre in British Columbia illustrates this well.

When parents may be no help

Jason[2] was a 14 year old boy, who was referred to the Allergy Nutrition Clinic by his family doctor who was becoming concerned about his growth and development. He was an only child, and came into the Clinic with his mother and father; his mother was a nurse and his father worked in retail sales. Jason appeared much smaller than would be expected for his age; both parents were of normal height and stature. He was pale and fragile-looking, wearing a baseball cap to hide his thin, sparse hair. His mother told the story:

Jason was a colicky baby and had developed eczema at about two months of age. At six months his mother had consulted an allergist who performed skin tests for food allergy. The parents were informed that the skin tests were "positive to everything," and a list of foods that Jason must avoid was provided by the allergist. Subsequently, mother had conscientiously eliminated all of the "allergy foods", and Jason had never eaten any of them. His diet consisted of about eight foods that were not on the allergist's "avoid list", which he had consumed exclusively since the age of six months. He had been given no nutritional supplements, because mother did not think they were "safe". Jason added his own story: he felt very unhappy in school. He was teased by the other children because of his sparse hair and his small size, which was more typical of a 9-year old than a boy in his early teens. Jason's father said little throughout the interview, but made it clear that he felt his wife was "overprotective" of the child, but thought that being a nurse she was entitled by her training to be in charge of Jason's health. He was obviously unhappy about his child's situation, but felt powerless to intervene in any way.

It was clear to me that Jason needed to start to eat a much wider range of foods than he was presently consuming. His size, fragile appearance, and obvious lack of development were unmistakable indicators that multiple nutritional deficiencies were very real risk factors for his health and well-being.

We arranged for Jason to undergo challenge tests, starting with small amounts of individual foods, and monitoring his reactions in a safe environment. I waited to hear the outcome, hoping for some encouraging news about his progress. Two weeks later, Jason and his mother came into the office; both were noticeably ill-at-ease. Apparently, the challenge test had been cancelled. No new foods had been reintroduced. Gradually, the sad story unfolded: Prior to the day scheduled for the first trial, Jason became extremely anxious and upset. He had become nauseated, vomited continuously, and was unable to sleep. Apparently he was convinced that he was going to die as a result of eating the "bad foods" and was so frightened that it would have been impossible for him to proceed with the reintroduction plan.

The father refused to take any further part in the process, because he disagreed with his wife's handling of Jason's diet, and felt she was over-protective of the boy, to the point of obsession. He had felt optimistic about the original plan for introducing new foods into the boy's diet, but defeated when he was again faced by the fears of his wife and son, and the distressing outcome of the proposed management strategy. He subsequently left the family, and the parents later divorced.

These two scenarios represent extreme examples of the fears and stresses that a diagnosis of food allergy can impose on individuals and families. But the stories are not unrepresentative of the anxiety and uncertainties that people experience when faced with the challenge of managing food allergies, especially in the infants and children who are so utterly dependent on them for their well-being and survival. Sometimes the responsibility seems overwhelming, especially when presented in such graphic terms as the first example, where food allergy appears as a loaded gun, primed and ready to end the life of the innocent child entrusted to their care. However, a loaded gun has to be aimed and fired in order to pose a threat – and even the family car can be an instrument of destruction. So let us be realistic as well as responsible – *be careful not fearful* - and all will be well.

My message to those living with food allergies or caring for an allergic child is: A diagnosis of food allergy is not a sentence of death – it is merely a signal that special caution and knowledge is required, especially in the feeding the youngest of our family of allergy sufferers.

As a result of my research and clinical practice I realized that information on food allergy – its diagnosis, management, and clear directives for meal planning, buying, cooking and recipes for allergen safe foods - was required at all levels. Physicians,

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health care professionals in every field, food allergy sufferers, their children, and families were all desperate for guidance in staying healthy and safe in spite of the challenges that avoidance of sometimes large numbers of foods imposed. In trying to meet these needs, I have written five books and a practice manual (a copy of which I am told is now in just about every health unit and most hospitals in Canada, and many in the USA) on food allergy.(1)

Of course, before an allergen-safe diet can be followed it is essential that the foods, food components and food additives that are responsible for food allergies and intolerances are accurately identified. No diagnostic test alone will reveal the identity of the specific foods that are causing a person's symptoms. Every allergist and medical practitioner in the field recognizes that identification of the culprit food requires a number of diagnostic criteria: a thorough medical history, carefully conducted appropriate medical tests, and elimination and challenge of the foods suspected to be involved in triggering symptoms. The latter is designed to demonstrate that eliminating the food avoids the symptoms, and, importantly, that eating the food will cause the symptoms to reappear.

It is not an easy journey through the maze of food sensitivity, and many factors in addition to the food itself will influence the expression of a person's symptoms. Nevertheless, there is a lot a person can do to improve their health and increase their enjoyment of life, despite a sensitivity to food. With the strong foundation of knowledge, a clear vision of the essential nutritional value of food and a dose of common sense, good health and happiness can be achieved in safety.

(Footnotes)

1. In this case, my son's eczema was clearly infected with bacteria: he should have been prescribed an antibiotic to clear up the infection. Applying corticosteroid cream only made things worse. Corticosteroids suppress the immune response, and therefore lead to increased bacterial growth. 2. Name has been changed

(Endnotes)

(1) Joneja, J.M.Vickerstaff *Dealing with Food Allergies in Babies and Children* Bull Publishing Company, Boulder, Colorado. October 2007 ISBN 978-1933503-05-9 Available from Merton Books, PO Box 279, Twickenham TW1 4XQ T:020 8892 4949, at Special Offer £13.75 inc.p&p.

Joneja, J.M.Vickerstaff *Dealing with Food Allergies: A Practical Guide to Detecting Culprit Foods and Eating a Healthy, Enjoyable Diet* Bull Publishing Company, Boulder, Colorado. May 2003 ISBN 0-923521-64-X. Available from Merton Books as above. £13.75 Special Offer.

Joneja, J.M.Vickerstaff *Digestion, Diet and Disease: Irritable Bowel Syndrome and Gastrointestinal Function* Rutgers University Press, Piscataway, New Jersey. August 2004 ISBN 0-8135-3387-2

For lots of helpful information on all aspects of food allergies and intolerances, visit Dr Joneja's website at www.allergynutrition.com