

**Editor's Notebook: Bernard Rimland, Ph.D.****Autism, digestive enzymes, the Internet, and fraud**

The Internet has become a major source of information on many subjects, including autism. The information ranges all the way from good, useful and reliable, through well-intentioned but incorrect or partially correct, to postings which are fraudulent and potentially harmful.

During the past few months many friends have called my attention to what appears to be an Internet scam, operated by people with questionable ethics, which may harm autistic children or their families both physically and financially.

**The Enzymes for Autism Story.** Best to start quite a bit earlier: As long ago as the 1960s I began to hear from parents whose autistic children improved remarkably when put on a strict dairy-free or wheat-free diet. Solid research—often reported on these pages—supported the parents' observations and provided an understanding of why the diet worked. The casein in dairy products and the gluten in wheat (and other grains) were not properly digested by autistic children. Peptides, very small fractions of these foods, escaped through the intestinal wall, into the bloodstream and disrupted the brain.

In January 1995, pediatrician Sid Baker, chemist (and fellow parent) Jon Pangborn and I convened the first Defeat Autism Now! (DAN!) think tank of 30 carefully chosen physicians and scientists to jump-start the agonizingly slow pace of productive research in autism. Unraveling the mysteries of the gluten/casein free (gf/cf) diet was a top priority. It was hard for mothers to maintain such a diet, since even tiny amounts of casein or gluten could be severely disruptive to the child's behavior. Since our group included the world's top experts, I was eager to ask a question I had been saving for the occasion: "How about digestive enzymes?" Jon Pangborn had long considered the problem. "The trouble with digestive enzymes is that they are mostly proteases, designed to break down proteins. Our problem is breaking down the smaller particles, the peptides." "Can't we design and produce peptidase enzymes that will break down peptides?" I asked. Jon thought a moment and said "Yes, I think it can be done." "Let's do it" I said. "The ARI will fund your efforts."

Using our Institute's funds, supplemented by his own money, Jon designed the chemical structure of the needed peptidase enzymes, then undertook a worldwide search for companies that could manufacture the product to his specifications.

In 1996, Claire Farr, whom I had known for 30 years, the owner of Klaire Laboratories, a small manufacturer of high-quality hypoallergenic supplements, joined the project, investing her funds and expertise in the effort, even though sales of the product

were expected to be miniscule. (This was long before the coming autism epidemic was recognized.) She assigned her top aide, Ilene Buchholz, R.N., to assist in the project. Several firms were contacted in a search for a palatable, effective embodiment of Jon's formula. One of these was the National Enzyme Company, which specializes in such products.

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The moral of this story is an old one: "Let the buyer beware." Especially on the Internet. Remember, a skilled Internet marketer can concoct 20 convincing—and unverifiable—testimonials in half an hour. Insist on seeing legitimate data from independent third parties before you turn your child into a guinea pig.

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On September 18, 1998, Ilene's records show, she spoke with representatives of National Enzymes, then sent them a sheaf of Jon's technical papers and specifications.

The product produced by National Enzymes was promising enough to warrant a field tryout. Ilene recruited six careful and competent pediatricians with whom she had worked closely in the past to provide medical supervision of the tryout of the new product, which Klaire Labs named SerenAid. Special evaluation forms designed by ARI were completed weekly for each child and collected and compiled by ARI. The purpose of SerenAid was not to replace the gf/cf diet, but to provide a safety net, so the small amounts of gluten and casein that escaped the mother's surveillance could be digested. SerenAid was a success. The children showed significant improvement. Jon announced the positive findings at our 1999 DAN! Conference in Cherry Hill, New Jersey.

Although Jon and I (especially Jon) were the inventors, we did not apply for a patent. We each had several patents, but this invention was to be a gift to our fellow parents.

In the meantime, Claire Farr sold Klaire Laboratories and retired. Ilene went to work for Kirkman Laboratories which, at my request, had started making a flavored vitamin B6 product in 1967, when there was almost no market for the product. Kirkman hired Jon as a consultant and soon began producing and medically field-testing its own enzyme product, named EnzymAid.

Imagine our dismay when Jon and I learned last year that the chemist employed by National Enzymes, who was sent Jon's technical papers by Ilene, had applied for and received a patent on the digestive enzymes Jon had designed for autistic children! He got the patent by falsely telling the U.S. Patent Office that he was the inventor, and falsely claiming that he had revealed all relevant "prior art" in his application. (He failed

somehow to mention Jon's papers which formed the basis for the invention.) The patent is useless, since it was fraudulently obtained.

The chemist then went on to make and sell his own enzymes for autism. He started a Yahoo Internet chat group to extol the virtues of his products (which had not undergone field testing for safety and efficacy by board-certified pediatricians and allergists, as had the Klaire and Kirkman products). Since his running the chat group violated Yahoo rules, he obtained the services of an Internet marketing specialist who lectures on "How to Use the Internet to Boost Your Sales." The chat group run by this marketer consistently heaps praise on the pseudo-inventor's products and disparages the legitimately tried and tested enzyme products produced by Klaire and Kirkman—trustworthy firms that truly *care* about the children.

If the issue were merely the unsavory business practices of the chemist and the marketer, I would not be wasting my time telling you all this. What really concerns me is the No-Fenol product the chemist has started selling to parents of autistic children, skillfully marketed by his agent. When Jon Pangborn—probably the world's top expert on the biochemistry of autism—learned of No-Fenol, he was alarmed. "This could be very harmful!" he told me. Sure enough, mothers are now reporting to the chat room that their children are experiencing side effects including extreme hyperactivity, aggression, hot flushed face and ears, profuse sweating, bedwetting, and constipation or diarrhea. The marketer, who has no medical training or credentials, reassures them by saying that the symptoms they are seeing are beneficial—signs that the child is getting better. Incredible! Intolerable! (Added in press: comment from Jon Pangborn, p. 7.)

Quite apart from the potential harm done by No-Fenol is the potential harm the chemist and the marketer may do as they insist that the gf/cf diet is unnecessary—"Just buy more enzymes." "That is contradictory to our experience," say Lisa Lewis, Karyn Seroussi and other recognized experts who have no financial incentive to give bad advice. See their website, [gfcfdietsupport.com](http://gfcfdietsupport.com).

The moral of this story is an old one: "Let the buyer beware." Especially on the Internet. A skilled Internet marketer can concoct 20 convincing—and unverifiable—testimonials in half an hour. Insist on seeing legitimate data from independent third parties before you turn your child into a guinea pig. The gf/cf diet unquestionably helps many children, as do digestive enzymes (see letters, p. 7).

For further information, and documentation of the foregoing, visit the ARI website: [www.autismresearchinstitute.com](http://www.autismresearchinstitute.com).