

Pure Facts

Newsletter of the Feingold® Associations of the United States



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Autism — the invisible prison

Can the Feingold Program help an autistic child? Volunteers are cautious not to offer false hope, but some parents report a significant reduction of symptoms.

The autistic child doesn't interact normally with other people, and may even be unable to relate to his parents. Development is slow in many areas, including speech, comprehension, and social skills. An autistic child may behave in bizarre ways, feeling compelled to obsessively repeat behaviors; or he may have an extraordinary sensitivity to stimuli such as noise, lights, touch, or odors.

This condition is estimated by the National Institutes of Health to occur in about five out of every 10,000 births and affects boys four times as often as girls.

Some children exhibit autistic symptoms to a lesser degree and may be labeled as "autistic-like". The child who has been diagnosed as hyperactive or ADD, may have some autistic characteristics. (See the April 1992 issue of *Pure Facts* which describes unusual sensitivity to noise, light, or touch.) This seems to indicate that rather than being separate conditions, various behavior disorders such as ADD, autism, and obsessive-compulsive disorder may be related, at least in some children. Tourette Syndrome may also fit into this pattern.

In the 1940's many doctors believed that autism was the result of a cold, rejecting mother, and the diagnosis was a life sentence. More recently, these ideas have been replaced with the belief that it is a physical disorder, not a psychological one; recent observations suggest that exposure to toxic chemicals can contribute to the birth of an autistic child. Innovative treatments are helping bring some children out of their shells, and important contributions to the understanding of autism are coming from parents and from their recovered children.



Mary Callahan's book, *"Fighting for Tony"* is an account of her successful struggle to deal with her son's devastating condition. Mary discovered that Tony's autistic behavior was due solely to a severe milk allergy.

Judy Barron and her son, Sean, co-authored the book, *"There's a Boy in Here"*. Judy persistently refused to allow Sean to divorce himself from the real world. It took years of effort on Judy's part, but at age 16 Sean began to leave his autistic isolation.

This approach has been dramatically related by Barry Neil Kaufman in his book about his child, *"Son-Rise"*, and his more recent, *"A Miracle to Believe In."*

Donna Williams wrote about her own struggle to emerge from her autistic prison in the new book, *"Nobody, Nowhere"*. She was able to benefit from many approaches, including a change in diet. Feingold members will be among the few who understand her reference to "salicylates" on page 160.

"The Sound of a Miracle", by Anabel Stehli, describes a technique which helps the autistic person who is extraordinarily sensitive to sound. For such a child the gentle patter of raindrops on a roof can have the intensity of explosions.

Another approach to opening the autistic prison is called facilitated communication. Proponents report that some autistic children who are unable to speak can communicate well by using a computer. A trained adult gently supports their arm and the child communicates by typing.

This technique was originally developed in Australia, and is being taught in the United States by Dr. Douglas Biklen at Syracuse University. (Facilitated Communication Project, Syracuse University, Division of Special Education and Rehabilitation, 805 South Crouse Ave., Syracuse, NY 13244-2208 / 315-443-9657.)

A pioneer in the search for treatment is Dr. Bernard Rimland, director of the Autism Research Institute. The institute provides information on current developments in the diagnosing and treatment of autistic children, as well as literature on controlled studies. You can request a "Parent Package" which includes a diagnostic checklist, sample of the informational newsletter and much helpful information. Write to: ARI, 4182 Adams Ave., San Diego, CA 92116. (The ARI is a nonprofit organization; please enclose a \$5 donation to defray costs.)

Parents are also playing a crucial part in the search for causes of autism. The keen observation of a Leominster, MA mother has strongly implicated the polluted air and water generated by a factory in her town as a cause of the birth of an extraordinary number of autistic children. Even when a parent has been away from the town for many years, their future children are at high risk. The closer the citizens lived to the factory site, the higher the incidence of autism.

The Feingold® Associations of the United States, Inc., founded in 1976, are non-profit volunteer organizations whose purposes are to support their members in the implementation of the Feingold Program and to generate public awareness of the potential role of foods and synthetic additives in behavior, learning and health problems. The program is based on a diet eliminating synthetic colors, synthetic flavors, and the preservatives BHA, BHT, and TBHQ.

Notes on Autism

Some parents of autistic children report that those behaviors lessen when they avoid synthetic chemicals. Other parents note that the child behaves normally while on the Program, but that an infraction results in behaviors characteristic of autism.

The Association is eager to receive feedback from members who have used the program for an autistic child. We are interested in hearing about both what helped and what did not.

Dr. Feingold's comment that this diet "entails no risk, no harm," and the observation of many professionals that "it's worth a try" seem especially appropriate for the parent facing the devastation of autism.

For the child who is not comfortable in our world, and whose body may already be suffering from the effects of toxic chemicals, what is to be gained by exposure to the non-essential synthetic chemicals added to foods?

Note: A TV documentary on the Leominster, MA community included an interview of the mother who traced her autistic child's condition to the town's industrial pollution. Ironically, one scene showed her frosting a brilliantly-colored birthday cake for her child.



Nontoxic Home and Work

Readers who have enjoyed the books by Debra Lynn Dadd will be pleased to know of her new book, *The Nontoxic Home and Office*. This is an updating of her earlier book, *The Nontoxic Home*.

It is published by Jeremy P. Tar-cher, Inc. and costs \$10.95.

Down the tubes!

The Dasun Company, manufacturer of Non-scents, now has a non-caustic, non-acid drain opener.

The product, called B.D.O. 101, (short for biological drain opener) uses bacteria organisms to break up and remove organic deposits in the drain, allowing them to be flushed out.

For more information contact The Dasun Company at P.O. Box M, Escondido, CA 92033 / 1-800-433-8929.

MCS - Multiple Chemical Sensitivity

The syndrome called "multiple chemical sensitivity" (an adverse reaction to a wide range of substances) continues to be a controversial topic within the medical community, but those who suffer from it have reason to be encouraged.

In October Congress appropriated \$250,000 for research on MCS, to be coordinated with the nonprofit National Center for Environmental Health Strategies (NCEHS). The funds will be used to hold workshops to develop research protocols and to establish a registry for people with this illness, according to NCEHS president, Mary Lamielle, a MCS sufferer.

Support for further research has also come from the National Academy of Sciences, which has released two reports on the subject of MCS. "Biological Markers in Immunotoxicology" discusses the problem of "sick building syndrome", which is believed to be a trigger for MCS. The second report is titled, "Multiple Chemical

Sensitivities". Both of these reports are available from the NCEHS, 1100 Rural Avenue, Voorhees, NJ 08043 (609) 429-5358.

While MCS is gaining recognition, it continues to face stiff opposition from some medical groups which regard it as imaginary. The president of the American Academy of Allergy and Immunology called Chronic Fatigue Syndrome and MCS "controversial subjects...unhappily exploited by some individuals in the medical and legal community."

The American Medical Association, by contrast, has adopted a neutral position on the treatment of these problems, which is generally referred to as "clinical ecology."

Fragrances — MCS nightmare

If you're sensitive to fragrances, you may have wondered about the regulations that govern their manufacture and use. In practice, there really aren't any.

The Food and Drug Administration is responsible for fragrances used in perfumes and personal care products, but manufacturers are not required to obtain FDA approval before using any such chemical additive in non-food products. (The exception is synthetic coloring, which is regulated.)

Writing in *The Human Ecologist*, Louise Kosta notes, "Since cosmetic manufacturers are not required to clear fragrance ingredients prior to product sale, they do not. Extensive research on fragrance materials has been done by the industry, but, like fragrance formulas, this information is proprietary. Moreover, reports of adverse effects received by fragrance manufacturers from consumers need not be reported to FDA. Their participation in FDA's 'passive surveillance system,' which monitors cosmetics' adverse reactions, is strictly voluntary."

California tackles perfume pollution

If you're one of the people who suffers from an unpleasant physical reaction to perfume, you may consider it a form of air pollution. It seems the state of California shares your opinion. The state's new anti-pollution laws will regulate not only perfume, but cologne, hair spray, and many household products which contribute to the formation of smog.

Pollution control officials in the state hope to reduce California's air pollution by a whopping 60 tons a day. Some products are being reformulated now, while others will be phased in gradually. California's Air Resources Board had initially intended for the regulations to take effect quickly, but industry protests have extended the time allowed for compliance.

New York state has initiated similar rules regarding deodorants, hairsprays and antiperspirants.

My son, Michael

Brenda Eskridge didn't want to believe her son was autistic. Michael didn't display all of the characteristics of autism, but he had so many that the prognosis looked bad.

From day one he had been extremely hyperactive, had numerous allergies, ear infections, poor sleep habits, cried frequently, seemed always to be agitated, and resisted being held. It was futile to try to comfort this little baby, who stiffened his body so that it was rigid and hard. By age two it was clear that Michael's language was not developing. He would later learn to speak, but could only repeat what he heard. If he was asked, "Would you

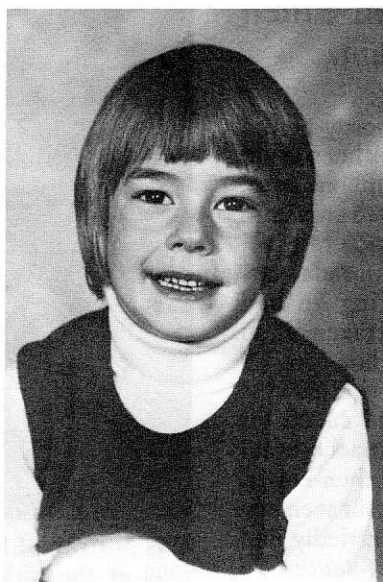
phenomenal and when he was only three he could identify his favorite records just by their titles printed on the label.

Brenda agreed to try medication. The first day was wonderful; the three year old could sit in a chair, and could look at his mother. The second day he sat in the chair, but that was all he could do; the little boy stared straight ahead with a vacant look. On the third day of Ritalin, Brenda describes him as a

pediatrics at the University of Oklahoma had a scale of 1 to 10 for rating hyperactive children — number 1 was normal behavior and 10 was the most severely hyperactive. He rated Michael a 13! Another doctor observed Michael in his school. Less than ten minutes passed when the diagnosis was "autistic". At the urging of the preschool teacher, the physician stayed to watch him for a longer time. The diagnosis was changed to "mildly retarded",

like to go outside, Michael?" his response, "Would you like to go outside, Michael?" was a code for saying "yes". When a preschool teacher tried to coax him down from climbing up a bookcase, he echoed her words, "No, no, Michael, please come back down!" with a tone of anguish that seemed like his body had taken on a will of its own.

The Eskridge's exhaustive search for answers was as distressing as their child's problems; Brenda was blamed for everything. Since she was 29 when he was born, her doctor reasoned that Brenda had "spoiled him rotten" and her refusal to accept



The picture on the left was taken in October of 1975. The one on the right is from January of 1976, after Michael had been on the Feingold Program for 2 1/2 months. Long after the portraits were taken, Brenda was struck by the difference in his appearance.

the verdict indicated her refusal to accept reality. She was told she was over-protective by some people while others blamed her for neglect. Brenda recalls a team of child developmental specialists who spent two and a half hours in a room with Michael. They went into the room prim and proper, and emerged later in a state of disarray, with the psychologist's blouse hanging part way out of her dress-for-success skirt. The recommendation Brenda received was "Michael was retarded below age 2; the Eskridges should institutionalize him, go home, and have another baby."

But this little boy had some remarkable strengths. His memory was

"raving maniac". Other drugs were tried, but Michael "freaked out" on them. (He was already on a heavy regimen of drugs to control seizures, asthma and allergic reactions.)

In the preschool designed for learning disabled children, four year old Michael continued to operate in a frenzy of activity. He had the autistic traits of rocking, twirling and walking in circles. Brenda saw he was trying to fit in, but was too agitated, stiff, and simply too busy to do so. His own negative behavior seemed to be very upsetting to him. He seemed impervious to pain, and it was as though his mind was too far ahead of his body and the body was unable to catch up. A professor of

reaction to the Feingold diet was terrible! Nearly two decades later, Brenda recalls the nightmare she went through after she removed the synthetic additives from Michael's food and medicine. He went from a "13" to a "20"; the experience was horrible. Brenda now believes that he was suffering from symptoms of withdrawal. (This is the opposite of what most families report, but underlines the importance of parents staying in close touch with their physician. They had changed doctors and Michael was now under the care of a sympathetic professional.)

and then later "really bright". The final diagnosis was a sincerely befuddled "I have no idea!"

Brenda's mother had heard of a doctor from California whose treatment for hyperactive children was generating a lot of controversy. It was the mid 1970's, and *Why Your Child is Hyperactive* had just been published. After much searching, Brenda located the book and decided that after trying everything else she would do this as well. At least there could be no harm from it — that proved to be wrong. Michael's

Continued on page 4

The Eskridges had committed themselves to give the Feingold diet a 100% effort for 30 days, and persisted through several weeks of Michael's destructive behavior. Brenda reasoned that patients are told to give medicine a 14 to 30 day period before it may work, and felt the same could be true of a dietary change. But her patience was wearing thin; there were only 2 or 3 days of the 30 day trial left, and Michael had shown no improvement.

Brenda saw Michael lying in the snow with his eyes closed. Michael opened his eyes and said "tired", then he closed them again.

It was a snowy day, shortly before Christmas, and Brenda took her son out to play in the snow. The phone rang, and she went inside briefly to answer it. When she came back outside Michael was nowhere to be found. Brenda searched frantically, expecting he had climbed over the fence and taken off, so it was a shock to discover him lying on the ground, in the snow, with his eyes closed. Alarmed, Brenda called his name and shook him. Michael opened his eyes and said "tired", then closed them again. Brenda had never seen him tired. She carried him hurriedly into the house, searching for evidence of a blow to the head or other injury, but could find none. She changed him into dry clothes and took his temperature, but Michael slept through it all.

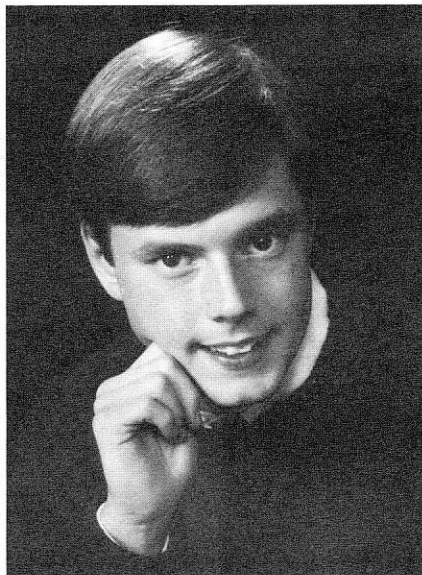
The Eskridges didn't dare talk about the change in Michael for three days.

Two and a half hours later he was still sleeping when Brenda rushed him to her pediatrician's office. The doctor knew Michael well, and feared head trauma. The office was filled with crying children, with the exception of one who slept peacefully on Brenda's lap. After a 1 1/2 hour wait the pediatrician went over Michael "with a fine tooth comb, checking for everything!" Finally a little smile came over the doctor's face, "Brenda, Michael is asleep." "Come here," he told her, "I

want you to feel his leg." She pressed her finger into the soft flesh and was startled that it was not characteristically rock hard. "What's wrong?" she asked anxiously. The doctor gently explained, "Honey, that's the way he's supposed to feel. I don't know if it's the diet you're on or a miracle, but this child's muscle tone is normal."

It was the first time Michael had experienced a restful sleep. He slept for a long time and then all night long.

The next day when Michael came home from school he willingly sat on Brenda's lap and listened to a story without her having to hold him there. She took him for a walk and didn't have



This portrait of Michael was taken in 1990 at the time of his high school graduation.

to hold on to him. "That night my husband and I sat in astonishment as we watched our son sit down quietly and eat his dinner. We didn't dare talk about what was happening for three days. It was as though doing so would somehow break the spell."

Similar wonders were taking place in the classroom as well and it was several days before Michael's teacher dared to say anything. "He can sit, he can listen to instructions" were the heavenly words Brenda heard, and the two women hugged from sheer joy. Within two months of beginning the diet, his hyperactivity went from a 13 to a 3. The seizures stopped after a year on the diet, only to return after an infraction.

The first infraction was a memorable event caused by a red sucker. The nightmare behavior came back in full

force and it was a week before the calm child returned. Another time Michael had a drink of Dr. Pepper, Brenda relates, and didn't know where he was. She found him in his bedroom, disoriented and acting spacy. He cried and hugged her, wanting her to take him home.

Since his verbal skills were still limited, Brenda had not said anything to Michael about their change in foods, and she assumed he had no idea he was on a diet. But the next time Brenda's brother came to the house, and Michael saw his uncle holding a bottle of Dr. Pepper, the four year old said, "Uncle Kenny, Dr. Pepper makes you wild and crazy."

Michael figured out a lot about food additives and their effect. He said that red suckers make his head hurt real bad. Other foods "make his stomach dizzy." He was extremely careful not to put anything in his mouth unless it came from his mother, grandmother or teacher. Today, at age 21, Michael still sticks completely to his diet.

At Michael's high school graduation Brenda ran into the doctor who had told her she had created all of her son's problems. There were no apologies.

He attended public school and graduated with a C average. Teachers who read Michael's history tried hard to avoid having him in their class. A few weeks later, they fought to keep him from being transferred out. He was invariably the hardest working and best behaved student, and was eager to win their approval.

The pediatrician who first told Brenda her son was sleeping normally has kept track of his patient to this day. He tells parents about Michael and that diet is an option to consider for their child. Professionals have expressed their appreciation to the Eskridge family for having opened the door to so many other children. They are not as quick to put limitations on any child and are open to trying new techniques that may be unproven, but cause no harm.

Today Brenda describes the son she was advised to give up on as "loving, responsive, bright, curious, wonderful, and a great kid."

Too Much Candy!

It used to be just the bank and the barber shop where every child left with a lollypop in hand.

Doctor's offices climbed on board, as did scouts and Sunday school. Candy sales helped to fund school clubs and athletics. Candy machines joined the soft drinks in nearly every place visited by children. Shopping malls sport enormous gum ball dispensers. It's hard to find a place where children are not met with synthetically dyed and flavored confections. Other than an occasional class party, the classroom was "safe" and of course, gum and school were longtime enemies.

Now children are learning their "A, B, C's for candy" and being given it on a regular basis by their teachers.

Our society equates candy with love; just think of all the terms of endearment that use the words "sugar" "sweet" or "honey". Most parents are likely to see no harm in teachers rewarding the child for finishing a math assignment or writing all of the spelling words correctly. But what about those parents who don't want their child to be given candy? The parent could be a dentist, a diabetic, an adult battling a food addiction, a Feingold parent, or a person who simply wants to be responsible for what her child eats. Whether the teacher gives candy to every child but one, or gives an alternative treat to that child, he is singled out and feels what most children don't want to feel — different.

That is not the only reason to question this practice. What effect might it have on the school's goal of teaching that learning has its own reward? And why does the candy payoff bring to mind the morsel a trainer gives the animal who has performed a stunt?

While it may not be possible to talk adults out of giving rewards, you might be able to convince some of them to switch to the inexpensive trinkets available through mail order companies. One such company is Oriental Trading Co., Inc, P.O. Box 3407, Omaha, NE 68103 phone 1-800-228-6800. Their catalogs list page after page of inexpensive toys and trinkets which could be used as prizes, fund raisers, and for concerned parents to give out at Halloween.

PIC Report

from the FAUS Product Information Committee

Hot Dog Time Wampler-Longacre Turkey Franks and Chicken Franks are acceptable for use by Feingold members. The turkey franks contain nitrites, and the chicken franks contain both nitrites and HVP. (HVP stands for hydrolyzed vegetable protein, which contains some monosodium glutamate, or MSG.)

According to the company, Wampler-Longacre products are available in California, Colorado, in states east of the Mississippi and north of North Carolina. For more details on finding these foods, you may wish to contact the company at P.O. Box 8, Franconia, PA 18924-0008 / 215-723-4335.

Other Wampler-Longacre products which may be added to your Stage One foodlist are:

Turkey Burgers (frozen)

Ground Turkey (frozen)

Ground Chicken

The various cuts of Wampler-Longacre fresh poultry are also acceptable.

New Breads and Rolls The following Roman Meal Mixed Grains products have been researched and may be added to your Stage One Foodlist. All of them contain corn syrup and calcium propionate.

Brown 'N Serve Rolls

Sandwich Rolls

Hamburger Buns

Hot Dog Buns

Sandwich Bread

Round Top Bread

Dinner Rolls

To Top it all off! Reddi Whip Lite (CS) whipped topping in an aerosol can has just been found acceptable for use. Look for the silver can and check the ingredient label as there are many varieties of Reddi Whip.

Product Alert!

Sorrell Ridge Pineapple Spreadable Fruit was reported in some local newsletters as acceptable for use on Stage One. This is incorrect as the product contains grape juice. It is acceptable, however, for Stage Two. The manufacturer apologizes for the error.

No (April) Foolin!

Dear PF,

Why do the foodlists have only Heniz distilled vinegar on Stage One?

Needless to say, vinegars made from wine and apples are excluded from Stage One because these are salicylates.

The process of making vinegar begins with alcohol, which can be produced through the fermentation of various foods, such as fruits, vegetables and grains. But it is also possible to make alcohol from non-food substances, including natural gas and petroleum derivatives! When you buy distilled vinegar the label need not tell you the source of the alcohol.

Heinz is specified on foodlist because its distilled vinegar is made from corn, and because it has long been well tolerated by Feingold members.

The Feingold® Associations do not endorse, approve or assume responsibility for any product, brand, method or treatment. The presence (or absence) of a product on a Feingold foodlist, or the discussion of a method or treatment does not constitute approval (or disapproval). The foodlists are based primarily upon information supplied by manufacturers, and are not based upon independent testing.

Flowers for Mother's Day

Your next floral order can help fund the work of the Feingold Association.

If you like to send flowers on Mother's Day — or any other time of the year — you may want to look into a new service offering freshly cut flowers flown in from Holland and delivered to the lucky recipient in approximately 48 hours.

By cutting out several "middle men" flowers reach their recipient fresher and healthier, can be offered at competitive prices, and allow the Feingold Association to receive a contribution of 20% of the cost of the order.

Bloomen is the name of the program which uses international jet service to bring flowers from the famous Dutch auctions to the U.S. The blooms are not only fresher than most domestic flowers, they are nourished, kept under controlled temperature and specially packaged. The stems are pre-trimmed so the bouquet will fall into an arrangement when it is placed in a vase.

You can place an order by calling 1-800-289-5151 and providing the "dealer code number" 10192. This will insure that a 20% donation will go to the Feingold Association. (Thanks to Bloomen for waiving all fees for the Association to sign up, and thanks to Judy Schneider for her work on this project.)

Whitman's Candy

The Whitman Candy Company has recently been purchased by the Russell Stover Company. We have found in the past, when a candy company changes hands it often means a change in the recipe — generally a switch to synthetic vanilla.

When you purchase Whitman's all natural milk chocolate bar in the future, check out the ingredient listing on the wrapper...just to be sure.

The high cost of beauty

The Food and Drug Administration reports that some beauty salons advertise permanent dyeing or tinting of eyebrows and eyelashes, despite the fact that this is illegal, and has been so since 1938.

Hair dyes used near the eyes have resulted in serious injury and blindness, and the law requires that they carry warning labels to this effect.

Advertisements for permanent dyes are more likely to be found during the summer months, as they won't wash off while swimming or from perspiration.

Cosmetic eye products such as mascara, eye shadow, eye liner and eyebrow pencils use "uncertified" colorings which are not considered harmful. The synthetic dyes eliminated on the Feingold Program are not permitted for use in cosmetics designed to be used near the eyes. (Of course, they are permitted to be used in other cosmetics, and in food and medicines.)



Pure Facts

Pure Facts is published ten times a year and is a portion of the material provided to members of the Feingold Association of the United States.

For information contact FAUS, P.O. Box 6550, Alexandria, VA 22306 or call (703) 768-3287.

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Confections

If you're in the market for chocolate or yogurt melting wafers, check the produce section of your supermarket for **Saco's Dulci Frutta**. Many stores carry these alongside the fresh strawberries, and may have them only in the spring months.

These confections have many uses. In addition to dipping fruits (try bananas on stage one) you can use them to coat pretzels, or make your own cereal & nut clusters. These treats are fast, nearly effortless, and they are projects you can do with your children.

Getting to know your Stage One list

Some new members find it's easier to use their foodlist if they first highlight the foods their family likes with a marking pen.

One mom said she had good results by making a note next to each product of which supermarket had it, or which one had the best price. Later, she made a list of all the items she routinely buys at each store, and carries it with her when she shops.

Healthy food help

Whether you're a new member, searching for toothpaste, or a more experienced mom in need of a new snack, consider a trip to some of the health food stores in your area. Or, seek out new ones when you're traveling further from home. Bring along your foodlist, and check ingredient labels, especially if you are salicylate sensitive. Many health food products are sweetened with fruit juice.

Here are some items you may prefer to get at health food stores:

Soy sauce — It's difficult to find a supermarket soy sauce which is free of both MSG/HVP and sodium benzoate. These additives are not likely to be found in the soy sauce sold in health food shops. Most carry a variety called "tamari".

Crackers and chips — There should be a good selection of tasty snack crackers, cheese puffs, caramel popcorn, etc. (If you buy natural cheese puffs, either buy extra to share, or don't let your junk-food friends find out how delicious they can be.)

Candy and gum — If you haven't checked out health food candy for awhile, take another look. Some taste as decadent as any you'll find elsewhere! Gum still has a way to go.

Chewable vitamins — To date, there are no acceptable chewable vitamins or vitamin drops outside of brands found in health food stores. If you're on Stage One stay away from rose hips and acerola berries. They are often added to natural chewable vitamin C tablets.