

Pure Facts

Newsletter of the Feingold® Associations of the United States



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The Damaged Children

If the Feingold Program doesn't appear to improve a child's behavior there may be other problems to consider; fetal alcohol syndrome is one possibility.

Hyperactivity is a behavior which can be found in children whose only problem is a sensitivity to synthetic food additives or salicylates. But it may also be a behavioral symptom of children who have conditions such as mental or emotional disabilities, in children whose mothers abused drugs during pregnancy, and in those who were exposed to alcohol while in the womb. This last category is called FAS, or fetal alcohol syndrome.

Unfortunately, not all our stories of "Feingold Kids" have happy endings. One of our volunteers recently discovered that her adopted daughter's problems are probably the result of FAS. The information on this syndrome is provided for our members who still search for answers.

Characteristic Behaviors

The FAS child: does not appear to have a conscience; takes chances without realizing the danger of an action; doesn't know right from wrong; is not aware of how his actions affect others; is very impulsive; doesn't learn from her experiences; shows no remorse.

In other words: no conscience, no fear, no guilt.

While these behaviors are distressing when the child is young, they become increasingly dangerous with the onset of adolescence — a time when youngsters acquire more freedom.

Solutions are Lacking

The support groups needed by parents of FAS children are not there, nor are there sufficient facilities where

such people can live in a safer, sheltered environment.

Dr. Ann Streissguth, of the University of Washington, is a leading authority on FAS. She and her staff are developing a roster of FAS parents in order to put them in touch with each other for support. Interested families may write to: Ann Streissguth, Department of Psychiatry and Behavioral Medicine, Mail Stop GG-20, Seattle, WA 98195. (Please do not call.)

What is Available?

The Broken Cord by Michael Dorris, is subtitled "A Family's Ongoing Struggle with Fetal Alcohol Syndrome."



This book describes the author's realization that his adopted son is afflicted with a condition that will not improve; the story was described on a recent broadcast of 20/20.

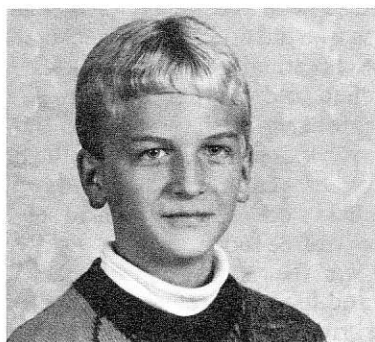
Identifying a FAS Child

Intelligence levels of these children are generally below average, and an FAS child may be extremely retarded.

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Michael

Michael was only about a year and a half old when he began the Feingold Program. As a La Leche baby, he was cool, calm, and collected, but all that changed at 8 months when he started eating table food.



Michael Sutton

We thought the difficulty Michael began to have sleeping at this time was caused by the fact that our family was moving, and all the upheaval this causes. We didn't consider that it could be the change in his diet.

Sleeping gradually became more and more of a problem. By the time Michael was a year old he was very hard to get to sleep and woke up repeatedly during the night. He wouldn't go down until about 11 pm, and was rarin' to go at 5 am the next morning. At 14 months Michael learned how to get out of his crib, and go explore the house, so I had to be ready to go after him at all hours of the night.

I would try to get him to sleep by rocking him. Just as he dozed off, he would have severe muscle spasms, which would wake him and we would have to start over again. (My husband and I later noticed that we experienced muscle spasms when we ate certain food additives.)

Continued on page 2

Trying to give Michael round-the-clock supervision while caring for my other two sons left me in a constant state of exhaustion, and I turned to our doctor for help. "You're just too old; you don't remember what it's like to have a child so active," he told me, and suggested I take medication for my nerves.

Michael was 15 months old when the runny nose began, and showed no signs of clearing up. The doctor couldn't find any evidence of allergies, but put him on benadryl—bright red benadryl! I later found out that the medicine did nothing to help Michael, and actually *caused* some of his problems.

So many things were not right. In addition to the sleep problems and runny nose, Michael was not gaining any weight. At 18 months he weighed the same as he had at 8 months.

I knew about the Feingold diet, and cut out the obvious additives to help my middle son, Steven, who was very irritable. His behavior improved when we were careful about what he ate; but Michael had such a sunny disposition that I never connected his sleep and health problems with foods or additives.

One day it dawned on me that I should be watching the baby's diet as well; I took him off the benadryl, put him on the Feingold Program, and his runny nose stopped right away. He began to sleep normally, and to gain weight. After having remained the same weight for the previous ten months, he gained three pounds in the first three months on the diet. The changes in Michael were so dramatic and obvious, we had no trouble convincing the grandparents, and even today, his grandmothers still bake special treats for him.

So many things were not right. In addition to the sleep problems and runny nose, Michael was not gaining any weight.

The sleep problems returned only when Michael wore pajamas treated with flame-retardant chemicals. We found that even clothing which had been washed many times still caused this reaction.

By the time he approached school age, Michael was an old hand at the diet. But very few people in our area of the

country understood the connection between diet and behavior, and I wanted to avoid conflicts with the school. Before kindergarten began I made an appointment to speak with the principal. I explained that I had a child who would be labeled "hyperactive" and he would need to have a teacher who would be able to work well with us. Michael's teacher would have to be willing to call me before every party, and would not give him any food unless I supplied it. She should understand he may need to wash his hands more often if the class would be using things like fingerprint. Even a little ink on his hand bothered Michael if he didn't wash it right off. While I did not say, "give us your best teacher," I believe this is what happened.



The word quickly got around that one of the classes had a "hyperactive" child, and in the first days of school those who did not have Michael in their class breathed a sigh of relief. His teacher told me her colleagues felt sorry for her, but she responded "I wish I had 25 kids just like him!" By the time Michael reached 2nd grade, the teachers were asking parents to send in additive-free food.

Over the years when Michael was offered food he preferred to accept it and bring it home, to trade for a natural substitute. He liked to be treated the same as everyone else outside the home, but in our house he tended to be singled out for royal treatment. "Michael gets the best; he gets the real food" was our philosophy, and while I encouraged our older sons to eat this way, they knew they were less sensitive and could get away with more. Michael still has a problem when he eats too many salicylates; an overload will cause him to have a nosebleed.

Scouting has been an important part of my sons' lives, and food is always part of an activity like this. Michael was able to do well, even when he was at camp for an extended time. We tried to focus on what he *can* eat, and I sent a copy of this information when I mailed in the registration form. Then I sent hard-to-find food off to camp with him.

When Michael is invited to sleep over at a friend's house I always make sure that whoever is nice enough to invite him is not inconvenienced. I will go to the extra trouble of sending his food.

We have learned that if you take the diet seriously at home, you're more likely to be able to get away with minor infractions when you are away. But when he does get too much questionable food I encourage him to drink a lot of water and that helps. Sometimes the reaction is dramatic — like the time we went to a favorite restaurant. Michael had always been able to eat the crackers they served, but one time he developed stomach cramps while we were eating there, and I discovered they had switched brands of crackers. As uncomfortable as these reactions are, they're a good reminder that you're on the right track.

The word quickly got around that one of the classes had a "hyperactive" child and in the first days of school those who did not have Michael breathed a sigh of relief.

At age 14, "hyperactive" is the last word anyone would use to describe Michael. He's a quiet person, and stays on his diet because, he says "I like myself better." He is an honor student, having been in gifted/talented programs throughout school, and will soon be joining his older brothers as an Eagle Scout. We have just learned the results of his California Achievement Test. Michael scored in the 99th percentile in the nation.

I believe that the younger the child is when he begins the Feingold Program, the more dramatic his response. We had some success with our middle son, but not the remarkable turnaround we saw in our youngest. I really feel we're fortunate ones, being on this diet; look at all the junk other people are eating, and how bad they feel.

Fran Sutton
Elizabeth City, NC

Carol Ann

"Not all children could be like this one," I kept telling myself. She was our firstborn and almost our last.

We really didn't have the problem identified until Carol Ann was ready to start kindergarten, but her uncontrolled behavior goes back to even before she was born. During the latter stages of pregnancy, this child was active! Sometimes in the evening our entertainment would be to watch her mother's abdomen as the baby went through a series of movements that would be the envy of most gymnasts. At times the movements were so violent that my wife would nearly be thrown out of bed.

As an infant, Carol was constantly fighting off ear and throat infections. The pediatrician would advise us to take the edge off with an aspirin (salicylate)...which seemed like a miracle drug because it turned our sick child into one who appeared to be fine as she "swung from the chandelier."

We frequently gave her an evening bottle of apple juice (salicylate) to get her ready for the night...or so we thought. Those were the times we would be up with her all night because she was wound tighter than a top.

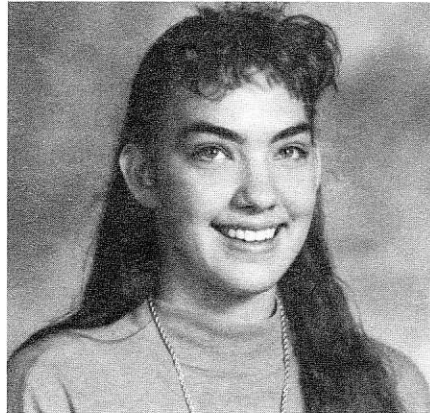
This didn't seem normal to us, but our pediatrician kept saying she was developing fine. He identified her as "a mouthy child" since she was having long "fussy periods." The longest was non-stop screaming for 17 hours! We couldn't keep her in her bed at night at the age of 1 1/2, but we did not follow the doctor's advice to lock her in her room and let her scream.

Carol Ann's behavior seemed abnormal to both my wife and myself. We were trained as teachers, and recognized that children had distinct personalities as they came into the classroom, but did we have to "get stuck" with the prize of them all?

Things didn't improve by themselves, and we were concerned that her problems would prevent her from attending school. We were even considering not sending her to school because it would endanger the other children with whom she would have contact. Should she be medicated?

One evening we were at a parent-teacher meeting, listening to a physician talk about children's health problems. Something he said that evening triggered our search for a cause of Carol's behavior problem. He men-

tioned — just in passing — "aspirin sensitive." For a long time my wife had suspected the problem could be related to diet, but I thought she was wrong. Later that evening we spoke with a woman who had a hyperactive child and told us of the local Feingold group.



Carol Ann Krueger

Marcia wanted to try the diet, so I went along with it — but with my usual skepticism since I knew it wouldn't work. And it didn't work; her behavior became worse...until the fifth day on the program, when we started to notice some obvious changes. The first to improve was her behavior, then her self-esteem. Probably the greatest signal of the diet's effectiveness came when she said, "Mommy, my head doesn't hurt anymore." She couldn't remember a time when she did not have a headache.

We had great success with the Feingold Program in our home, but we dreaded the times away from home and the potential for infractions. Just one bite of the wrong food sent her into a three day tailspin, usually ending with an ear infection and visit to our doctor, who complied with our insistence on uncolored, unflavored medicine.

School...well, the kindergarten teacher was very cooperative but the first grade teacher was not. We finally threatened legal action if she broke our instructions and gave our daughter the prohibited foods. Marcia became the room mother and made sure additive-free goodies were served at the parties. Acceptable cookies, candy, cupcakes and ice cream were stashed in the school's freezer for unexpected events.

Traveling across the country was fun — we packed three suitcases of clothing

and six of foods! Twelve years ago there weren't many acceptable brands, but now we can generally find what we need at local grocery stores.

As much as we wished she would outgrow her sensitivity, we now realize that will never be the case. When Carol entered sixth grade she discovered ways of releasing some of that wonderful bound-up energy through choir, volleyball, softball and basketball. Her body chemistry was changing and we found she could tolerate some natural salicylates.

Over the years we have had our ups and downs, and many times it seemed like the downside would win out, but Carol Ann is doing well. She is a junior in high school now, with a 3.9 GPA, and today she was inducted into the National Honor Society. She was invited by the People-To-People organization to join the Friendship Caravan to the Soviet Union this summer.

As Carol got older and able to manage her diet she became a skillful gymnast, proficient on the piano, and last year was chosen the M.V.P. on her volleyball team. She loves working with younger children, and works each spring and fall for one week as a junior counselor in our district's outdoor education program.

She plans to attend college and major in biology and English, and hopes to go into either teaching or work with environmental concerns.

It hasn't been easy for Carol, her parents, or her brother...but it was worth it. She has learned to read her body's needs and respond in a positive way. Recognizing that her body is a gift from God and taking care of this special gift has become important to her. There are times of infringements on the diet and she knows that she pays the price by not feeling well "after the fun," but it is her choice and she almost always chooses to respect her body's needs. She openly talks about this and sometimes gets discouraged when her peers don't believe that some substances can cause problems for her while they seemingly don't for others.

The effort for good health through this drug-free program is certainly worth a lot to this family.

Bob Krueger
Milwaukie, OR

Brian

The South Pacific may sound like paradise, but for our family it brought baffling problems.

Back in the 1970's my husband's work with computers took us to the Marshall Islands, where we lived on an atoll called Kwajalein Island. (An atoll is an island made of coral.) Coconuts were just about the only thing which grew there so we had to import our food. Since the Marshall Islands are about 2,000 miles west of Hawaii, and the supplies were brought in by boat (a very slow boat!) it took about 40 days for food to travel the 4,000 miles from California. We ate lots of canned food, and the "fresh" fruits and vegetables were dipped in a preserving solution.

There were many things we enjoyed on the islands. The Army provided plenty of recreation and the schools were good, but after our arrival, we gradually began to notice that our youngest child, Brian, was not doing well.

A sore throat and continuous earaches plagued him, and he began to experience a hearing loss. We had tubes put in, and gave him medicine, but it didn't seem to help.

His motor skills were poor. He was very uncoordinated, whiny, and was always the last one chosen for team sports. Brian was diagnosed as dyslexic, and began to develop a school phobia.

If I asked him to spell a word or do a math problem orally he was fine, but he just couldn't put it down on paper.

We later found that he suffered from a condition called "nystagmus," where the eyeball vibrates back and forth, making it very difficult for him to pick up the small words in a sentence. In Brian's case the nystagmus was not obvious as his eyes oscillated so rapidly.



Brian Kusler

During one of our trips back to the states I discovered Dr. Feingold's book, "*Why Your Child is Hyperactive*." I wanted to begin the diet right away, but we were staying with my mother, who had orange trees growing in her yard. She believed in oranges every day, along with cocoa (artificially flavored, of course) at night.

Back on the island, I read every label at the tiny grocery store we called "Surfway". Brian was eight then, and after three days on the Feingold Program his whining and crying stopped. Two weeks later the school phobia stopped, and by Christmas the learning and visual problems were gone, and he was getting straight A's!

Brian wasn't the only one who benefitted. That year both of our daughters raised their grade point averages a full point. Arnie and I felt better as well, and the family atmosphere improved. We were all nicer to be around, and there was far less bickering going on in our household.

I had been a conscientious budget-stretcher. We ate lots of hot dogs, and the children drank Kool-Aid. But with the results we now saw, it didn't seem like too much trouble to find the right foods. We were able to place special orders for some staples, and my friends

would share a case with me. When we got to Hawaii for "R&R" every six months, the first thing we did was head for the nearest restaurant salad bar to enjoy the fresh fruits and vegetables we had missed. We would bring empty suitcases with us and then load them up with groceries to take back.

It wasn't hard to make our diet a family affair, especially since the girls were so glad to see the change in their little brother.

Today Brian is 20 years old, and is a happy person. He is now working at the Los Angeles Coliseum and Sports Arena — home for the L.A. Raiders. It's interesting work; he has done everything from helping build the Raiderette's locker room, to setting up the wiring and lighting for rock concerts and the circus.

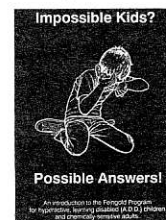
Although it's been 12 years since he began the program, Brian still retains the distaste he developed for school in those early years. But we are seeing signs of change. He would like to go into the same line of work as his dad — programming computers for businesses — and is enrolled in a class at a nearby college.

We still need the program as much as ever. Having worked as a volunteer with the association in Southern California for many years, we're a Feingold family in every sense of the word.

Eleanor Kusler
Sylmar, CA

Thanks to You!

Feingold members are sharing their copies of our 21 minute VHS videotape, "*Impossible Kid? Possible Answers!*" They are donating tapes to schools and libraries, and the word is getting out.



We are now receiving phone calls from parents who have seen the tape and recognize symptoms in their child.

This is an excellent way to introduce a friend, relative, or teacher to our program. Copies are available from the FAUS office: \$10 for one tape or four tapes for \$25. (We pay the shipping.)



Watch Out for Vacation Bible School!

If the church serves Kool-Aid and Oreos, vacation Bible school may turn your little angel into a devil. What can you do? Here are a few suggestions:

- Offer to shop for the food if it is centrally purchased.
- Offer to provide the snacks for your child's class.
- Provide your child with his own safe snacks to take in.
- Suggest that "Biblical foods" be served. Some possibilities are: pita bread, matzoh crackers, honey, dates, figs, as well as raisins, grapes and grape juice (salicylates), and — of course — water.
- Send us the name and address of your pastor, the director of religious education, etc. We can provide information on our program, including a copy of our special *Pure Facts* issue on religion and the Feingold Program (March 1989).

One of our members wrote: "I am sending an envelope to you to send the March *Pure Facts* to my minister and religious education administrator...it would be nice if my son weren't the only Feingolder in his Sunday school class.

"The diet, an understanding teacher, and your newsletter have really helped my 2nd grader settle down and receive "Outstanding" on his report card, and assignment to the Talented & Gifted program. Thanks again.

"Love, K.C., Cherry Hill, NJ"

Just when you thought it was safe to turn on the lights...Sylvania has developed a new light bulb, "Lite Scents." These synthetically perfumed bulbs come in pine, cranberry and orange blossom scents, guaranteed to torment the chemically-sensitive person.

What are Emulsifiers?

Feingold members often ask about food additives such as emulsifiers, stabilizers, anti-caking agents, etc. Although it's tempting to be leery of any additive with a strange-sounding name, most of these substances are well tolerated by our members.

Here is a description of emulsifiers, written by Phyllis Lehmann, and published by the Food and Drug Administration:

Some liquids don't mix unless there is an emulsifier around. In salad dressing, for example, oil and vinegar normally separate as soon as mixing stops. When an emulsifier is added, the ingredients stay mixed longer. In pickles, beverages, and candies, emulsifiers help disperse flavors and oils that otherwise would not be soluble in water. Without these compounds, ice cream and other frozen desserts would separate and lose their creamy texture. In baking, emulsifiers improve the volume and uniformity of breads and rolls as well as make batter and dough easier to handle.

Many emulsifiers come from natural sources. Lecithin, naturally present in milk, keeps fat and water together. Egg yolks, which also contain lecithin, improve the texture of ice cream and mayonnaise. The mono- and diglycerides come from vegetables or animal tallow* and make bread soft, improve the stability of margarine, and prevent the oil and peanuts in peanut butter from separating.

***Note:** In some cases mono- and diglycerides *do* present a problem for the Feingold member. When the processing of a food involves bringing it to high temperatures, anti-oxidant preservatives may be added to the mono- and diglycerides. Animal fats are also generally preserved with BHA/BHT. You can avoid these additives by using the brands on your Foodlist.

"Safest Stripper"

This is the name of a new paint and varnish remover which has been developed by the 3M company. Since the product contains no methylene chloride, it doesn't emit harmful fumes, or give off an unpleasant odor, a company spokesman told *Pure Facts*. It is non-flammable, and can be washed off of tools and your hands with soap and water.

Feingold members often report problems with paints and solvents, particularly those with a strong odor. This product appears to be a good choice for the chemically-sensitive individual, and we would be interested in feedback from readers.

The product is available at hardware and paint stores, and at home and building supply centers. If you have trouble finding Safest Stripper, you can write to Longine Beck, Customer Service, 3M Center, Bldg. 223-4S-01, St. Paul, MN 55101.



New from Japan

Japanese researchers have devised a new method of preserving food without the need for petroleum-based chemicals like BHA, BHT and TBHQ.

The Allergy Information Association of Canada reports, "A tiny package of hydrogenized iron oxide is enclosed in food packages. The package is sealed so it never comes in contact with the food, but is air-permeable. Oxygen is the prime cause of food spoilage. The hydrogenated iron oxide absorbs oxygen from inside the food package by combining with it to form ordinary, harmless iron oxide and hydrogen."

The product is being test marketed in Canada under the name "Ageless."

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.

But this measurement is deceptive, and some test out with average intelligence.

The syndrome is associated with specific physical characteristics, but this too is misleading, as some FAS children have a normal appearance. The classic physical signs include one or more of the following: eyes too far apart; lacking a ridge above the lip; thin upper lip; flattened midface (cheekbones); small chin; droopy eyelids; dental malformation; oddly shaped ears.

Three clusters of characteristics are an indication of alcohol involvement: 1. Small height, weight or head circumference; 2. facial appearance as indicated above; 3. central nervous system involvement such as learning difficulties or hyperactivity or other behavioral problems. Even if there is no knowledge about the child's birth mother or alcohol involvement, the presence of all three is considered to be a confirmation of FAS. When there are fewer symptoms, it may be called "fetal alcohol effect."

A specialist should be able to make the determination, even if the infant/child does not seem markedly different in appearance. The specialty which would deal with this is a physician trained in medical genetics. A hospital or medical school should be able to provide a referral for interested parents.

Dealing with FAS

The increased attention being given to FAS should help adoptive parents to be aware that the problems were not of their making. Too many professionals jump to the conclusion that a child's disturbed behavior is due to poor parenting.

Parents need to accept the hard reality that their child's condition is permanent, to go through their grief, and try to search for a way to deal with the child's condition.

The Feingold Program

Although there is no known treatment, including the Feingold Program, which can reverse FAS, behavior generally improves when a child's diet is free of synthetic additives. Unlike most children, however, the FAS youngster may be unable to make the important connection between his diet and behavior. It is this realization which motivates our children to stay on their diet, gradually assuming total responsibility for it.

How Much is Too Much?

When a pregnant woman drinks, alcohol goes into the bloodstream of her unborn child. This alcohol has the ability to damage the developing brain and all of the systems of the body. Although FAS symptoms generally are the result of a mother who drank excessively or in binges, there is no known safe level of alcohol consumption for the pregnant woman.

If excessive alcohol can produce extreme symptoms, then it is possible that small amounts of alcohol could produce subtle symptoms — a slight reduction of intelligence, or poorer coordination, eyesight, etc.

Alcohol consumption, even in excess, does not automatically mean a child will be born damaged. But the problem with FAS is that so little is known; the use of alcohol in any amount is playing with fire. A nursing mother who drinks will also pass alcohol directly to her baby in the breast milk.

Feingold parents who want to speak with a member dealing with the issue of an FAS child are invited to call Judie Frid (301) 460-1118.



Thanks to Dad!

This is the time to say thank you to Feingold dads for the many ways they help. Thanks for: going back to the grocery store to get the right brand of ice cream...for telling your co-worker about the help available for his troubled child...for doing without catsup during the first weeks...and for not complaining when dinner is late because your diet assistant wife was on the phone with a mom who desperately needed to talk with someone...or for doing the cooking yourself that night.

**The next Pure Facts will
be our combined
July/August issue.**

Remembering Dr. Feingold

June 15 would have been Dr. Feingold's 90th birthday. Here is a photo taken of him in 1935.



This month has another special meaning for Feingold volunteers. Many years ago, Dr. Feingold was made the honorary Godfather for our children, and honored at our conference each June.

Moving?

Please let us know in advance. The post office will not forward your newsletter.

Pure Facts

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