

Pure Facts

Newsletter of the Feingold® Associations of the United States



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The Feingold Adult

In the December-January *Pure Facts* of last year Preston Edwards, M.D. included a questionnaire for adults on the diet. Dr. Edwards chairs FAUS's Adults on the Diet committee.

The purpose of the survey was to determine if he could identify a syndrome of symptoms which would help professionals pick out salicylate and additive sensitive adults. He hoped that this information would also help in the literature we produce for the public. Dr. Edwards is interested in this both as a physician, and as a result of his own personal problems with foods/additives.

Of the 120 members responding, 80% were female. The survey showed a higher rate of reaction to additives than to salicylates.

The most frequent symptoms were: irritability, mood swings, loss of concentration, restlessness, compulsive doing, and poor sleep. These central nervous system symptoms represent an adult version of the Feingold child, or, more accurately, the adult Feingold syndrome.

The next most frequent set of symptoms were sinus congestion, headaches, fatigue, and muscle aches. These correspond very well to a medical syndrome of nasal polyps, sinusitis, asthma and hives known as the "aspirin idiosyncrasy reaction."

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Hives and Stress

Deborah Hickman never had any reason to be concerned about food additives and salicylates . . . until she was 32.



That was a very stressful time in Deborah's life: A divorce, move to a new home, a new job . . . and hives! "Horrible hives, body welts," Deborah told *Pure Facts*.

Deborah Hickman

Itchy, disfiguring hives were appearing every other day, accompanied by fatigue.

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Ann Landers Withdraws Support

In a letter to the Feingold Association on November 7, syndicated columnist Ann Landers wrote: "I am so sorry to have to write this letter and tell you that I am unable to continue to support the Feingold diet . . . I've been overwhelmed with letters and phone calls from first-rate pediatricians, allergists, professors of medicine at Harvard, Yale and Duke and from physicians at the Mayo Clinic. They are all telling me that I should not have recommended the Feingold diet because it has no scientific validity."

A Scientist Looks at 'Scientific Validity' — What Does it Mean?

"The Feingold Diet for the treatment of hyperactivity has no scientific validity." What does this sentence mean? How is it interpreted?

Words are mischief makers. Often the definitions of words are subtly different for each individual. What the world sorely needs is clarity of communication. In no area is this more apparent than in the research involving hyperactivity, where, it is my opinion, most of the controversy arises from imprecision of communication.

To begin with, the medical community has agonized over the de-

finition of the disorder. The name has changed numerous times and will probably change several times more in the future. Since hyperactivity is generally considered to be a cluster of symptoms, where the choice of cluster is still somewhat vague, it is likely that many causes exist. It is also likely that the discovery of all the causes may not be made for generations. It is my pre-

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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.

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diction that a cure for cancer will be found before "hyperactivity" (however you define it) is completely understood. This prediction is based on our present knowledge of function at the cellular level compared to our present knowledge of brain function and network interaction.

So if even the definition of the disorder is unclear, the difficulties in studying it in a "scientific way" are discouragingly great. How does one define the conditions to be maintained constant in a scientific test? What conditions may be varied? Are all the variables known? Are all the variables controlled? What are the appropriate statistics to apply to the problem? (More than thirty different probability distributions have been studied by statisticians.) These are among the ingredients needed to establish scientific validity.

"The correct interpretation is that the Feingold hypothesis has neither been proved true nor false."

I have been following the literature on hyperactivity as listed in *Index Medicus* since 1979. It is my view that with our present state of knowledge we are not ready to state with certainty that *any hypothesis* has "scientific" validity. So what are we left with?

Many creative, caring people with imagination and intelligence have been attacking the problem at the cellular level, at the level of neurotransmitters and communication between cells, at the level of neural integration, at the psychological level of behavior, conditioning and learning, and finally at the level of whole body function. At each of these levels some individuals have found something that perturbs the human system for good or ill in connection with hyperactivity. For example, the drug methylphenidate helps some (but not all)¹ while its action in hyperactives is by no means well

understood.² By my definition, this drug's use has pragmatic validity but absolutely no scientific validity.

How does the Feingold hypothesis stand in relation to the above? Dr. Richard Mailman, in 1982, exclaimed in frustration that he could give rats enough Red Dye #3 to make them turn pink and they showed no behavioral response. Dr. Feingold hypothesized that Red Dye #3 (as well as other chemicals) caused a behavioral response in children; and studies on some individuals who served as their own controls have supported this hypothesis. Most people can, like the rats, consume Red Dye #3 with impunity. My interpretation of these observations is that the responder must have a pre-existing structural brain dysfunction or biochemical or functional abnormality (which may be environmentally induced as in the case of lead poisoning) upon which Red Dye #3 acts to produce a symptom. Red Dye #3 is therefore not a "cause" but a "provocateur." In a situation this complicated how can "scientific validity" be ascertained?

Dr. Feingold's approach was more pragmatic. Isolate and eliminate the provocateurs so that life can go on with as much normalcy as possibly. Chemicals in the diet are by no means the only provocateurs. Stress and conditioning surely play a role.

What disturbs and mystifies me is how many people with professional training say with so much arrogance and finality that "The Feingold Diet doesn't work." Do they have a special pipeline to God that they have this certainty of knowledge? My own view is that we are still at a very primitive, pragmatic stage. All avenues should be explored if they do no harm. Each afflicted individual is burdened with the task of discovering his or her own provocateurs and then must do the best to cope. What Dr. Feingold offered with his diet was a broad filter for discovering some provocateurs, not the causes of the disorder. This filter is not perfect. Many people, even if not all, have been helped.

"On a pragmatic basis, the diet works for some and doesn't work for others. Its basis is not understood. Similarly, on a pragmatic basis, methylphenidate works for some and doesn't work for others. Its basis is not understood, only hypothesized."

The difficulty for the non-professional is that when a professional states that "The Feingold Diet has no scientific validity," the non-professional interprets the words to mean "The Feingold hypothesis is false." This interpretation is logically and linguistically incorrect. The correct interpretation is that the Feingold hypothesis has neither been proved true nor false. On a pragmatic basis, the diet works for some and doesn't work for others. Its basis is not understood. Similarly, on a pragmatic basis, methylphenidate works for some and doesn't work for others. Its basis is not understood, only hypothesized.² Its use also "has no scientific validity." Both the provocateurs eliminated by the diet and the methylphenidate perturbed the system with the conditions for action undetermined.

All of us need to be more critical and questioning when we hear the words of others, even the words of experts.

1 Silbergeld, E.K. (1977) "Neuropharmacology of Hyperkinesis," *Current Developments in Psychopharmacology*, Volume 4, pp. 180-213.

2 Gualtieri, C.T., Hicks, R.E. (1985) "Neuropharmacology of Methylphenidate and a Neural Substrate for Childhood Hyperactivity," *Psychiatric Clinics of North America*, Volume 8, pp. 875-892.

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Editor's note: Methylphenidate is the generic name for Ritalin.

Feingold Adult, from page 1

Less frequent reactions included skin rashes of all types, recurrent illness, sore throats, stomach pains, dizziness, diarrhea, wheezing and bladder irritation.

He found that 78% of the respondents were allergic to other foods, much higher than national estimates of 10-20% for the general population. There was a very strong correlation between a family history of food, pollen, and Feingold sensitivity, and the adult Feingold syndrome.

The length of the reactions varied from a few hours to weeks, but the majority lasted 2-3 days.

53% of the respondents said their problems started during early childhood. Another one third noted their problems began anywhere from age 7 to 45. Most of the Feingold adults apparently had a gradual onset of symptoms. But in those who could find a reason for the change that occurred, childbirth was the most common precipitating event.

Most people found out about the connection between their problems and aspirin/salicylate sensitivity through friends, by reading about it in publications, or in using the Feingold Program for a child. One fourth were put on the diet by their physician.

One out of four are sensitive to fumes of various types. Others mentioned MSG, caffeine, sulfites, and benzoates.

"We cannot really say how many Feingold children go on to become Feingold adults," Dr. Edwards noted, "but there certainly are some who have an inherited tendency to have a lifelong problem with salicylates and additives. We also do not know how many people outgrow their problems."

Dr. Edwards hopes to do other larger surveys in the future which will give answers to these and other interesting questions.

The Aspirin Triad

She is in her forties, and has recently begun to suffer from nasal congestion, recurrent sinus infections and nasal polyps.

We'll call her Carol Smith — a fictitious name, but she exhibits some very real symptoms of aspirin idiosyncrasy reaction, or the "aspirin triad."

The nasal problems are the most common portion of the triad. The other two symptoms are asthma and urticaria (hives). Statistically, Carol has about a 10% chance of developing asthma and/or urticaria in the future. Some unfortunate people develop all three at the same time.

Carol's mother was able to tolerate aspirin when she was younger,

but now experiences a life-threatening reaction with wheezing and shortness of breath if she takes any. And both women find they are allergic to other substances as well, including food additives.

Both are under the care of an allergist, and are among the estimated 1 to 2% of the patients in any allergist's practice who are aspirin-sensitive.

These women represent a very typical picture of the aspirin triad. It is considered to be hereditary, and can begin during early childhood; but it is most common in middle-aged women, and generally takes a while to develop. The earlier it begins, the more severe the sensitivity is likely to be.



Food Technologists Acknowledge Feingold Program

When the criticism changed from "Food additives do not provoke behavior problems" to "Food additives affect only a small percentage of children" Dr. Feingold knew his major goal had been accomplished. "Now," he commented, "it's just a matter of numbers."

Recently, the Feingold concept received an unexpected acknowledgement from the Institute of Food Technologists Expert Panel on Food Safety & Nutrition. The panel's report included the following statement:

"A review of research on food colors and behavior concludes with these observations: (a) The Feing-

old diet may be helpful to a small number of children with hyperkinesis but not at the 50% level reported by Feingold. (b) Learning ability might be depressed in susceptible children as a result of the pharmacological effects of very high dose food color challenges. (c) Observed changes in behavior are probably not associated with food hypersensitivity or other immunological reactions to foods or food additives." (*Editor's note: the term "immunological reactions" is what the average person refers to as an "allergy."*)

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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.

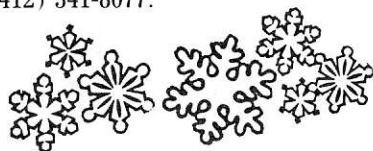
ACLD Symposium on Food & Behavior

The Association for Children and Adults with Learning Disabilities is having its annual International Conference at the Hilton Hotel in **San Antonio February 26-28, 1987.**

A preconference Symposium will be held February 25. The subject will be: "Food and Substance Effects on Brain and Behavior: Scientific, Medical and Practical Foundations."

Among the Symposium speakers will be Ken Bonnet, Ph.D. from the N.Y. University School of Medicine; Iris Bell, M.D. from Langley-Porter Neuropsychiatric Institute, University of California; and John Crayton, M.D., University of Chicago.

Feingold members are invited to attend what promises to be an outstanding event. For the full Conference program or a flyer on the Symposium write ACLD, 4156 Library Road, Pittsburgh, PA 15234, or call (412) 341-8077.



Professional Mailing List

Dr. Preston Edwards is interested in starting a mailing list for professionals who serve our members as their physician, counselor, dietitian, dentist, or guidance counselor. He would use this list to keep them informed of scientific developments which support the Feingold Association and the work that it does. This would help them gain a better understanding of Feingolders as patients, encourage their interest, and perhaps help them with their other clients.

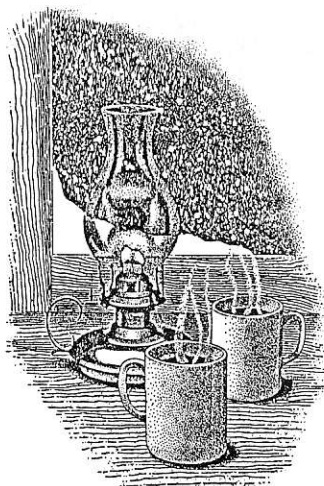
Please show this newsletter to any professionals you believe would be interested in being on this list and invite them to contact the FAUS office. Contact FAUS for an extra copy of Pure Facts.

FAUS Representatives Testify at NIH

Past President Mary Kistler, and FAUS Director Jane Hersey testified at the October 15 meeting of the National Institutes of Health Interagency Committee on Learning Disabilities.

Established by the U.S. Congress, the committee is made up of various agencies of the NIH. The purpose of the committee is to investigate the incidence, causes, and treatment of learning disabilities.

The Feingold presentation consisted of describing the program and relating its value in helping both the child who is having learning problems in school, and identifying the young child who is considered a "high-risk" learner.



Pure Facts

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For further information write to: Feingold Association of the United States, Inc., Box 6550, Alexandria, VA 22306. (703) 768-FAUS

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She sought help from four different dermatologists in the San Francisco area. "These were highly respected doctors," she explained, "top men in their field, and they told me they were sorry. 'There is nothing we can do.'"

"One of them gave me an antihistamine (bright blue pills), but not one said anything about aspirin sensitivity or about a change in diet."

"My boyfriend finally persuaded me to see his doctor — the head of the department of internal medicine at the University of California/San Francisco." Through his efforts Deborah learned about the Feingold Program.

"I began the Program in April and within three days the hives were gone."

"My boyfriend is so excited about the change the diet has brought for me. He is on it himself, feels great, and tells everyone about it."

"I began the Program in April and within three days the hives were gone."

Deborah hasn't been eager to try adding back salicylates. After two years of suffering from hives, she is enjoying feeling good, and finds plenty of food to enjoy on Stage I (non-salicylate list).

Even the smallest infraction (dye especially) brings a return of the hives, and a bad case can take as long as seven days to go away.

Although she did not have a history of the childhood behavior problems typical of many Feingold adults, Deborah noted that she experiences behavior changes (as well as the hives) when there is an infraction. She becomes very tense, irritable, uncoordinated and accident-prone. "I'm a tense wreck!"

As assistant manager of a tennis-health club, Deborah has no difficulty staying on the diet at work. Those around her have been very interested, and she has provided them with information about the Program.

Feingold Association of the United States
SURVEY OF SALICYLATE SENSITIVITY
(for all ages)

Your name _____ Age _____

Address _____

Length of time on the Feingold Diet: _____ years _____ months

This survey is ONLY for members who feel they react to SALICYLATES.

If you can identify a specific set of symptoms you experience in response to salicylates, please describe what occurs:

When does the reaction start? _____ Minutes _____ Hours

When does it end? _____ Hours _____ Days

Is there anyone else in your family with (circle):

salicylate sensitivity	yes	no
asthma	yes	no
nasal polyps	yes	no
urticaria (wheals)	yes	no

Do you have your **typical reaction** to the following foods? (circle)

1. almonds	yes	no	unsure	11. nectarines	yes	no	unsure
2. apples	yes	no	unsure	12. tangerines	yes	no	unsure
3. berries**	yes	no	unsure	13. oranges	yes	no	unsure
4. cherries	yes	no	unsure	14. peanuts	yes	no	unsure
5. cantaloupe	yes	no	unsure	15. pineapple	yes	no	unsure
6. cucumber	yes	no	unsure	16. peaches	yes	no	unsure
7. dates	yes	no	unsure	17. plums & prunes	yes	no	unsure
8. grapes	yes	no	unsure	18. raisins	yes	no	unsure
9. grapefruit	yes	no	unsure	19. tea	yes	no	unsure
10. green pepper	yes	no	unsure	20. tomatoes	yes	no	unsure

** (Are there any berries you do **not** react to?) _____

Please assist us in better understanding the problems of the salicylate-sensitive member by filling out this questionnaire and returning it to:

Preston Edwards M.D.
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Roanoke, VA 24018



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