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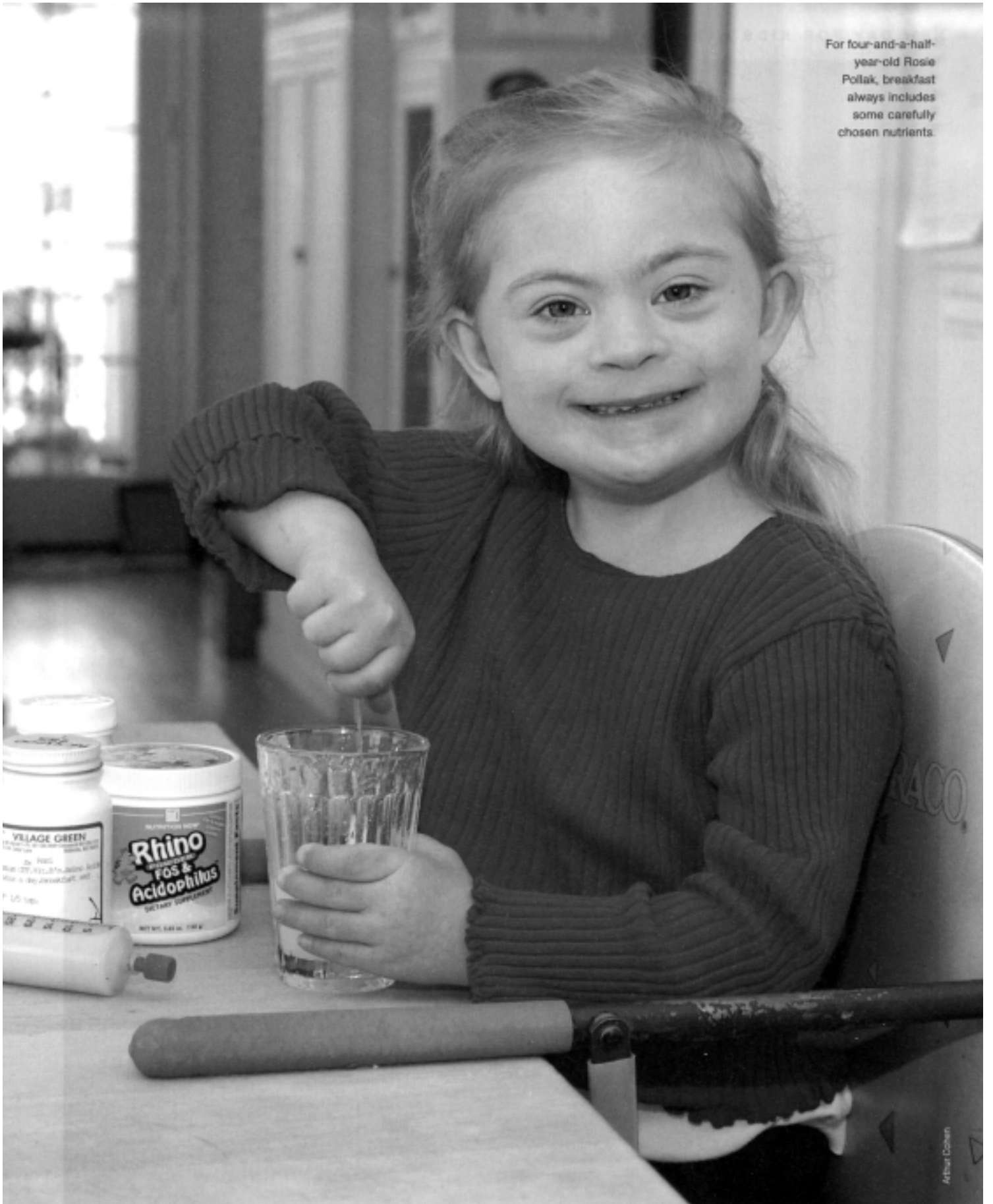
A New Day for Kids with Down's

Some experts say the right mix of supplements may well change the course of this frustrating condition. ● By Melanie Haiken

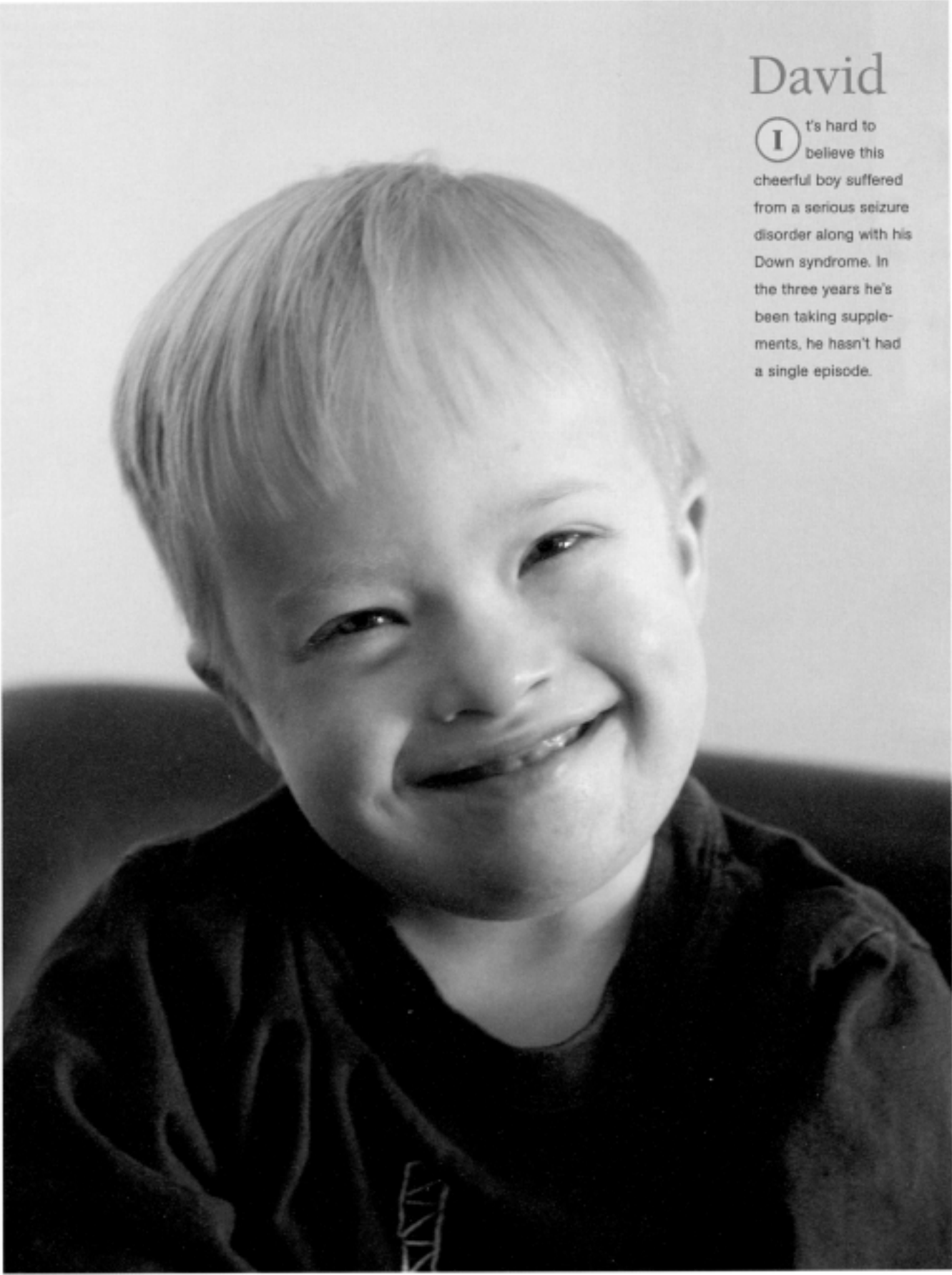
As soon as Wendy Deaton's son Mackenzie was old enough to swallow solid food—just two months after his birth in August 1995—she began stirring a powerful blend of vitamins, minerals, and amino acids into baby food and spooning the mixture into his tiny mouth. The reason? Mack was born with Down syndrome (DS), and Deaton, a nurse in Brownsburg, Indiana, had heard that other parents were successfully treating their DS children with a regimen of nutritional supplements especially developed for this purpose.



For four-and-a-half-year-old Rosie Pollak, breakfast always includes some carefully chosen nutrients.

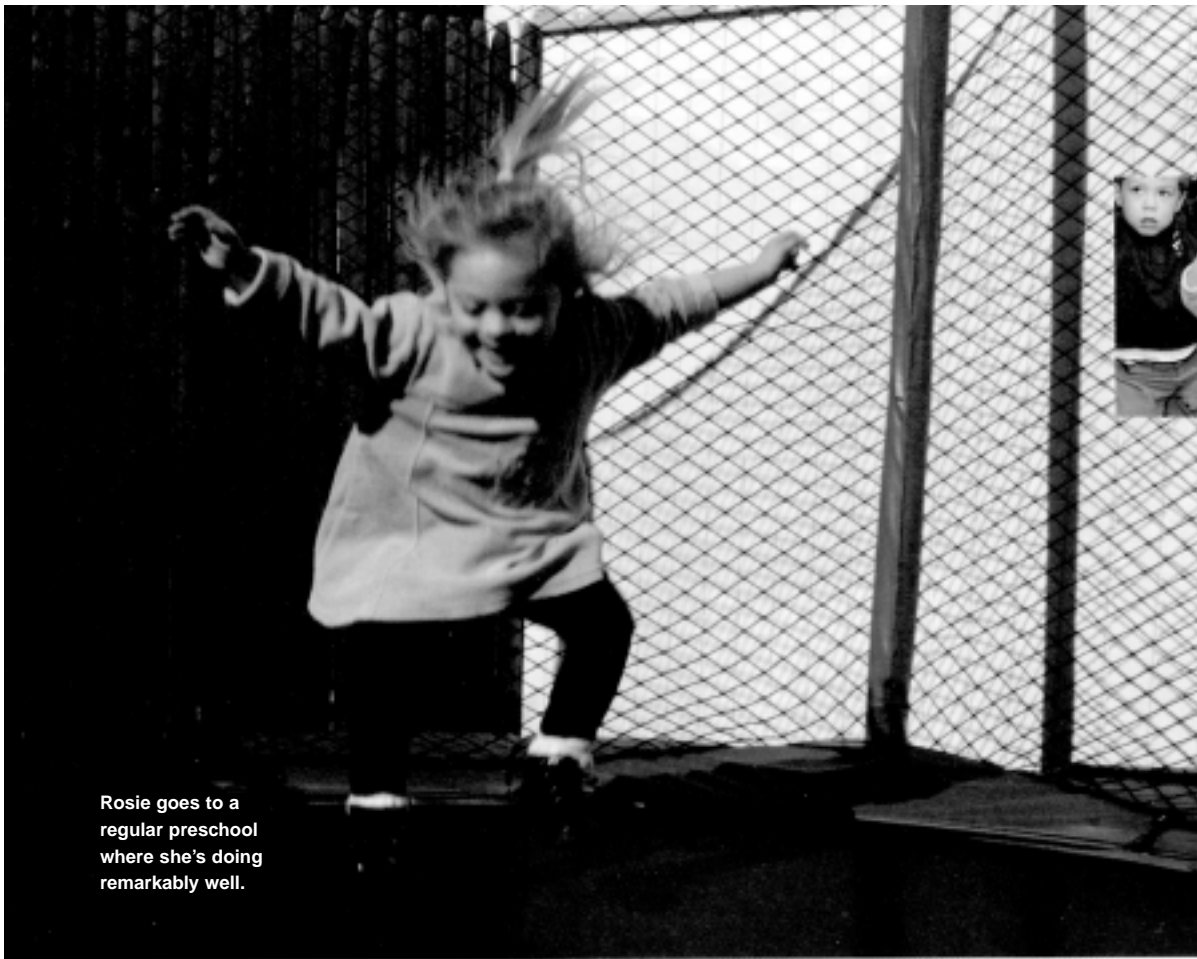


Alfred Cohen



David

It's hard to believe this cheerful boy suffered from a serious seizure disorder along with his Down syndrome. In the three years he's been taking supplements, he hasn't had a single episode.



Rosie goes to a regular preschool where she's doing remarkably well.

Rosie

She's been taking supplements since she was just weeks old—and her therapists now estimate her IQ to be well within the normal range.

It was Deaton's mother who first heard about nutritional therapy, on a 1996 episode of the TV news program *Nightline*. The program focused on the crusade of Dixie Lawrence, a former bodybuilder from Louisiana, who had consulted with several gurus of nutritional therapy for DS, and was now mixing up formulas in her kitchen to treat her adopted daughter Madison. The episode featured dramatic testimonials by other parents, too, who claimed that nutritional therapy, along with a "smart drug" called piracetam, had made their children healthier and more alert and even improved their cognitive abilities. The show included contact information for the company that produced the Lawrence formula, called NuTriVene-D.

Deaton immediately ordered the supplements and began giving them to Mack. He's been on them ever since. "I'm a big believer in the power of nutrition and supplements," says Deaton, "and what the parents were saying about their kids was very convincing."

Because Mack, now nine, has been on nutritional therapy all his life, Deaton admits she has no way of knowing what he would have been like *without* the supplements. But she can compare him to

his peers, the other kids with DS who are also mainstreamed with Mack in his public school. And she does know about the health problems typical of kids with DS, which include chronic ear infections, gastrointestinal distress, sleep disturbances, and weakened immune systems.

Mack, by contrast, has had only one ear infection in nine years, and has as good an attendance record as any other kid in his third-grade class. Not only is he more verbal than might be expected, he has been reading since first grade.

This story has all the makings of a classic case of hucksterism: the overeager television host, the desperate parents, the supplement marketers with extravagant promises. Except it's not so. Some experts believe there's real promise in nutritional therapy, largely because of a new way of thinking about how Down syndrome progresses—namely, that its course depends in part on the body's stores (or lack) of certain nutrients.

"Studies going back to the sixties show that people with Down syndrome have unusually low levels of certain vitamins, minerals, and other critical nutrients," says Warren Croom, a professor of nutrition and physiology



Because of certain Down's-related health issues, Rosie gets supplements through a tube.



Collette

She was so depressed that she'd sit alone in her darkened bedroom and cry. Then she started taking supplements, and doing behavioral therapy, and now finds joy in simple things (like her dog, Napoleon).



at North Carolina State University who, it must be noted, consults with NuTriVene-D's parent company. And there's anecdotal evidence that supplementing kids with these nutrients can make a big difference in both their physical and their mental health.

Deaton was lucky to encounter one of the practitioners who's led the way. Her son is being treated by Lawrence Leichtman, a clinical geneticist and director of the Genetics and Disabilities Diagnostic Care Center in Virginia Beach, Virginia. Leichtman has become such a fervent advocate of nutritional therapy that he travels around the country holding clinics so he can reach the parents who can't afford to come to him. Leichtman, who has treated 2,500 children with Down syndrome over the past 25 years, has become something of a legend.

"Leichtman has really put himself on the line to help these kids," says Steven Fowkes, a biochemist who is the director of the Cognitive Enhancement Research Institute, an information and advocacy organization for users of nutritional therapy for brain enhancement.

On the line may well be an understatement. The use of nutritional therapy for people with Down syndrome is so controversial that the website Quackwatch questions it, and mainstream organizations actively distance themselves from

it. "The rationale advanced for these therapies is unproven; and the previous use of these therapies has not produced any scientifically validated, significant results," reads a position statement by the National Down Syndrome Society. And in an editorial published in the *Down Syndrome Quarterly* in June 1997, physician Mary Coleman specifically attacked the *Nightline* program for its "extravagant claims," and then went on: "No study that adhered to even minimal scientific methods documented any definite improvement or even suggestive

This story has all the makings of a classic case of hucksterism: the overeager television host, the desperate parents, the supplement marketers with extravagant promises. Except it's not so.

trends in intelligence, speech or language, neuromotor function, height, or health."

Even advocates acknowledge the lack of good research on the subject. "The truth is, there has yet to be a large-scale, double-blind study of nutritional therapy for Down syndrome," says Leichtman, though he adds that several are in the works. (One winds up this August.) And the early studies are either too small or too poorly designed to be of much value.



Robert Thiel

When his son David was born with Down syndrome and a seizure disorder, this California naturopath made it his life's work to find help—and did. David hasn't had a seizure for three years.

Besides, it's not hard to be skeptical about the theory itself. Down syndrome is, after all, a genetic disorder, something programmed at birth. So how can dietary supplements affect the symptoms of a built-in condition?

The key, according to Leichtman, is understanding how genetic defects operate. Most people think the defect that causes Down syndrome (having an extra 21st chromosome) is directly responsible for the delayed mental development that characterizes the condition. But some experts argue that there are some intermediate steps in the process. That's what nutrient therapy is designed to influence. The extra chromosome, they say, causes several metabolic disorders that themselves may be prime causes of mental dys-

function in these kids. The first boils down to a phenomenon we're all pretty familiar with: oxidative stress.

Thanks to the additional genes on that extra chromosome, the theory goes, the activity of a key enzyme known as SOD (superoxide dismutase) is heightened, leading to an overabundance of a particularly damaging free radical known as superoxide. Without sufficient antioxidants to escort these potent substances from the body, they can damage, and even kill, cells. Advocates of nutritional therapy think this process contributes greatly to the deterioration in memory, mood, and general intelligence that DS kids suffer from.

But there's an upside to these findings: By fingering cellular oxidation as a culprit, the research also suggests that

some of the deterioration that occurs after birth can be stopped, or at least slowed, by taking high levels of particular antioxidants. In other words, if you intervene in the metabolic dysfunction that's causing cells to weaken or die, you may be able to prevent some of the brain cell degeneration that was previously considered inevitable.

A second metabolic dysfunction interferes with something called methylation, a complicated process that's involved in many different functions in the body. Supplementing with substances that play key roles in the methylation process, such as folic acid and vitamin B-12, is crucial to addressing this problem, advocates say.

Of course, no one's suggesting nutritional therapy can reverse or "cure" Down syndrome—just help modify

some of its symptoms. "Holding the line with these kids so they don't lose cognitive function is a huge concern for parents," says Jay Lombard, director of the Brain Behavior Center, in Nyack, New York.

The story of four-and-a-half-year-old Rosie Pollak, in Washington, D.C., certainly suggests it's possible to do that, and more. When Rosie was just weeks old, her mother, Whitney, began pumping breast milk and mixing in NuTriVene-D powder, then squirting it into Rosie's mouth with a syringe. She's been giving Rosie the powder ever since, and the girl's development has been nothing short of amazing.

She's too young to take an IQ test, but her health care team estimates her IQ to be in the high nineties, well within the normal range (100 is average). She walked at 18 months, became toilet trained at three, and "has hit many other developmental milestones on target," her mother says. She is mainstreamed in a preschool for non-DS kids, where her teachers, too, are impressed with her progress.

"No one can believe how well she's doing," says Whitney. "Whenever there's a new baby born with Down syndrome, her therapists put the parents in touch with me so I can tell them about nutritional therapy."

Of course, the brain isn't the only organ sabotaged by Down syndrome's metabolic dysfunction. These children are more likely to have problems ranging from digestive issues, such as celiac disease, to thyroid conditions, childhood leukemia, and even early Alzheimer's disease. (Virtually all

people with DS will have signs of Alzheimer's by the age of 40.) They tend to have emotional difficulties and can have physical symptoms such as low muscle tone, short stature, and swollen tongues that can cause speech problems. Again, studies on these specific problems haven't been done, but practitioners have had progress easing some of these symptoms in patients who've been getting nutrient therapy.

Some of this is easier to see in older children. Collette Johnson, a 16-year-old in San Luis Obispo, California, only started on nutritional therapy about a year ago, but it has helped her enormously.

common in older kids and adults with Down syndrome, had also become an issue for Collette; often she would stay awake until four in the morning, talking to herself. But Johnson wasn't eager to start her daughter on drugs, so she did some research instead and eventually ended up in the office of Robert Thiel.

A naturopath in Arroyo Grande, California, with a Ph.D. in nutrition science, Thiel is highly motivated: His five-year-old son, David, has Down syndrome. David also suffers from a second disease that some DS kids get and that causes severe seizures.

Unable to accept his son's prognosis, Thiel immersed himself in the search for help. His research took him to Jack Warner, an early proponent of nutritional therapy for DS. For four years, Thiel collaborated with Warner, poring over his records and refining the regimen Warner had created. He's since published several papers on the therapy, and has been using it to treat his son, who's been seizure-free for three years—an almost unheard-of result.

Thiel's program, along with a type of therapy called applied behavioral analysis, which helps people identify and change behavior problems, brought equally impressive improvement for Collette Johnson. After a year of taking supplements and meeting regularly with a therapist, Collette's sleep issues are gone and she's no longer depressed. "I can't tell you how dramatic the changes have been," says her mother. "She's a different person."

The next few years are likely to be the turning point for nutritional therapy and Down syndrome. In the meantime, Deaton, Johnson, and Thiel, along with the thousands of others who are giving their kids supplements, are glad they didn't wait for mainstream science to prove them right. **A**

Melanie Haiken is a contributing writer.

Resources for Down's Kids	
Nutrient therapy for Down syndrome is a fledgling field, so practitioners and resources can be hard to come by. For more information, start with these:	805.489.7188 members.aol.com/dsepilepsy/org.htm
PRACTITIONERS:	SUPPLEMENTS:
Dr. Lawrence Leichtman Genetics and Disabilities Diagnostic Care Center Virginia Beach, VA 757.425.1969	NuTriVene-D International Nutrition, Inc. 11436 Cronridge Drive Suite W Owings Mills, MD 21117 800.899.3413 410.902.1760 Fax: 866.902.1767 410.902.1767 ask@nutrivene.com
Dr. Jay Lombard Brain Behavior Center Nyack, New York 845.382.6444 braincures@yahoo.com	SUPPORT GROUPS: To join a Nutrition Therapy-oriented listserv, go to groups.yahoo.com and search on DSTNI under "Join a Group"
Dr. Robert Thiel Doctors Research Inc. Arroyo Grande, CA	—M.H.

In the past few years, Collette had been experiencing psychological symptoms so extreme that a psychiatrist recommended putting her on antipsychotic medication. "She was so depressed she would sit in her room with all the lights turned off, crying," says her mother, Elizabeth. Sleep problems, very