

# Autism Research Review

I N T E R N A T I O N A L

A quarterly publication of the Institute for Child Behavior Research

Reviewing medical and educational research in the field of autism and related disorders

## Fenfluramine: the controversy continues

The first trial use of fenfluramine on autistic children was announced in a letter to the editor of the *New England Journal of Medicine* in July of 1982. Based on an open clinical trial of fenfluramine on three autistic boys, the report attracted greater media attention than had ever before been focused on a treatment for autism. The television networks, the national news magazines, and newspapers throughout the country reported the treatment as a breakthrough.

Now, five years and more than a dozen studies later, there is disagreement about whether the drug's usefulness outweighs its side effects.

In a sharply worded editorial in the *Journal of Pediatrics*, C. Thomas Gualtieri, of the University of North Carolina, argued that fenfluramine "does not seem to be particularly effective in the treatment of autism" and has never been proven to be safe. Jon Matthew Farber, of the Alexandria-Lakeridge Pediatric Centers, concurs, expressing concern that some researchers are over-stating positive results and creating "more false hopes for families." Edward Ritvo of UCLA, and other authors of the original article (Geller et al.), reply that "the data to date on the therapeutic effects seem sufficient...to justify—indeed to require—further study."

Fenfluramine is an amphetamine-like drug which has previously been used as an appetite suppressant. Studies have shown that 30 to 40 percent of autistic people have high levels of serotonin, one of the substances which help transmit impulses between brain cells, and that fenfluramine reduces these levels. Whether or not this leads to behavioral and cognitive improvements in autistic individuals, however, is still under

debate. Gualtieri notes that "there is no correlation between fenfluramine-induced serotonin reduction and therapeutic response," and other investigators believe the drug's effects actually may be due to its influence on levels of the brain chemicals dopamine and beta-endorphin. Paradoxically, while fenfluramine was originally intended for use with autistic patients with elevated serotonin levels, Ritvo has subsequently reported that fenfluramine is most useful for patients with initial *low* serotonin levels.

### Several studies show benefits

Ritvo reported positive results in a 1983 study of 14 autistic children which determined that "patients with both normal and elevated baseline serotonin had symptomatic improvements" during fenfluramine administration, including decreased restlessness, motility disturbances, echolalia and sensory problems; improved sleeping patterns, eye contact, spontaneous language and socialization; and more appropriate expression of emotion.

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## Device stops head-banging

A new electronic device may quickly and dramatically stop severe head-banging, according to Thomas Linscheid, an Ohio State University researcher who has tested the equipment on three autistic children.

The Self Injurious Behavior Inhibiting System (SIBIS) was developed by scientists at the Johns Hopkins University Applied Physics Laboratory at the request of a Washington, D.C. couple whose autistic daughter's life-threatening head-banging had not been controlled by medication, behavior modification or other interventions. The young woman's head-banging—which had forced her parents to take turns sleeping, so that one parent was always present to restrain her—had been so severe that at one point her ear was nearly severed from her head. According to the parents, Leslie and Mooza Grant, their daughter—who had banged her head for 15 years—reacted "instantaneously" to the device, ceasing her head-banging after only two blows.

The device, now manufactured by Human Technologies, Inc., consists of a lightweight headgear which is worn along with a special arm or leg band. When the head is struck, the device beeps, then delivers a mild electric shock through the band. The shock, which lasts less than one tenth of a second (and is only one hundredth as strong as the "shock sticks" used a decade ago), feels like a pinch. A nine-volt transistor radio battery provides power for the SIBIS.

While the device would seem aversive, Linscheid says the children he has tested want to wear the device and will actually lean their heads forward to get it on. When one girl's device fell off, she rolled her wheelchair over to it and tried to replace it.

The Grants agree, saying that "If the

headpiece was removed, Linda [their daughter] would resume her head-hitting and struggle to have the headpiece put back on her. When it was put on, her hitting would stop and she would radiate with happiness." Linda Grant has worn the prototype device for 17 years and has not resumed her self-injury.

Linscheid says the most dramatic result seen so far was with a child who had been hitting herself 3,000 times a day; when the SIBIS was put on, the child's head-banging stopped completely within one day. All three autistic individuals Linscheid tested have virtually stopped injuring themselves.

The SIBIS unit contains sophisticated electronic microcircuitry and costs \$3,000. Proponents say the cost is far less than that of life-long institutionalization and the medical costs resulting from head-banging, which can lead to blindness, brain damage, or death.

Address for information about Ohio State University study: Thomas Linscheid, Department of Psychology, Children's Hospital, 700 Children's Drive, Columbus, Ohio 43205.

—also—

"SIBIS-A system for the treatment of self-injurious behavior," Human Technologies, Inc., 1325 Snell Isle Blvd., N.E., St. Petersburg, Florida 33704.

—and—

"Device's weak shocks inhibit head banging," Dina Van Pelt, *Insight*, September 28, 1987, page 51.

—and—

"Autistic child's parents find own help," Mary Knudson, *The Baltimore Sun*, Vol. 301, No. 88, August 27, 1987, section A, pages 1 and 10.

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