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

Japanese R-THBP tests: Phases II, III completed

As reported previously in the ARRI, Japanese researchers have succeeded in developing methods for mass producing a stable form of the enzyme tetrahydrobiopterin (R-THBP, also called apropterin HCL), which a 1987 study on autistic children had shown to be safe and useful.

In the 1987 Phase I study, on 84 autistic children three to 12 years old, 54 percent of the children showed significant improvement compared to 31 percent in the control group. Best improvement was seen in the children under age five, in the 12-week trial.

The newly released Phase II study used 99 autistic children in a clinical, uncontrolled design. The subjects were given R-THBP for periods ranging between five and 44 weeks. "Useful" improvement was reported in 55 percent and mild adverse effects were reported in seven percent. Since some of the subjects showed improvement onset later than 12 weeks, it was recommended that the Phase III study continue treatment for 24 weeks, if necessary. A dosage range of one to three mg/kg/day was recommended.

The Phase III study was a multi-center cooperative effort by 33 institutions, involving 138 patients (113 males, 25 females) ranging from two to 17 years of age (average 6.5 years). Treatment continued for 12 to 24 weeks at the one to three mg/kg/day dosage recommended in the earlier clinical study. "Slight or better" improvement was seen in 87 percent of the subjects with 49 percent showing "marked or moderate improvement." Side effects, such as diarrhea and bed-wetting, not considered serious, were experienced by 30 percent of the patients. In this study, as in the previous two, the chief areas of improvement were in social relations and other symptoms considered central to autism. No increase in improvement was seen beyond the twelfth week.

While children under five showed the best results in study I, there was no age difference seen in study II, and data from study III indicated that the treatment was most effective for higher functioning children between the ages of two and three. Children diagnosed as having "autism with developmental delay" also showed good results.

R-THBP is not a drug, but rather a natural enzyme produced normally by the body. Thus R-THBP should be expected to be much safer, especially for long-term use, than conventional drugs.

R-THBP will be marketed in Japan in 1991. A U.S. pharmaceutical firm is attempting to import R-THBP into the U.S. for clinical trials on autistic children, but is encountering legal and technical problems. The Institute for Child Behavior Research has been assisting the U.S. firm for several years in its effort to establish clinical trials. It is hoped the difficulties will be overcome before long. Progress on this important development will continue to be reported in future issues of the ARRI.

VACCINE INJURY CLAIMS: DEADLINE EXTENDED

President Bush has signed a bill giving parents whose children died or were injured by mandated vaccines before Oct. 1, 1988 until Jan. 31, 1991 to file for compensation under the National Childhood Vaccine Injury Act of 1986.

To date 123 payments totalling more than $65 million have been made in compensation for vaccine deaths and permanent injuries including retardation, seizure disorders, paralysis and learning disabilities. Most awards have been for pertussis vaccine deaths and injuries.

For information write to the National Vaccine Information Center, 128 Branch Road, Vienna, VA 22180, or call (703) 938-DPT3.

Surprising success reported with facilitated communication

"I've tried for thirteen years to be normal and I'm still where I started."

"I do not decide not to talk. My brain [decides]."

These comments may sound familiar to parents of high functioning autistic individuals. But what is surprising about them is that, according to Douglas Biklen of Syracuse University, they were typed by low-functioning autistic children who, until recently, had never spoken.

Readers of ARRI are aware that certain low-functioning autistic persons may show remarkable communicative ability with proper facilitation (ARRI 2/1, 4/1 editorials). ARRI urged that researchers explore this phenomenon on an urgent basis.

Now international attention has been directed to the issue as a result of Biklen's extensive article in the *Harvard Educational Review*. Biklen describes sophisticated conversations carried on by non-verbal or minimally verbal autistic individuals using a Canon Communicator (a small electronic typing device with a dot matrix tape printout). Biklen's report seems to indicate that high levels of non-verbal language ability may be the norm, rather than the exception, among even the most severely handicapped autistic individuals.

Biklen writes in the *HER* article that he first witnessed remarkable language breakthroughs at the Dignity through Education and Language Communication Center in Melbourne, Australia, where Rosemary Crossley teaches autistic individuals "facilitated communication" techniques employing the Canon device. According to Biklen, the students, generally non-verbal and considered significantly retarded, carried on typed conversations of amazing complexity and abstraction, discussing such topics as economics, self-determination, and society's attitudes toward the disabled. They discussed feelings and emotions, exhibited high-level vocabularies, and even joked with each other and with Biklen.

The Ouija Board phenomenon?

Crossley's technique involves using hand or arm support to help people with autism type. While some individuals type independently, many others will not type without "facilitators" touching a shoulder, a hand, or the student's clothing.

The technique's success, skeptics say, may be due to the "Ouija Board" phenomenon; in other words, facilitators are influencing the communication—albeit unintentionally—with subtle body movements. A government-sponsored Intellectual Disability Review Panel in Australia investigated Crossley's technique with equivocal results,

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