

Letters To The Editor

To the Editor (Rett Syndrome):

As mentioned in the ARRI, bromocriptine improves some symptoms of Rett syndrome. I have tried bromocriptine on several patients with Rett syndrome. Two showed improved circadian rhythm (sleeping well in the night and taking little daytime naps), and better facial expression.

Not all of them showed improvement, but I do believe that bromocriptine is worth trying, since waking up and screaming in the night, which is often observed in Rett syndrome, is a burden for the family.

*Hisaharu Suzuki, M.D.
Tokyo, Japan*

To the Editor (facilitated communication):

Like other parents, I have tried to provide my severely autistic non-verbal nine-year-old daughter with the very best but I have also learned to speak with restraint and to be cautious over the years. To expect a lot but to define "a lot" in very small increments. Like other parents, I see the depth and light in my child's eyes, but in her day to day life, I see only those behaviors which we collectively term "autism."

So, hardly daring to hope, I did not rush to try the latest miracle: facilitated communication. Only when another parent with a child very similar in functioning to Adri reported that his son successfully communicated did we investigate. Two facilitators from Syracuse came, Marilyn Chadwick and Annegret Schubert. Eleven children participated in the workshop. Adri was one of those.

Since that moment, I have been living my dream. I sat and watched in awe, tears streaming down my face, as Adri answered questions about herself, about things that she knows. In the second session, she answered questions about science; she did addition, subtraction, multiplication and division. That she could do so much is both a tribute to her own capacity and to her school which believed in her enough to teach her even when no apparent learning was taking place.

Some critics charge that the facilitator is doing the talking. I watched and I participated and I am convinced that the information originated with my child. My hand was under Adri's helping her to isolate her index finger and pushing her hand back, towards her chest. She had to push against my resistance to choose and strike a key. At times, Adri was slow and somewhat sloppy, but other times she went very fast and very purposefully. Most of the time, neither Marilyn nor I knew what to expect from her. In fact, when she "absolved" me forever with the words, "I just wanted to tell Mom she is terrific!" I felt quite certain mid-word that she would write not terrific but terri...ble!

The facilitators reported that all eleven children produced written material using the communicator. Furthermore, Marilyn stated that all of the autistic people she has worked with have learned to communicate on some level with the Canon, some in a matter of

minutes, others in a matter of days.

The work is not over. Adri is Adri and her behavior is still autistic. But the "lost" Adri, the one inside for such a very long time, has been found and nothing will ever be quite the same again. I write this in hopes that other parents, too, might find their "lost" children.

Kristi Jorde

Editor's Note: Our cover stories in this issue and the previous issue present information from both proponents of facilitated communication and those who are skeptical about the technique. We will continue to cover this important controversy.

The above letter has been greatly abbreviated because of space limitations. Parents and professionals wishing a copy of the entire letter, and documentation accompanying it, may write to the Adriana Foundation, 2001 Beacon Street, Room 214, Brookline, MA 02146, or call the foundation at (617) 232-8634.

To the Editor (facilitated communication):

I am amazed to see that the work my daughter and I are doing on our Epson computer is so well documented — a fact I had no idea about! The fact that I have to hold my index finger under her wrist has resulted in a credibility battle with the local school system (which tries to deny the authenticity of this communication). We are now in court trying to get an alternative educational placement for her.

Gayle Marquez

To the Editor (non-urban alternatives):

I read with interest your article, "The Non-Urban Alternative," and was moved by the personal elements it contained. I was also reassured to discover that your views and the views of others who have established such communities in the U.S. and Europe are compatible with our own. In a book we published back in 1980, *Autism: New Directions in Research and Education* (Webster, Konstantareas, Oxman and Mack, Eds.), we described just such an alternative, Kerry's Place. Having for years been a professional member of the Board of Directors of the now much larger non-profit "Kerry's Place Corporation" until a year ago, I can attest to the success of establishing programs in rural settings.

We have found that a rural setting at times constitutes a much better placement option for an autistic individual than an urban setting possibly could. On a number of occasions, for example, for administrative reasons, clients were moved from one of our rural to an urban residence. Although some of these moves were unremarkable, others precipitated a crisis for the autistic person, which necessitated a return to the rural and more relaxed setting from the far more constraining "integrated" urban setting. We never had the reverse crisis, i.e. a problem in switching from an urban to a rural context.

Although admittedly not enough sys-

tematic information is available on this, to my knowledge, it does appear that the rural alternative is an option well worth considering for a number of our clients, particularly the more hyperirritable.

*M. Mary Konstantareas, Ph.D.
Professor of Psychology and Psychiatry
University of Toronto*

DMG

We continue to receive letters from parents who report that the nutrient DMG (see ARRI 4/2) produces remarkable improvement. In a recent phone call, the mother of an almost six-year-old autistic girl told me she had given her daughter one DMG tablet at 6 p.m. The girl had spoken only a few words in her life. Yet the next morning, at 7 a.m., rather than turning on the TV, she went to her mother's room, shook her, and said, "Wake up mommy, it's time to get up." The mother told me that if she had not been lying down, she would have fallen down. The girl's teachers immediately noted greater awareness, eye contact, and language. Remarkable? Yes. Unprecedented? No. Here are a few letters: (For information on DMG, send SASE.)

To the Editor:

I want to pass on to you my son's successful use of DMG! He has been on it for about four months, and says it does definitely help his frustration level. He has taken a lot of different treatments over the years, and this is the very first time he has thought something has made a difference.

*An Oregon mother
of a high-functioning autistic adult*

To the Editor:

Hurray for DMG! Our 14-year-old daughter [diagnosed as attention deficit disorder and hyperactive, with strong autistic tendencies] recently started on DMG, and within two days we were noticing some major changes in behavior. She had a greatly reduced frustration level; teenage hostility and/or oppositional behavior has diminished substantially; homework is now as pleasant as it can be; her organizational skills, which were non-existent before, are definitely appearing; logic is developing; neatness is increasing; and we are seeing humor and cracking jokes about everyday problems. The bottom line: she is a much happier person. One of the most notable things was her asking for her "happy pills." She had become aware of the changes in herself, made the association, and liked the feeling.

A California mother

To the Editor:

We started our son Isaiah on DMG the day after we received your newsletter. He has become more alert and interested in interacting with his environment . . . I have had several people at church come up to me and tell me how much better they think he is doing in terms of being "with it" or paying attention to what's going on around him.

Ruth Shade