

# LETTERS TO THE EDITOR

*Who, us?*

To the Editor:

Here is my \$16 for a subscription to your cranky little newsletter.

(name withheld)

**Editor's Note—Well...I never!!**

## *Diet, megavitamin therapies*

To the Editor:

I read with interest your article on gluten and casein intolerance and autism (ARRI 7/1). We subsequently discovered just such intolerances in our eight-year-old autistic son, Andrew. Immediately we put him on a gluten- and dairy-free diet (sugar-free as well), and now, four months later, Andrew has gained three pounds. (Previously, he ate ravenously but gained at most two pounds per year.) Also, he is beginning to show some of the behavioral improvements noted by the Norwegian researchers.

I am eager to hear from other parents whose autistic children are gluten and/or casein intolerant.

Harriet Barnett  
104 Douglas Road  
Belmont, MA 02178

To the Editor:

Our 5-1/2 year old son, Harrison, was diagnosed with PDD-NOS in 1991. Although he functioned in the normal range of IQ, Harrison's behavior was so severe he has always been placed in special education classes for severe communication and behavioral disordered children, because of his behavior and extremely poor gross and fine motor skills. He has been placed on several types of medication for hyperactivity and behavior control.

I heard of your research on vitamin B6 and also noticed that Harrison craved foods containing the B vitamins. He would eat up to a dozen pieces of whole wheat bread per day! I started Harrison on B6 and magnesium.

The following days showed dramatic decreases in Harrison's tantrums and whining and increases in symbolic play and talking about feelings. Before the B6 therapy, he would lash out at anyone who made him angry and now he is beginning to talk about his feelings and say: "You hurt my feelings," instead of screaming, pinching and biting the other family members. While he used his imagination somewhat before the therapy, he really uses it now. Almost every game he plays, he plays appropriately.

The most startling of all is a sudden spurt of development in fine motor skills. Harrison had been in occupational therapy for over a year and still couldn't draw or trace a letter. Suddenly, he picks up a crayon and draws the entire solar system to scale!

Finally, Harrison is going to be "included" full time in regular kindergarten

starting in a couple of weeks. He has been mainstreamed in first-grade reading since the school year started. He is no longer taking any Mellaril and doesn't eat an inordinate amount of bread now. His doctor is very excited about the B6 therapy.

Susan Murray  
Memphis, TN

## *Anafranil (Clomipramine) "rage"*

To the Editor:

The ARRI article about Anafranil (ARRI 7/3) is of particular interest to me. My 22-year-old daughter Diana was placed on Anafranil (50 mg. increased to 75 mg. in April) because of her compulsive/obsessive behaviors and refusing to dress.

When Diana was first placed on Anafranil it was like a miracle drug. No longer was she bothered by her clothing. Within three days she was able to dress without help. Her compulsive behaviors were no longer considered a problem. The drug worked so well, we had faith that increasing it would reduce Diana's anxiety, which continued to cause problems.

During the end of May, June, and July (125 mg. Anafranil) I recorded fits of rage, something we never experienced before. The rage attacks were so severe that the aftermath of these attacks has resulted in over \$1,000 worth of damage in our home. Diana bit herself so severely during these attacks that she has nine scars on her upper arms. Seventeen times we had to restrain Diana to keep her from hurting herself, us, or doing extensive property damage. I recorded 27 rage attacks. The attacks were so severe once I almost called the police. [The drug also] caused Diana to have an insatiable appetite. She said, "I'm hungry all the time," and gained 25 pounds.

We reduced the Anafranil to 25 mg. every other day. There has been a little increase of compulsive behavior, but it does not interfere with her life as it did before.

Carol A. McNulty  
Phoenix, Arizona

## *Facilitated Communication*

To the Editor:

I have just read your editorial on F/C. While I agree with your call for moderation, I am still concerned that using your criteria some valuable material typed through F/C will be lost.

My daughter, age 6, is opposed to testing, instantly literate, and typing sophisticated content. In fact, she has written an essay she calls *Living as an Autistic: the True Life Story of an Autistic Child*. Numerous people have been moved by her writing and all have said they understand better about autism.

Both her facilitator and I have no doubts that this is Emily's work. Yet, if I read your editorial correctly, you would say she could not have written this essay. What a loss to the world that position would be.

Moderation yes, but let's leave the door open for the miracle. It's miracles that give us the insight to make progress.

Susan Zimmerman  
Hanover, CT

To the Editor:

When our son Bill—37 years old, autistic, nonverbal and retarded—started facilitated communication we hoped that he would increase his literacy skills beyond just printing his first name.

But we were informed that our goals were too modest. Within three weeks Bill's facilitator claimed that he was writing sentences via F/C. He wanted to go to a "go-go bar," she said, but he was afraid to tell mom because she would be mad if he went to a "house of ill repute." I was expected to give \$15 to the facilitator's husband who had volunteered to take Bill to the bar. Through F/C Bill "told" the facilitator that such a bar was at "Dupont Circle in Washington, D.C." If Bill could name the street he has lived on for fifteen years it would be a miracle. We refused, and in the next session the facilitator asked Bill if he was afraid to ask his parents for money. Not surprisingly, he typed "yes."

Other facilitators also claimed incredible messages from Bill. One reported that he wanted to return to the institution where he had spent three unhappy years. I was stunned that Bill's case manager and group home director showed no skepticism when the facilitator reported these stories, and I resented the fact that public money was being spent for this hoax.

After several months of F/C Bill became aggressive toward strangers for the first time in his life. Following the third incident he was committed to a State hospital—far from his family and where it was often necessary to put him in restraints. Was Bill confused and terribly frustrated by people telling him that he was saying things that were not even in his mind? We think so. Bill has always resisted communicating, except for making known his basic needs, and the F/C episodes seem to have confirmed him in his attitude.

Anne Murphy  
Springfield, VA

To the Editor:

I am the disillusioned facilitator who was shown on the *Frontline* program [see page 7]. As you know, the other facilitators and I were very upset when we realized we were influencing the typing of our clients. We have started a support group for facilitators in similar circumstances. Concerned facilitators are welcomed to call or write to me (Marian Pitsas, O.D. Heck Developmental Center, Balltown and Consaul Roads, Schenectady, N.Y. 12304, 508-370-7505), or to Janyce Boynton, P.O. Box 1343, Ellsworth, ME 04605, 207-667-8074.

Marian Pitsas  
Schenectady, NY