

# LETTERS TO THE EDITOR

## "Face blindness" and food intolerance

To the Editor:

I am writing in response to your article about "face blindness" and the letter about celiac disease in ARRI 9/3. I have been a big part of the recent movement within the Irlen Centre which is now treating people with autism for Scotopic Sensitivity Syndrome (SSS). Basically, SSS is a visual-perceptual problem affecting how the brain makes sense of visual information. SSS is like dyslexia, but in my case—a severe case—it involves inability to process a whole picture so that everything becomes meaningless impression and only a single fragment gets processed at a time. In effect, a person IS a nose or a coat or a pair of glasses, just like the man described in the article.

Now, here's the link with the celiac disease letter. I have been on a diet for six years which basically cut out foods high in a substance called phenol. The changes, as documented in my first two books, were dramatic. Nevertheless, my visual perceptual problems remained and were corrected by Irlen lenses.

For the past two months I have been on an extremely restricted diet which completely excludes all foods high in two phenolic compounds: gallic acid and malvin. The effects are overwhelmingly incredible. My senses are far more integrated [and I have a] consistent ability to hold two or more concepts at once and link new information without losing the old [and an] ability to consistently experience thought and feeling together... basically my information processing is becoming very close to normal.

Wheat is a food rich in gallic acid, and the intolerance of it in a brain-affected person with autism may have nothing at all to do with gluten intolerance or celiac disease. Cow's milk is one of the highest phenol-containing foods and is rich both in gallic acid and in malvin, and its intolerance may have nothing to do with lactose intolerance. In both cases, it may be phenol intolerance which is responsible.

The [phenol-free] diet is NOT easy to

### Correction

In reporting on research by Christopher Kearney et al., in ARRI 9/3, we mistakenly stated that "Kearney, Durand, and Mindell found that the individuals moved to the larger facility were given greater freedom of choice." Kearney et al. actually compared subjects' amount of choice *after* the subjects originally placed in the larger facility had been moved to group homes. Kearney notes that "some residents were moved to a larger facility initially, but levels of choice in this setting were the lowest of all the settings in the study." ARRI regrets the error.

implement and involves sometimes severe substance withdrawal. [Nevertheless], those who have attempted the Feingold diet and had partial but significant improvement probably could try excluding foods in the malvin (as well as gallic acid) groups and it may be that success will be even greater.

Donna Williams

**Editor's Note:** Donna, who is autistic, is the author of *Nobody Nowhere* and *Somebody Somewhere*, and has several new books en route. I can personally attest to Donna's remarkable improvement: in several recent letters and a phone call, the clarity of her thought and expression, resulting from the dietary changes she mentions, was *immediately* apparent to me. When I remarked on this in the phone call she jubilantly agreed: "It's wonderful," she stated. "I'm now in touch with Heaven!"

### Nutritional treatments for Rett's, autism

To the Editor:

I saw a child for the first time in January this year who was then diagnosed as being severely developmentally delayed. In fact, she was, had stopped speaking, and had stopped growing.

I placed her on a high-dose vitamin program and saw her again today after several in-between visits. There is a tremendous improvement in her now, and her parents were delighted with the change.

The reason I write to you is that she has just been diagnosed as having Rett's syndrome by a geneticist who is considered to be an expert in this field. I thought I would let you know that if this is true, then we have a child with Rett's syndrome who is responding well to an orthomolecular approach.

Abram Hoffer, M.D., Ph.D.  
Victoria, British Columbia

**Editor's Note:** Dr. Hoffer is a world-renowned psychiatrist who pioneered the megavitamin treatment of schizophrenia in the early 1950s. I am also familiar with a case of Rett's syndrome on whom megavitamin therapy was used with dramatic results. The teenaged Rett's girl was extremely self-injurious until the vitamins were given. When the vitamins were stopped, her self-injury recommenced—on two occasions.

Rett syndrome is a progressive disorder, almost always diagnosed in girls, which resembles autism in its early stages. One of its most distinctive symptoms is a constant "hand-washing" or hand-wringing motion. Girls with Rett syndrome commonly also have scoliosis, feeding difficulties, and episodes of hyperventilation.

To the Editor:

We are the parents of autistic twins, four years old. One of the twins was accepted

into an early intervention program here in Oslo that is connected to Dr. Lovaas at UCLA. [The other] twin started behavior modification in daycare, with help and guidance from his brother's program.

After about four months, the boys had not progressed as well as we had seen with other children. We met a British boy who had been in the program for about as long as our boy, but performed much better. Although they had similar scores on testing, the British boy had much better comprehension, spontaneous language, and "normal" behavior. From his parents, we heard about megavitamin supplements (mainly B6), to which they attributed the difference. Their boy had had dramatic improvements after starting on megavitamin supplements.

We ordered megavitamins from the U.S. and started these as soon as we could. After three weeks on megavitamins, we discovered a marked difference in both the twins' behavior. We observed more normal play, less self-stimulation, and better attention and comprehension. At that point we were unsure whether to attribute this effect to the behavior treatment program or the vitamin supplement. However, about three months later, we inadvertently ran out of the megavitamins. After about a week, we started to notice a marked difference in our boys' behavior. The higher functioning twin's "stimming" increased dramatically, his attention span decreased, and he became more difficult to train. The other twin's behavior also changed, with much more self-stimulation and a reoccurrence of behavior-induced vomiting episodes which had disappeared after starting on the vitamins. When the vitamins arrived, it took another 1-1/2 weeks for [their behavior to improve]. After this episode, we vowed to never run out of vitamins again.

Our primary physician is a neurologist and primary pediatrician for southern Oslo. He was very skeptical at first. However, after seeing the result in our boys, and having received similar information from France, he has changed his mind, and is currently recommending megavitamin supplements to other autistic children.

Ketil and Sarah Stokke-Johnsen  
Oslo, Norway

### Group homes

To the Editor:

[Re article on group homes vs. institutions:] To adequately compare these two environments that foster learning, would one not start by clearly defining the objectives? A group home is a building, yes, but is not the goal to closely resemble normal adult life, and as such what constitutes the full range of normal needs to be defined, not simply behaviors or the concept of choice?

I would suggest that normalcy is equivalent to the following range of options:

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