Response to letter

A letter was written in 2007 and posted on Down Syndrome Education's website that rebukes the Changing Minds protocol. It covers the protocol point by point. I would like to address the issues surrounding medicine and supplements for the Down syndrome population.

The letter begins with a false assumption, and that is that the CMF protocol has not been tested for efficacy and safety. This is blatantly not true. All the herbs and medicines have had many studies done in children and adults. The studies have not been specifically directed toward DS but aren't we people first? For example, when your child has an infection, don't you give them an antibiotic? No studies have been done specifically on DS for antibiotics, yet you are willing to give this drug to your child. Why? Because it has been thoroughly tested on the average person, and it is safe and effective for them. The same can be said for ibuprofen, acetaminophen, insulin, antihistamines, sinus medications, vitamins, etc. etc.

Most of us go to the doctor with a specific set of symptoms and the physician prescribes a medicine that should address those symptoms. Most of the time the medicine helps, sometimes you get too many side effects and a dose adjustment must be made. But my point is medicine is based on trial and error.

With our children and adults with down syndrome, the doctor stamps their chart DS and that is where the diagnosis ends. Why aren't we looking at symptoms?

The letter states over and over that this combination of medicines and supplements is ***potentially* dangerous.** That statement is unfair and said only to scare parents. All the medicines and herbs have been used by people for 30 to 5000 years. What I find to be frightening and ***absolutely dangerous*** is the following:

* **Microcephaly (small brain size) is *absolutely* dangerous**
* **Lack of neurogenesis is *absolutely* dangerous**
* **Neurodegeneration is *absolutely* dangerous.**
* **Loss of cognitive function is *absolutely* dangerous**
* **Developing Alzheimer's early in life is *absolutely* dangerous**

This is the reality of down syndrome.

**Ginkgo Biloba**
Ginkgo Biloba has been used by people for over 5000 years. There are hundreds of studies showing what it does in the body.  The most exciting study involves an Australian study where it was shown that the biloba part of ginkgo biloba turned down a major problem in the nerves of patients with down syndrome.
This nerve problem was first discovered at Stanford University in 2003, published in the *Journal of Neuroscience* in 2004. The link to the study is below.

<http://www.jneurosci.org/content/24/37/8153.long>

It is presently 2012. It has been 8 years and no institution has even proposed a study for Down syndrome using ginkgo biloba.  Roche pharmaceutical company has started a phase 1 trial on a drug that has a similar function as ginkgo biloba. The average drug trial length is 12 years. So, this treatment, if it makes it, will be available 2024 at the earliest.

I am not saying run to the health food store and buy something to give your child without understanding it, but please read the details about ginkgo biloba and its function in DS. Read the information on our website and/or blog to be informed and make up your own mind.

<http://www.changingmindsfoundation.org/documents/prozac.html>

<http://www.changingmindsaboutdownsyndrome.blogspot.com/>

**Prozac**
The first sentence in the letter states that only one study has shown that Prozac (fluoxetine) increases and supports neurogenesis (the growth of new neurons). This is blatantly untrue. Many researchers are very interested in Prozac for numerous neurological conditions. Go to the website ***pubmed*** and plug in Prozac and neurogenesis to see for yourself.
Their other argument is that Prozac may be dangerous during pregnancy.  For all those mothers with down syndrome.......

The only somewhat valid point they make is that we do not know exactly what Prozac does in newborns and very young children. However, there has since been a study that looked at every point in time for the Down syndrome mouse and it showed improved brain development at every stage.

<http://www.jneurosci.org/content/30/26/8769.long>

The entire study is at the link above.

I realize these physicians and professional groups are well meaning and want to protect this population. But in their attempt to protect they have inadvertently put those with Down syndrome in danger.  We have a known neurological disorder that has been hijacked by groups that insist this is only an acceptance problem. If only you accepted my son, then he would perform.  No he will struggle. You can't tell his brain "just think better". How unfair! We now, for the first time in history, know what is impairing memory and learning, and they want you to wait for them to decide it is the right time to treat.  Eight years after the major discovery, they have started pharmaceutical trials at Roche.  It will be another 10 to 15 years until the pharmaceutical company will get government approval.  My son deserves more than that. Does yours?

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