

Cure Down Syndrome?

By Christy Sanchez

According to Webster's Online Dictionary, the definition of cure is **to remedy; to remove; to heal**. We have always been told that there is no "cure" for Down syndrome. That is – we've been told there is no **remedy** for Down syndrome. But is that really true? Is that really the case in 2010? According to the National Down Syndrome Society, in 1983, the average life expectancy of a person with Down syndrome was just 25 years old. Fast forward to **now** - the current life expectancy averages 56 years. What caused this change in life expectancy? Did Down syndrome change in 27 years? Did the trisomy of chromosome 21 change between 1983 and 2010? Of course not - the genetics are exactly the same **now** as they were then. A baby born in 2010 with Down syndrome has the same trisomy of chromosome 21 as the baby born in 1983. So what caused the increase in life expectancy? The answer is quite simple – advances in medicine. Not one parent or professional will argue this point. It is evident in the result – longer life expectancy.

Longer life expectancy is now achieved by addressing the physical problems associated with Down syndrome one by one. By identifying the issues that are more common in children with Down syndrome and screening patients – appropriate treatments are prescribed. These common problems have a **remedy** or cure. For example, an underactive thyroid has a **remedy** – medication. Celiac disease has a **remedy** – follow a gluten-free diet. Heart problems such as ASD and VSD have surgical **remedies** to treat them. *People with Down syndrome still have the same triplicate chromosome 21, but there are now **remedies** for the physical problems associated with the overall syndrome. What do we know about what's different in their brains? Is there a **remedy** that can help **now**?*

In the last 10 years an accurate mouse model (of Down syndrome), Ts65Dn, has been developed. According to the NIH National Human Genome Research Institute, the Ts65Dn mouse mimics trisomy 21 (Down syndrome) and exhibits many of the behavioral, learning, and physiological defects associated with Down syndrome in humans, including mental deficits, small size, obesity, hydrocephalus and thymic defects. This model represents the latest and best improvement of Down syndrome models to facilitate research into the human condition. In the lab, researchers are **now** able to reveal answers or **remedies** for the neurological disorders associated with Down syndrome.

Too often when we talk about a **remedy** or cure for problems in the brains of people with Down syndrome, parents and professionals alike say, "No, a cure is impossible. People with Down syndrome are the way they are – just accept it and move on!" Before you jump to that same conclusion, I encourage you to take a look at current science. Read it yourself. That is exactly what Teresa Cody did. Teresa is the mother of Neal, who has Down syndrome. At the age of 8, Neal couldn't read, write or distinguish shapes. "The main problem was he really couldn't remember. He did not ask questions. He could not verbalize," said Teresa. "He used to pick up the pen and stare at the paper and you could see he had no idea which way to make the pen go to copy something." Teresa studied the research. Based on Dr. Craig Garner's work at Stanford, she devised a protocol that contained compounds shown in Garner's research to target the underlying cause of learning and memory problems. Just one year later, Neal was reading at a second grade level and doing multiplication by hand. Neal's academic gains while taking the treatment protocol inspired Teresa to create the Changing Minds Foundation, a 501(c)3 non-profit organization, dedicated to improving the mental ability of persons with Down syndrome – **now** – with available medical treatments and proper education. A documentary film called 'Changing A Mind' tracked the progress of Neal and several other pilot protocol participants over the course of two years. You can view a trailer of the documentary on their website www.changingmindsfoundation.org.

National Down Syndrome Society's (NDSS) Position

The following excerpt is taken directly from the National Down Syndrome Society's website.

“Myth: Down syndrome can never be cured.

Truth: Research on Down syndrome is making great strides in identifying the genes on chromosome 21 that cause the characteristics of Down syndrome. Scientists now feel strongly that it will be possible to improve, correct or prevent many of the problems associated with Down syndrome in the future.”

The only difference between NDSS's position and that of Changing Minds Foundation is that the future is here and treatment to improve cognition is available **now**.

Changing Minds Foundation Holds 1st National Conference

CMF held its 1st National Conference on July 23-24, 2010, in Houston, Texas. Attendees came from numerous states and as far away as Singapore. Thanks to a generous stipend provided by the Heart of Illinois Down Syndrome Association (HOIDSA), I was able to attend the conference. The following report is a summary of information gathered at the conference and information from the CMF's website and blog.

Neurobiology

The terms neurobiology and neuroscience can be used interchangeably. They refer to the biology or science of the nervous system. Researchers in the Department of Neuroscience at Stanford University are dedicated to developing therapeutic strategies for normalizing cognition in people with Down syndrome. Neurotransmitters regulate learning. In the brain of a person with Down syndrome these neurotransmitters are a little off or out of balance. They need a **remedy** to bring them back into balance. The good news is that we can treat this imbalance just like any other psychiatric disorder – with modern medicine. ***Just as life expectancy has improved since 1983 with medical advancements, cognition can be improved with medical advancements - now!***

What Problems are Addressed by the CMF Protocol?

The Changing Minds Foundation (CMF) has created a treatment protocol to address four of the neurological problems identified in Down syndrome. ***Most people with Down syndrome fall into the mild to moderate range of intellectual disability so even a small increase in cognitive ability (or IQ) can move an individual from being dependent on others throughout their lives to becoming independent members of society.*** The following is based on information taken from CMF's website and conference handbook.

Brain Problem 1: The *major* cause of cognitive impairment in mouse models of Down syndrome is over inhibition by the GABA receptor system. In 2003, Stanford University researchers discovered that the GABA receptor, an inhibitor, was continuously stimulated. Since the GABA receptor is an inhibitor of brain function, this stimulation actually causes a decrease in cognition. The nerves in the memory area of the brain are prevented from firing efficiently. Another way we can think about this is the use of alcohol or benzodiazepines, (Valium and Versed). Both alcohol, Valium and Versed stimulate GABA receptors in the brain. This results in slowed activity in the brain. Just as many of us have seen people's brains (and thus cognitive function) altered by alcohol or tranquilizers so too may the brain of one with Down syndrome be slowed by over-inhibition.

Related Articles for Problem 1:

Stanford, PTZ, & GABA

http://med.stanford.edu/news_releases/2007/february/down.html

Ginkgo Biloba & GABA <http://www.changingmindsfoundation.org/documents/ginkgobiloba.html>

Remedy for Brain Problem 1: To get the proper level of GABA (so that learning can occur); a GABA antagonist was used to turn the inhibition down. Bilobalide, a component of Ginkgo Biloba extract, reversed the cognitive impairment in the mouse model. Stanford researchers are raising money to do a formal clinical trial with a GABA antagonist drug called PTZ, but it is not yet approved by the FDA - and this process will unfortunately take up to 10 years. Ginkgo Biloba (also a GABA antagonist) is widely available in health food stores - **now**. Participants using the CMF protocol are realizing good results using Ginkgo Biloba. We now know that lack of memory is the lock on the door of learning for people with Down syndrome. Ginkgo Biloba is the key for opening the door of learning! Protocol participants as young as five weeks old are using Ginkgo Biloba.

Brain Problem 2: Loss of neurons in the hippocampus: Babies with Down syndrome lose 50% of their neuronal structure by 6 months of age. This seems like an insurmountable problem. In fetuses with Down syndrome, neurons fail to show normal dendritic development, yielding a "tree in winter" appearance. This developmental failure is thought to result in cognitive impairment.

Related Articles for Problem 2:

"Tree in winter" dendritic development

http://journals.lww.com/jneuropath/Abstract/2004/07000/Trisomy_21_and_the_Brain.1.aspx

2010 Prozac (Fluoxetine) Study

<http://www.jneurosci.org/cgi/content/abstract/30/26/8769?maxtoshow=&hits=10&RESULTFORM=AT=&fulltext=fluoxetine+Renata+Bartasaghi&andorexactfulltext=and&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT>

2006 Prozac (Fluoxetine) Study

<http://www.ncbi.nlm.nih.gov/sites/pubmed/16624293?ordinalpos=1>

Additional Information about Prozac

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

Remedy for Brain Problem 2: In 2006, the University of Maryland School of Medicine treated Down syndrome mice with Prozac (generic name Fluoxetine). They discovered that Prozac treatment doubled the neuron count resulting in a normal level after 24 days. This is like increasing the hardware on your computer. It allows you to run more complicated software. Prozac received FDA approval in 2003 for ages 6 years and older. It seems clinically logical that people with Down syndrome could benefit from this drug because of the loss of neurons that occurs early and on an ongoing basis. Additionally, many people with Down syndrome commonly exhibit symptoms of anxiety and OCD early in life and depression later in life. Prozac can be used to address these issues as well. Participants as young as 10 months old are using the Prozac component of the protocol. Many young participants have been using Prozac for nearly 2 years without negative side effects.

Brain Problem 3: Early onset Alzheimer Disease/Inflammation: How do you lower the inflammatory markers safely and for a lifetime in a syndrome that represents an Alzheimer model?

Related Articles for Problem 3:

Phosphatidyl Choline

http://www.changingmindsfoundation.org/documents/phosphatidyl_choline.html

Omega 3, 6, 9 Oil

http://www.changingmindsfoundation.org/documents/body_bio_balanced_oil.html

Minocycline and Ts65Dn

http://www.ncbi.nlm.nih.gov/pubmed/15468085?ordinalpos=1&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_DefaultReportPanel.Pubmed_RVDocSum

Inflammation Resolution and Lipids

<http://www.ncbi.nlm.nih.gov/pubmed/19630766>

Remedy for Brain Problem 3: There is tremendous evidence that Alzheimer's disease is a state of chronic inflammation, specifically neuroinflammation. Inflammation is the body's natural response to injury or assault. It begins the healing process. There is a flip side to inflammation called resolution. Resolution is an 'active' process with specific chemicals that clears and limits the inflammatory response. A recent study from Harvard identified chemicals that reduce or control the magnitude of the inflammatory response. These chemicals are called Specialized Pro-resolving Mediators (SPM). These chemicals are derived from lipids, in other words, fatty acids – thus the importance of Body Bio Oil and Phosphatidyl Choline. You want your body to make these SPM's. SPM's include resolvins, protectins and maresins and are biosynthesized from essential omega-3 fatty acid precursors. The CMF's protocol aims to decrease inflammation by using fatty acids such as Phosphatidyl Choline (PC), Sunflower oil and Flaxseed oil. When used in the correct ratios they provide a safe, effective way to lower C-reactive protein, Interleukin 1 and Tumor Necrosis Factor which can contribute to inflammatory processes in the brain. Phosphatidyl Choline is a phospholipid that makes up 50% of the cell membrane. The membrane is the lining of every nerve cell that carries our signals. PC is a safe and essential fatty acid that studies have shown to protect the nerves from damage. Sunflower and Flaxseed oils are known for reducing inflammation by triggering a "restoration pathway."

Brain Problem 4: Norepinephrine is a neurotransmitter that nerve cells use to communicate. Norepinephrine has been found to be deficient in the brains of Down syndrome mice. Additionally, many children with Down syndrome have a lack of concentration and behavior problems (ADD/ADHD symptoms). According to an article by Dr. Joseph Carver, some studies suggest that children/adults (typical) with ADHD may have only ten to twenty-five percent of Norepinephrine found in the normal brain.

Related Articles for Problem 4:

Focalin XR

http://www.changingmindsfoundation.org/documents/focalin_xr.html

Stanford – Norepinephrine

<http://med.stanford.edu/ism/2009/november/down-syndrome.html>

Methylphenidate and Norepinephrine study <http://www.ncbi.nlm.nih.gov/pubmed/20691429>

ADHD and Norepinephrine, Dr. Joseph Carver <http://www.enotalone.com/article/4121.html>

Remedy for Brain Problem 4: The benefits realized from adding a mild stimulant medication such as Focalin XR is twofold. First, stimulant medications (ADHD drugs) have been shown to enhance attention and learning. Second, ADHD drugs work on the Norepinephrine system! This type of medication is very individualized. Focalin XR works well for many people with Down syndrome. However, some individuals may have better results using a different stimulant medication.

Thoughts From Teresa Cody

“Do we wait until every detail is known? Did you know that no one knew how aspirin worked until the early 1990’s? The details of biological systems are understood more today than any time before but why not use the information in real time? All of the medications in the protocol have been through clinical trials. OK, not specifically for Down syndrome but NO medication has been through clinical trials specifically for Down syndrome. For example, have you ever given your child an antibiotic? We know their immune system can be described at least, as different, if not immunodeficient. But faced with pneumonia or strep throat, the logical decision is to treat with a medication the rest of the population uses. Scientific research has shown that these medications should help correct specific problems in the brain. Problems current science indicates are present in the brains of people with Down syndrome. Some protocol participants have been using the protocol for four years now. The clinical observation of the 300 children and adults on the CMF protocol is that there is an amazing improvement of function including: verbal abilities, long term memory, working memory, gross motor and fine motor. What part of this do you not want?”

Frequently Asked Questions

- 1.) **Is the CMF protocol the solution to all brain problems associated with Down syndrome?** *No – but it is a start. It is something we can do **now** to improve cognition as demonstrated by current protocol users.*
- 2.) **Will the CMF protocol make my child learn as well as a typically developing child?** *No – but it does allow most participants to learn and comprehend better than before - **now**.*
- 3.) **Where can I find suggested dosing information?** *You can find a Dose Chart at http://www.changingmindsfoundation.org/documents/dose_chart.html*
- 4.) **How much does the CMF protocol cost?** *Ginkgo Biloba is widely available, over the counter. It is a standardized formula, so the quality is consistent from brand to brand. A quick internet search found a bottle of GB with 100 capsules for \$12.99 from one company. Prozac, generic name Fluoxetine, is available by prescription only. You can get a 30 day supply at most pharmacies for about \$4. The cost of prescription ADHD drugs vary – generic drugs are cheaper than name brand. The recommended Body Bio Oils are the expensive part of the protocol: Phosphatidyl Choline – 100 softgels \$62 or an 8 ounce bottle \$94, Body Bio Balance Oil (Omega 3,6,9) – 180 softgels \$30, 16 ounce bottle \$26. Other brands of Phosphatidyl Choline and Sunflower/Flaxseed oils are widely available online and in health food stores.*
- 5.) **How do I find more information about starting the protocol?** *Read the links attached to this paper. They include a wealth of information and will answer many of your questions. You can also order the documentary film and see participants as they are followed while on the protocol (available at www.changingmindsfoundation.org).*
- 6.) **How long does the protocol work? Do the kids plateau after being on it for a period of time?** *According to the CMF, the kids who have been on the protocol the longest are still advancing and learning new things all the time. Just like any medicine, the dosage of these medications have to be rebalanced with time and growth. Be sure to click on “Success Stories” on the CMF’s web page for further information.*
- 7.) **How do I present this information to my doctor?** *You can take a copy of this article along with printed copies of the referenced articles linked throughout. Organize the information in a folder and leave it for your doctor to review. Schedule a follow up appointment to discuss after he/she has had time to read the information.*
- 8.) **More questions?** *Contact the Changing Minds Foundation at changingmindsfoundation@gmail.com*

Research Needs Funding – You Can Help – NOW

We, as individuals, must take it upon ourselves to financially support cognitive research like that being done by Dr. Craig Garner at Stanford's Down Syndrome Research Center. If families do not find cognitive research in Down syndrome a worthy charitable cause, then who else will?

The Changing Minds Foundation currently has two opportunities for you to help fund research to improve cognition in people with Down syndrome. The first is a campaign called, "Spare Change for Changing Minds." You can read more about it and learn how to receive your cans for spare change on CMF's home page – click on '**We Can**' or see Teresa's blog about it at <http://changingmindsaboutdownsyndrome.blogspot.com/2010/08/we-can.html> .

The second opportunity is to enter CMF's Ball Drop Contest. Purchase as many numbered golf balls as you want for \$25 each. Every ball will give you a chance at a trip to Cabo San Lucas, Mexico!! On October 28th, at Wildcat Golf Club in Houston, all balls will be dropped from a helicopter hovering over the driving range. The first ball to land in the hole (or closest to the pin) wins the trip. The ball drop is limited to 2000 balls. Go to http://www.changingmindsfoundation.org/golf_tournament.html to purchase your balls. Ask friends and family to support cognitive research by purchasing golf balls.

For Additional Information Please See the Following Websites

Changing Minds Foundation www.changingmindsfoundation.org

Changing Minds Foundation's blog by Teresa Cody
<http://www.changingmindsaboutdownsyndrome.blogspot.com/>

Join Changing Minds Foundation on Facebook
<http://www.facebook.com/pages/Changing-Minds-Foundation-Treatment-and-Research-for-Down-syndrome/101325513376?ref=ts>

Join Changing Minds Foundation's NING site where parents discuss the protocol and their children
<http://changingmindsfoundation.ning.com/main/authorization/signUp>

Stanford's Down Syndrome Research Center <http://garnerlab.stanford.edu/>
<http://dsresearch.stanford.edu/research/>

Join Stanford Down Syndrome Research on Facebook – keep updated with their blog
<http://www.facebook.com/pages/Stanford-Down-Syndrome-Research-Center/378357949509?ref=ts>