

Dystonia Living Magazine

Volume 1, Issue 7

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From the Laptop

Special points of interest:

- Jennifer Cannon runs a marathon
- Review & discussion of a book on neuroplasticity
- New in fiction and poetry: "Castigated"
- Line Bellavance recounts the amusing events of a Bleph affected life.
- Access & Nutrition

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It has been 15 years since my high school graduation. Fifteen years that have been full of adventure, excitement, pleasure and pain. None of my former friends and classmates have had the pleasure of learning about this odd jackpot of neurological confusion, Dystonia, first-hand. I am on my way to present myself to them.

Do I sound slightly apprehensive? Perhaps, it's just emotional fatigue, having more to do with the challenges I met when booking my train ticket than any fear of rejection.

I have a service animal who works as a mobility support. After much training, he is extremely well-behaved and professional, even though I tend to feed him from the table. When initially booking my ticket I was told my service dog could not

accompany me, a condition which, had it been met, would have made the trip an impossible effort. So it was, when faced with an ignorance-based barrier, I forged



Mobility Support

forward to achieve access and compliance with the law.

Fortunately, I have always taken an interest in access issues and was able to follow up with informed calm, though I was truly stressed. I should say, that prior to speaking with the complaint department I spoke with several other agents, who exhibited a startling disregard for the law, customer service and the simple concepts of po-

lite interaction.

Having to stand firm and challenge wasn't a pleasant experience, but perseverance paid.

So here I am, riding the Amtrak Wolverine on my way to my 15th year reunion. I glance at my netbook's power. I seem to have finally reached the promised high capacity; 11 1/2 hrs. Does it

know we are on a train? I've tried every power trick I could to get there and now, as some fluke... I could use a positive fluke or two... or a blessing.

You know, living with a disability is enough of a challenge without having to deal with the barriers in the world. Yet, there is nothing else one can do. If we choose not to meet the challenges or fight the barriers, we are choosing not to live. Let's fight. Justice is on our side.



**Jennifer Cannon
in training.**

***“Every step
of the way,
I’ll be
thinking of
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Dystonia
fighters who
aren’t able to
run the miles
with me.”***

Ready to Run

Training for a marathon requires perseverance and persistence; even more so when you’re running with Dystonia.

Despite the pulling and tugging in my neck, and the spasms in my abdominals, I pressed on all summer long and am ready to run the Twin Cities Marathon on October 3rd.

But I’d be lying if I said I wasn’t scared.

It’s been six weeks since I last had Botox. This round they did my abdominals, too. It was a trial, to see how I’d do. I’ve not been sure whether it’s been helping. But I can tell now that it has been, because the pain is coming back.

In recent weeks, I haven’t had to lie down with nearly as much frequency. I also discovered that if I slowed my normal pace by about a minute a mile, it kept the spasms from getting so intense that it forced me to stop. But I see now that Botox clearly had something to do with the improvement, too.

It’s starting to wear off. And I’ll be near the end of my cycle when race day rolls around.

I might not be able to run the pace I used to. But I can still keep moving forward, despite this new challenge. I hope the Botox holds up. I hope I line up on race day feeling refreshed and ready. But, I also have to keep in my

mind that my health is the most important thing here. Vigorous exercise helps my muscles relax once I’m done. But, 26.2 miles is a long ways for anyone to run; let alone someone with Dystonia.

I’ll give it my best effort. And every step of the way, I’ll be thinking of my fellow Dystonia fighters who aren’t able to run the miles with me. I’ll hold onto the thought as I keep inching towards that finish line.

Jennifer Cannon is a runner and writer. She recently completed her memoir. To learn more heck out her blog: <http://lifebeyondaddiction.blogspot.com>

The Fuel Food Diet

The human body is an amazing organism, nearly autonomous in its function. Like a faithful servant, it quietly accepts the constant changes in the environment --- temperature, altitude, air quality, humidity, light --- and makes it work. However, one of the most immediately influential performance catalysts in terms of

health and efficient production is fuel.

What medical professional wouldn’t encourage each patient to maintain a moderate, varied, fresh foods diet? The things we take in greatly affect what our body is able to do and how quickly it is able to heal.

Foods high in anti-oxidants help combat

carcinogenic mutations. Phyto-estrogens like those found in soy are also good for this.

However, not only do we need to add more naturally healthy foods to our diet, but the dramatic reduction or even removal of some foods is imperative to improving over-all health and wellness.

(continued on p. 3)



Fruits, nuts, grains, vegetables are the source of disease fighting nutrients.

Funny Situation ...

To be able to laugh at oneself is always a sign of good health. Since it is my opinion that everything that is healthy is welcome in dealing with Dystonia, I am going to tell you about funny situations brought about by Dystonia.

The year 2007 was particularly fruitful in funny situations. That year, I experienced a progression of my Dystonia symptoms. 2007 was the year of my moving into a new home. I have been particularly worn out and every effort seemed to be too much. This is why I called Dystonia the “DISEASE OF THE EFFORT” and it was that long before the move.

Let me explain. I am suffering from Meige’s Syndrome (Blepharospasm and Oromandibular Dystonia). It’s a post-traumatic Dystonia, the result of a car accident nine years ago in which my head was hurt. That year, Blepharospasm increased its disabling effect.

Fuel Food, cont.

Since we know our body basically becomes what it ingests and is affected by environment, then it logically follows that it is true for other similar living organisms. In fact, the science supports this conclusion and many regulations in regards to the treatment of cattle and poultry have been changed.

When choosing meat, it is a great

I used to say that I “flashed” just like headlights do. Walking across the road to get my mail was quite an undertaking, my road being a busy one with speedy traffic. I had to look attentively on both sides before crossing, uneasy with ocular spasms.

I would look on one side and by the time I would open my eyes sufficiently, I had to look again at the other side because too many seconds had passed by. Looking at the other side with ocular spasms was also taking a lot of time until I could open my eyes. In brief, I would cross the road to the sound more than by sight, as a blind person would.

Once, I happened to cross that road on the garbage collection day. We have enormous garbage containers on wheels. In fact, they are almost as high as my shoulders. Once on the other side, with my eyes closed behind my sunglasses, I stretched out my hand holding my mail key a

idea to know from whence it comes. Is it organic, modified, farmed, free range, local, fed a natural diet? A little history doesn’t hurt and the more you know the better choice you will be able to make.

Stay up to date on the chemicals used in the production

little lower than my shoulder, where I knew my postal compartment was. When I finally managed to open my eyes, I realized that I was trying to unlock my neighbor's garbage container. Poor him! If he saw me through his window, he must have wondered what his new neighbor was trying to do with his garbage!

Also in that memorable year, I remember one evening, I was preparing supper with my son, bustling about, trying to do a thousand things at the same time. Obviously, ocular spasms occurred and soon, it was impossible to keep my eyes opened. I decided to sit in my rocking chair to allow for the spasms to stop. I stretched my left hand to grasp the left arm of the chair. With my eyes closed, and very sure of myself, I sat...on the floor. It was not the left arm of the rocking chair I had reached, it

(continued on p. 5)



“When I finally managed to open my eyes, I realized that I was trying to unlock my neighbor's garbage container.”

and preservation of your food. For instance, did you know that aspartame, phenylalanine causes a drop in serotonin levels?

Talk about useful news.

Rebekah Willis is actively trying to live healthily and promote overall health. She has early-onset generalized torsion Dystonia.

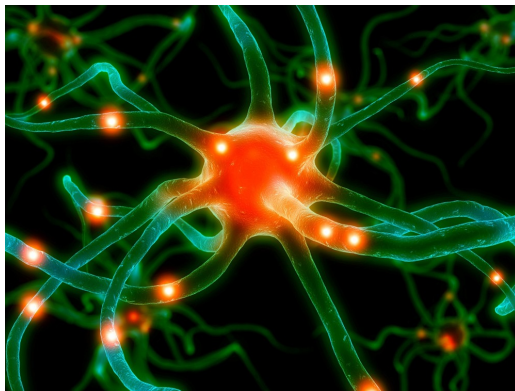
Review: *The Brain that Changes Itself* by Norman Doidge

A friend of mine, originally from the States, who had read the English version of this book, recommended it to me, knowing that I am suffering from Dystonia (Meige's syndrome) and that I am interested in any writing concerning the brain. Therefore, in 2008, I bought the French version of this book, entitled *Les étonnants pouvoirs de transformation du cerveau*. I was in a period of amplified symptoms. Since then, my symptoms have been decreasing.

I rapidly identified that Dystonia is due to a neurochemical imbalance and that any adrenalin secretion amplifies its symptoms. As I proceeded in the reading of the book, I was truly aware of these experimented beliefs. For Dystonia Living Magazine, the following text explains what this book brought to me and how it helped me to deal with Dystonia (Blepharospasm and oromandibular spasm).

First of all, I am astonished at the way the author, Norman Doidge, makes available to everyone his explanations on the functioning of the brain. He is

an honest and powerful communication expert. Uniting mind and heart in his writing, he has clearly shown that neuroplasticity can cure and/or destroy, hurt the body. Hats off to Norman Doidge for his integrity.



Upon writing this reading summary, I skimmed through the general opinions written concerning this New York Times best-seller. As it is implied in the French subtitle of the book *Guérir grâce à la neuroplasticité* and in the English subtitle *Stories of Personal Triumph from the Frontiers of Brain Science*, different authors speak highly of the positive effect of neuroplasticity. However, I feel it is very important to remain aware of the fact that negative neuroplasticity is also and even more present in Dystonia.

This book has increased that awareness in me and I have been on the look-out for it.

As Pascual-Leone (one of the doctors who met Norman Doidge) says, neuroplasticity can be compared to tracks dug into the snow by a skier. Mental tracks created in the brain can induce good or bad habits. Just as it is easier for a skier

to slide into the same tracks, one has to be careful not to let those dig deeper when they are harmful.

This book has also confirmed my belief that it is definitely possible to modify for the best what is disorganized in Dystonia. Since 2008, I have many examples of concrete

improvements of my condition, things that were hard work at the beginning of my investment towards eroding Dystonia troubles and that suddenly improved. Among these examples,



I want to relate the Blepharospasm that I presently manage with, I would say, a percentage of 95 to 98% and that, in spite of the fact that I always refused to receive Botox (botulinum toxin). I only intake 5 mg of Frisium every day and, as a result, I am experiencing very few ocular spasms.

I would like to add that I marvel at the author's passion for his domain of interest. One can recognize that passion in the reference notes which constitute about a quarter of the book. It is as if he always has to add up something, as if he could never be satisfied with what he wrote. He always has more and more to say. Almost endlessly. I just love that feeling of infinity that I get from reading both the core of the book and the reference notes. I advise you to read with two bookmarks, one where you are at, in the core of the book and one for the notes.

Equally engaging are his descriptions of the persons he met all along his data collection. With a minimum of words, he portrays people such as Paul-y-Rita, a doctor opposing the established dogmas concerning the unchanging brain or such as (continued on page 7)

Initiative

Dystonia may not be as rare as many think, but it is definitely a little known condition. People living with this disorder may not know they have it, or may understand so little of how it affects their function they feel no true connection to the name.

It is, therefore, extremely important that those who have a greater understanding of what Dystonia actually does direct some portion of their energies into promoting awareness.

Official organizations and committees have a work to do for the affected community, but there is no limit to the benefits we receive when we are willing to challenge ourselves, investing in our future. The personal initiative is the core strength of the awareness effort.

Recently, Grace Correia has



put her creativity to use in the design of Dystonia awareness badges, such as the one to the right. Her effort, I think, is a prime example of how much good can come of one individual's desire to make a positive impact on the world and her situation. The graphic is a teaser to those who have never heard of Dystonia and an empathetic boost to those who have felt the effects of it.

Grace's graphic sparked a whirlwind of ideas, raised awareness, encouraged many to do more in their own lives and brought a

positive attitude, confidence and/or smile will register a positive memory about others with similar traits.

Still, there are many who can learn about Dystonia without ever having first-hand contact.

Do you have an idea you've been harboring which, if pulled into play could be of some benefit to others living with Dystonia? Share it.

I love it already!

- **Rebekah**

smile to the face of everyone who saw it.

Dystonia is not going anywhere soon and neither are we. Living life to the fullest, staying active, healthy and visible is an important awareness component. Everyone who sees your movements coupled with a

“There is no limit to the benefits we receive when we are willing to challenge ourselves, investing in our future.”

Funny Situation, cont.

was the right one. Bang! I was laughing and crying at the same time. It was a foolish situation giving me the exact knowledge of my pitiful state: ridiculous enough, self-assured, on the ground.

Since MULTIPLICITY always amplifies Dystonia symptoms, especially as tired out as I was in 2007, this type of situation

would occur over and over. I finally understood that I had to learn to deal with MULTIPLICITY. Next time, I will tell you how.

Line Bellavance lives and laughs in Canada, where she is able to enjoy the lovely vistas of the enchanting town of La Pocatière. Translation to English : Louise Cantin



Access & Service Animals

In all of recorded history, Man has enjoyed a real connection to animal. Dogs, above every other creature seemed particularly keen on the relationship, serving not only as a worker and protector, but as a companion and playmate.

It is no surprise that service animals have become such an indispensable part of the lives of many living with a disability. Though the majority of service animals are dogs, they are by no means the only working species, which sometimes causes conflict in the as yet able bodied community.

(Recently, the legal definition of service animal was significantly narrowed, leaving mostly working dogs. Learn more at dystonialiving.com)

However antagonistic some may become (likely out of ignorance), service animals provide a very real, high quality and professional service to their handlers. I won't go into this more here, but check out the related podcast.

(dystonia.podbean.com)

Service animals are not pets and do not behave like pets while they are on duty. It is the responsibility of the handler to ensure that the animal represents the standard.

So what are your rights? (Note: They are your rights. The service animal has no rights. Therapy dogs are not do not share the same rights as assistance animals. Assistance animals include mobility, hearing and guide animals.)

As a person with a disability, you have the right to form a trained, working team with a service animal.

The service animal must be specifically and individually trained to provide you one or more services. The service animal must be in your company. The service animal must be controlled at all times.

You must be allowed access to public places where others are allowed access, including public transportation, businesses and public buildings. You may not be charged extra fees to gain access to these public places, neither may you be kept separate from other citizens because of your working animal. However, if your service animal causes damage you are responsible for it. A service animal that causes a

disturbance or is out of control or not accompanied by a handler with a disability may be expelled.

Persons of responsibility may not ask you about your disability. They may, however, ask what service the animal provides you. Although it is a good idea to carry identification and use an identifying vest with your animal, it is not required. Although states may have laws regarding service animals, Federal law (ADA regulations) supersedes state law.



Service animals are an amazing treasure, a tool that must be protected. If you have a service animal, please learn the rules and respect them. Keep your animal tuned. Learn to recognize when the partnership is working and when it isn't. If your animal is not a trained, service providing animal, please do not represent him as one.

For more information on service animals, how to acquire one or even how to train your own, visit us online @ <http://dystonialiving.com/suite.html>

Castigated

Me
 Hardness, fleshy, tight
 Sip through straws and dribble
 This
 like a symbol of the essence of the thought
 ...of the whim when you were thinking
 way too hard
 Scramble
 screwed on with the vigor of the fingers
 that only sometimes (and then, one time) twist
 turn
 because they like it
 when they like it
 ...um, and while they like it, the tugging
 In my eyes, the lids, the globes, the little odes to
 what is never
 or could be
 Wow.
 Who did this thing to me?
 To me
 the sunshine lover, who is fearful of its shine
 the fitness glutton, who sits stagnant all the time

And me
 the singer, speaker
 whose tongue and breath and jaw decide alone
 without my will
 And this is how it is and still
 I wonder what the witless thought, who scowl
 at me
 as if I ought to help them stay the silly same
 ...to veil my form and hide their shame...
 A mystery for men to chide
 A glory for the God to hide
 A challenge fair, I must decide
 Whose hands are on the reins?

Rebekah Willis lives and doggedly creates in the midwest. She has early-onset generalized torsion Dystonia.

Review, cont.

Barbara Arrowsmith Young, a woman, so-called “mentally retarded”, who discovered by herself how to cure of a cerebral dysfunction and who founded a school to accompany children and adults with learning problems. Mental exercises are used in that school, according to each person’s disabilities.

Appreciation for this book which is closest to my own is the Chicago Tribune’s critique entitled Lucid and absolutely fascinating. It satisfies in equal measure the mind and heart.

Line Bellavance lives and laughs in Canada. Translation to English : Louise Cantin



Dystonia Living publishes a lifestyle magazine, podcast and resources every second month and is available for free download online. Dystonia Living is independent of all organizations. Interested in contributing? Have something to share? Questions or Comments? Contact Rebekah :

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On Facebook— Dystonia Living Magazine

Dystonia Living — Empowered. Connected. Alive!

Dystonia Kids

I like to laugh. I have lots of things that I do that are fun. I play on the computer and listen to old time radio shows. Those are just like tv shows, but they are meant to be heard, not seen.



you-are-beautiful.com

I like school. I have friends who know about my Dystonia and some who don't care. Sometimes people are mean, but most people are nice about it. It doesn't matter if they want to be nice or

not. I am ok with my Dystonia.

I think a boy or girl who has Dystonia should know that they are just like everyone else, even though their body may be different. Dystonia can not control your mind, just like sometimes your mind can't control your body.

I like the You Are Beautiful art project because it reminds a lot of people about the truth. I am beautiful, Dystonia and all! — Co



Did you know that The Milky Way is in a group of galaxies called, "The Local Group"?

Some more galaxies are: The Andromeda Galaxy, The Pinwheel Galaxy, The Large Magellanic Cloud, and The Small Magellanic Cloud.

It's A Natural Fact! by Ryan Mitchell

Did you know that the Bee Orchid gets pollinated because it looks like a female bee? The male bees try to mate but the plant gets pollinated. The real bee flies away.



It's a natural fact!

Wanna learn more about animals? Try the National Geographic Kids site or kidsites.com!

For more information on the planets and to see great, real photos, visit NASA.gov. They even have a section for kids!



Did you know that Clouded Leopards have the longest canine teeth of all carnivores?