



# BransonGoers Gazette

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If you have anything you would like posted concerning your local support group, please contact me.

## **The Snapp Therapy**

*by Don Hansche, editor*

I don't know if any of you have heard of this 'Snapp Therapy', but this particular article caught my attention.

### ***Chronologically Controlled Developmental Therapy for Physical Disability***

*Laurance Johnston, Ph.D.*

Chronologically controlled developmental therapy (CCDT) has considerable potential for treating physical disability, including spinal cord injury (SCI) and post polio syndrome. Because CCDT consists of a combination of fairly standard, widely accepted physical therapy techniques, it really should not be considered an alternative medicine treatment. CCDT's uniqueness is related to how these techniques are applied, the sequence in which they are applied, and the patient's passive involvement. Futures Unlimited, a clinic in Columbus, Miss., carries out this treatment.

The facility's director is Ed Snapp, a physical therapist who acquired polio at the age of 18. His impressive credentials include extensive experience with most commonly used physical therapy techniques. He has been a member of many national and regional committees and has made numerous presentations at professional meetings. Early in his career, he had a key role in establishing the nationally recognized Texas Institute of Rehabilitation and Research (TIERR) in Houston, TX.

Snapp has an almost Zen-like appreciation of the human body. Through assessing the subtlest aspects of one's movement and reactions to stimulus, he obtains an array of valuable diagnostic information. His abilities remind me that in this era of impersonal high-tech medicine, true healing skill is more than a science learned in books or a classroom. It is an art that is learned through experience and, more importantly, receptivity to the experience.

Perhaps due to the understanding acquired through his own disability, he is a compassionate man with great empathy towards his patients. He combines this compassion with a sharp, eclectic intellect that is consistently attempting to integrate and expand concepts from a variety of disciplines. Through a why-not "just-do-it" attitude, hope seems to re-emerge like a Phoenix from the ashes - even from cynics.

Columbus is the birthplace of Pulitzer Prize winning playwright Tennessee Williams. Although some airlines serve this small city, visitors often fly to other cities, such as

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**If you have articles you'd like to contribute, please contact me at the above email address**  
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Birmingham or Memphis, and drive to the clinic. Columbus' relative geographical inaccessibility is offset by a low cost of living, which facilitates a much more affordable treatment program.

### The Treatment:

The clinic targets a wide-ranging variety of neurological disorders, including post polio syndrome (PPS), spinal cord injury, head injury, cerebral palsy and various developmental disorders. The clinic has been especially successful treating post polio syndrome symptoms and claims that 85% of the patients have had some functional improvement. In



some cases, progress has been profound, including individuals who no longer need ventilators or scooters. Even when improvements are modest, Snapp notes that they can result in greatly increased independence and quality of living.

Chronologically controlled developmental therapy consists of a number of physical therapies performed in a specific, defined sequence. These include, but are not limited to, pressure stimulation, hydrotherapy, light-touch massage, movements on an oil table, and rest in a sling apparatus that mimics a fetal position. People carry out the program twice daily for two-weeks. To further build on progress made at the clinic, a home-

therapy program is designed that does not require technical expertise. Periodic visits to the clinic will further augment the progress.

Unlike many rehabilitation programs, the therapies are passive - the therapy is done to you; you exert no effort. You receive encouragement to let go of any conscious effort to control the situation. To keep your nervous system from being distracted from non-therapy stimulation, the procedures occur in an environment that minimizes distractions (e.g., under dim light, no talking, etc.).

### Firsthand Experience:

To get a better feel for the process, I subjected, myself, to some of the program. The hydrotherapy was especially interesting. With the support of virtually imperceptible harnesses and slings, I became immersed, floating in a tank with only my face out of body-temperature water. With the exception of a gentle flow of water that would periodically change directions, my body was deprived of virtually all sensations. Under these conditions, I was soon adrift in the twilight between consciousness and sleep. I can only imagine how I would feel if I did this for two weeks. As discussed below, these conditions are meant to mimic the womb's environment.

### Patient's Reactions:

During my visit, I interacted with several patients. Julia, a charming seven-year old girl with haunting blues eyes, has cerebral palsy. She has been coming to the clinic since she was two. Her mother, Marilyn, indicated that before starting the program, Julia almost seemed to be regressing (e.g., becoming more spastic). Once Julia started therapy, she made tremendous progress. Marilyn is convinced "all improvement is due to the treatment." Julia achieved more balance, more dexterity, and flexibility. She had an overall personality change: for the first time, she "started giggling." She enjoys her visits to the clinic because she is the center of attention.

Nancy, a photographer and teacher, has post polio syndrome. Before the treatment, she used to wake up late and feel tired. "Now I am in the habit of getting up at 6:00 a.m.," she says.

She says that her improvement is in places that only she can see, such as the back and hips. "I can keep my balance in my wheelchair much better than before. And I can keep going day after day, unlike recent years when I had to take every other day off. That's the best." Although enjoying her treatment, she missed sunlight. "The staff had lunch on the patio overlooking the woods, but we were inside in the dark with blue lights and instructions not to talk."

Regarding Snapp, Nancy states "This guy has his whole heart and soul in his work. He's charismatic - and a genius at his theory."

Nancy says, "[I am] appalled at how little interest there is back home from the medical community. I am now getting an education in the schism between traditional and alternative medicine. This seems so unnecessary and blind. When something works, it ought to be emulated and investigated, not just shrugged off as a fluke. Although I have not seen my physiatrist yet, I hope he will accept my results."

During my visit, several individuals with spinal cord injury were being treated at the clinic, but I did not have the opportunity to speak with them. Although progress is often slower, Snapp has had some notable success treating SCI. For example, Nick fell 25 feet from a hunting platform and crushed his spine in the thoracic/lumbar region. Although

two years later his legs were jammed with extreme spasms, after several years of treatment, Nick was walking with crutches and short braces.

#### Measurement of Improvement:

These examples, of course, do not prove effectiveness according to scientific standards. A frequent criticism of any potential treatment concerns how improvement is measured. Snapp recognizes that this is a tough, but valid issue. However, he says that the restored function that he sees is often so overt, (e.g., patients no longer needing scooters or ventilators) that effectiveness cannot be denied. To ensure objectivity, he ideally would prefer that the patient's own neurologist independently measure improvement after treatment.

He also says that the use of extensive sophisticated assessment procedures would greatly increase the treatment costs. "My foremost goal is to help people, not to do a scientific study."

#### Treatment Theory:

Although the clinic's procedures are relatively straightforward, the theory behind them is not. Snapp emphasizes that restored function is not due to neuronal regeneration. Basically, he focuses on activating intact - but dormant - neurons and pathways.

A growing base of scientific knowledge indicating that the nervous system is much more complicated and sophisticated than previously thought supports this focus. In the case of spinal cord injury, scientists now conclude that most non-penetrative injuries (i.e., other than gunshots or stabbing) that have been classified as complete in terms of physical function are neuronally incomplete injuries. In other words, usually there are intact neurons that cross the spinal cord injury site that have been turned off by the injury process. In animal models, the spinal cord needs only about 5% neuronal functioning to have substantial physical function. Theoretically, if we can activate even a small percentage of dormant, intact neurons, considerable function could potentially be regained.

Snapp speculates that more regeneration may occur after injury than previously thought, but the regenerated neurons have not been turned on. As a consequence, even if successful, current research efforts that target neuronal regrowth may have minimal benefit if activation is not considered.

Paraphrasing the famous movie line, the prevailing scientific assumption that "if we build it, it will conduct" may be fundamentally flawed.

Snapp's program for activating neurons is based on a rather complicated thought-provoking theory encompassing concepts of evolutionary development. He believes that turning on dormant neurons requires a sequence of cues that mimic events from our early fetal and infant development. In turn, these developmental cues reflect a genetic memory of our evolutionary development.

If a fully developed neuron has been turned off, its reactivation requires that it receive and sense external cues in a defined sequence that is correlated to the neuron's initial development. There is no avenue to deliver these cues except through the peripheral senses - the basis of Snapp's physical therapy program. Out-of-sequence cues will not work. This, according to Snapp, is why many standard physical rehabilitation programs are so limited in outcome. As a professional with a disability, he believes "most standard rehabilitation policies make robots."

Snapp compares his process to pulling a computer's plug. The computer's circuits remain intact, but the program is lost. To be reinstated, the program must reboot, which involves a sequential series of steps.

Likewise, Snapp believes that a significant proportion of neurological dysfunctions result from a deprogramming of specific portions of the central nervous system. In the same fashion that a disk can reboot a computer program, an appropriate external cue will trigger information residing within a nervous system's genetic code. This information will then be reprogrammed back into the operating system in the same order as it was learned in the embryonic nervous system.

For further information and feedback from a Snapp Therapy patient, check out [futuresunlimited.com](http://futuresunlimited.com) Blog » [Blog Archive](#) » [JR Post Polio Syndrome](#)

Sharon has an appointment with Dr. Valbona at TIRR on September 17 in Houston. I'll ask more about this when we see him. I'll also try to get more information (if there is any more) from Dr. Spann.

- Don Hansche

## God's Gift to You

by Joe McDonald, A 9<sup>th</sup> grader in Delaware

Being disabled is not a crime. It is a gift that God gave to you. Have you ever heard of the crippled lamb in the stable the night Jesus was born? The little lamb wondered why he was different and why God made him that way. But the night that Jesus was born, the little lamb crawled over to Jesus and baby Jesus held tight to the little lamb to keep warm. Then it struck him, this was why God made him like this and this is what he was put on this earth to do. So, if anything ever happens to you or your friends and you become disabled or you are born disabled, think of that little lamb.

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Everyone can make you happy in your life . Some do it by walking into your life. Some do it by walking out.

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## Power Chair Safety

found in an online blog by Rainey826

- Keep your power chair in good condition - don't abuse it outdoors.
- Read and understand your power chair's owner manual.
- Don't use reckless high-speeds.
- Always shut the power off while not driving your power chair, or when transferring it by lift. This will preserve battery power and prevent disaster if your joystick gets bumped.
- Announce yourself at closed doors. The sudden opening of a door could knock you out of your chair.
- To avoid tipping, don't place heavy loads on the back of your power wheelchair.
- Don't let children play with your wheelchair, its controls or ride on the back.
- Attach a brightly colored flag to your wheelchair. At night use headlights, reflector tape or flashing taillights.
- Don't brave steep hills or curbs. You could lose control and tip over.
- Never remove the anti-tip wheels from your power chair.
- If your wheelchair casters tremble, get them fixed . Castor flutter occurs at high, downhill speeds, and can throw you out of your chair.
- Avoid operating power chairs in the rain. The electronics aren't waterproof and your wheels can also lose traction if wet.
- Turn your motorized chair off before using a cell phone. If any electric device affects your chair in a strange manner, shut it off immediately.
- Plan ahead for emergencies; check your wheel chair's brakes, belts and gears regularly, bring an extra wheelchair battery or wheelchair charger along for lengthy trips.

From the editor: And this one I'm adding: Never attempt to remove yourself from a power chair without first turning the power off.

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Getting rid of all the crap in your life is the best thing you can do for yourself . So remember, it's your life and it's only as complicated as you make it.

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## Fatigue and "Brain Brownout"

by Richard Louis Bruno

Difficulty focusing attention and word finding associated with fatigue — are the most commonly reported, most disabling and, unfortunately, the least believed of all Post -Polio Sequelae. The biggest problem is that there is no medical test to prove that you have fatigue. Research that we began in 1993 on the post -polio brain has documented damage done by the original poliovirus infection that prevents survivors from activating their brains and thereby causes fatigue and brain brownout. There are three new studies that support our findings.

A summary of the first study begins with a sentence that warms my heart: "While individuals with post -polio syndrome do not have diminished mental function when they are well rested, their mental function declines considerably after even moderate mental fatigue." Researchers at the U.S. Uniformed Services University of the Health Sciences asked 65-year-old polio survivors to complete computerized neuropsychological tests of attention, thinking or memory once and then again one hour later. The so-called "practice effect" typically improves scores the second time anyone takes neuropsychological tests. However, more than 40 percent of polio survivors had a *decrease* in performance on the second administration of seven of the eight computerized tests, while 50 percent did more poorly on at least three tests. Subjects didn't make more mistakes the second time; they were just much slower performing the tests after being fatigued by taking the first set of tests. Slower performance on neuropsychological tests is exactly what our studies found. Polio survivors reporting severe daily fatigue required 23 percent to 67 percent more time to complete tasks requiring attention than did polio survivors with no or mild fatigue.

Why has our neuropsychological research and this new study found brain brownout to be related to fatigue in polio survivors? In our other studies, we used magnetic resonance imaging to look inside the brains of polio survivors. We found small individual or multiple "white spots," (technically called hyper-intense signal) in the brain activating system of 55 percent of polio survivors reporting moderate or higher daily fatigue, and no spots in those with mild or no fatigue. The more white spots, the more severe were polio survivors' fatigue, problems with memory, thinking clearly, staying awake, mind wandering, attention and concentration.

Recently, researchers at Duke University published a study using both regular MRI, which we used, and a new, more sensitive imaging technique called DTI to look at white spots in the brains of individuals 60 and older *without* polio or any neurological disease. The study found that visible white spots on regular MRI may be just the tip of the iceberg, since DTI found that damage to the brain under the white spots was larger than the spots themselves. What's more, the researchers concluded that those with white spots in one part of the brain may have invisible damage in brain areas where spots have not yet become visible on regular MRI, and that this damage may be preventing brain neurons from talking with each other. This could explain why 45 percent of polio survivors with significant fatigue had no visible spots on regular MRI. When it comes to seeing damage on an MRI to a polio survivors' brain activating system, apparently little spots mean a lot.

So, there actually is physical evidence that poliovirus damage is related to brain brownout in fatigued survivors. But listen to this: Mayo Clinic researchers studied a virus in the same family as the poliovirus — the virus that causes the common cold. They infected some mice with cold virus and not others. Both groups had their memory tested by completing a maze. Virus -infected mice made more errors and couldn't figure out where they were going. Sound familiar? The mice that made the most errors had greater damage to their brains. The study concluded that even the cold virus could cause "at least some degree of neurologic deficit" in humans.

If having a cold can cause brain damage, how can so many doctors still say that the poliovirus, a known

killer of brain neurons, couldn't possibly cause polio survivors to have brain brownout and fatigue? Time for doctors to read a medical journal or two and start seeing the spots.

*Dr. Richard Bruno is chairperson of the International Post -Polio Task Force and director of The Post -Polio Institute and International Centre for Post -Polio Education and Research at Englewood Hospital and Medical Center .*

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Don't live life in fear. Forgive and forget, but don't forget why you're here. Take your time, Pray and thank God for each day!

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## **The Swine Flu Dilemma**

*by Michael Kossove, Prof. of Microbiology*

As a Microbiologist, I get interested and somewhat concerned when I hear about outbreaks of disease. Right now specifically Swine Flu. When I sent out my blurb on Understanding Swine Flu, I predicted it would return, but I thought late October or early November, in time for the new vaccine. However, that doesn't seem to be the case. Now the Government is predicting an outbreak in September.

Although most people affected before the summer were younger than we are, the one statement you heard over and over each time a death was announced "the patient had other medical conditions." We must understand that this virus knows no age group. Perhaps the children were affected because they were in school with other children where sneezing and coughing goes on all winter, sending tiny droplets into the air containing bacteria and viruses. That's why "cover your mouth" and "wash your hands" are very important statements.

A major concern is the school system. If there is an outbreak will they close the schools? In New York and other large cities with large inner city populations, these children get two meals at school, break fast and lunch, and for some they are the only meals they might get. Furthermore, consider the safety aspect. The school creates a safe environment or an environment a great deal safer than the street. The schools also get monies from the Government as long as they have a certain amount of school days during the year. These calendars take into account snow days in the areas that have snow. Should money, food, and safety play a role in school closings? If the kids pick up the virus they will bring it home, with the potential of infecting the entire family, and if the parents get sick and can't go to work, the family income as well will be affected. It's a dilemma, and I'm glad I'm not in a position to make that decision. Parents can always opt to keep the children home if an epidemic occurs in their area.

If there is an outbreak this fall in epidemic proportions, I wonder how honest the Government will be with us so as not to scare the population. They've held back before, especially during the early AIDS problems.

As for the vaccine, please understand that a vaccine without major clinical trials, and tight quality control during its production is extremely dangerous. You recall how many cases of vaccine related polio there were due to a vaccine with a very active virus inside which should have been totally inactivated, and was missed by quality control. I'm sure each one of the polio groups has one or more members who contracted polio from the vaccine. Although the vaccine for Swine Flu is a necessity, and I'll get it as soon as I can, I will not be comfortable for a few weeks until I know I did not get sick. And each of us has an underlining condition, polio. Along with polio some of us are diabetic, have high cholesterol, heart disease, breathing problems, and a host of other problems that might not make us good candidates to fight this disease if we catch it.

It is always a major concern when we know from all the media that Swine Flu it's coming, and yet we know little else. We also know that some Swine Flu strains are Tamiflu resistant. So, what do we do? How do we handle this? I learned a good lesson from Post Polio Syndrome. You can't get upset over something you have no control over. Just go about living your lives as you do now. If ever there was a time to look at your nutritional intake and supplements to keep your immune system functioning, this is the time. And as important, wash your hands often. Remember the popular song, "Que sera, sera, whatever will be, will be. Hopefully we'll all get through this.

Michael Kossove  
 Prof. of Microbiology  
 Touro College  
 School of Health Sciences

*(Mike is a member of Post-Polio BransonGoers and from time to time sends some interesting articles to add to our newsletters. Thanks Mike, for another great article. – Don Hansche)*

Instead of thinking about what you're missing, try thinking about what you have that everyone else is missing.

### Answer to August Sudoku

5	2	9	8	1	7	4	3	6
1	4	8	2	6	3	9	7	5
7	3	6	9	5	4	2	8	1
3	5	1	6	7	9	8	2	4
4	8	2	5	3	1	7	6	9
9	6	7	4	2	8	1	5	3
8	1	5	7	9	6	3	4	2
2	9	4	3	8	5	6	1	7
6	7	3	1	4	2	5	9	8

When the going gets tough, make yourself realize that no matter what your problem is, someone is and always will be fighting a harder battle.

## September Sudoku

		9	3	5		6	2	
	8					9		
5					6		3	
						2	8	
			7		3			
	1	7						
	9		8					4
		6					1	
	3	5		9	4	8		

### About This Newsletter:

The BransonGoers Gazette is published and placed online on or about the first day of each month. Although articles are managed to be found to include in the publications, it does take a lot of time. ***Your help and contributions are much needed and appreciated!*** If you have articles you'd like to contribute, please send them to [bgg.editor@gmail.com](mailto:bgg.editor@gmail.com). All articles or edits must be received by the 20<sup>th</sup> of the month prior to publishing.

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