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STQuarterly

THE NATIONAL SPASMODIC TORTICOLLIS ASSOCIATION

National Spasmodic Torticollis Association

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Front and back cover photos provided by NSTA Member Rosetta Santee

HUNGRY MOSQUITOES

Whenever I step outside,
I hear the buzzing din
Of hungry mosquitoes
Who are searching for my skin.

They like to bite my arms
And my tasty little chin
Or maybe even sample
My two delicious shins.

These annoying insects
Never bite my friends or kin.
I'm the only person who
They stick their noses in.

Why do I taste so good?
Perhaps I'll never know.
Yet I am their favorite dish
Everywhere I go!

Carolyn Bolz

NSTA
NATIONAL SPASMODIC TORTICOLLIS ASSOCIATION

MISSION STATEMENT

The National Spasmodic Torticollis Association is a non-profit, 501c(3) organization established in 1980 dedicated to:

- Providing information and support to people with ST and to their families and friends
- Educating the public and the medical community about ST
- Advocating for the rights of those with ST
- Promoting research on ST

Dear Readers:

This is your magazine. We would love to hear from you. Please send:

- tips about how you cope with ST
- news about your support group
- news about members
- concerns and complaints
- (we also appreciate praise if it is sincere)
- original cartoons and jokes
- letters to the editor
- essays
- poems
- and anything else other readers might enjoy

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Email info@cdtorticollis.org for a PDF copy of the magazine that you can send to your friends/family.

President's Column

by Ken Price

The NSTA has decided to hold regular support group care and share meetings over the Internet via Zoom. We have held two thus far on Saturdays from 10 to 11 AM PDT, one on July 29th and a second on 2 September. We had quite a few attendees at each meeting and had vigorous and informative sessions that went well over the hour allocated for the meeting. One of the great advantages of Zoom meetings on the Internet is that people from across the country and even from other countries can join us.

One topic of discussion was the introduction of a new botulinum toxin for dystonia by Revance Therapeutics, Inc. They report that their formulation can extend the time between shots to as long as six months compared to the three-month cycle with the current forms on the market. If so, and if it is as effective as the current toxins, it will be a welcome addition to the dystonia formulary. You can find more information about this at:

www.daxxifytherapy.com

Exercises for ST are another topic that is often discussed. One participant on the 2 September meeting, Debra, introduced us to Qi Gong, an exercise style similar to Tai Chi used by many STers. There are a series of Qi Gong videos on YouTube produced by Jeff Chand that explain the technique and lead you through various routines. See, for example:

https://www.youtube.com/watch?v=Y88zYo0YlOo

Jeff has a number of YouTube videos with variations on the exercises for various purposes. You can subscribe to his videos or just look up other videos using his name on a search engine. Check this out and let us know at an upcoming meeting how well it works for you.

Justin Aquines announced that we are planning a live symposium in Las Vegas at the Palace Station Casino and Hotel (www.palacestation.com) scheduled for April 7 & 8, 2025. Note the year, which is being planned a bit further off in the future than we have done in the past to make it easier for people to plan for vacation and travel well in advance. More information will be posted on the NSTA website at http://www.cdtorticollis.org/

We are pleased to have met someone in the physical therapy field who is interested in treating people with dystonia. Apurva Zawar, DPT, PMP®. She is the Founder of BeyondRehab, an exercise and therapeutic clinic serving ST patients among many others with muscle and neurological problems. You can find out more about her approach at:

www.beyondrehab.health/about

We have scheduled a Zoom Webinar with Apurva for Friday, 22 September from 3 to 4 PM, Pacific Time. This will probably occur before you read this, but Justin has sent out the meeting notice with Zoom link, so you should have been able to participate. In any case, the Webinar will be recorded and available on the NSTA web site for future review.

We are very pleased with the results of our Zoom Support Group meetings and all the discussions on many topics. We hope more of you can join in future meetings.

Executive Director's Column

by Justin Aquines

The International Association of Parkinsonism and Related Disorders (IAPRD) 2023 World Congress was held at McCormick Place in Chicago from May 13th to 16th. The scientific program was developed by Drs. Rajesh Pahwa, Chair of the Scientific Program Executive Committee (SPEC); Cynthia Comella, Congress Chair; and other members of the SPEC: Alberto Albanese, Hubert Fernandez, Karen Frei, Shinsuke Fujioka, Claire Henchcliffe, Ioannis Isaias, Andreas Puschmann, Marie Helene Saint-Hilaire, Huifang Shang, Tanya Simuni, and Diego Torres-Russotto. The IAPRD 2023 Congress features a comprehensive program in movement disorders led by a global faculty, focusing on the theme of *Evolving the Treatment Paradigm in Movement Disorders*. Delegates experienced a stimulating range of subjects in plenary sessions, parallel tracks, skills workshops, and poster sessions. The emphasis of the World Congress in Chicago was on discussion and a positive critical attitude.

This marked the first time the NSTA has attended a conference since the start of the Covid pandemic. I represented the NSTA together with the help of a long-time friend and volunteer of the NSTA, Donna Lubanga, RN. You may remember her from the NSTA annual symposiums. Together with Vi, she would help check in registrants and assist people with questions.

If you have never been to McCormick Place in Chicago, it is an impressive venue in terms of size. McCormick Place is the largest convention center in North America. It consists of four interconnected buildings and one indoor arena situated on and near the shore of Lake Michigan, about 2 mi (3.2 km) south of downtown Chicago. McCormick Place hosts numerous trade shows and meetings. The largest regular events are the Chicago Auto Show each February, the International Home and Housewares Show each March, the National Restaurant Association Annual Show each May, and the International Manufacturing Technology Show in the fall every other year.

DONNA LUBANGA, BSN, RN ON HER WAY TO THE CONGRESS

We flew into O'Hare Airport from John Wayne Airport in Orange County, CA on Friday. This is the day before the 2023 World Congress began. We stayed at the Hilton Garden Inn McCormick Place which is conveniently located across from the convention center. The commute from the hotel to the convention center was a ten-minute walk using a building-to-building walkway. This was a pleasant surprise as we didn't have to set foot outside to get to the venue. We set up on Saturday morning and have everything set up in an hour. We were situated in the main hallway beside

JUSTIN AQUINES AT THE NSTA EXHIBIT BOOTH

the Dystonia Medical Research Foundation (DMRF).

We ran into Janet Hieshetter of the DMRF. We have known Janet since she took on the role of Executive Director of the DMRF in 2004. It was nice to catch up and discuss the programs and plans of each organization.

The IAPRD 2023 Congress featured a comprehensive program in movement disorders led by a global faculty in support of the theme *Evolving the Treatment Paradigm in Movement Disorders*. The program sessions ran parallel with each other and are categorized as the following sessions and types.

Plenary Sessions

These sessions included lectures on phenomenology, pathophysiology, diagnostic and therapeutic approaches to various movement disorders. Each lecture with a plenary theme will be 30 minutes, delivered by world-renowned senior faculty members.

Parallel Tracks

The sessions within a track were arranged to provide a deep dive into a diagnostic or therapeutic area. Each lecture was 30 minutes (25 minutes of didactic followed by 5 minutes of Q and A)

Grand Parade of Movement Disorders

A video session where both faculty and attendees present pre-selected cases from around the globe to showcase the breadth of movement disorders. This event was co-hosted by several of our most astute and experienced clinical experts.

Coffee with the Professor

There were brief mentoring sessions sprinkled throughout the duration of the congress where young and aspiring clinicians and scientists can engage with a renowned faculty member, in a relaxed setting, over a cup of coffee.

Corporate Sessions

These sessions, sponsored by industry partners, were held during lunchtime.

Oral Poster Sessions

Poster authors presented their posters and answered questions from the moderator as well as from the audience of the Oral Poster Session. The author or presenter must be registered for the congress.

DR. KAREN FREI, NSTA CHAIRMAN OF THE MEDICAL ADVISORY BOARD IN CONVERSATION

Resident and Trainee Program

Shorter, classroom-style educational sessions The 2023 IAPRD World Congress had presentations that discussed other movement disorders such as cervical dystonia. The following are ab-

stracts of studies that were presented in the Oral Poster Session. The authors and presenters were registered attendees of the congress. Poster authors present their posters and answer questions from the moderator as well as from the audience during this session. These are studies that concern cervical dystonia and dystonia.

Adult-onset cervical dystonia with botulinum toxin resistance and approach to severe spine deformity for deep brain stimulation: a case report

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1 Keck School of Medicine of University of Southern California (USC), Neurology, Los Angeles, United States,

2 Keck School of Medicine of University of Southern California, Neurosurgery, Los Angeles, United States

Background: Cervical dystonia (CD), the most common adult-onset focal dystonia, can cause abnormal postures of the head/neck and is often treated with injections of botulinum toxin. Secondary non-response/resistance can occur in patients who previously derived benefit. Cervical spine degeneration often affects upper cervical levels in CD patients. We report the management complexity of a patient with longstanding CD and severe cervical degeneration with concern for osseous fusion.

Methods: An 81-year-old woman with 30+ year history of CD had developed secondary resistance to both onabotulinumtoxinA and rimabotulinumtoxinB. In 2021, she developed a fixed posture with severe right head tilt (ear touching shoulder), right shoulder elevation, and notable hypertrophy of right posterior neck musculature. Therefore, consideration was given to pallidal deep brain stimulation (DBS) for her CD. Results: Further complicating her presentation was severe cervical spine coronal deformity with possible autofusion at multiple cervical levels, making her a difficult candidate for DBS. Attempts to reduce her deformity under general anesthesia were unsuccessful. Additional imaging sequences revealed destruction in the right-sided C2 lateral mass. She underwent cervical traction and partial reduction that ultimately allowed her to undergo successful DBS lead placement. Six months later, she has had an 80% reduction in pain/spasms and an improvement in neck range of motion.

Conclusions: The complexity of this case illustrates the importance of careful consideration of the sequence of interventions. In patients with CD, there is greater concern for spinal hardware failure given CD is an abnormality of central motor processing which can overcome any attempted spine fixation. This often results in a preference to first proceed with treatment of CD, but in cases such as this where a patient has botulinum toxin resistance to both serotype A and B, as well as multilevel cervical spine deformity such that posture appears fixed, the management pathway is more challenging.

Long-term safety of magnetic resonance-guided high-intensity focused ultrasound in movement disorders: a systematic review and meta-analysis

A. Abusrair 1 , D. Abo Alsamh 1, N. Szejko 1 , T.M. Pringsheim1,2, D. Martino1,2

1 University of Calgary, Department of Clinical Neurosciences, Calgary, Canada, 2 University of Calgary, Hotchkiss

Brain Institute, Calgary, Canada

Background: Magnetic resonance-guided high-intensity focused ultrasound (MRgFUS) has emerged as a promising novel modality in the treatment of various movement disorders. Both frame- and lesion-related adverse events are reportedly transient. The aim of this study is to compare long-term safety profiles in Essential Tremor (ET), Parkinson's Disease (PD), and dystonia.

Methods: A systematic review and meta-analysis were conducted by database search in MEDLINE and EMBASE. Studies of unilateral MRgFUS lesioning until December 2021 were included. The primary outcome measure was the rate of long-term lesion-related adverse events (defined as events reported to persist between 3 and up to 12 months). Adverse events were classified as bulbar, sensory, motor, and cerebellar. Multiple variables were correlated with reported outcomes.

Results: The total number of included studies was 39 for ET with 1,001 patients, 10 for PD with 90

patients, and 3 for dystonia with 14 patients. The ventral intermediate nucleus of the thalamus was the main target in 40 studies, followed by the cerebellothalamic tract in 6. Ataxia appendicular) persisted up to 12 months in 59 ET patients (5.8%), whereas only 2 PD (2.2%) and none of the patients with dystonia had persisting ataxia. The percentage of ataxia across all studies did not correlate with the mean values of disease duration, skull density ratio, or number of sonications. Sensory symptoms (numbness or paresthesia) were the most reported events in dystonia (2 patients; 13.3%) and in PD (8 patients; 8.8%), followed by 45 (4.4%) in ET. No report of complete sensory loss in all studies. Compared to ET, other movement disorders showed a significantly higher frequency of sensory symptoms (chi-squared = 5.22, p = 0.002).

Conclusions: On long-term follow-up, MRgFUS therapy is associated with low and comparable frequency of persistent ataxia across all movement disorders. Sensory symptoms are more frequently reported in PD and dystonia.

Benefit of multiple incobotulinumtoxinA injections for pain reduction in adults with cervical dystonia: an analysis of pooled data

A. Albanese 1 , J. Wissel 2 , W. Jost 3 , A. Castagna 4 , M. Althaus5 , G. Comes 5 , A. Scheschonka5 , M. Vacchelli 5, H. Jinnah 6

1 IRCCS Humanitas Research Hospital, Department of Neurology, Milan, Italy, 2 Vivantes Hospital Spandau, Department of Neurorehabilitation and Physical Therapy, Berlin, Germany, 3 Parkinson-Klinik Ortenau, Wolfach, Germany, 4 IRCCS Fondazione Don Carlo Gnocchi, Milan, Italy, 5 Merz Therapeutics GmbH, Frankfurt am Main, Germany, 6 Emory University School of Medicine, Department of Neurology, Atlanta, United States

Background: The long-term effects of repeated incobotulinumtoxinA (incoBoNT-A) injections on cervical dystonia (CD)-related pain were assessed in a pooled analysis of studies in adults with CD. Methods: Pooled data from four phase 3 and 4 studies in adults with CD-related pain at baseline (N=678) were analysed over five incoBoNT-A injection cycles. Pain was assessed at each injection visit (IV) and control visit (CV) 4 weeks post-injection using the TWSTRS-pain severity subscale or a pain VAS. Both pain scales were analysed using a score range 0–10 and pain was categorized as mild (>0–<3.5), moderate (3.5–<6.5) or severe (6.5–10). Response was defined as ≥30% or ≥50% reduction in baseline pain score, reflecting at least moderate or substantial clinically important improvements, respectively. Complete pain relief (pain score=0) was evaluated at each IV and CV. Pain scores in the subgroup of patients not taking concomitant pain medication (N=379) were also examined.

Results: Baseline pain was moderate or severe for 64% of patients. Pain reduction was observed over multiple treatment cycles; response rates and % with complete pain relief tended to increase over the five injection cycles (Table). A cumula-

	Patients (%) with pain response at Control Visit (CV) 4 weeks after incoBoNT-A injection				
	CV1	CV2	CV3	CV4	CV5
All patients	N=669	N=263	N=235	N=215	N=179
≥30% pain reduction from baseline	48.1%	49.8%	54.0%	57.2%	53.1%
≥50% pain reduction from baseline	34.4%	34.2%	40.4%	39.1%	40.2%
Complete pain relief	10.3%	11.8%	13.2%	12.6%	16.8%
No pain medication	N=379	N=116	N=107	N=101	N=86
≥30% pain reduction from baseline	54.4%	49.1%	57.9%	57.4%	55.8%
≥50% pain reduction from baseline	41.4%	32.8%	46.7%	37.6%	45.4%
Complete pain relief	13.2%	14.7%	16.8%	14.9%	22.1%

Table. Pain severity results at each control visit for all patients with a pain assessment at that visit and in the subgroup not taking concomitant pain medication

tive effect was demonstrated in the proportion of patients whose pain had not returned to baseline levels by the next IV. Pain responses were generally slightly higher in the subgroup not taking concomitant pain medication (Table).

Conclusions: Patients with CD-related pain experienced clinically important and sustained reductions in pain during repeated incoBoNT-A injections with or without concomitant pain medication, confirming the benefits of long-term incoBoNT-A treatment.

Pain reduction in adults with cervical dystonia following a single injection of incobotulinumtoxinA: a pooled analysis

A. Albanese 1 , J. Wissel 2 , W. Jost 3 , A. Castagna 4 , M. Althaus5 , G. Comes 5 , A. Scheschonka5 , M. Vacchelli 5, H. Jinnah 6

1 IRCCS Humanitas Research Hospital, Department of Neurology, Milan, Italy, 2 Vivantes Hospital Spandau, Department of Neurorehabilitation and Physical Therapy, Berlin, Germany, 3 Parkinson-Klinik Ortenau, Wolfach, Germany, 4 IRCCS Fondazione Don Carlo Gnocchi, Milan, Italy, 5 Merz Therapeutics GmbH, Frankfurt am Main, Germany, 6 Emory University School of Medicine, Department of Neurology, Atlanta, United States

Background: Pain is a common and disabling symptom of cervical dystonia (CD). This pooled analysis evaluated the effects of a single injection of incobotulinumtoxinA (incoBoNT-A) on pain in adults with CD-related pain. Methods: Pain severity data were pooled from four phase 3 and 4 studies of incoBoNT-A for the treatment of CD in adults. CD-related pain was assessed at baseline and 4 weeks after a single injection of incoBoNT-A using the TWSTRS-pain severity subscale or a pain VAS. Both were analyzed using a score range 0–10 and pain was categorized as mild (>0–<3.5), moderate (3.5–<6.5) or severe (6.5–10). Response was defined as ≥30% or ≥50% reduction from baseline pain severity score. The percentage of patients with complete pain relief (pain score=0) at 4 weeks after incoBoNT-A injection was determined. Sensitivity analyses evaluated pain responses in the subgroup of patients not taking concomitant pain medication. Change in pain severity from baseline to Week 4 was assessed using a one-sample t-test.

Results: Of the 678 patients with pain at baseline, 36.4% had mild pain, 42.9% moderate pain and 20.7% severe pain; mean pain severity score was 4.26 (SD 2.32). At Week 4 after incoBoNT-A injection, there was a significant reduction from baseline in mean pain severity score (−1.25 (SD 2.04; $p<0.0001$), a shift to a lower level of pain severity, response rates reflected clinically important improvements (48.1% had ≥30% pain reduction and 34.4% had ≥50% pain reduction), and 10.3% were pain free. Of the 678 patients, 64.2% were not taking concomitant pain medication and had a baseline mean pain severity score of 3.83 (SD 2.41). Pain improvements in this subgroup were consistent with those in the total population.

Conclusions: These results show significant pain reduction in patients with and without concomitant pain medication following a single injection of incoBoNT-A in patients with CD.

A novel THAP1 variant presenting with early onset generalized dystonia

A.M. Dellert 1, B. Rodrigues 2, N. Prakash 2

1 University of Connecticut School of Medicine, Farmington, United States, 2 University of Connecticut School of Medicine, Parkinson's and Movement Disorders Center, Department of Neurology, Farmington, United States

Background: DYT6 or DYT-THAP1 is a genetic dystonia caused by pathogenic mutations in the THAP1 gene. It predominantly presents with early-onset segmental or generalized dystonia with preferential craniocervical and upper limb involvement.

Methods: We report a novel mutation in the THAP1 gene presenting with childhood-onset generalized dystonia in a family.

Results: A 37-year-old female (proband) presented with dystonia starting at 12 years, initially developed right-sided neck tilting, progressing to left-side predominant abnormal posturing of the arm and leg within a few years. With time she developed truncal posturing with worsening speech and swallowing functions. All her symptoms developed during her teenage years with slow pro-

gression since then. Pertinent exam findings included a high arched palate, mild dysarthria, facial and oromandibular dystonia, right laterocollis with left torticollis, and mild left more than right-hand dystonia with minimal leg involvement. Mild truncal leaning to the right was noted. Her Burke-Fahn-Marsden Dystonia Rating scale was 44. Her parents and siblings are asymptomatic. Her 15-year-old daughter is symptomatic with the onset of dystonia at seven years, starting with cervical involvement. She has a similar phenotype. GeneDx dystonia panel reported a heterozygous THAP1 mutation, c.61T>G for the proband classified as a variant of unknown significance. The daughter also carries the same variant.

Conclusions: The c.61T>G mutation changes the amino acid at position 21 from serine to alanine in exon one. This variant is not observed frequently in large population cohorts. Other variants at nucleotide positions 61 and 62, changing serine to threonine, cysteine, and phenylalanine, have been associated with dystonia. To our knowledge, this is the first description of this variant in a family with early-onset generalized dystonia with craniocervical predominance. Interestingly, the daughter was symptomatic earlier than the proband. Further studies are needed to elucidate the clinical heterogeneity in DYT-THAP1.

The IAPRD 2023 Congress hopes that the attendees are comprised of clinicians, scientists and other healthcare professionals who are interested in neurodegenerative disorders like Parkinson's disease, secondary parkinsonisms, hyperkinetic and hypokinetic movement disorders, and more generally any disorder affecting muscle tone and motor control have gained insights from the presentations and enjoyed ample time to exchange ideas with colleagues.

Next year, the IAPRD will host the 2024 conference in Lisbon, Portugal. Me and Donna will be not attending the meeting, however, our Chairman of the Medical Advisory Board, Dr. Karen Frei is Chair of the Scientific Program Executive Committee (SPEC) of the IAPRD and we will ask her to write an article that will include the latest information on treatment and research on cervical dystonia and dystonia.

DR.CYNTHIA COMELLA SPEAKING AT THE PODIUM

In Memoriam: Dr. F. Harvey Bollich

Dr. F. Harvey Bollich, age 78, died on August 24, 2023 in Austin, Texas. Born in 1945 in the Cajun prairie land of Eunice, Louisiana, he graduated from its St. Edmund High School at which he lettered in boxing. He then obtained an M.A. from Notre Dame School of Theology and Loyola University in New Orleans. That was followed by a Ph.D. in systematic-ecumenical theology from Aquinas Institute in Dubuque, Iowa and its consortium with the regional Protestant and Eastern Orthodox theologates and the University of Iowa School of Religion. He also held a certificate of master catechist and a certificate of public notary.

Dr. Bollich was a longtime theological educator, ecumenist, and canonical specialist. He taught at several colleges and high schools in Louisiana, Iowa, Ohio, and Texas. In Cleveland, he was the layman secretary of a clergy association and specialized in ecumenical relations with the Orthodox Church. As an associate member of a public-schools board there, he helped pioneer the teaching of courses in world religions in Ohio public high schools. Recently he served as the academic assistant principal at St. Thomas More High School in Lafayette, Louisiana. He later taught at St. Edward University in Austin and at the city's Lifetime Learning Institute. He retired as a canon-law judge with the tribunal court of the Catholic Diocese of Austin and as a canonical editor with the tribunal of the Diocese of Dallas.

Harvey was known to his students as a demanding but humorous teacher who helped them relate Christianity to the world religions, science, and the arts. He was a member of the American Academy of Religion, the Catholic Theological Society of America, and the Canon Law Society of America.

Dr. Bollich was a contact volunteer of NSTA for many years. He had the denervation surgery for his spasmodic torticollis/cervical dystonia and was very helpful in sharing his experience with others who were interested in the procedure. He also volunteered for Meals on Wheels. For comical entertainment, he enjoyed membership in the Flat-Earth Society, the Luddite Society, and the Nicholas Cage Fan Club. Always an avid boxing fan, he had coached the sport at a boys' home in New Orleans.

Excessive Psychological Stress can Trigger the Onset of Idiopathic Cervical Dystonia

Dirk Dressler, MD, PhD has been member of the Medical Advisory Board of the National Spasmodic Torticollis Association, Los Angeles, CA, USA for many years.

He obtained his medical education at Georg-August University, Goettingen, Friedrich-Alexander University, Erlangen and at Harvard Medical School, Boston, MA. During this time he was scholar of Konrad-Adenauer-Foundation. He is a fully board certified neurologist and psychiatrist. After several years of postgraduate training at the National Hospital for Neurology and the Institute of Neurology, Queen Square, London, UK he took over a position as consultant neurologist and Associate Professor of Neurology at Rostock University, Rostock, Germany. In September 2008 he was appointed Full Professor of Neurology and Head of Movement Disorders Section at the Department of Neurology, Hannover Medical School, Hannover, Germany. Since 2021 he is Co-Director of the Neurotoxin Research Center, Tongji University Medical School, Shanghai, China.

He is one of the pioneers of botulinum toxin therapy in Europe. He published over 800 articles, book chapters and abstracts as well as several books on dystonia, other movement disorders and on botulinum toxin therapy. He is the author with the world-wide largest number of publications on botulinum toxin therapy. He received a honorary professorship of the University of Santiago de Chile, a honorary doctorate of the Medical University of Sofia, Bulgaria and numerous other prestigious awards for his contributions to the development of botulinum toxin therapy. He holds visiting professorships of Sao Paulo University, Brazil, Monterrey University, Mexico, Sechenov University, Moscow, Russia and Tongji University, Shanghai, China. He also holds several patents on botulinum toxin therapy.

The original publication will appear as:

Dressler D, Kopp B, Pan L, Adib Saberi F (in press) Excessive Psychological Stress Preceding the Onset of Idiopathic Cervical Dystonia. J Neural Transm

Question: Professor Dressler, you have just completed a study on excessive stress triggering the onset of idiopathic cervical dystonia. What is the background?

Dr. Dressler: Idiopathic cervical dystonia is by far the most common form of cervical dystonia. Idiopathic means that there is only cervical dystonia and that it occurs without any identifiable cause. Genetics appear to play a role, as a number of associated gene defects have been identified and the condition typically runs in families. However, when gene defects are identified, only a few percent of gene defect carriers actually develop the condition. This means that there must be additional factors that trigger the manifestation of the gene defects. These factors are known as epigenetic factors.

Question: What do we know about these epigenetic factors?

Dr. Dressler: Very little. Stress has been implicated in these speculations since cervical dystonia was first described. However, most of these reports are anecdotal. There is virtually no published evidence. This is what we wanted to change.

Question: What did you do?

Dr. Dressler: We collected 100 consecutive patients with idiopathic cervical dystonia from our clinics and described the natural course of their disease. In 13 of these patients, we found that excessive psychological stress preceded the onset of cervical dystonia.

Question: How was this excessive stress defined?

Dr. Dressler: It was defined as the worst stress the patients had ever experienced before and after the onset of their cervical dystonia.

Question: Can you give examples of these stressful situations?

Dr. Dressler: There were partner conflicts, including divorce, separation and domestic violence. There were special family burdens, legal disputes and migration. Some patients even had several of these factors combined.

Question: How was the onset of cervical dystonia related to stress?

Dr. Dressler: Cervical dystonia started 8.3±3.9 months (mean±standard deviation) after the onset of the stress.

Question: Was the cervical dystonia in these patients unique or special?

Dr. Dressler: The clinical presentation of their cervical dystonia was indistinguishable from idiopathic cervical dystonia without psychological stress. However, its course was very different: in 85% of our patients, the onset of cervical dystonia was very rapid. It took only 5.8±4.4 weeks for the cervical dystonia to reach maximum severity. This usually takes several years. 2.7±0.8 years after disease onset, remission began. Eventually, the disease severity decreased to 54.5±35.3% of the maximal severity. Again, this was very different from idiopathic cervical dystonia without psychological stress, where remissions are very rare and only mild. In short, cervical dystonia with psychological stress has a very rapid onset and an unusually good chance of remission.

Question: Why are your findings important?

Dr. Dressler: For the first time, we have described in detail a relatively large number of patients with idiopathic cervical dystonia in whom psychological stress seems to be the trigger for its manifestation. With this, we can now differentiate three main types of interactions between stress and dystonia: 1) Stress can be a trigger for the manifestation of dystonia. 2) Stress may modulate the severity of existing dystonia. 3) Stress may cause psychogenic dystonia.

Question: Any warnings?

Dr. Dressler: Everything we have said so far refers to idiopathic dystonia. Psychogenic or functional dystonia is a completely different condition. Although psychological stress can play an important role in the development of dystonia: Dystonia is not psychogenic in the vast majority of patients.

Question: What are the mechanisms linking stress and the development of idiopathic dystonia?

Dr. Dressler: This is largely unknown. Some potential mechanisms have been suggested in the literature, but they are very vague.

Question: Strictly speaking, your study was on cervical dystonia. Do you think that your findings apply to other forms of dystonia?

Dr. Dressler: You are absolutely right. Other forms of idiopathic dystonia would also need to

be studied, before we could make definitive statements. However, it would be plausible that basic mechanisms such as those described here also apply to other forms of dystonia.

Question: So far, you have studied patients with massive psychological stress. Could the same mechanisms explain why milder stress modulates dystonia?

Dr. Dressler: It would not be surprising, if the same mechanisms were responsible for the dystonia-modulating effects of milder stress. This could have far-reaching implications for therapeutic considerations.

Question: What is the outlook?

Dr. Dressler: If we understand epigenetics and the mechanisms involved, we might be able to intervene. This could lead to preventive therapies for idiopathic dystonia in patients at risk. Even in patients where idiopathic dystonia has already manifested, modulating these mechanisms might allow us to reduce its severity. This would be the first causal therapy. Both would be major breakthroughs.

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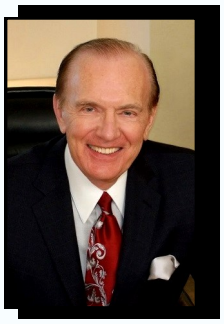
VISITING THE LIBRARY

There is no place
I'd rather be
Than sitting in
A library
With a stack of books
Next to me
And time to read them
Leisurely.

Carolyn Bolz

Emeritus
Medical Advisor

Drake D. Duane, MS, MD
Director, Arizona Dystonia Institute



Questions and Answers

Dear Dr. Duane:

My name is Kathy and I live in Las Vegas, Nevada. A few years ago, I had a "TIA" although some doctors say it was a stroke. I've had an MRI and I have about an inch and a half of damage in the front part of my brain. I didn't know this until I was reading some doctor's notes. I asked my neurologist what does this mean? They said "nothing" and I haven't had another MRI in over two years because the neurologist's office could not get it approved due to COVID. I've been told I have a severe case of cervical dystonia. I just recently went on disability after working 25 years and so that's been a struggle as well. I'm not getting the Botox shots anymore because, after my last injections, I called my doctor's office and told them that I feel a burning in my shoulders and the pain is still there. They told me to go to urgent care (I assume that is what she meant) which I didn't even bother because that's not going to do anything. Can you recommend someone in Las Vegas or where I can go for treatment because I'm in constant pain?

My doctor prescribed Klonopin which I don't take because it doesn't do anything for me. I'm in constant pain, it hurts to drive, and my neck is tilted to the right and nobody knows why or how it happened. I was just reading some information on how it could be from the TIA but yeah, I just need some directions on where I can go from here because it's really difficult living this way. I don't take muscle relaxers. I'd appreciate some directions. Thank you very much. I look forward to hearing from you.

Kathy

Kathy: Your situation will require you to be seen with the prior MRI studies available to confirm that study's implications and to physically examine you. If cervical spine x-rays were taken, they should be available as well as any bloodwork results.

If the word TIA was used it means a temporary blockage of a brain blood vessel that produced temporary symptoms but no damage to brain tissue. So, the MRI change should not be due to a TIA by definition. If due to that event it means a stroke did occur but there should have been symptoms. Thus, the MRI may represent some other even remote event. However, by the location you gave, it is unlikely it caused your "cervical dystonia" if that is what you have. However, in a study, we did years ago and presented at the Movement Disorder Society meeting that year in Toronto, our study of MRIs in CD patients did not reveal lesions likely to be causal to the neck symptoms but tended to occur in patients unresponsive to botulinum toxin treatment. We speculated that the lesions might have interfered with the "relaxing" effect of the treatment by interfering with the pathways essential for their effect in

the brain. Although improbable, did anyone inject your forehead to see if the muscles got weakened to be sure you are not resistant naturally or from your treatments causing botulinum toxin antibodies? Places to consider for evaluation:

- Dr. Daniel Truong in Southern California
- Mayo Clinic either in Phoenix Arizona or Rochester Minnesota
- Dr. Joseph Jankovic at Baylor University in Houston.
- The movement disorders group at the University of California San Francisco

Although I am still in practice you may be better served by a multidisciplinary center. I hope these comments are of help.

Dear Dr. Duane:

Background of my cervical torticollis problem

In my spine, there is a narrowing of the disc space (cervical spondylosis) in vertebras C4-5 and C5-6, which has been similar for about 20 years. No family member has had cervical dystonia.

My main symptoms are that my neck forces my head to move from left to right many times a day, and I cannot stop my neck from moving or jittering even when I am in bed. Those symptoms began shortly after July 4, 2019, when I fell onto a boating dock and broke my arm. On October 19, 2022, I had my first Botox injections, which were in both sides of my neck because on July 12, 2022, I was diagnosed with cervical torticollis. After the injections, my neck felt better and the involuntary movements were less frequent, but there were side effects. Below is my medical history and an account of when the cervical dystonia symptoms started.

- *On May 12, 2019, I had an MRI for cervical spondylosis. On that day, I was able to prevent my neck from moving, so the MRI image was clear (I have a CD of the MRI image).*
- *On June 28, 2019, I saw a spine and rehabilitation doctor for pain, but there were no symptoms of cervical dystonia at that time. I have supporting documentation about this.*
- *On July 4, 2019, I fell and suffered a broken left arm and upper extremity---which was a complex injury---and I had Open Reduction Internal Fixation surgery. I still have prosthetics in my left arm.*
- *On August 28, 2019, my medical record stated that I had "difficulty controlling neck movement, along with pushing of the neck," and my October 3, 2019, medical record indicated that the "left side of the neck often pushes the head from left to right every single day."*
- *On August 15, 2020, I had an MRI of the cervical region, and for the first time during an MRI exam, my head was jerking involuntarily, which made the resulting image blurry, as compared with the above May 12 MRI. I have a CD of both images, and a Sutter Image Department employee confirmed the difference between those two images.*
- *On July 12, 2022, I had another MRI of the cervical region, and during the exam, I still could not keep my head from moving, and the image was also blurry according to the technician who processed the image for me.*
- *On July 12, 2022, UC Davis Spinal Center surgery doctors and UC Davis professor indicated that they could perform surgery to remedy the cervical stenosis in C4-C6, but they cannot cure the involuntary movement disorder, because that disorder is not a symptom of cervical stenosis. They said that I had torticollis and suggested that I see a neurologist. The spine surgery doctor confirmed that cervical stenosis does not cause torticollis or cervical dystonia.*
- *Ever since the July 4, 2019, fall, my left shoulder still has pain extending from my left wrist to my left earlobe. The pain occurs even if I just carry a purse on my left shoulder for a few minutes, bend my left elbow, or carry grocery bags with my left hand.*

My questions

1. *Do you think that when my left arm struck very hard on the metal boating dock, my left shoulder and the left side of my neck could have been affected?*
2. *Do you think torticollis is usually due to a sudden muscle spasm in the neck that may be caused by injury to a muscle? Or could the injury be so minor that I don't even recall it? Or could the cause sometimes be inflammation in the neck or a spasm due to nearby inflammation?*
3. *On the basis of the above information, what caused, contributed to, or is related to the cervical torticollis that I suffer?*

Susan

Susan: Despite much research, we still search for why ST occurs. Genetic factors likely play a role in many cases family members or patients may have had scoliosis since adolescence, and tremor is relatively common as well. Light eye color (blue, gray, green, hazel) and female sex in North America are prevalent. 21 % of our study of about 200 patients carefully studied had a history of painful injury to the head, neck, or shoulder within a year of symptom onset. We found 24 characteristics were virtually identical in those with or without injury therefore pain may trigger onset but itself is not the cause.

We do know the dysfunction is in the brain and that the benefit of botulinum toxin takes 10 to 15 days because it takes that long to go from injected muscle to the brain via the nervous system. Justin can direct you to a YouTube lecture [https://www.youtube.com/watch?v=XilMGt0gfBw&t=658s] I made last year that may be helpful for you. Those whose symptoms begin before age 30 have the highest rate of symptoms clearing for some months but many, especially those with a painful but not nervous system serious injury have the symptoms come back. This is called remission and recurrence.

Dear Dr. Duane:

Is myofascial syndrome the same as cervical dystonia? I understand dystonia is a movement disorder and fascial is in the muscle. If you are diagnosed with myofascial syndrome, do you also have cervical dystonia? I ask this as they both contract muscles, but which comes first? Thank you for your help.

Judy

Judy: They are separate and distinct disorders without a connection between the two. Many conditions cause muscle spasms and muscular pain. Dystonia is a brain disorder expressed in changes in muscle tone and consequently in neck/head/spine posture.

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In Memoriam: Lillian Margaret "Peg" (Diehl) Miller

Lillian Margaret “Peg” Miller, of Martinsburg, PA, died at the age of 91. She was born in Everett, PA, the daughter of Robert and Nellie (Calhoun) Diehl. On February 21, 1953, she married James Miller of Bedford, PA.

Peg was a registered nurse, devoted wife, mother, grandmother and great-grandmother. She worked at the Bedford and Bellefonte hospitals as well as in a private medical practice in State College, PA. Upon her husband’s graduation from Penn State and their move to Vestal, NY, she became a stay at home mom, caring for her children through their school years. Peg was very active in her church, teaching Sunday school, chairing the Altar Guild, and taking Stephens Ministry and Bethel Bible Series classes. Peg was a hospice volunteer and worked for the Vestal Board of Elections for 12 years. When Jim retired in 1992, they moved to Fayetteville, PA, where Peg continued caring for others as a member of the church Barnabas team, visiting nursing homes and shut-ins and mentoring young people from the church, becoming a certified Adult Ministry Specialist. Throughout her life, Peg’s love of quilting, sewing, needlepoint, embroidery, knitting, crocheting, hat making, memory books, holiday decorations, and more resulted in countless keepsakes and mementos shared with friends and family. Some of the more than 100 quilts she made were exhibited in shows and now keep her children, grandchildren and great-grandchildren warm with memories of the love she stitched in them.

Peg’s faith was strong. She loved to talk about the Lord and set a good example for her family and friends.

What is QiGong?

Note: This material is for your information. It is not intended to substitute for the medical expertise and advice of your health care provider(s). We encourage you to discuss any decisions about treatment or care with your doctor. The mention of any product, service, or therapy is not an endorsement by NSTA.

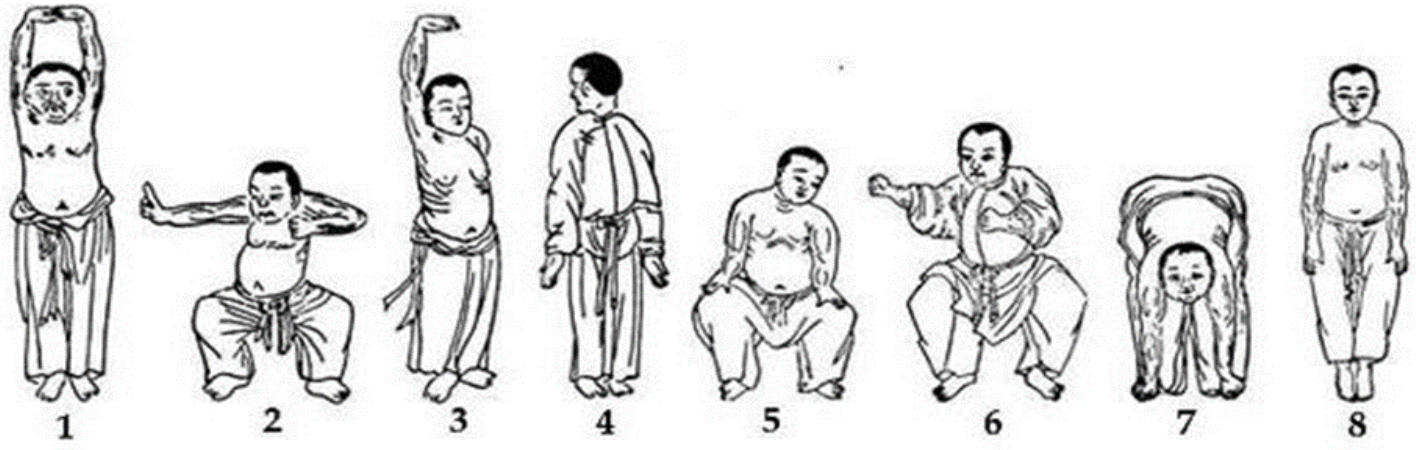
Definition

Qigong (pronounced chi gong) is a mind-body-spirit practice using meditation, posture, breathing, movement, and intention setting to optimize energy and help the body to heal itself based on traditional Chinese medicine (TCM) principles and is believed to be over 4,000 years old. According to TCM, a person's "qi" or "vital energy" must travel freely throughout the body for the person to feel their best, if qi becomes stagnant or blocked in certain areas of the body, health problems can develop. Qi has two main sources: non-renewable, which is the life force energy a person is born with, and renewable which is life force energy that comes from the food a person eats, the air, and nature, including meditation or mindful exercise. When qi flows freely the body engages in its healing process.

Forms and Practices

There are thousands of qigong styles, schools, traditions, forms, and lineages around the world. Tai Chi may be the most well-known forms of qigong. Baduanjin is one of the most basic forms with eight movements.

There are two types of qigong practice, internal and external. Internal qigong is movement-based, has been more researched, and used in general terms when describing the practice. Internal qigong is a self-directed practice of using techniques (meditation, movement, visualization, and breathing techniques) to promote the circulation of qi through the practitioner's energy system. It is a form of mind/body and behavioral medicine that depends on the frequency and duration of practice. Most of the techniques require you to hold a



The eight movements of Baduanjin qigong: 1. Pressing the Heavens with Two Hands; 2. Drawing the Bowstring and Letting the Arrows Fly; 3. Separating Heaven and Earth; 4. Wise Owl Gazes Backward; 5. Punching With Angry Gaze; 6. Bouncing on the Toes; 7. Big Bear Turns From Side to Side; 8. Touching the Toes Then Bending Backwards. (Image credit: Public domain)

posture (standing or sitting) accompanied by meditation, imagery, and breathing techniques. Some methods involve stationary posture while others may involve movements.

External qigong is more in the class of biofield (energy medicine). Other examples of biofield therapies are Healing Touch, Johrei, Reiki, and Therapeutic Touch. External qigong is an interpersonal healing practice involving a practitioner projecting qi (from the palms of the hands or the fingers points several inches away) into the recipient to promote the recipient's health or flow of qi. A pilot study published in the Journal of Alternative and Complementary Medicine found that two-thirds of 18 trials reviewed demonstrated at least partial effectiveness of biofield therapies. For now, there is no scientific evidence supporting external qigong in treating health conditions or disease though research on biofield is ongoing.

Practical Elements

For the rest of this article when the word qigong is used it would be under the internal practice. Qigong has different forms, but all contain elements that are combined and used in different ways. The body is regulated through posture, while the mind is regulated through meditation, quietness, and relaxation. Breath is regulated by limb movement and self-massage.

How it Works

Qigong uses simple poses and patterned breathwork. Its physically slow gentle movements are believed to warm tendons, ligaments, and muscles; mobilize the joints; tonify vital organs and connective tissue; and promote circulation of body fluids (blood, synovial, lymph). Deep breathing in qigong may help calm the sympathetic (fight-or-flight) nervous system and activate the parasympathetic (rest-and-digest) side of your autonomic nervous system which regulates involuntary processes like breathing, heartbeat, and digestion.

You only need 10 minutes a day to do qigong. The movements are simple and can be modified easily. It does not require special training or equipment and is cost-effective. It is generally easy for nearly everyone and would engage you in your healthcare.

It is considered safe for people in general if practiced in moderation unless you are pregnant. The movements of qigong are less challenging to your balance but if you are not able to stand there are chair-based qigong.

Qigong is similar to Western behavioral medicine in terms of using visualization, meditation, and breathing exercises. It must be practiced daily as with other mind/body and behavioral self-help practices.

The best way to learn qigong is to take a class but it isn't necessary—many people can learn from online videos and instructions. Integrative medicine specialist Yufang Lin, MD's advice for beginners: "Pay attention to the form and learn it properly. Then you can focus on breathing and being present."

Possible Health Benefits

Studies have shown the potential benefits of qigong, but large and controlled studies and high-quality research are needed to prove that it can treat and may be able to prevent health problems. Qigong is not considered hazardous to one's health as it typically entails gentle movements and relaxation. Traditionally, it was practiced regularly to promote health. Other benefits may include increased strength, stamina, range of motion, and flexibility, removing toxins, improving the function of the immune and digestive system, and enhancing healthy sleeping patterns.

The strongest evidence of qigong benefits is its use as an adjunct therapy for treating hyperten-

sion. There is also fair evidence for using it to manage pain-related anxiety. Some studies found qigong can help in the treatment of arthritis, back pain, cancer, chronic pain, cognitive impairment, depression and anxiety, fatigue, muscle strength and posture, Parkinson's disease, and stroke.

A 2007 study published in the Journal of Hypertension found that qigong exercise had a mildly positive effect in lowering blood pressure. One study concluded that the blood-pressure lowing effect of qigong is like that of a conventional exercise routine. The authors theorized qigong's benefits to the heart may be partly due to its repetitive movements, which boost blood flow and improve organ function. Several studies suggest qigong combined with conventional medication may be an effective strategy for reducing hypertension.

One of the largest studies involving qigong was published in the American Journal of Health Promotion in 2012, the study found various positive results suggesting qigong exercises improve bone health and balance.

A 2007 study published in the Journal of Alternative and Complementary Medicine concludes that qigong has a mildly positive effect in controlling diabetes.

A few small studies and two clinical trials have found that frequent and consistent qigong practice may be helpful for people with fibromyalgia in areas like pain, sleep, and physical and mental function.

A study with 64 participants with chronic fatigue experienced improvements in their symptoms after four months of practicing qigong, they had better mental function and less fatigue compared to those who did not.

Qigong's gentle movements may help joint conditions like wear-and-tear knee osteoarthritis. A 2017 published clinical practice guidelines by Ottawa Panel (an international group of research-method experts) recommended tai chi to boost quality of life, lower pain, and improve function for people with knee osteoarthritis. A review of seven studies found that qigong relieved knee osteoarthritis of pain, stiffness, and improved physical function more than the control group.

A review of 22 studies of people with various cancers found that qigong significantly improved psychological and physical symptoms related to cancer and its treatment. A randomized, controlled trial of 162 breast cancer patients found that those who took part in a qigong program twice a week for 10 weeks reported greater improvements in their quality of life, and that they had greater reduction in tension, anxiety, depression, and fatigue compared to patients who only received traditional care. The authors of the trial think qigong was effective because of the deep breathing and mood-boosting effects of movement and exercise. A 2019 review included seven studies of patients with different cancers on qigong concluded that it significantly improved symptoms of fatigue and sleep quality; though not statistically significant it also had positive effects on anxiety, stress, depressive symptoms, and overall quality of life.

The amount of research on qigong and movement disorders is very limited. A 2020 review of seven studies suggested that qigong helped improve movement, walking ability, and balance in people with Parkinson's disease; the amount of improvement seen in movement and walking ability was similar to that seen with other forms of exercise, such as walking and using a stationary exercise bike. However, improvements in balance were greater with qigong than with the other types of exercise. The qigong exercise programs ranged from 8 to 48 weeks, with 30- to 120-minute sessions two to seven times per week. Unfortunately, no study of dystonia and qigong has been done.

Things to Consider

Qigong is not regulated by the federal government

or individual states; therefore, instructors do not need to be licensed and there is no national standard for certification. If you would like to use qigong as a complementary therapy for a medical condition it would be better to work with a qualified medical qigong practitioner. Do your research before choosing an instructor. You can find qualified qigong practitioners through:

Red Thread International Qigong Institute
https://redthreadinstitute.org

International Medical Qigong College
www.medicalqigong.org

The National Qigong Association
www.nqa.org

If you are curious about qigong, Viet Hong Pham, a Licensed Acupuncturist who practiced qigong for over 15 years demonstrated the practice at the NSTA 2019 Fountain Valley Symposium. You can view the presentation on NSTA's YouTube channel:

Viet Hong Pham - Qi Gong Relaxation and Breathing Techniques - PART 1
https://www.youtube.com/watch?v=Tkz-NNcI0NA&t=341s

Viet Hong Pham - Qi Gong Relaxation and Breathing Techniques - PART 2
https://www.youtube.com/watch?v=l1r_zTC7tWU

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Cervical Dystonia: A Comprehensive Guide to Learning and Coping

by Apurva Zawar, DPT, PMP®
Board Certified Geriatric Clinical Specialist

Dr. Apurva Zawar, the founder of BeyoundRehab is a multi-disciplinary healthcare expert with over a decade of experience, she understands the limitations of traditional approaches to rehabilitation. She believes that rehabilitation should not only focus on the condition or injury, but on the unique needs and goals of each individual.

Introduction:

Cervical dystonia (CD) is a complex movement disorder characterized by sustained or intermittent muscle contractions that cause repetitive movements, fixed postures, or both.

As the most common form of focal dystonia, CD requires a deep understanding of its multi-component pattern and clinical diversity to provide effective care and support.

This comprehensive guide aims to empower individuals with CD by providing insights into the condition and offers strategies for learning and coping.

Exploring Multi-System Changes:

Recognizing the multidimensional nature of CD is essential to address its wide-ranging impacts. CD affects various systems, including motor control, sensory processing, the autonomic system, and physical abilities. A thorough assessment is crucial to gaining a holistic understanding of an individual's unique challenges and tailoring treatment accordingly. Assessments should encompass:

1. **Motor Control:** Analyzing changes in movement patterns due to positional adjustments and environmental triggers. Monitoring muscle activities through techniques like surface electromyography (EMG) to identify muscle activity and design treatment plans.
2. **Sensory System:** Assessing sensitivities to light, sound, and somatosensory experiences (such as touch, pressure, and vibration) and vestibular changes associated with rotational or transitional movements, dizziness, and balance issues.
3. **Autonomic Nervous System**: Observing changes in blood pressure, heart rate, exercise tolerance, and breathing patterns to address any dysregulation.
4. **Physical Limitations**: Assessing flexibility, strength, joint mobility, nerve mobility, biomechanics, posture, and gait analysis to identify areas for improvement and develop targeted interventions.

In addition, it is essential to consider lifestyle factors such as sleep patterns, diet and nutrition, fitness routines, social engagement, coping strategies, life stressors, and psychological & cognitive changes. Taking a comprehensive approach to care ensures a well-rounded treatment plan that addresses individual needs.

Prominent Sensory - Motor Changes:

Sensory-motor changes are key features of CD and significantly impact daily functioning. These changes may manifest as sensory deficits, affecting the ability to process and integrate sensory information effectively. Abnormal muscle activity can also disrupt the brain's signaling to the muscles. Recognizing these transformations is crucial in developing interventions that can address these challenges and improve overall function.

The Impact on Daily Life:

Living with CD presents unique challenges that can interfere with daily activities and overall well-being. However, a multifaceted approach involv-

ing collaboration with a movement disorder neurologist, a neuro-physical therapist specializing in movement disorders, and neuropsychologists can help individuals navigate these challenges effectively.

A multidisciplinary team-based approach, including treatments such as Botox injections, neurorehabilitation, and cognitive behavioral training, is recommended. Evidenced-based and patient-centric care with a focus on active coping, continuous learning, collaboration, and gradual integration of positive changes into the daily routine.

Movement discovery, repetitive practice, and finding joy are essential in achieving the highest level of function and improving quality of life.

Unlocking Neuroplasticity:

Neuroplasticity offers hope for individuals with CD. This remarkable concept refers to the brain's ability to reorganize, rewire, and adapt by forming new neural connections. In the context of CD, neuroplasticity provides the opportunity to retrain and relearn sensory-motor pathways, facilitating functional recovery and enhancing quality of life.

Research and clinical practice have demonstrated that positive neuroplastic changes can occur in CD with persistent practice and targeted interventions. Rehabilitation approaches that emphasize task-specific functional training, sensory-motor training, and repetitive movements can stimulate positive neuroplasticity. Close collaboration with a neurorehabilitation team ensures the supervision and guidance necessary for harnessing the potential of neuroplasticity.

Continuing the Journey:

Recovery in CD is an ongoing process of learning and progress. By staying informed and exploring novel approaches, such as neuroplastic training, task-specific exercises, sensory-motor training, and repetitions, individuals can achieve meaningful gains and reach their highest level of function.

Remember, your journey with CD is unique and filled with discoveries, learning opportunities, and gradual gains. Stay committed, stay informed, and keep striving towards achieving your goals.

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Dystonia & Aging

by Carol Flynn

I am a senior who was diagnosed with Cervical Dystonia in 2005 which spread to my back a few years later. I will share some negative aspects of Dystonia & Aging first, then I will discuss the positive side. Believe it or not, there are some positives.

NEGATIVES:

As we deal with Dystonia and celebrate additional birthdays, we are often faced with new challenges. Just because we have Dystonia, we are not immune to the normal problems that occur as we approach those golden years. To name a few:

- Eyesight & hearing issues....cataract surgery, hearing aides, anyone?
- Arthritis....oh my achy joints
- Decreased strength and balance.....I'm falling & I can't get up
- Decreased energy.....my "get up & go" got up and went
- Other body betrayals: cardiac issues, cancer, etc.....why me Lord?
- Transportation issues.....did you hide my car keys?

Increased sense of isolation. Younger family members are busy with their own growing families. Old friends some times fade away due to age or illness themselves. Often we can't just drive, fly, walk, take the bus, etc. where we want to go like we used to do.

POSITIVES:

We are hopefully older & wiser and can take steps to help mitigate the negative issues. We know the advantages of routine doctors visits, not ignoring new symptoms, importance of exercise, better diet, maintaining social contacts as best we can & maintaining a positive attitude. We know isolation is not healthy.

If we have battled Dystonia for some time, we are no longer overwhelmed by the diagnosis. We have done a little research. We have learned a few tricks to deal with our particular challenges, such as:

- What meds or treatments have helped us & what has not. (We are all different, no one treatment works best for everybody.)
- Botox...who's afraid of needles, not me!
- Rest periods....I am not lazy, I'm recharging
- Hot packs....thank God for microwaves
- Pillow assortment available...too big, too small, ah...just right
- Me Time.....need it NOW
- Read a book...enrich the mind or fantasy trip out of my world
- Music.....enrich the soul
- Vitamin Sunshine...hello Mother Nature
- Movie time....where's the popcorn?
- Reach out to another human.....hello, is anyone out there?
- Prayer &/or meditation....calm me, strengthen me

That gray hair & those wrinkles can offer additional benefits:

We are experienced enough to know that there will always be bad days but better days may start as early as tomorrow or an hour from now.

Seniors are more likely to enjoy a less physically active lifestyle. Water skiing may be in my rear

view mirror but there are many things I can still enjoy.

There are two sides to daily stress as we age. If we are not trying to balance work, home, & the demands of a young family, we have less stress. If we can't work but need the money a paycheck brings in or covered health care we can have added stress.

We do have more time as we get older. How we use that time is up to us. We can relax more & pursue activities that make us happy. More time to volunteer if we desire to do so, which increases satisfaction in knowing that we can contribute something to a cause we believe in, even if only in small ways.

BEST OF ALL:

We are not slaves to the clock. We can get up as early or late as we want, retire to bed whenever we want, etc. Finally, we get our teenage dream!

Carol Flynn
Support Group Leader
Dystonia Support Group, Fairfield, CA
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BIRD NEST SURPRISE

by Carolyn Bolz

Last Saturday morning when I was walking to my mailbox, I almost stepped on this tiny bird nest. It was so well camouflaged that I barely managed to avoid crushing it. As I peered closer at the little nest, I wondered what type of bird had built it and used it to raise a family. I also wondered if the nest had blown off of a branch in a nearby tree during our recent windy weather.

No matter what had caused the small bird nest to land near my mailbox, seeing it there lifted my spirits and made me feel grateful once again for all the delightful little surprises in nature.

The Role of Neurological Physical Therapy in Managing Idiopathic Focal Dystonia

by Apurva Zawar, DPT, PMP®
Board Certified Geriatric Clinical Specialist

Dr. Apurva Zawar, the founder of BeyoundRehab is a multi-disciplinary healthcare expert with over a decade of experience, she understands the limitations of traditional approaches to rehabilitation. She believes that rehabilitation should not only focus on the condition or injury, but on the unique needs and goals of each individual.

Introduction:

Idiopathic focal dystonia is a neurological disorder characterized by involuntary muscle contractions and abnormal postures in specific body parts. The condition varies from person to person and can change over time, suggesting the brain's potential to improve motor function.

Neuro-physical therapy care for dystonia help people with idiopathic focal dystonia manage their symptoms and enhance their quality of life. Treatment comprises a wide range of neurorehabilitation approaches including:

- **Sensory Motor Training**:
Sensory motor training involves exercises designed to improve the brain's ability to process sensory information and control movement. Through targeted interventions, Neuro PTs aim to enhance sensory processing and motor control, leading to improved motor function and coordination.
- **Task-Specific Training**:
Task-specific training focuses on helping individuals perform specific activities or tasks affected by dystonia. Whether it's writing, performing neck movements, or engaging in various activities, this training method aims to enhance functional abilities and minimize compensatory movements.
- **Movement Augmented Feedback**:
To optimize movement accuracy and reduce compensatory patterns, Neuro PTs utilize movement-augmented feedback techniques. This involves incorporating different stimuli such as visual, auditory, and vibrational feedback during exercises that involve various body parts. By combining these feedback mechanisms with motor learning principles, the accuracy and efficiency of movements can be improved.
- **Biofeedback**:
Biofeedback employs electronic sensors to provide real-time feedback on muscle activity, assisting individuals in learning to control their muscles. By enhancing muscle awareness and facilitating voluntary control, biofeedback can contribute to reducing dystonia -related pain and improving motor function.
- **Virtual Reality Therapy**:
Virtual reality therapy utilizes computer-generated simulations to create safe and controlled environments for individuals to practice specific movements. This immersive approach helps individuals improve motor skills, increase confidence, and enhance functional abilities.

It’s important to note that techniques employed by neuro PTs may vary based on your presentation, learning styles, and available resources. Nonetheless, the primary objective remains constant: to improve motor function, and daily activity engagement, reduce pain, and enhance the quality of life for individuals with idiopathic focal dystonia.

Benefits of Neurological Physical Therapy:

Engaging in Neuro PT can bring several benefits for individuals with idiopathic focal dystonia:

Improved Motor Function: Neuro PT interventions target balance, coordination, and range of motion, enabling individuals to perform everyday tasks with greater ease and participate in activities they enjoy.

Reduced Pain: Neuro PT techniques help alleviate dystonia-related pain, leading to increased comfort and improved overall well-being.

Enhanced Quality of Life: By reducing symptoms and promoting independence, Neuro PT can significantly improve an individual's quality of life, enabling them to engage more fully in daily life.

Most importantly, neuro-physical therapy, in conjunction with other treatments like Botox, plays a vital role in managing dystonia symptoms and improving quality of life. To ensure effective management, individuals are encouraged to connect with Neuro PTs specialized in treating dystonia and gain a better understanding of how Neuro PT can benefit their specific condition.

Conclusion:

Recovery is possible with diligent practice, engagement, and the right multidisciplinary team managing your dystonia care. Neurological physical therapy plays a crucial role in this process, helping individuals improve motor function, reduce pain, and enhance their overall quality of life. By understanding the benefits of Neuro PT and finding a qualified practitioner, individuals with idiopathic focal dystonia can take significant steps towards better management and improved well-being.

LABOR DAY???

Labor Day's for resting
And relaxing too,
For not even thinking of
The work we need to do.

We can grill outdoors
Or take a weekend trip,
Perhaps make lemonade
And enjoy an ice-cold sip.

We'll sleep late, of course,
Or maybe lounge in bed,
But we won't do any labor.
We'll have fun instead!

Carolyn Bolz

mail bag

Dear NSTA,

This renewal comes with a sincere thank you for your publication. My mom has had ST for over 20 years. As her caretaker, I am grateful for EVERY article. My mom sincerely appreciates the publication as well.

Thank You Again,
Carol Horlock

Justin,

Hello!

Just wanted to say "Thank you" one more time, to you and Dr. Duane.

Earlier today, my mom went to see a doctor who is subbing for her regular Botox doctor. She had her printout of info in her purse, and she had studied it intently last night in preparation for her appointment.

The fill-in doctor discussed every point that Dr. Duane had brought up — without any prompting from my mom. She was so, so pleased with the visit. "Satisfied" was the word she used. She is anxious to begin treatment with this new doctor and is hopeful that she will feel better in the year ahead.

So, once again, thank you for the time and effort you invested last year. Fingers crossed; it will pay off handsomely for my mom. FYI, she'll turn 92 in September. To see her so happy today on our FaceTime call was priceless.

Sincerely,
Jean Gill

Dear NSTA,

Please send me about 50 of the NSTA Missing Pieces brochures. I would like to hand them out at church, at my Silver Sneakers Class, and to family and friends.

Enjoy reading your ST Quarterly. I have had Spasmodic Dysphonia since about 1995 and developed Cervical Dystonia in 2015. So far, the Botulinum Toxin treatments have not worked for me. But am going to try it again with my Cervical Dystonia.

Blessings,
Martha Breedlove

Clint and Me

From Gunslinger to High School Teacher

by John Lee

July 23, 2023

My relationship with Clint Eastwood began in 2008. I was at a wedding in New York. A cousin I hadn't seen for many years, greeted me in passing, complimented my appearance, and said "You got that Clint Eastwood thing going." Huh?! I hardly thought of myself as that craggy old icon of American masculinity, but over the next ten years, friends and strangers kept telling me this. It was the beginning of a wave.

– // –

In 1990 I worked for many months as a Sales Store Clerk in the museum shops of the Portrait Gallery and American Art museums. It was a great crew whom I will never forget. Years later, I happened to be browsing in one of the shops. The woman behind the counter looked familiar. Ellen?. I kind of thought it was her, and then"John?" She said tentatively. Both of us delighted to see each other, I replied "Ellen?" After a short catching up she said "You look like Clint Eastwood..." oh no, I thought... "But in a good way." Phew!

– // –

Cleveland. I was at a conference, sitting in an outdoor tent having lunch at one of those round tables for eight or so, not talking to anyone. "I know!" exclaimed one man as he got up and came around the table towards me. "Clint Eastwood!" and proceeded out of the tent.

– // –

Maryland, Kensington Antique Town, near DC. On a group tour of the stores, we had lunch together in a nearby restaurant. As we were getting up to go, a man on his way out, from a nearby table, whom I did not know, approached. "I'm sure people have told you that you look like Clint Eastwood".

– // –

Washington, D.C. Friday Happy Hour at a bar. I had come with a couple friends to enjoy the music and a cocktail. Watching the crowd, across the room I noticed a younger group gathering, and joined by a friend who came in carrying a skateboard. They seemed not to notice anyone else in the room except each other. As I was talking to my friends, suddenly skateboard guy is coming up to me and asks mischievously "Are you Clint Eastwood?" I tried to play along by saying, unconvincingly, a line from "Dirty Harry." "Are ya feeling lucky today, punk?" He just smiled and walked away. One of my friends stared at me incredulously, as if this happened to me all the time.

– // –

The Eastwood wave seems to have passed. I went for a checkup with the eye doctor last year. The gentleman I checked in with said with a big smile on his face "Hi Mr. Hand [pause]... you know, the history professor in the move Fast Times at Ridgemont High?, you look like him." I had to look it up. A 1982 movie. According to the Web site Looper, Mr. Hand was the straight-laced history teacher in a perpetual battle with his student, Jeff Spicoli, played by Sean Penn. And Mr. Hand was played by none other than Ray Walston, my favorite Martian. It's true! I do look like him. Somehow I have transformed from Clint to Ray. No confirmations so far. Maybe I'm anonymous again. The last time I went for an eye check, I asked the man "Did you do your homework?"

Volume 25, Issue 131

NSTA SYMPOSIUM

April 7&8, 2025

In

Las Vegas, Nevada

Following is content from the fifth NSTA newsletter, published June 1985. If you are interested in reading the entire newsletter, please email us to request a PDF copy.

MEDICAL ADVISOR'S LETTER

The annual meeting of the Academy of Neurology was held this year in Dallas, Texas from April 30 to May 2. The association's booth was visited by many neurologists from around the world who showed considerable interest in the NSTA. The first meeting of the newly formed Medical Advisory Board took place on May 1 at the meeting. The following physicians, in addition to myself, have agreed to serve on the board:

Robert E. Burke, M.D.
Neurological Institute
710 West 168th Street
New York, NY 10032

Drake D. Duane, M.D.
Section of Neurology
Mayo Clinic
Rochester, Minnesota 55901

Anthony Lang, M.D.
Toronto Western Medical Building #205
25 Leonard Avenue
Toronto, Ontario M5T 2R Canada

Peter LeWitt, M./D.
Department of Neurology
Lafayette Clinic
951 East Lafayette Blvd.
Detroit, Michigan 48207

The following two physicians have agreed to serve as Honorary Medical Advisors:

Stanley Fahn, M.D.
Neurological Institute
710 West 168th Street
New York, NY 10032

Professor C.D. Marsden, F.R.S.
Department of Neurology
Institute of Psychiatry
De Crespigny Park
Denmark Hill, London SE5 8AF
England

The NSTA would like to thank all of them for their support, without which the association could not continue to grow. With their help, research into the cause and treatment of spasmodic torticollis will be greatly facilitated.

A number of subjects were discussed at the board meeting, including the establishment of a brain bank, collection of cerebrospinal fluid, transcutaneous neuromuscular stimulation, spinal cord stimulation, and the establishment of a universally accepted rating scale for use in clinical research.

The Medical Advisory Board has formally recommended the following goals for the NSTA:

1) Evaluation of potential treatments
2) Preparation of a referral list of physicians
3) Preparation of a referral list of physical and occupational therapists
4) Facilitation of disability claims by patients with ST
5) Recruitment of brain donors and volunteers for research
6) Media exposure
7) Patient and physician education
8) Fund raising for medical research

Paul A. Cullis, M.D.

SUPPORT GROUP MEETING ANNOUNCEMENTS

Dystonia Support Group
Birmingham, AL

3rd Saturday of February, May, July & October
10:00 a.m.
1st Saturday of December
10:00 a.m.

Healthsouth/Lakeshore Rehabilitation Facility
3800 Ridgeway Road
Birmingham, AL 35209
off Lakeshore Drive

Pat Wyatt
support@dystonia-Alabama.org
www.dystonia-alabama.org

Quad-City Area Dystonia Support Group
Eldridge, IA

For more information, contact:
Cyndy Bauer
(563) 285-4688
cabauer42@aol.com

Fairfield, CA

For more information, contact:
Carol Flynn
(707) 429-9668
caflynns@gmail.com

Dystonia Support Group
Seattle, Washington

For time and location contact:

Judy Yoon
(202) 288-9630
judyhyoon@gmail.com

Denver/Colorado Springs, CO Dystonia Support Group

For time and location contact:

Paul Kavanaugh
Support Group Leader
Colorado Springs, CO
pwkavanaugh@comcast.net
719-635-6620

or

Cheryl Sheldon
Broomfield, CO
ncodystonia@comcast.net
303-466-2033

Albuquerque, NM Dystonia Support Group

For time and location contact:

Mak Ellison
505-589-8763
mywigglewalk@me.com

SUPPORT GROUPS AND CONTACT VOLUNTEERS

What follows is an updated listing of our devoted support group leaders (marked with hearts) and phone contact individuals (marked with telephone receivers).

If you've been either a leader or phone contact person in the past, do not see your name on this list and wish to be on the list, please contact Sandra Levine, Support Group Coordinator at levinesy@comcast.net or 505-466-4041.

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♥ Harpersville
Pat Wyatt
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Talladega
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256-268-9357

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WE ARE DEEPLY GRATEFUL TO THE FOLLOWING PEOPLE

FOR THEIR GENEROUS CONTRIBUTIONS TO NSTA DURING THE FIRST & SECOND QUARTER OF 2023

MAJOR BENEFACTORS

Merz Pharma & Revance Therapeutics

In Loving Memory of Lillian "Peg" Miller

Lisa Baldwin
Berachah Sunday School Class
Melony Fisher
Rosa Gomez
Daniel & Cheryl Horton
Margaret & Robert Marino
Tyler Miller
James Miller
Iolene & Jack Mitchell
Anna Smith

Sandra Bogle, In Loving Memory of her mother, "Elizabeth Duncan Keck's 26 years of essential tremors and vocal dystonia."

Rita Kerstiens, In Loving Memory of her daughter and grandson, Tanya and Benton Rowe

Jim Ruetz, In Loving Memory of his wife of 20 years, Jennie Flood-Ruetz, "I miss my beloved spouse Jenine greatly and all her loving and artistic attributes."

Beverley Wilber, In Loving Memory of her husband Col. Harold B. Wilber, USMC, "Despite his battle with Agent Orange, he continued his love and support of me and my ST."

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Beverley Wilber

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ST Quarterly

The National Spasmodic Torticollis Association

National Spasmodic Torticollis Association
17151 Newhope Street, Ste. 208
Fountain Valley, CA 92708
www.cdtorticollis.org

NSTA
NATIONAL SPASMODIC TORTICOLLIS ASSOCIATION

REMEMBER...
YOU ARE NOT ALONE!