



The VA Parkinson Report

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Robert A McDonald: New VA Secretary



Robert A. McDonald was nominated by President Obama to serve as the eighth Secretary of Veterans Affairs and was confirmed by the United States Senate on July 29, 2014.

Prior to joining VA, Secretary McDonald was Chairman, President, and Chief Executive Officer of

The Procter & Gamble Company (P&G). Under his leadership, P&G significantly recalibrated its product portfolio; expanded its marketing footprint, adding nearly one billion people to its global customer base; and grew the firm's organic sales by an average of three percent per year. This growth was reflected in P&G's stock price, which rose from \$51.10 the day he became CEO to \$81.64 on the day his last quarterly results were announced—a 60 percent increase from 2009 to 2013. In 2012, Chief Executive Magazine named it the best company for developing leader talent. The Hay Group, a global management consulting firm, consistently cited P&G in its top-tier listing of the Best Companies for Leadership Study. The company received recognition for its environmental and social sustainability initiatives, including receipt of the Department of State's Award for Corporate Excellence for P&G's operations in Pakistan and Nigeria. In addition, using the company's

innovative water purification packets, P&G committed itself to the 2020 goal of “saving one life every hour” by annually providing two billion liters of clean drinking water to people in the world's developing countries.

An Army veteran, Mr. McDonald served with the 82nd Airborne Division; completed Jungle, Arctic, and Desert Warfare training; and earned the Ranger tab, the Expert Infantryman Badge, and Senior Parachutist wings. Upon leaving military service, Captain McDonald was awarded the Meritorious Service Medal. Secretary McDonald graduated from the United States Military Academy at West Point in the top 2 percent of the Class of 1975. He served as the Brigade Adjutant for the Corps of Cadets and was recognized by The Royal Society for the Encouragement of Arts, Manufacturing, and Commerce as the most distinguished graduate in academics, leadership, and physical education.

Secretary McDonald earned an MBA from the University of Utah in 1978. The recipient of numerous leadership awards and honorary degrees, in 2014, Secretary McDonald was awarded the Public Service Star by the President of the Republic of Singapore for his work in helping to shape Singapore's development as an international hub for connecting global companies with Asian firms and enterprises. Secretary McDonald and his wife are the parents of two grown children, Jennifer and Robert, and the proud grandparents of grandsons, Matthew and Michael.

Development of a Botulinum Toxin Program in a VA Consortium Center
Brandon Barton, MD, MS., Director of Jesse Brown VA Consortium Center in Chicago, IL

Botulinum toxin has been re-appropriated from its more ominous role as a potent biological danger to being used as therapeutic agent in movement disorders. This molecule works by a process called chemodenervation, in which the release of presynaptic acetylcholine from nerve terminals is reduced, resulting in the relaxation of overactive muscles and overactive glands. Botulinum toxin has been FDA approved to treat various movement disorders including manifestations of dystonia, spasticity, and other disorders of muscle hyperactivity (such as hemifacial spasm). In addition, the product is used in many off-label situations to significantly and safely improve complications of Parkinson's disease, including secondary dystonia (often manifest as muscle spasms, cramping, and twisting movements in the face, neck or limbs), sialorrhea (excessive drooling), and chronically abnormal postures of the spine or limbs. In stroke or traumatic brain injury, the toxin can be applied to treat spasticity and allow for less pain, better daily function, and reduced stiffness.

Our experience at the Jesse Brown VA in Chicago, IL (JBVA) illustrates the impact on how the organization of the Consortium Centers has led to a major opportunity to provide this therapy to Veterans in the Chicago area. In 2008, the JBVA was designated as a Consortium center, leading to the hiring of a movement disorders specialist part time in 2009 (Dr. Barton, who also works at Rush University Medical Center), in order to transfer skills and knowledge of state of the art care of the management of Parkinson's disease and movement disorders to the JBVA. Previously, Veterans who needed botulinum toxin injections were referred to outside universities at the expense of the VA, which often was prohibitive given the expensive nature of the treatment and the complicated approval process.

In 2010 Dr. Barton recruited the skills of the new PM&R physician Dr. Patrick Barrett, who was previously trained in administering botulinum toxin in a rehab setting, and also trained general/stroke neurologist Dr. Kurian Thomas in the application of the toxin for complications of strokes and migraines. As a result of their combined efforts, a multidisciplinary botulinum toxin injection clinic (Chemodenervation clinic) was

formed. This clinic is scheduled for every Thursday afternoon and staffed by each of these specialists, providing a broad range of care for the many needs of Veterans with spasticity, dystonia, migraine, and other movement or pain disorders. The JBVA Chemodenervation clinic has injected approximately 300 Veterans since the clinic started in 2010. The clinic has served a total of 98 Veterans, many with repeated injections over the entire time period, typically every 3 months. Diagnoses included 37 with spasticity, 43 with dystonia, 15 with migraine and 3 for sialorrhea. The reports of the great majority of patients and involved physicians, as well as the fact that the majority Veterans continue to return for ongoing treatments, is a testament to the positive impact on the quality of life and ongoing efficacy.

Other symptoms addressed by botulinum toxin include excessive drooling, or sialorrhea, a common complication of many chronic neurological diseases including Parkinson's disease, amyotrophic lateral sclerosis, and stroke. While any brand of toxin may help with this problem, rimabotulinum B is often chosen given its higher autonomic side effect profile. Onabotulinumtoxin A was recently approved for the treatment of chronic migraine headaches and has proven effective for significantly improved headache control in our clinic.

An ongoing challenge is the competition between the several commercially available brands of botulinum toxins whose companies often offer a better financial advantage to the VA. Currently there are four brands on the market: 3 types of type A toxin (onabotulinumtoxin A, abobotulinumtoxin A, incobotulinumtoxin A), and one type of type B toxin

(rimabotulinumtoxinB). The relatively recent arrival of multiple competing brands has had the favorable impact of driving down costs for the VA due to competition. We have changed our toxin use profile depending on encouragement of the local pharmacy and interactions with the company representatives who are trying to negotiate the best price for the VA.

In our experience, Veterans have not shown a preference for one product over the other. We have chosen to diversify our use of different toxins to gain familiarity with the different brands, and have realized that they are *Continued on page 3*

equally efficacious at the recommended doses. Careful training of staff members such as our technician, Joyce Gill, to dilute the toxins appropriately is key as all toxins are not equivalent in dosing strength. Different concentrations and strengths of individual brands are starting to emerge (i.e. onabotulinumtoxin A now comes in 100U and 200U vials). In summary, the JBVA botulinum injection clinic is a success story of how a VA in a large city went from providing no services to having broad range of services for botulinum toxin injections in a period of 4 years. The primary reason this occurred was because of the growing network and resources of the VA Parkinson's disease Consortium Centers. Although the treatment itself can be expensive, it is far less expensive

to provide this service in the setting of the VA since charges for these services are many times more expensive in other health care coverage systems due to markup of costs and hospital charges. Additionally, the amount of effort to coordinate injections outside the VA is prohibitive to Veterans. Therefore we are providing these services to many Veterans that would have otherwise never received them. Few interventions in neurology can be as clearly helpful in reducing the burden of chronic disease as the proper administration of botulinum toxins. We recognize this every week in our multi-disciplinary clinic as Veterans report how this treatment significantly helps their lives.

Improving Access to Speech Therapy for Veterans with Parkinson's Disease through Telehealth
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Idiopathic Parkinson's Disease (iPD) is a neurodegenerative disorder that affects 1% of the population over age 60 and 4% to 5% of the population older than 85. A peak disease incidence occurs between 55 and 65 years of age with more men than women being affected. The prevalence of iPD is likely to double by 2040. Age is the most consistent risk factor and with approximately 35-40% of Veterans being over age 65, an increase in iPD may be seen in the Veteran population. Further, neurodegenerative diseases are expected to surpass cancer as the second leading cause of death among elders in Canada by the year 2040. Although there is no cure, early detection and treatment can alter the progression of this disease and enhance quality of life (Paulson & Stern, 1997). Rigidity associated with this disease affects striated muscles, causing difficulties in respiration, facial expression, swallowing, mastication, and speech. Individuals with iPD usually develop a speech disorder characterized by reduced loudness, hoarseness and breathy voice, monotony of pitch, short rushes of speech, and imprecise consonants (Critchley, 1981; Darley, Aronson, & Brown, 1969a, 1969b). Normal voice is produced by a steady flow of air from the lungs as a series of air puffs released through the vocal folds. Vocal intensity increases as subglottal air pressure increases; and for continuous loudness during speech, subglottal pres-

sure must be held constant. Increased subglottal air pressure is the foundation of increased vocal intensity. This phenomenon cannot be accomplished without the interactive and coordinated roles of vocal fold adduction and the respiratory system (Ramig, Countryman, Thompson, & Horii, 1995). Treatment to increase vocal loudness should be directed toward improving respiratory support and increasing vocal fold adduction. Thus, treatment focused on enhancement of the interactive roles of the respiratory and laryngeal systems in individuals with iPD will contribute to effectiveness of treatment strategies (Ramig, et al., 1995). The inability to effectively communicate impairs ability to function in society and impacts quality of life.

A successful program developed to improve speech in these individuals is the Lee Silverman Voice Treatment (LSVT) (Ramig, Sapir, Fox, & Countryman, 2001). LSVT has demonstrated short and long-term (2-year) retention in loudness (Ramig et al. 2001), as well as generalized improvements in articulation, facial expression, swallowing, and communicative gesturing. Additionally, increased quality of life is also among the benefits of this program. If the progression of iPD, as it affects communication, can be slowed it may result in an improved quality of life for Veterans living with this chronic disease. However, a requirement and

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critical component of this treatment is intense daily therapy for 4 weeks, a regimen that is difficult for many elderly Veterans living in rural areas to complete. Administration of LSVT four times a week for four weeks is consistent with principles of neuroplasticity, motor learning, skill acquisition, and muscle training (Fox, Ebersbach, Ramig, & Shapir, 2012). Nonetheless, the high intensity and required consistency that make this program successful is associated with a tendency for individuals to decline starting therapy or to miss therapy appointments. The developers of LSVT realize that the frequency of treatment can be an obstacle to providing this therapy to clients, especially those with mobility problems or who are still employed (Spielman, Ramig, Mahler, Halpern, & Gavin, 2007). They are also aware that some clinicians withhold treatment, provide group therapy, or offer fewer weekly sessions. Although such treatment variations may be more convenient for clients, studies examining the effects of these modifications remain inconclusive (Stroud & Belin, 2004; Wohlert, 2004). Speech-Language Pathologists (SLP) from the Veterans Health Administration (VHA) have used one such modification to provide Veterans with iPD an option of using telehealth technology to enable them to receive services in their homes or in a setting closer to their homes.

VHA has a lengthy history of using telehealth technology to provide care to rural and remote Veterans beginning in the 1970s (Lindeman, 2010). VHA's Office of Telehealth Services (OTS) was created in 2003 to further develop and implement telehealth services. Though the initial focus was the use of in-home technology for the management of chronic disease, there was a fairly rapid move toward the provision of telehealth services to meet other needs of the remote/rural Veteran. Nearly 40% of Veterans reside in rural regions, geographically remote from VA facilities. The need to care for these remote/rural Veterans was identified. OTS provided a framework and resources to allow a systematic roll-out emphasizing consistent and quality care. Speech pathology programs in VHA have provided services through telehealth technology for decades. Initial reports date back to the 1970s, when Vaughn (1980) at the Birmingham VA Medical Center used "telecommunicology" (a telephone and Dictaphone) for treatment

of a Veteran with aphasia. Wertz et al. (1992) compared the results of in-person evaluations with remote assessment demonstrating a greater than 90% agreement. More recently, telehealth treatment for voice therapy of Veterans with Parkinson's Disease was shown to be effective in comparison to in-person treatment (Tindall, Huebner, Stemple, & Kleinert, 2008). VHA Speech Pathology Telehealth has increased steadily over the years (Figure 1). Currently, VHA speech pathologists are using telehealth for the evaluation and treatment of Veterans with swallowing, speech, cognition and communication deficits. Historically, the majority of VA speech pathology telehealth

visits were completed between hospitals and community based outpatient clinics (CBOC). An emerging modality of telehealth care is clinical video telehealth (CVT)

directly in to the Veterans home using the Veterans computer or tablet. This allows treatment to be provided with the frequency recommended without the need for daily travel to the nearest VA facility. Thus, the use of telehealth technology has developed into a promising method of delivering LSVT to Veterans with IPD.

CVT to CBOC

Clinical video telehealth (CVT) to CBOCs allows SLPs to conduct therapy remotely from the medical center to a CBOC close to a patient's home. Patients travel to a CBOC in their community and are placed in a treatment room where a video connection is made to the main medical center. A sound pressure level (SPL) meter is sent to the telehealth technician at the CBOC for use during each session of LSVT. Sound pressure level meters measure vocal intensity in decibels (dB) allowing patients and clinicians to monitor vocal loudness. Meters are placed so the clinician can see the SPL readings throughout the session. It is important to position SPL meter the same distance (about 12 inches) from patient's mouth for each session so measures are comparable from session to session. One of the challenges to

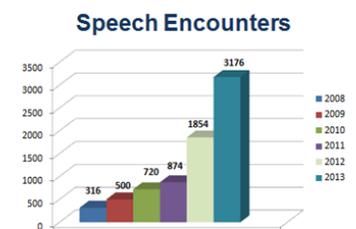


Figure 1. VA Telehealth Speech

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providing LSVT to CBOCs is the availability of the TeleSpeech clinic time slots for the required 4 times per week for 4 weeks. The SLP must work closely with the telehealth technician at the CBOC to work out a schedule that is possible for the patient, the CBOC staff, and SLP at the medical center.

CVT to Home

CVT to the home is the preferred option for Veterans with IPD receiving LSVT. Patients need to have a web camera on their computer or tablet along with high-speed Internet access. Software or an App are required to be downloaded to their device. Using a VA generated email message, instructions on how to connect for a therapy visit are sent to patients. Either patients or caregivers must have the capacity to complete these procedures before a therapy session takes place. If the conditions are met, CVT to home allows patients to remain in the comfort of their homes for therapy and scheduling therapy time is easier because it only involves the SLP and patient. To measure vocal intensity from home, patients can download a SPL app on a smart phone or the SLP will send a small SPL meter to the patient for use throughout the 4 weeks of LSVT. The SPL meter is positioned so the readings can be viewed by the clinician at the same distance from the patient's mouth for each session. With CVT to home there are fewer missed appointments and compliance with the LSVT program improves.

Patient Safety

Safety and security of Veterans is always a priority. When providing therapy to patients in remote locations, emergency phone numbers and contacts must be identified and readily available in the event of an emergency. Strategies for action in emergency situations should be planned, practiced, and familiar to all involved when using telehealth to provide care.

Patient Satisfaction

Patients have been satisfied with the technology that enables them to receive speech therapy they would otherwise have forgone due to issues associated with travel. Savings in time and finances ease the burden of health care for participants and caregivers.

Lessons Learned

When LSVT is provided over CVT, whether it is to the patient's

home or CBOC close to the patient, it is vitally important to see patients in person at the beginning and, if possible, at the end of therapy. Prior to initiation of LSVT, the rationale, methods and goals are explained and patients may be given a folder with homework and stimulus items included. A videostroboscopic assessment of the larynx can also be completed at this initial visit to ensure that the patient has no contraindications to therapy. LSVT requires significant commitment of time and effort from patients, therefore the process will be most successful when they understand this commitment before deciding to participate in the therapy program.

Although not crucial, at the conclusion of the LSVT program, the last session should be administered in person so the maintenance homework can be described and the clinician can review patient progress. It has been the experience of SLPs that by the time patients have completed 16 sessions, a good clinical relationship has been established and the patient desires to come in person for the last session.

Additionally, it is important to have an SPL meter at the patient site when doing CVT to the home. It is not effective to use an SPL meter at the clinician site and get a "relative" SPL reading over a speaker. With desk top web cameras and speakers, the louder sounds get damped by the speaker system and when the patient reaches 80 dB on vowel prolongation, the sound can be completely diminished making it impossible to get a true dB reading unless there is an SPL meter at the patient site for the clinician to view. However, this has not been a problem when providing LSVT to the CBOC using a dedicated CVT system and not a web camera.

Use of Secure Messaging

My HealthVet is helpful to provide homework sheets to the patient each week and to receive completed homework sheets from the patient if they have access to a scanner. Review of the homework is an integral part of the LSVT program and keeps the patient aware of and accountable for goals of treatment. If patients do not have access to a scanner to return the completed homework sheets, the sheets can be mailed to SLP at the medical center.

Finally, when providing CVT to the home, it is beneficial to schedule a test call with the patient *Continued on page 6*

prior to starting the 16 sessions to ensure that the Veteran can go through the process of calling and connecting to the SLP through the video software. It is recommended that the SLP call the Veteran on the telephone and then have him/her try to call in on the video software. In one instance, a patient who was able to go through all the necessary steps received an error message during a test call. The video telehealth technician at the medical center was present for the test call and was able to assist the Veteran with specific, step-by-step instructions on the phone to upgrade his computer's video capabilities to allow the VA video software to work properly.

The Evidence

Research studies compared outcomes of LSVT delivered via telehealth technology to published outcomes of traditional in-person treatment (Tindall, et al., 2008). When compared to a previous study by Ramig et al. (2001) the magnitude of the treatment effects were similar. Constantinescu, et al. (2011) reported results from a randomized controlled non-inferiority trial that compared online delivery to traditional in-person delivery of LSVT. PC-based videoconferencing equipment was used for online treatment. Results indicated comparable treatment outcomes were achieved in the online and traditional in-person methods of delivery of LSVT. Presently a randomized controlled trial is under way at the Lexington VA Medical Center comparing traditional in-person LSVT to telehealth-delivered LSVT. Thus far, outcomes have been comparable. Missed appointments and discontinuation of therapy has been significantly less for the telehealth group.

Future Directions

Speech-language pathologists in VHA continue to refine the process of providing Veterans with IPD access to LSVT by using CVT to the home or CVT to CBOC. Despite the challenges, it is a very rewarding and effective therapy for both the patient and the clinician that otherwise would not be possible due to difficulties with distance, travel and mobility. Telehealth technology enables SLPs to reach remote and/or immobile patients of all etiologies to allow them access to speech and language services.

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Drug-induced Parkinsonism

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Drug-induced Parkinsonism (DIP) is a common cause of parkinsonian symptoms resulting in significant treatment non-compliance, morbidity and disability (1). DIP can be impossible to distinguish from Parkinson's disease (PD) on clinical grounds and DIP has been described as the second most common cause of Parkinsonism after PD (2, 3), highlighting the frequency with which clinicians face this challenging differential diagnosis. Further, the magnitude of the problem continues to increase as culprit drugs (see below) are prescribed for an increasing number of clinical indications.

Culprit drugs and mechanisms DIP is most commonly associated with dopamine receptor blocking antipsychotic (AP) drugs prescribed for schizophrenia and affective disorders(4). Commonly prescribed antiemetics (prochlorpromazine) or promotility agents (metoclopramide) share dopamine receptor blocking activity with APs and are frequently associated with parkinsonism (5). Drugs that interfere with dopamine synthesis (methyldopa) or transport (tetrabenazine, reserpine) are other well-described culprits in DIP(6). Thus, while some agents associated with parkinsonism [antiepileptics (7) (particularly valproic acid), lithium (8), antidepressants (9) and calcium-channel blockers (10)] operate through less well-characterized mechanisms, the vast majority of DIP cases share perturbation of dopaminergic signaling as a common endpoint. A summary of agents reported in a 17-year pharmacovigilance study (4) is shown in Table 1. Functional dopamine brain imaging studies suggest that DIP begins to manifest at 60-80% dopamine receptor blockade (11, 12), in keeping with estimates that motor symptoms occur after degeneration of 50-75% of nigral dopaminergic neurons in PD.

Epidemiology and determinants The overall reported incidence of DIP has varied depending on the offending agents, duration of exposure and populations studied (13) but is estimated to be at least 10-15% in routine practice (14). Most commonly, DIP occurs within the first three months of exposure, but some patients manifest symptoms only after years of treatment (4). A question garnering significant clinical interest and controversy is whether the risk of DIP is reduced with the newer "atypical" AP drugs (e.g. risperidone, olanzapine) compared to

older "typical" APs (e.g. haloperidol, perphenazine). This idea seems plausible given the differences in dopamine receptor affinity and off-site actions between the classes, and early evidence suggested this might be the case. However, many of these studies were sponsored by the drug makers and there were additional concerns about the appropriateness of haloperidol and the doses used as comparators. Such concerns over both claims of superior efficacy and decreased AEs prompted a large randomized trial comparing several atypical APs to perphenazine (a mid-potency typical AP) in schizophrenia and found that the incidence of DIP was similar among all of the drugs (15). Thus, it is unclear whether there is a significant difference between the classes and atypical drugs (with the exception of clozapine and possibly quetiapine) should be considered as potential culprits when treated patients develop parkinsonism. Older individuals are at higher risk for DIP, likely reflecting age-dependent loss of nigral neurons and dopaminergic innervation during normal aging, revealing lower functional reserve in the face of dopamine receptor blockade (16). Other previously described risk factors for DIP include female gender, HIV, and intensity (dose, potency) and duration of drug exposure (4, 13, 15). Additional unmeasured risk factors could include pharmacokinetic or pharmacodynamic processes affecting drug concentrations in the brain or drug-receptor interactions, as the magnitude of DIP is thought to be related to receptor occupancy (17). Patients with a history of drug-induced extrapyramidal symptoms are at higher risk for future episodes upon re-exposure or treatment with a different drug, supporting the idea that some individuals harbor a predisposition to DIP (18). The risk factors described above (other than personal history of DIP) do little to inform risk before treatment or to aid in making an accurate clinical diagnosis for an individual patient.

Clinical Characteristics Cohort studies suggest that DIP is associated with less tremor and upper extremity predominance compared to patients with PD (19). Additionally, common teaching suggests that symptoms in DIP should be symmetric, as might be expected for a metabolic trigger. However, asymmetry has been reported in up to half of *Continued on page 8*

patients in some DIP cohorts(20), and some PD patients present fairly symmetrically. As described above, some patients develop parkinsonism after a year or more of exposure, obscuring the temporal relationship between a potential offending agent and DIP. The presentations can be nearly identical, often making diagnosis impossible based on clinical features alone. (21).

Treatment of DIP starts with consideration of whether the symptoms are sufficiently bothersome to warrant a change in management. When indicated, the mainstay of treatment is to remove, reduce, or replace the offending agent with a drug associated with a low risk of DIP (quetiapine or clozapine in the case of APs). There is little evidence to guide therapy. A small placebo controlled crossover trial suggested that amantadine and trihexyphenidyl were equally effective in reducing parkinsonism and superior to placebo. Other anticholinergics like benzotropine are used empirically but adverse effects can be limiting, especially in the elderly. Dopamine replacement therapy is the mainstay of treatment in most forms of parkinsonism, but the response to levodopa is mixed in DIP (especially when treatment with dopamine receptor blockers continues) (20) and is often withheld over concerns of worsening psychiatric symptoms. Interestingly, a recent study used transdermal rotigotine (which binds 5HT-1A in addition to its dopamine agonism) reported a 50% reduction in motor symptoms while average psychiatric measures were stable (22). While it has not been systematically studied, several case series describe benefit from electroconvulsive therapy in severe refractory DIP (23, 24).

Outcomes A common approach to management in DIP is to withdraw or replace the offending agent and observe whether parkinsonism resolves over time. In one series, two-thirds of patients fully recovered after 9 months, most had done so within the first 2 months consistent with conventional wisdom that DIP should resolve within weeks to months. However, several series have described persistent or worsening parkinsonism after drug withdrawal (25, 26). Persistence of parkinsonism is sometimes taken as evidence of underlying PD, but this has been difficult to study in the absence of a gold standard. A recent report described two patients with persistent DIP 6 months after drug withdrawal with normal functional dopa-

mine transporter imaging. DIP eventually resolved after more than a year, suggesting that protracted recovery periods can be seen in normal individuals. A few recent studies have examined dopamine transporter imaging in patients with DIP and found abnormalities in 30-50% (27, 28), suggesting the presence of an underlying degenerative disorder.

Does DIP reveal underlying neurodegeneration? Taken together, these findings suggest that in a potentially substantial proportion of patients, DIP represents “unmasking” of subclinical nigrostriatal dysfunction, such as, incipient PD. In support of this idea, an epidemiologic study from Olmstead County Minnesota indicated a 24-fold higher risk of future PD in patients with a history of DIP (29) and a small autopsy study has shown the presence of PD-related Lewy pathology in patients who were thought to have drug-induced symptoms (30). Such a scenario might occur in the setting of pre-motor PD where 25% of nigral neurons have been lost and functional reserve is compromised by even relatively low levels of dopamine receptor blockade. Consistent with the idea that some DIP patients manifest parkinsonism as part of prodromal PD, we have recently reported olfactory dysfunction and dream enactment behavior to be common manifestations of pre-motor PD, and are more frequent in patients with persistent DIP (31). Examining cohorts of DIP patients to identify those with prodromal PD may offer opportunities to both intervene and better understand the earliest stages of disease, and this possibility warrants further study.

Conclusion DIP is common and disabling with the magnitude of the problem continuing to increase. Future studies to better understand the determinants, differential diagnosis, management and outcomes of DIP are necessary to help improve the care of Veterans treated with these agents. In particular, the relationship of DIP to idiopathic PD and how drug-induced symptoms may help identify underlying neurodegenerative disease at the earliest stages is of particular interest.

Class	Agents	% reports
Central dopaminergic antagonists	haloperidol, fluphenazine, chlorpromazine, risperidone, olanzapine	49
Miscellaneous	valproic acid, lithium, amiodarone	28
Anti-depressants	citalopram, paroxetine, venlafaxine	8
Calcium channel blockers	flunarizine, cinnarizine, verapamil, diltiazem	5
Peripheral dopaminergic antagonists	metoclopramide, domperidone	5
H1 anti-histamines	hydroxyzine, alimemazine	5

Table 1. Common culprits in DIP *Adapted from Bordoni-Guttton *et al.* 2011

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A Paradigm Shift Leads Us to Basics

Virginia Janovsky, MN, MS, RN Southwest PADRECC, VA-GLAHS

Support groups are a wonderful source of information as well as social and emotional support for people with Parkinson's disease (PD), their care partners and family members. Often called PD education or advocacy groups, they traditionally meet in-person and may include education, behavioral training (such as relaxation or meditation to reduce stress), or serve as a public relations voice.

The West Los Angeles VA Medical Center also ran the traditional group meeting once a month. Initially, ten people came-- some walked in, some with the aid of walkers. Others came in wheelchairs, some came with their spouses. For people with PD and dealing with Los Angeles traffic, this is no easy task. Unfortunately, over the years, participation fell

significantly, at times with only a single participant. It was quite embarrassing to have highly qualified speakers who had spent hours preparing their talk and creating slides and handouts, only to face a dismal turnout.

We knew that we needed to do something differently. We asked the usual, what are you interested in? Do we need to change the day or time? They answered, "Anything is fine." "Keep doing it the way you're doing..." but things didn't improve. Low turnouts were common in densely populated areas such as ours. Group leaders said managing the large number of participants was overwhelming. All agreed that despite the problems, we owed it to our PD community to maintain support groups that they deserve and need. *Continued on page 10*

We were discouraged, no doubt, but we had not lost hope. We recognized that with our VA Medical Center situated in the middle of a busy business section in Los Angeles might be the main culprit. We looked for solutions to connect with the PD Veterans and their families in a meaningful way. In this day and age of information technology, suggestions involved computers and webcams, yet we also knew not everyone had computers or the capability to use them. We put the thinking cap back on again. "How about telephone? Everyone has a phone..." Again, there was some disagreement. "How can you run a support group by phone?" many staff protested, adding "You have to meet face to face... and you can't see the speaker or the slides...The group leader always runs the meeting and stands in front of the group...Don't forget that the main principle of learning is what you see..." Nevertheless, we agreed the idea deserved a try. Even speakers who were invited initially questioned, "Telephone? OK, why not..." We implemented the telephone meetings – *PD @ Home*, on the second Tuesday of each month. During the inauguration call in January 2013, twenty phone lines were used and on several lines, both the Veterans and their spouses were on the same line, in the comfort of their home or from work. Three months into it, we were pleasantly surprised as we realized that effective listening to the speaker by telephone without visual aid actually worked and attracted participants. Contrary to the typical American corporate culture these days that a meeting is "incomplete" without a complex audio-visual presentation, speakers suddenly could do without slides and became less formal speaking the language lay persons could understand. A thirty-minute presentation could serve as a jumping point for group discussion, which is the main goal of support groups. Topics important to PD patients have included : depression, anxiety, nutrition, medication management, im-

portance of exercise. We have also covered topics pertaining to more advanced stages, such as falls (and overall ambulatory safety), problems with speech, swallowing, drooling, and guidelines for advanced care and legal planning. We have received great feedback from the Veterans and hope that the word of mouth will bring more people to the meetings. Teleconferencing became a very effective and economical way to achieve our goal, thanks to POTS – Plain Old Telephone System. The most obvious and most important aspect is the easy access to telephone by everyone and the toll-free VA VANTS line system that was already in place. It allows us to reach interested people nationwide, not just locally. People with PD and family or caregivers could all be on the call. They could also share experiences and ideas, ask questions and provide answers just as they would in a group meeting held on site. All of this without the stress, time and cost of transportation or traffic, without wheelchairs, looking for parking or locating the meeting room. Speakers appreciated the convenience of being able to call in from anywhere, saving time by optional use of handouts and slides, and navigating Los Angeles traffic. That in itself is a boon to everyone. In addition, the teleconference further promoted the VA's telehealth mission. Room reservations, internet access and audio-visual equipment were no longer needed. It allowed us to become a "same time, same station" type of meeting that supported success. The *PD @ Home* program is affordable for every household and it is a viable alternative of supporting Veterans and their families across the country regardless of their socioeconomic status. It is an easy way to circumvent the many challenges of physical meetings and an excellent way to help Veterans with PD and their families and caregivers to improve their quality of life by working and sharing together.

We just needed to think outside of the box...

More Veterans Obtain Movement Disorder Specialty Care in Richmond PADRECC's Expanding Telehealth Program

Jackie Johnson, BSN, RN, Richmond/Southeast PADRECC

It is estimated that the rate of Parkinson's disease (PD) in the U.S. will double over the next 20 years. Our Veteran population is aging along with the U.S. population. With the aging process comes a rise in PD and other movement disorders.

To help meet the needs of veterans with movement disorders who live in rural areas or a far distance from Richmond, the Southeast/Richmond Parkinson's Disease Research Education and Clinical Center (PADRECC) *Continued on page 11*

is expanding its virtual reach! As a VA Center of Excellence, we were chosen as one of seven pilot sites for the Telehealth/Integrated Neurology Project by Veterans Affairs Central Office (VACO).

Expanding Capacity Our PADRECC has expanded the Telehealth clinic availability from two days a week to five. Currently we are serving more than 48 veterans per month with the expanded Telehealth appointments, and have increased total Telehealth visits by 134% in the first 5 months of 2014. The target is to double the number of Veterans served by Telehealth over the next six months. We consult via Telehealth with more than 32 Veterans Affairs Medical Centers (VAMCs) and Community Based Outpatient Clinics (CBOCs). This effort has brought quality specialty care to distant and rural Veterans, while minimizing their travel burden to Richmond. One of the keys of success for our PADRECC Telehealth providers is that each provider has Telehealth capacity at their desk. The ready availability of technology allows for the expanded scheduling and timely access to care for the Veterans.

New Staff to Support the Mission

The current staff of Movement Disorder Specialists (Dr.'s Baron, Lehosit and Qutubuddin), Neurosurgeon (Dr. Holloway), Psychologist (Dr. Carne), Educator (Lynn Klanchar, RN), DBS Coordinator (Miriam Hirsch, RN), Clinical Coordinator (Peggy Roberge, RN), Research Specialist (George Gitchele, MS), Administrative Officer (Cathy McGrady), and Program Support (Vanessa Rowlett) are joined by a new PADRECC Telehealth Nurse Practitioner (Marie Bradley RN, MSN, FNP) and two new Telehealth Clinical Coordinators (Jackie Johnson, RN and Mark Lawson, RN). Marie Bradley has over 35 years in patient care including over 13 years as a Nurse Practitioner, most of those years dedicated to Neurology and Neurosurgery. Jackie Johnson, RN has over 27 years of nursing experience, including over 12 years in Neurosurgery. Mark Lawson, RN has experience most recently as an operating room nurse, and also as a military reserve nurse.

PADRECC Telehealth Services, Virtual Care and Education at Richmond, Virginia

The Telehealth/Integrated Neurology Project has made it possible to bring our specialized services to a broader range of veterans. Our services include:

Telehealth or CVT (Clinical Video Telehealth): is a live, secure, two-way interactive video telecommunication link between the movement disorder specialist in Richmond and the veteran at the VAMC or CBOC where he/she is enrolled. Telehealth minimizes the expense and burden of travel time to Richmond.

Telehealth general consults for movement disorders: We provide diagnosis, evaluation, and treatment recommendations for tremor, gait, or other symptoms of movement disorders and assistance with best medical therapy.

Deep Brain Stimulation (DBS) surgery screening:

Initial assessment and education for possible surgery. DBS is used for the treatments of Essential Tremor, Parkinson's Disease, obsessive compulsive disorder, depression, and torticollis along with other movement disorders. Surgery is considered when significant symptoms persist (i.e. poorly controlled tremor, dyskinesia, motor fluctuations, or poor "off" time) despite best medical therapy.

DBS programming follow up:

Remote DBS programming via Telehealth, including staff education regarding the DBS device and programming.

Botox/neurotoxin therapy screening:

Evaluation of movement disorder related symptoms such as dystonia, muscle spasms, and sialorrhea for possible treatment with neurotoxins.

SCAN-ECHO (Specialty Care Access Network): Starting in the fall of 2014 we will be providing continuing education for clinicians via didactic and case studies presentations by our movement specialists.

Veteran Group Education: Monthly PD education and support group presentations are broadcast from Richmond using video teleconferencing (V-Tel) to CBOCs in Charlottesville, Emporia and Fredericksburg. Plans include adding with more V-Tel sites. The Richmond/Southeast PADRECC receives referrals from VHA providers from the southeast states including Virginia, West Virginia, Maryland, DC, North Carolina, South Carolina, Tennessee, Kentucky, Georgia, Alabama, Florida, and Puerto Rico. Because of our unique services we can treat Veterans from all over the east coast. For outlying VA providers or Veterans who are dealing with a puzzling movement disorder, needing support or treatment, we can provide individualized and comprehensive

Continued on page 12

Telehealth services to even the most remote Veterans. If you would like to consult to Richmond/Southeast PADRECC, please send an inter facility consult through CPRS under the title: “**Movement Disorder/Parkinsons/PADRECC OUTPT**”.



Mark Lawson, RN



Marie Bradley, RN, FNP



Jackie Johnson, RN, BSN

Houston PADRECC News at the Michael E. DeBakey VAMC

Frameless Stereotactic DBS surgery, Ashwin Viswanathan, MD

The Michael E. DeBakey VAMC in Houston continues to offer the best technology and surgical experience available to patients. With the recently acquired O-Arm (Medtronic), Houston PADRECC affiliated neurosurgeons have the ability to intraoperatively confirm the location of the deep brain stimulating electrodes to ensure they are placed with exceptional accuracy. This technology will help prevent a repeat surgery due to a suboptimally placed deep brain electrodes, and has streamlined the intraoperative process for patients. In addition, over the past two years, Houston PADRECC patients have been offered frameless DBS technology (NexFrame, Medtronic) which can provide a more comfortable patient experience, compared with traditional frame-based approaches.

Palliative Care Services at Houston, Karen Stonecypher, PhD

The World Health Organization (WHO) defines Palliative care as “the active total care of patients whose disease is not responsive to curative treatment.” Areas provided by palliative care places an emphasis on the quality of life and the desires of the individual with life limiting diseases. Parkinson’s Disease [PD] is a progressive neurodegenerative disease that affects body motor functions. In 2011, PD was considered the 14th most common cause of UD death. As the disease progresses, people with PD become less able to care for themselves. This eventual progression affects the quality of life of the person with PD and their family. The National Parkinson’s Foundation has defined advanced PD as either Hoehn &Yahr stage 3 or greater, presences of dementia, presences of psychosis or significant caregiver strain (Miyasaki, 2013). Meeting with the patient and caregiver and knowing what the Veteran desires is paramount. Having a comprehensive plan in place can decrease the burden on the caregiver caused by this disorder when the level of care changes from symptom

management to an emphasis on overall quality of life.

The Houston VA is fortunate to have a Palliative Care Consult Service. This service consists of chaplains, MDs, nurses, and social workers, to name a few. Additionally, an End of Life Nursing Education Consortium [ELNEC] Course is offered four times a year to all members of the nursing staff (RNs, LVNs, NAs, MSAs). A new program is being offered through the Talent Management System (TMS) [VA computer-based professional learning center] to address the knowledge gap in palliative and end-of-life care for all professionals caring for seriously-ill Veterans. This series will address communication using key words at key times; conducting family meetings; pain management; spirituality; and use of the TMS to access nine web-based courses on education in palliative and end-of-life care (EPEC) issues in order to improve care of Veterans at the end of life. The newest session will discuss the use of the TMS to access the *EPEC for Veterans* curriculum. These courses are available to all staff at our facility who cares for Veterans. The Palliative Care Clinic (PCC) project at the Houston PADRECC was launched in May 2013 and is currently being restructured. As we strengthen our palliative care team and reorganize our resources in preparation to effectively join hands with the members of the hospital wide palliative care services, we are confident that the joint venture would improve the quality of lives of our patients and fully address their end-of-life issues.

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SF VA PADRECC New Programs:

Susan Heath MSN, RN, Movement Disorders Clinical Nurse Specialist.

San Francisco's DBS Scan Echo program is a novel way of connecting providers around the country with a 60-90 minute collaborative and educational session using video technology. This video teleconferencing system allows attendees to see each other and communicate 'live' as if 'rounding' in a single location. The goal of this program is to offer high quality clinical experience for VA clinicians who wish to increase their expertise in DBS patient management. The sessions are designed to discuss clinical management strategies for implanted DBS patients (deep brain stimulation.) Topics include patient selection, tailoring the target based on symptomatology and programming strategies. San Francisco PADRECC's current Scan Echo DBS Programming series includes clinicians from Hawaii, Minnesota, Colorado and Palo Alto VA. Participants are encouraged to bring a case to share for the group to discuss.

Current schedule is: 4th Monday of each month, 2:00pm - 3:30pm Pacific time. Contact susan.heath@va.gov for further information how to join.

(All physicians, Nurses, NP's, CNS's and PA's invited.)

San Francisco's Susan Heath RN, MSN and Portland's Dr. Jeff Kraakevik teamed up with the VA's EES system to produce patient educational content on YouTube: **My Parkinson's Story**. There have been over 30,000 hits on the YouTube web site. These webisodes are perfect method of outreach to those patient/families who are rural or have no access to specialty clinics. Additionally these short videos are beneficial for new providers or primary care providers who need to learn more about the current care of Veterans with Parkinson's disease. To date, 16 webisodes are published; four more are in the que. Each vignette is seven to nine minutes long and features Veterans with Parkinson's disease from the VA Medical Centers around the country. The patients are filmed with their local VA health care experts (Physician, Nurse, Speech therapist, Physical Therapist and other allied health or rehab team members) and the content discusses how to best manage the specific clinical issue common to Parkinson's disease. Videos were shot on location at National PADRECC sites using

PADRECC staff and patients.

Videos are posted online on the VA PADRECC website

www.parkinsons.va.gov/patients.asp and on YouTube:

[https://www.youtube.com/playlist?](https://www.youtube.com/playlist?list=PL3AQ_JVoBEyxd5tkfQG-S3p_SDYBFtJ6c)

[list=PL3AQ_JVoBEyxd5tkfQG-S3p_SDYBFtJ6c](https://www.youtube.com/playlist?list=PL3AQ_JVoBEyxd5tkfQG-S3p_SDYBFtJ6c)

DBS Surgery – (please see other article posted in Armed Forces Medicine 2014 - Veterans Neurology) San Francisco VA is the first VA in country to offer deep brain stimulation implants in the interventional MRI (3Tesla strength magnet.) Dr. Paul Larson and Dr. Phil Starr are the Neurosurgeons and pioneers for this method of implanting deep brain electrodes in asleep patients.

Palliative Care Clinic for Advanced Parkinson's Disease

San Francisco has developed a palliative care (PC) clinic to manage the complex problems of our patients with advanced Parkinson's disease (PD). As PD progresses, previously-helpful medical treatments have led to complications and do not address many disabling problems. PD is an under-recognized cause of death; prognosis is often inaccurately communicated, caregiver burden can be severe, and resources such as palliative/hospice care are under-utilized, and quality of life suffers. Standard PD clinics are frequently inadequate to address the needs of advanced patients. Patients from our center's standard PD clinic were screened for referral to the new Palliative Care clinic, according to criteria we developed. At the visit, nurses, neurologists, a chaplain and a social worker address and prioritize the medical, psychosocial, and spiritual concerns of patients and caregivers. Patient/caregiver goals are clarified and plan is outlined including medication clarification, advanced directives, disposition planning, obtaining needed resources, and any needed referrals to services such as PT/OT, Speech/Swallow, and hospice. Most follow-up care for these patients/families are transitioned to visits in their homes, utilizing the VA's video-to-home technology (VA-approved type of Skype.)

Consortium News

2014 National VA PD Consortium East Coast Meeting Philadelphia, PA

The foundation of the National VA PD Consortium is built on education, collaboration, and advocacy making it critical that our leaders have the opportunity to meet face to face for the purpose of alliance and professional development. Recent restrictions on VA travel have required the Consortium to implement bi-coastal versus national conferences. The first bi-coastal Consortium conference (West Coast) took place in September 2012 in Portland, Oregon. On April 24-25, 2014, the Consortium held the East Coast conference in Philadelphia, Pennsylvania. PADRECC Directors and several Directors from our East Coast Consortium Centers gathered for didactic lectures, case presentations, and a poster session. The VA Employee Education System (EES) served as co-sponsor, providing continuing medical education credits. Dr. Glenn Graham, National Deputy Director of Neurology provided the welcome. He emphasized the VA's vision to expand virtual care, encouraging conference attendees to include Telehealth into their everyday practice. The conference faculty was comprised of PADRECC Directors and staff, former Philadelphia PADRECC Director, Matthew Stern and two Consortium Directors, Ruth Walker and Fredy Revilla. Day one sessions included discussions on DBS placement and programming of difficult patients; epidemiology in Parkinson's disease; evaluation, diagnosis and management of chorea; and diagnostic tools for movement disorders. Day two started with the intriguing topic of redefining Parkinson's disease, followed by a session on mental health and PD. The junior staff's research presentations concluded the conference. We look forward to a National Conference in FY 2016.



Left to right PADRECC Directors: Joe Quinn, MD (Portland), Aliya Sarwar, MD (Houston), Mark Baron, MD (Richmond), Glenn Graham, MD (Deputy National Director of Neurology), Jeff Bronstein, MD, PhD (West LA), John Duda, MD (Philadelphia), Caroline Tanner, MD, PhD

DaTscan— Now Available at the Houston PADRECC

On July 2, 2014, the Houston PADRECC collaborated with the Nuclear Medicine team to perform the first DaTscan at the MEDVAMC. DaTscan is the only FDA approved radiopharmaceutical agent used in single photon emission computed tomography brain imaging to assist in evaluation of adult patients with suspected parkinsonian syndromes. It is not indicated to confirm the diagnosis of Parkinson's Disease. FDA approved for use in patients with clinically uncertain Parkinsonian Syndromes, e.g. in order to help differentiate Essential Tremor from tremor due to parkinsonism syndromes, e.g Parkinson's disease.

Telehealth in the Bronx

Telehealth is now being utilized for management of Parkinson's disease and other movement disorders at the PADRECC Consortium site at the James J. Peters VAMC (Bronx). Patients are usually seen on-site for an initial evaluation, but then are followed by telemedicine visits. Dr. Ruth Walker stated, I am using telemedicine whenever it will make things easier for the patient, and I feel like I don't need to examine them in the flesh. They get the choice. I receive a number of referrals from the Northport VA on Long Island, which also serves parts of Queens - and it is a challenge for these patients to get to the Bronx. I am learning all the time about new CBOC sites, and thanks to the flexible VA telemedicine staff, am able to add visits at these sites whenever needed. Sites involved to date include; Northport VA (Long Island), Castle Point VA, Manhattan VA, New City CBOC, Port Jervis CBOC, Carmel CBOC (all Hudson Valley), and Valley Stream CBOC (Queens).

Our Mission

To support the provision of optimal care for veterans diagnosed with Parkinson's disease and related movement disorders through professional education, collaboration and advocacy.

Consortium News: Welcome on board

San Francisco PADRECC Director

Caroline Tanner, Ph.D., MD, Director, Parkinson's Disease Research Education and Clinical Center, San Francisco Veterans Affairs Medical Center and Adjunct Professor, Department of Neurology, University of California – San Francisco. Dr. Tanner completed a residency in Neurology and fellowship in Clinical Neuropharmacology and Movement Disorders at Rush University and a doctorate in Environmental Health Sciences at the University of California - Berkeley. Her clinical practice specializes in movement disorders, particularly Parkinson's disease (PD), atypical parkinsonism and dystonia. Her research interests include investigations of descriptive epidemiology, environmental and genetic determinants, biomarkers, early detection, non-motor disease features and interventions for the secondary prevention, disease modification and symptomatic treatment of movement disorders and neurodegenerative diseases. Dr. Tanner serves as advisor to many scientific, governmental and voluntary groups. Her honors include the Parkinson's Disease Foundation Outstanding Woman Parkinson's Disease Researcher Award (2004), the University of California-Berkeley Alumni Association Award for Excellence in Achievement (2008), the American Academy of Neurology Movement Disorders Research Award (2012) and the Spanish Neurological Society Cotzias Award (2013).



Castle Point VA Neurology Specialist



Dr. Ruth Walker is now seeing Veterans one day/week at the Castle Point VA (Hudson Valley), located 60 miles north of New York City. Veterans with a variety of movement disorders previously traveled to the James J. Peters VAMC in the Bronx for care. Bad weather and hazardous travel conditions often cause patients to miss their appointments. They will now be able to receive local botulinum toxin A injections for various dystonias, as patients diagnosed with spasticity. In addition, she will see patients with typical/atypical parkinsonian disorders. Her colleagues at Mount Sinai do the initial deep brain stimulation (DBS) programming following surgery for Parkinson's Disease (PD) and essential tremor (ET), she will do follow-up care and programming at the Castle Point VA. These Veterans will now be able to receive specialist evaluation and management locally.

Richmond/Southeast PADRECC

Jessica Lehosit, D.O. is the new Neurologist, Movement Disorder Specialist, and Associate Director of Clinical Care at Richmond/Southeast PADRECC. She earned her Doctor of Osteopathic Medicine degree from Touro University in San Francisco. Dr. Lehosit did her medical school internship and neurology residency at Virginia Commonwealth University in Richmond, VA.



Marie Bradley, R.N., M.S.N., F.N.P. is the new PADRECC Telehealth Nurse Practitioner for Richmond/Southeast PADRECC. She is a graduate of Virginia Commonwealth University MSN/APN program in Richmond, VA. Marie has been a Nurse Practitioner since 2001 and brings a solid knowledge of the VHA, plus 8 years of neurosur-

Houston PADRECC Neurology staff!

Dr. Fariha Zaheer graduated from King Edward Medical University, Pakistan. She completed her Internal Medicine training in Pakistan then she moved to the United States to complete her Neurology residency at University of Kentucky/Lexington VA Medical Center, Lexington, KY. She remained at the University of Kentucky, completing a fellowship in movement disorders. Her primary clinical/research interests include Parkinson's disease, essential tremor and deep brain stimulation (DBS). She was recently recruited to the Houston PADRECC at the Michael E. DeBakey VA Medical Center and Department of Neurology at Baylor College of Medicine.



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