

## IS A CURE IN SIGHT FOR PARKINSONS DISEASE ? by Eleni Fakotakis, Director of SSHQ

April is Parkinson's Disease awareness month. We are an aging society and I am sure that everyone who reads this report, knows of at least one person who has Parkinson's Disease (or PD) amongst their friends or relatives. Parkinson's and related diseases are on the rise. Parkinson's is a neurodegenerative disease, simply put, PD causes progressive damage to the nervous system. Different parts of the brain are affected in each patient. The disease is named after James Parkinson who was born in the month of April and who wrote the first, detailed document on Parkinson's Disease in 1817, *An Essay On The Shaking Palsy*. A significant amount of people do not know what Parkinson's disease is and of those who do, most are aware of the evident symptoms of Parkinson's Disease. Those that affect movement, the slower walking, leg cramping shuffling gait, low, slow and monotonous voice, hand and other body tremors. I would have to clarify here, studies indicate that about 30% of the PD patients do not experience tremors at all. When one has PD, they have difficulty doing the everyday things that we all take for granted. As many who have PD still work, especially in the initial stages of the disease, it is critical for them to be able to get through their day and to manage, as much as possible their roles, as employee, partner, parent, even grandparent. Like getting up in the morning, getting dressed, preparing a meal, etc. Before having taken their medication, these tasks are very overwhelming and at times impossible. Over the years, studies and scientific advances have illustrated how very complex Parkinson's is and occasionally, frightening, because of everything that still remains a mystery about the risk factors, cause, treatment and cure and for all the non-visible internal damage that has been done already by the time a person realizes they may have symptoms of PD, where a great amount of neurons have already been destroyed. Research is consistent with this fact as doctors diagnose PD when it is already 55% into the condition.

Symptoms usually affect one side of the body first, later spreading to the other side and often remaining worse in the first side. It seems to affect men and women a little differently. Studies indicate that men have more upper body symptoms and women more lower body symptoms that affect mostly walking. After the general neurological exam, it can take months to receive a diagnosis, as the diagnosis is a clinical one, there are no tests that can actually prove one has Parkinson's beyond a doubt. It is important to note that although someone can have tremors or another symptom of PD, it may not mean that they actually have PD. This is why a GP will refer a patient suspected to have PD to a specialist, a neurophysician, who can perform the appropriate neurological tests and to be as sure as possible that the patient has PD before prescribing anything. It is not because one has recurring tremors that PD is definitely present. The best example of this is the actress, Katherine Hepburn, she had a *Central Tremor* not actually PD. Although she had the tremors, she did not have slowness of limbs and all the other devastating affects of PD. **Dr. Michael S. Okun**, states that certain migraine, headache and heart medications can block dopamine and illicit in an individual symptoms similar to PD, which will eventually disappear unless of course someone is predisposed to PD and the PD was triggered earlier because of these medications. Dr. Okun also states that his **Center for Movement Disorders** focuses on individualized, interdisciplinary patient care at all times. They hold interdisciplinary discussions on each patient or test subject resulting in the coordination of medications and treatments for all the patient's concerns. As a result, no medication will work against the PD treatment plan. In conclusion, not all PD – like symptoms lead to Parkinson's Disease and yes, there are delays in diagnosis and sometimes even misdiagnosis, which apparently happens in 10% of cases. To be misdiagnosed and treated wrongly can also worsen PD. This is why it is better to exercise caution, everyone is responsible for their health as well, therefore becoming well informed and getting the right diagnosis and to be as sure as possible, is not only the doctor's concern but the patient's as well. Getting **at least** one other opinion is always a great idea. Sometimes trial medications can do more harm than good. However, On the upside, they could work, it could make a patient feel much better because they are

contributing to their well being and to the well being of others in the future by trying different interventions and not being inactive.

**According to statistics and the Parkinson's Society of Canada, there are nearly 100,000 people living with Parkinson's in Canada. This number is expected to double by the year 2016.** There are one million people in the USA who have Parkinson's Disease. According to Dr. Michelle Hu, a researcher at the Oxford PD Research Center, one person is diagnosed with PD every hour in the United States. Another statistic illustrates that in the year 2020, 168,000 people will be diagnosed with PD in the UK. Like Alzheimer's and Dementia, as the population increases in age and numbers, so does Parkinson's. It is the second most common disease after Alzheimer's, which affects mostly women. Parkinson's, affects mostly males and most cases begin between the ages of 50 and 65 years. Yes, PD does affect the younger people as well, for example, actor Michael J. Fox who raised 285 Million \$ for PD research after he was diagnosed with it when he was only 29 years of age! Other famous celebrities that were diagnosed with PD include singer, Linda Ronstadt and boxer, Mohamed Ali.

I have no doubt that scientists are dedicated to finding a cure, however Parkinson's Disease is so complex and there simply isn't enough long-term data available therefore, more scientific evidence is necessary before finding a cure or before knowing how to reverse damage. If PD runs in the family, the incidence increases by three times. Genetic predisposition accounts for 10% of the cases of PD. It is suspected, that the other links to getting PD appear to suggest pesticide exposure or brain injury. With better monitoring of the disease and other revolutionary studies on the subject, scientists are trying to find clues as they unravel what patients experience before they are diagnosed with PD. In most cases, quality of life had already been affected. Most people who have participated in studies had one or more of the following symptoms, at least two years prior to their diagnosis of PD. These symptoms or clues mostly cited are : Anxiety, **depression, chronic insomnia, REM Behavioral Disorder**, which are nightmares involving involuntary violence, **loss of sense of smell** ( 90% of test subjects diagnosed with PD) , **chronic constipation**, eye focusing difficulties, sexual dysfunction, overactive bladder, blood pressure control disturbances, unexplained pain in legs, Attention Deficit Disorder (or ADD), persistent fatigue, excessive daytime sleepiness, subtle changes to one's speech patterns, slight occasional hand tremors. In one of Dr Michelle Hu's studies, the results indicate that 80% of test subjects who have been diagnosed with PD, all had REM behaviour Disorder approximately two years prior to their PD diagnosis. Another interesting phenomenon about this REM disorder group, is that it will generally develop worse PD symptoms later on as the disease progresses.

There is no current cure or medication that will stop or reverse the damage done by the disease. However, science and the medical world increasingly improve treating the symptoms as scientists have identified five major group clusters of symptoms to better shape treatment monitoring. It has been illustrated often enough that some symptoms are reversible within a year if the medication is taken at the onset. **Dr. Michael S. Okun** also adds that PD patients must always take their medications ON TIME! He cannot stress this enough. If not treated at the onset or if medications are not taken on time, symptoms will worsen quicker, balance will fail, there will be a freezing of movement and difficulty participating in conversation. He cautions that when patients are in residence or in a hospital, the attending nursing staff, often do not administer medications on time. Although this may be ok for most conditions, it is not ok for the PD patient at all. A delay can have serious consequences. In order to help prevent this from happening, his research center has created PD kits that the PD patient can always have with them with prescriptions and medications, when they have to be hospitalized temporarily for other reasons.

Over time generally, symptoms become increasingly more significant in intensity and harder to control, memory impairment also becomes inevitable much later on. However, quality of life can be greatly improved by treating the symptoms as they appear with medication and by simultaneously engaging in other treatments and activities known to help. This is why the earlier the detection, the better the quality of life, as the progress of the disease can be considerably slowed by managing the symptoms effectively. A number of visits to various specialists such as

neurophysicians is a must in order to be well informed, to have at least a second opinion and to decide on the best treatment option(s). Medication effectiveness varies from person to person, so taking what someone else is taking because it is working well for them, may not be the solution for all PD patients. Not everyone reacts the same to medications, not all medications work in the same way for everyone and eventually, as the disease progresses, medications lose their effectiveness in treating a symptom, therefore a constant tweeking, reevaluation, and adjustment of the medication, eventually taking a new medication is important to the PD patient's treatment plan! Everyone's treatment plan should be unique to them.

For patients that do not react well to medications and all their side-effects there are natural medications, as well as a popular surgical procedure called the **DBS, Deep Brain Stimulation** a surgery performed with the assistance of robot technology stimulating precise areas of the brain (that are affected) with electricity, and the patient himself is asked to stay awake and to do certain small tasks during the procedure, this helps the surgeon know if the appropriate part of the brain is actually being stimulated. This procedure must be exact, to the millimeter, otherwise the positive effects will wear off within a very short period of time and the procedure will have to be done again much sooner than expected. After the procedure, the patient generally experiences a 60% improvement in status, much less tremors, better walking and balance, no falling and there is only a necessity for 50% of the medications originally prescribed. The opening to the skull is not closed permanently to allow for future treatments as well. According to studies, when it gets to the point where medications are no longer effective in controlling the disease, neither is the surgery. Medications and surgery should be considered at the onset of the disease to maximize effectiveness in slowing the progression of the disease. Linda Ronstadt mentions on Youtube that the natural medications she takes only last three hours at a time, so she either has to prepare a bag of medications to take with her when she goes out or plan to return home on time to take the next doses. Some people find that Marijuana smoking helps control the shaking symptoms and pain.

The future looks quite promising in the area Gene therapy, as some great advances have been made with Stem Cell research. Scientists hope to deliver drugs directly to the brain where a particular chemical is missing. Most medications do not penetrate into the brain, past the very thick cortex. They are looking for ways to deliver the protein to the brain using natural vehicles. Such as the way sugar and insulin are transported across the barrier of our brains.

It is also important to note, that physiotherapy is very important and must be done throughout the course of disease. Other important interventions that must be considered if one has been diagnosed with PD, are home adaptations in order to prevent accidents and falls and to facilitate the accomplishment of daily activities at home. One would have to contact the CLSC in their area (usually goes by postal code), who will assign a social worker who makes the initial home visit and home care analysis and care plan and assigns an occupational therapist that will visit the home and recommend the appropriate adaptations required in the home, to utensils, cups, chairs, the bathroom, bedroom, a special bed may be required, etc. The social worker can also request a physiotherapist to make home visits.

The faster the PD afflicted deal with their disease and take charge of it, the better for them in the long-run. They have to face it head on, continue to lead their life but with adjustments. One has to maintain as active a lifestyle as possible. The important thing is not to hide and become isolated, to let the depression take over. A lot of people with Parkinson's acquire dogs so they can be encouraged to walk them and to remain active, this is also therapeutic, as animals generate a lot of affection from their owners.

Another great way to handle stress, anxiety and depression, that is absolutely paramount, is through exercise. Muscle strengthening and learning to keep one's balance, will ultimately help to prevent falls and helps one feel better mentally as well. There are specialized exercise programs for the elderly for this purpose such as the PIED program that we offer in Hellenic Social Services and by other community groups in one's area of residence and other specialized

exercise programs more specific to Parkinson's by geriatric institutions.

Other fun ways that the PD patient can keep active are doing Yoga or Tai Chi, dancing, swimming, taking daily walks, joining a support group. All these activities keep one socially active and emotionally and physically in much better shape. A support group is especially important to healing psychologically and emotionally through friendship and the support of others who also have Parkinson's and can share their experiences and knowledge of the disease both positively and effectively. It works on a give and take basis. There are also on-line support groups when someone feels that their mobility is much too challenging. There is always strength in knowing you have helped someone feel better about their situation or problem, it somehow lessens the gravity of one's own PD situation.

Last but not least regarding the factors that are important when one has PD and perhaps even as a preventative measure, is diet. Drinking lots of water and eating healthy, no processed foods. Proteins are an important precursor to dopamine and many other substances in the body. Meats such as turkey, chicken, beef, fish and eggs provide a complete form of protein the body can use to produce dopamine. Vegetables and fruits such as beets (also a great antioxidant), avocados, artichokes, seaweed, apples, ripe bananas, strawberries, prunes and blueberries also help regulate and boost dopamine production. In addition other dopamine level boosters are: nuts such as raw unsalted almonds, pumpkin seeds, sesame seeds; herbs, Fenugreek, milk thistle, ginseng, red clover, nettles and peppermint; and let's not forget, fava beans and dark chocolate (hopefully not taken together... I think!). I will be bold here and state that we should really avoid foods that have been doused with pesticides, try to eat fruits and vegetables that have been grown without pesticides and foods that carry the little round red and green Canada organic and biological symbol, if it does not have it, it is not truly organic. There is also a Quebec equivalent symbols (little oval with the Quebec sign and Bio written beside it or label of Ecocert) for products grown in Quebec.

As presented, there is no actual cure, nor does science have enough data and clues to prevent the onset of Parkinson's, in spite of the fact that PD is one of the most researched diseases. Scientists have yet more studies to do before they can accurately predict who is at risk well before the onset of PD and to delay this onset or to prevent the disease from appearing at all. Two very important clues appear to be losing one's sense of smell and sleep disorders. Other important issues presented earlier on, regarding the treatment plan, is the importance of tailoring and coordinating treatment to individuals.

Science and technology together have made incredible headway in the treatment and in the monitoring of this disease and this is very optimistic. Perhaps with the advances of Stem cell research and more data collected in trial studies, a cure could be around the corner. There are many longitudinal studies currently studying large groups of people who do not have PD (which include people who have had PD in their families) along with others who do have PD and recording blood draws, spinal fluids, saliva, recording CT brain scan results, analyzing skin biopsies, in order to find consistent **Bio Markers** (clues). Such as the research of Dr. Michael S. Okun of the Center of Movement disorders; also Michelle Hu at Oxford who is studying at "risk" brothers and sisters who have insomnia, and get ready for this, ... prefers to use an assessment tool from Montreal! She claims that it is a more accurate cognitive assessment tool (MoCO) and that it is even better than the Mini Mental State of Diagnosis (MMSE). Bravo to Montreal's achievements in this area!

Incredible as it sounds, there is even data being collected with the use of Apps and an iPhone. Particularly used to monitor fluctuations in symptoms by doing a three-minute test four times a day, such as balance, gait (by walking with iPhone in the pocket) and other tests of manual dexterity, tremors, etc. can be recorded and sent automatically to a monitoring service.

It is important to keep in mind that having PD is not a death sentence. No one's life is guaranteed (not for the young and not for the older). Those who have been diagnosed, should strive for the

life they want just the same. Family and friends should be supportive in helping to make this happen. People who have PD, do not need our pity, just our understanding and some quality time with us.

There is a YouTube video of Dan Rather interviewing Linda Ronstadt on June 23<sup>rd</sup> 2014. She has written her memoirs called, "Simple Dreams". She says that when she was growing up they did not have a TV in her home, everyone sang for entertainment to each other. Throughout her life, she has sung mostly for herself, family and friends than for the public, singing is a major part of her life. In 2009, she could no longer sing publically because her voice had changed significantly, she was diagnosed with PD. In spite of this loss, she optimistically states to Dan, that everyone should sing, that it is therapeutic and that, ***"There are so many ways to leave behind a song!"***