



movement

News Journal of
Parkinson's Disease and Movement Disorder Society (PDMDS)

Issue 03 | September 2005

World Parkinson's Day - 2005

Parkinson's disease patients and caregivers were invited to celebrate "World Parkinson's Day" at a function organized by the Parkinson's Disease and Movement Disorder Society on the 16th of April, at the Dr Antonio D'silva High School Hall, Dadar. The meeting commenced with a rendition of bajans by Ms Deepshika Mathur who invited the audience to join in the singing.

Dr Charulata Sankla's presentation on stem cell research evoked great interest from the audience. The presentation was followed by an interactive session facilitated by Dr Jimmy Lalkaka. The distinguished panel of neurologists included Dr N. Surya, Dr C. Sankla and Dr A. Kumar who answered questions raised by patients and caregivers.

PD patients and caregivers then presented different perspectives related to the disease. Mr. Bahel, a PD patient spoke about how he fought its debilitating effects. Mrs. Kohli, wife of Mr Kohli, (Editor of the newsletter) highlighted the important role a caregiver plays in understanding the needs of the patient. The importance of local support groups was effectively brought out by Mr D'lima, a PD patient, the coordinator of the support group started in the western suburbs. He informed the audience of the activities of the group. Mr. N.M.Mundra, Deputy Income Tax commissioner and a caregiver apprised the patients and caregivers of the income tax concessions available and explained the procedures required to avail of them.

Dr. Roshan Vania addressed the group and highlighted the importance of a regular exercise routine for a Parkinson's patient. This was followed by a demonstration of simple exercises by her team of assistants. The final session was a demonstration of breathing exercises by Ms Sunita Nair, the yoga teacher who has been conducting yoga at the support group meetings in Borivili.

The celebration concluded with refreshments and an opportunity for patients and caregivers to meet and share their views and experiences.



Dr. C Sankla addressing the PD support group

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The contents of *movement* aim to provide the maximum possible facts / information but since some information involves areas of personal judgement, their publication does not mean that the PDMDS necessarily endorses them.

All contributions are welcome. Essays should be restricted to 750 words, and letters to 200.

Your questions too are welcome.

Contributions must include your name, address, phone no. and occupation. All materials submitted become the property of PDMDS.

Also please address all correspondence to:

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The Editor (G. S. Kohli),
Flat D-510, Milton Apts.,
Juhu Azad Rd., Juhu Koliwada,
Santacruz (W), Mumbai- 400 049.
Phone : 55761242

FOUNDER MEMBERS

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Mumbai

PDMDS Co-ordinator

Dr. Maria Barretto

Registered Office :

6, Jasville,
1st Floor, Opp. Liberty Cinema,
Marine Lines,
Mumbai-400 020.

From the editor's desk



In keeping with our main objectives to improve the care of those afflicted with movement disorders & disseminate knowledge amongst the public, medical community, caregivers & patients, I am pleased to report that this issue of your News Journal brings to you extremely relevant information : new PD drugs, dietary considerations in PD & a detailed essay on motor fluctuations suffered by PD patients. We also have for you 'The Quest', which answers all your queries.



Each of the newly introduced PD drugs has a unique feature. Parcopa is an immediate release formulation that melts when placed on the tongue. The absorption process starts in the mouth itself, giving faster relief. Rotigotine has a unique delivery system. It is worn as a patch on the skin & is uniformly absorbed through it. It's assimilation therefore is more dependable. Stalevo has the convenience of a single tablet dosage. It will probably also provide smoother motor relief.

Nutrition is the key to leading a near normal life with a chronic ailment. Protein, the virtual muscle builder & therefore ALL important part of nutrition, interferes with the absorption of levodopa. Patients are therefore advised to avoid having a protein rich diet through the day & compensate by having their protein requirement with the night meal; the night requirement of levodopa being low. In this context, 'Parkinson's Disease Food Guide', a publication of the Mumbai Parkinson's Disease Support Group (MPDMSG) a booklet listing over 450 common food items with their protein content was distributed free of charge at a meeting of the PDMDS, a couple of years ago. You may write to the PDMDS for a copy. It is a handy single source of advice on what can be eaten during the day & what should necessarily be eaten only in the night.

Another very useful article clearly defining various terms used for the conditions, symptoms & medical side effects in Parkinson's Disease has also been included in this Update. Knowing these will not only help you identify them but also use them in your descriptions to be more meaningful.

Parkinson's Disease and Movement Disorder Society (PDMDS), a 'charity society' brings you this update as one of its commitments, to bring about awareness & information on movement disorders, with the objective of helping the patient, his caregiver, the social worker and, of-course the medical community to collectively improve the quality of life of those afflicted by them. All those interested in knowing more or helping promote the cause may call me on phone 55761242, or e-mail at : guru_kohli@rediffmail.com



PDMDS *Support Group Meet*

On the 30th January 2005 the PDMDS Society organized an interactive session on the management of Parkinson's disease at the S.P.Jain auditorium, Bombay Hospital.

The session commenced with the showing of a video film on the inaugural function of the 7th world Parkinson's Day International Symposium held in December 2003. This was followed by the lighting of the lamp by Mr. Mahavir Prasad Jain, industrialist and philanthropist.



Mr. Mahavir Prasad Jain inaugurating the meet.
On the right is Prof. S. M. Katrak

Dr. B.S.Singhal welcomed the gathering and introduced the distinguished panel of doctors : Dr Katrak, Dr Lalkaka and Dr. Sankla. The interactive session moderated by Dr B.S.Singhal was well received by the audience as it provided an opportunity for patients to interact with the panel of doctors present.

Ms Malavika Athavale a consulting nutritionist, detailed the importance of nutrition being a key to good health. The presentation clearly explained important aspects of the diet for Parkinson's patients. This was followed by demonstrations in yoga and physiotherapy, which highlighted their importance in the patient's management of the disease.

STOP PRESS

The **World Parkinson Congress** is to be held in Washington D.C., February 22-26, 2006. The Congress is an international, interdisciplinary forum showcasing the most important developments in the world of Parkinson's disease. These include scientific discoveries, medical practices and caregiver initiatives related to Parkinson's disease. Physicians, scientists, allied health professionals, caregivers and people with Parkinson's disease will come together, to create a worldwide dialogue that will help expedite the discovery of a cure and best treatment practices for this disease. The Parkinson's Disease and Movement Disorder society is an organizational partner of the congress and information related to the congress will be posted on the website of the society www.parkinsonssocietyindia.com

Dr Maria Barretto informed the audience of the new initiatives undertaken by the society including efforts to form more local support groups to reach out to patients. Mr. Sunil Parikh, a patient, related to the audience his efforts at coping with the disease reassuring them that as patients they had the capacity to manage the disease and to cope with it effectively.

After the session refreshments were served to the audience in which time they had an opportunity to meet and share their experiences.

Motor Fluctuations: On, Off & Dyskinesias

When a PD patient starts treatment with levodopa, the effects are typically dramatic. The bradykinesia (slowness), rigidity and tremor are greatly improved & the person may be almost unaware of his problems. This "levodopa honeymoon" period usually lasts 2 to 5 years. During this time the patient usually does not feel any wearing off of the medication. However, many patients eventually begin to experience a decrease in mobility or an increase in the tremor between doses. Their level of motor function begins to fluctuate. This is the 'wearing off' phenomenon.

Wearing off may occur subtly; for example, when a person awakens in the morning and finds that the symptoms of the disease are particularly prominent. He may also experience a return of symptoms prior to the next scheduled dose of medication (end-of-dose motor fluctuations). Some patients experience more abrupt, rapid swings of on/off which may be very unpredictable. They compare their on-off periods to a light switch. When they are 'on', their symptoms are very well controlled. When they are 'off', however, the Parkinson symptoms are very noticeable. It is important that the patient and the physician use the same terms to describe the motor function they are discussing. Terms which will be used to describe motor function include off, on, freezing, tremor, dyskinesia and dystonia.

"Off time" is when the medication is not working. It includes all periods of relative bradykinesia or akinesia as compared to the individual's normal level of motor function. Bradykinesia is a slowness of movement. Akinesia is complete or partial loss of muscle movement. Off time includes early morning akinesia and lack of movement experienced before taking the first morning dose of medicine. End of dose deterioration, the most common cause of motor fluctuation, comes, as the name suggests, at the end of a dose period. Freezing is the temporary, involuntary inability to move. It is as if one's feet were stuck to the floor. Tremor most commonly occurs when the muscle is at rest. It can be a rhythmic to-and-fro motion involving the arm, leg, jaw, lower facial muscles and even the lips. It can also be a "pill-rolling" motion involving thumb and finger movements. Tremors usually disappear during sleep and increase under stress. A person may well be on and still have some tremor. 'On' is when the medication is working, not necessarily an absence of tremor.

"On" is used to describe the period when the patient's medication is working. Movements are normal or near normal. The patient is in a relative state of good motor function. Such on time may or may not be associated with dyskinesias. Dyskinesias are abnormal, involuntary movements of the muscles, e.g. in the arm, leg, hand, etc. They can vary greatly in pattern from barely discernible twitches and jerks to twisting, writhing movements involving almost the entire body. They are frequently the result of too much levodopa in the body rather than too little. Please note that dyskinesias are not the same as tremor. Dyskinesias and tremor are different phenomena.

Dystonia is frequently seen as a turned-in foot or twisted trunk. Dystonias usually consist of sustained muscle contractions. Patients describe them as severe muscle cramps. They can be a result of Parkinson's disease itself, or a side effect of levodopa. If the dystonia is a result of medication, the dosage may need to be adjusted. If it is because of Parkinson's, other anti-parkinsonian medications may help alleviate the dystonias.

The PD patient who experiences daily fluctuations in motor performance requires a thorough and accurate assessment of motor function for proper dose adjustment. The motor diary is one method of assessing motor function. The patient is asked to record the level of motor function each hour during several 24-hour periods. The physician will then seek to determine a pattern evolving in the person's motor performance, analyze this performance in relation to medication and adjust the dosage or timing of the medication accordingly. In this way, the physician can best optimize treatment in order to help each patient function at his or her best possible level.

G. S. KOHLI



Quest - A question of answers

Q1 I am 60 years old and I have Parkinson's disease. Have I got an inherited disease? Will my children and grandchildren get Parkinson's disease?

A1 The large majority of cases of Parkinson's disease are not hereditary. As you are 60 years old and no other family member has this disease, it is unlikely that your children or grandchildren will get PD. A few cases of PD are inherited but they usually occur at an early age, and have several members of the same family affected.

Q2 Is there a definite investigation or test that can confirm the diagnosis of Parkinson's disease?

A2 There is no blood test or laboratory investigation that can confirm Parkinson's disease. It is essentially a clinical diagnosis made by the doctor. A CT or MRI scan also cannot diagnose Parkinson's disease. They may be useful to rule out other conditions that may resemble Parkinson's disease.

Q3 I am 55 years old. I have a tremor of both hands since the last 35 years. This tremor is made worse when I try to hold something in my hand. I am otherwise active. People say I have Parkinson's disease. Please comment.

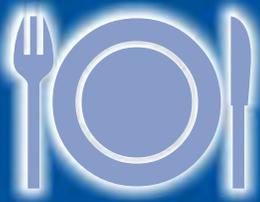
A3 You do not have Parkinson's disease. You have a "benign essential tremor" which occurs more on action like holding an object. The tremor of Parkinson's disease on the other hand, is a rest tremor - it occurs when the hands are at rest and subsides when an object is held. You also do not have the slowness of movement or rigidity which are typical of Parkinson's disease.

Q4 I am a 75 year old male who has recently been diagnosed as having Parkinson's disease. I have been advised to start trihexyphenidyl (pacitane). Please comment.

A4 As you are over 65 years, I would prefer if you avoid trihexyphenidyl. This drug can cause urinary retention especially in the elderly male who may already be having an enlarged prostate. It can also cause memory impairment and confusion in the elderly. Over the age of 70 years, one would prefer to start drug therapy with a small dose of levodopa.

Q5 I have Parkinson's disease for the last 10 years and have been on levodopa and other anti Parkinson's medication. Since the last 1 year I have been having hallucinations. I have been seeing imaginary animals and dead people sitting in front of me. Am I going mad? Should I consult a psychiatrist.

A5 Visual hallucinations occur commonly in Parkinson's disease of long duration. They are mainly caused by high doses of levodopa and other anti PD drugs. By reducing the levodopa dose and/or withdrawing other medications like amantadine and selegiline or trihexyphenidyl, the hallucinations usually subside. However, you must not do dose adjustments by yourself. You must consult your neurologist for the same. If hallucinations persist, a small dose of an atypical antipsychotic drug like quetiapine can be given. Unless hallucinations are very severe, it is usually not necessary to consult a psychiatrist.



NEW DRUG FORMULATIONS IN PD

PARCOPA

This is an orally disintegrating tablet of levodopa-carbidopa. It is an immediate release formulation. When placed on the tongue, it dissolves in seconds and is then swallowed with saliva. The onset of action is quicker than with the regular tablet. It is especially useful for those patients who have difficulty in swallowing.

RASAGILINE

This is a new MAO-B inhibitor (the other commonly used MAO-B inhibitor is selegiline). It is more potent than selegiline on a weight basis. Unlike selegiline it is devoid of amphetamine like metabolites. Recent double blind placebo controlled trials have confirmed the efficacy of rasagiline both as monotherapy in early PD and as an adjunct to levodopa in the later stages.

STALEVO

Stalevo is a combination tablet containing levodopa, carbidopa and entacapone. It is available in 3 strengths Stalevo 50 (levodopa 50 mg, carbidopa 12.5, entacapone 200 mg); Stalevo 100 (levodopa 100, carbidopa 25 mg, entacapone 200 mg) and Stalevo 150 (levodopa 150, carbidopa 37.5 mg and entacapone 200 mg). With this combination tablet, the number of daily tablets swallowed by the patient would be reduced. It may also ensure a smoother control of parkinsonian symptoms.

ROTIGOTINE

This is a lipid soluble dopamine receptor agonist with a unique delivery system. It is a lipid soluble compound and it is applied as a "skin patch" on the forearm. The drug gets absorbed slowly through the skin, ensuring a steady constant supply. Prof. Peter Lewitt of Michigan, USA has done trials on this drug and found good benefit in patients with advanced PD.

DIETARY TIPS IN PARKINSON'S DISEASE

Parkinson's disease is a clinical syndrome consisting of impairment of voluntary movements, rigidity and tremors.

Good nutrition is a key to good health. Correct inclusion of all the five food groups is very important. The five food groups are: Carbohydrates, Protein, Fats & Oils, Vitamins & Minerals, Fiber and Water. All these together form a Balanced Diet. Diet plays an important role in Parkinson's disease. Especially today, after a lot of research it is found that a High Protein Diet interferes with the action of "Levodopa", and its effect is reduced. Therefore it is very important for patients taking this medication, to monitor their dietary habits.

Generic Nutrition tips:

- Have small and frequent meals.
- Drink 8- 10 glasses of water daily.
- Cut foods into smaller portions use blenders or food processors to make drinks more enjoyable.
- Drink some juice after your breakfast to avoid nausea. If nausea persists have some crispy foods like khakra, toast, soup sticks etc.
- Fresh fruits especially, citrus fruits leave a pleasant taste in mouth, try and eat them regularly.
- Have enough fluids and fibre through out the day to avoid constipation. Fibre is available through salads, fruits, whole wheat, daliya etc.
- Avoid saturated fats and foods high in cholesterol, like eggs, red meat etc.
- Avoid excessive intake of caffeine.
- Have foods rich in antioxidants like tofu, fruits, vegetables, nuts, soya products, olive oil etc.
- Avoid mixing of hot and cold foods.
- Go for a daily walk.

Parkinson's is a journey; good nutrition will help you smoothen this road.

Malavika Athavale - Consulting Nutritionist.



Yoga Sessions for PD Patients in Borivli

In our continuing endeavor to reach out to more PD patients, one of our prominent care-givers, Mr. N.B. Mundra along with Mr. Sunil Parikh, an active patient organized Yoga camps (Pranayam) at Borivali. The invited Yogacharya demonstrated some techniques for the benefit of both patients & the local Yoga instructor. This was made possible by Mr. V.M. Shah, a local social worker & supporter, offering his premises free of charge, besides serving snacks & refreshments at his expense.

Now that patients from Santacruz to Dahisar, who attended these camps, are familiar with the correct technique of Pranayam, they meet once a month between 9 a.m. & 12 p.m. for Pranayam sessions under the supervision of the local Yoga Instructor.

To make these meetings more useful for the patients, Dr. Maria Baratto of the PDMDS arranged the participation of a Physiotherapist & Clinical Psychologist on a couple of such occasions.

For more information on these activities & for participation, you may contact Mr. Mundra on phone# 9322667276 or Mr. D'lima on 28939457

We are grateful to Intas Pharmaceuticals Ltd. for their generous contribution towards the newsletter.

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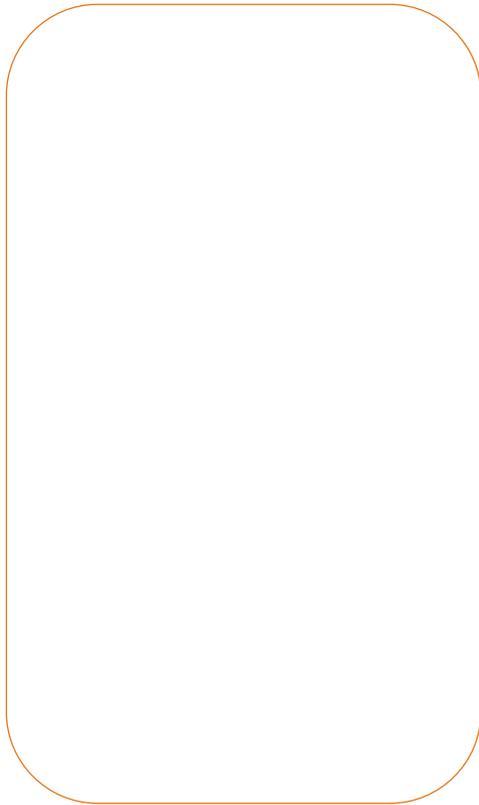
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The ball is in your court & we would like it returned. Tell us your views on the contents of this update. Also tell us what you want from *movement*. You are invited to write to us your comments & suggestions (for details, refer pg. 1, 'Inside This Update').

So, let your response flow.

Moved Recently ?

To ensure you don't miss an update of *movement* inform us of your changed address & phone number.

Help make the PD world smaller

Any support group or organization in India or overseas associated with the causes of Parkinsons disease or other movement disorders can write for enrolment in our mailing list free of charge. Likewise, we request enrolment in your mailing list. I'm sure that such interaction will help make this world smaller, & us closer.

Help and Money go Hand in Hand

PDMDS is a 'Charity Society' formed with the main objective of improving the care and treatment of the afflicted and to disseminate knowledge amongst the medical community, public, patients and caretakers. This it accomplishes by encouraging the formation of localized support groups, membership of which is open to all the above mentioned individuals in fact, to any-one who is concerned, & would like to get involved with the cause. These support groups organize a number of activities/ meetings to make a 'difference' in the lives of the sufferers. Obviously, these activities need funding, as HELP & MONEY go Hand in Hand. All those interested in knowing more about such a localized help-group, or in helping by making a donation may contact G. S. Kohli on phone No. 55761242, or e-mail at : guru_kohli@rediffmail.com

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