



movement

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

Issue 04 | April 2006

Life in Balance for people and families living with Parkinson's Disease

- Ronald Rodrigues

When I was diagnosed with Parkinson's in August 1996, I realized that living with a progressive disease was going to require continuing adjustments through the years and that the word Hope would hold new importance in my vocabulary. I also recognized that the decision as to how I would hope was mine, as it is yours. I chose to focus on positive. Life is certainly more difficult for me today, but whatever the circumstances, I still feel a smile and a positive attitude makes it easier to face the future.

Living with Parkinson's: From being a healthy individual to one with chronic, progressive disease, there is a sense of anger (why me ?) and then a gradual acceptance that this is a disease one must learn to live with successfully. The big adjustment is the realization that one will never return to a normal state.

Positive Suggestions: Enjoy the moment; don't dwell on what's going to happen to you in the future. But you have a way to know, way of determining what stage you'll be in five, ten years from now. May be they'll find a cure in the next few years. In our battle with Parkinson's, knowledge is power & Hope is everlasting. The cause and cure of Parkinson's will be found.

If you're like most of us, you'll have days and periods of time when you feel "pretty good." Relish the good experiences. Learn how to tell someone, I'm feeling good

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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.

movement

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From the editor's desk



“Editor : a person employed by a publication, whose business it is to separate the wheat from the chaff, and to see that the chaff is printed.” – Elbert Hubbard, 1856–1915.



When I was diagnosed having Parkinson’s Disease 25 years ago, things were not how they are today. For one, apart from my busy neurologist there wasn’t a soul who could tell what the diagnosis meant or should mean to me. So I decided to put aside my fact finding for a while ; after all, an ailment with a ‘posh’ name could hardly spell disaster! However, many reading years since, I realized that I’m not young enough to know everything.

Though a cure is not yet in sight, the last decade has seen some exciting developments in the management of the disease. Most drugs used in PD are now available in India. Non ergot derivative dopamine agonists Ropinirole & Pramipexole are now available besides Piribedil & Carbergoline apart from the ergot derivative Bromocriptine. Entacapone, a drug that slows down dopamine metabolism in the brain & thus extends the duration of action of levodopa has proved to be very useful. A rapidly dispersible levodopa preparation which dissolves in the mouth, is also now available. Rasagiline as a possible modifier of the progression of PD is under study. Deep Brain Stimulation is emerging as an accepted surgical option. Stem cell research has gained greater prominence because of controversy, yet appears to hold promise. As with all of you, I too am waiting for a cure & feel confident that it will happen when I’m still young. To me, old age is always fifteen years older than I am. And while we wait, let me remind you of some important ‘dos’ :

- 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 when present simultaneously. Patients are therefore advised to avoid having a protein rich diet through the day & compensate by having their full day’s protein requirement with the night meal. Request for a free copy of ‘Parkinson’s Disease Food – Guide’.
- Everyone benefits from exercising within the limits of their capability. PD patients have particular requirements both to maintain their present strength & flexibility and prevent degeneration of muscles & joints. Patients have to make an increased level of effort to carry out normal tasks. They may feel fatigue, become slower & drag their feet. This is due to temporarily using up

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A Capsule of events of the PDMDS

- 3rd September '05: A meeting on “Yoga & Parkinson’s” was held at The S. P. Jain Auditorium, Bombay Hospital. Dr. Rajvi Mehta of Iyengar Yogashraya, Mumbai, made a presentation on Yoga for patients with PD. Dr. Maria Barretto, coordinator of PDMDS further explained the details of a research project “To Study the Effects of Yoga on Parkinson’s Disease” that was to be conducted by the PDMDS in association with the Iyengar Yoga Institute. Those interested were requested to enroll.



Speech Therapy at Hinduja Hospital support group meeting.

- The research project “To Study the Effects of Yoga on Parkinson’s Disease” was started in September '05.

- Volume 3 of ‘Movement’, the PDMDS newsletter was published and distributed to patients, in October '05.

- A meeting of the Borivli Support group was held on 1st October '05, where patients shared their experiences and discussed their individual problems with each other.

- Dr. Maria Barretto, Coordinator of the PDMDS represented the society at the 5th International symposium of the Asian and Pacific Parkinson's Disease Association (APPDA) held in Melbourne, Australia from 21st to 24th October '05. A multidisciplinary range of speakers experienced in research, clinical management, allied health, patient, and caregiver support provided interesting and up-to-date information on Parkinson's. Dr. Barretto addressed a plenary session on the 'Multidisciplinary management of Parkinson's in India' as well as presented a report on the 'Management of Parkinson's Disease in India'.



Physiotherapy at the Borivali Support Group

- The Borivli Support group met on 12th November '05. Clinical Psychologist Ms. Navaz Irani, did a presentation on “Sleep Disturbances in PD”, where the patients were informed of the various disturbances, their causes, and the ways to deal with these problems through an interactive session.
- A patient awareness programme for PD patients of the MP Chapter (of PDMDS), convened by Dr. J. S. Kathpal, was held on 8th January '06. Dr. B. S. Singhal spoke on PD, while Dr. Maria Barretto, coordinator of the society made a presentation on Yoga and PD.



A Capsule of events of the PDMDS

- A support group meeting was held for the first time for the South Mumbai PD patients on 12th January '06. Patients introduced themselves to each other, moving onto a cathartic discussion on positive attitudes through the course of the disease. Further Mrs. Rekha Shivdasani, an artist informed patients about the nature of the art classes that were being planned for PD patients organized by the PDMDS.



PD patients practicing Yoga

- A meeting of the Borivli Support group was held on 4th February '06. Clinical Psychologist Ms. Navaz Irani and Occupational Therapist Ms. Deepa Israni conducted an informative and demonstrative session on “Pain and PD”, informing patients of the incidence, types, and causes of pain in PD. Several tips were given on how to manage the pain, and exercises were demonstrated in this respect.

- Art Classes for PD patients from South Mumbai commenced on 8th February '06. Artist Mrs. Rekha Shivdasani conducted these weekly classes.

- The second support group meeting for PD patients from around the Dadar to Santacruz area was held at Hinduja Hospital on 16th February '06. Neurologist Dr. Charu Sankhla, answered the questions patients had about the disease and medications, while Neurosurgeon Dr. Milind Sankhe informed patients about the option of surgery in PD. Ms. Pooja Singh, Speech Therapist demonstrated various exercises for patients to deal with speech and swallowing problems.

- A support group meeting was held for the first time for PD patients from Central Mumbai at Nair Hospital on 2nd March '06. Neurologist Dr. Pettarusp Wadia gave an in depth overview of PD, while Ms. Sandhya explained the symptoms of the disease. Physiotherapists Dr. Hutoxi Writer and Ms. Sonal Chaudhry introduced the concept of physiotherapy to the patients and demonstrated a few exercises.



An engrossed audience at the Nair Hospital support group.

- On 4th March '06, Mr. Divakar Deo, Vice President of the PDMDS and founder Chairman of the Parkinson's Society of India, Cochin organized the “21st Seminar cum Free Medical Camp” at Cochin. Dr. B. S. Singhal and Dr. Maria Barretto of the PDMDS were invited to speak at the seminar.

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The Madhya Pradesh Chapter - Patients Awareness Program [Indore - 8th January, 06 : A Report by Dr. J. S. Kathpal]

It was decided to hold a program for the Parkinson's patients at Indore. This was basically to create awareness amongst the patients of Parkinson's disease about the new modalities of treatment and futuristic plans being worked out for this disease. The idea was also to involve all the caregivers of these patients, so that they can understand the intricacies of the chronic ailment.

About 150 patients were invited for the above program along with their caregivers. Dr. B. S. Singhal, a noted neurologist from Mumbai and Dr Maria Barretto, coordinator of Parkinson's disease and Movement Disorder Society (PDMDS) were invited as special guests to interact with the patients. Choithram Hospital and research Center and Neuroclub of Indore participated actively in the program.



Seated on the Dias (R to L) : J. S. Kathpal, Maria Barretto, B. S. Singhal & K. Vaidya

85 patients and more than equal number of caregivers, not only attended the program but also actively participated throughout. The activities included an exhibition on Parkinson's disease, on overall view of Parkinson's disease and

formation of Parkinson's club by Dr.J.S.Kathpal, convener of the above program. Dr B. S. Singhal informed about the charter signed on World Parkinson's Day and deliberated on the disease itself. Dr. V. G. Dakwale and Dr. Rajneesh Kachcha deliberated on surgical aspects of this disease. Dr Maria Barretto spoke about the ongoing study on Yoga and Parkinson's disease. Dr Sudhir Kothari gave a detailed lecture not only on physiotherapy but also on day-to-day management of Parkinson's patients. In the end, a beautiful drama lasting for 20 minutes, depicting the life of a Parkinson's patient was enacted. There was a long interactive session between the patients and the entire visiting faculty. In the end, it was decided to form a Parkinson's club, which would be meeting regularly.



Audience

Newer P D drugs – now available in India

Three PD drugs have been recently introduced in India – pramipexole, entacapone and levodopa-entacapone combination pill.

Pramipexole :

It is a dopamine agonist. It exerts its effect by stimulating the dopamine receptors in the brain. Being a non ergot compound, it does not have the ergot side effects of the older dopamine agonists like bromocryptine and pergolide. It comes in different strengths starting from 0.125 mg and going up to 1 mg. Treatment has to be started with the lowest dose and gradually increased. It has a good anti PD efficacy and is especially useful in younger PD patients in whom we want to delay the use of levodopa. It should be used with caution in people over 70 years as it may worsen confusion and hallucinations in elderly people.

Entacapone :

This drug is a catechol-o-methyl transferase inhibitor. It is always given along with levodopa. Its main action is to prolong the duration of benefit of a levodopa dose by preventing the enzymatic degradation of levodopa in the brain. It is available as a 200 mg tablet and is usually given with the levodopa dose. It is particularly useful in those PD patients in whom each levodopa dose gives benefit for a short period of time. Hence the on period is increased with addition of entacapone.

However, it tends to worsen or precipitate dyskinesias (involuntary levodopa induced movements). So the dose of levodopa / entacapone would need to be adjusted. Entacapone gives a brownish colour to the urine – so do not worry if the urine does change colour.

Combination Pill - (levodopa + carbidopa + entacapone)
PD patients generally tend to take a large number of pills every day. Combining entacapone with levodopa – carbidopa, as a single tablet, has the advantage of reducing the number of daily tablets the PD patient takes, so it is more convenient. It is available in 3 strengths : 50, 100 and 150 mg.

Levodopa MD (mouth dissolving)

Levodopa is now available in a sublingual form i.e. it can be absorbed in to the blood stream directly from the mouth. This MD preparation is especially useful for patients who have difficulty in swallowing.

Parkinson's Disease Society, Gujarat (India)

[Institutional Member - Parkinson's Disease and Movement Disorder Society]

Parkinson's Disease Society Gujarat (India) was formed in the year 1997 by Mr. Vinod R. Shah a person living with Parkinson's disease. The society is an institutional member of the Parkinson's Disease and Movement Disorder Society (PDMDS). Mr. Vinod Shah was nominated as a Vice President of the PDMDS. However in 2005 he resigned due to his ill health.

Based on his own experience of living with Parkinson's Mr. Shah believes that drug treatment helped in stopping the progress of the disease; however, it was Yoga exercises which helped to physically and mentally alleviate some of the sufferings and distress caused by the disease. It was this experience that prompted him to form the society. The main objective of the society is to spread awareness of Yoga as an additional therapy of Parkinson's disease. To achieve this objective Yoga exercise classes are conducted every Sunday at 9.00 a.m. at Yog Sadhan Ashram, Pritamnagar, Ellisbridge, Ahmedabad -380006. A sizeable number of those attending have reported that Yoga coupled with medicines, has resulted in reduction in their suffering and distress; and more important in the development of positive thinking and confidence and an improvement in the quality of life.

The society holds an annual general meeting of the members of the society and organizes, an annual Parkinson's disease Symposium (in vernacular language Gujarati) involving Doctors, Neurologists, Ayurveda Doctors and Yoga Aasana Specialists. The society has circulated the following charts and publications, in Gujarati

- a) Charts of Yogic Exercises
- b) Booklets on Parkinson's Disease
- c) News Letters containing information relating to Parkinson's Disease
- d) Article on Sleeplessness and Relaxation
- e) Yogic is additional therapy in Parkinson's Disease.

The society is now under the leadership of acting president Dr. Neeta Goswami who takes over from Mr. Vinod Shah who continues to guide the society as 'President Emeritus'.



Sleep and Parkinson's Disease

"I have never taken any exercise except sleeping and resting."

With this seemingly palpable attempt at humour, Mark Twain, has inconspicuously stated a very important fact that is the importance of a good night's sleep to improve ones quality of life. However, this escapes around 80 – 90% of PD patients.

Sleep disturbances in PD patients can be of various kinds such as, insomnia (difficulty sleeping), frequent awakenings during sleep, difficulty in going back to sleep, hypersomnia (excessive sleepiness), usually during the day time, sudden sleep onset, and dream enactments. Of these, the most common problem affecting PD patients is frequent awakenings during sleep.

Sleep disturbances can be due to various reasons: The 'wearing- off' of the effect of the PD drug; PD symptoms such as tremors, bradykinesia, rigidity, which each contribute to difficulty in moving smoothly in bed; dystonia (painful cramps), especially early morning dystonia; nocturia (waking up with the urge to urinate); and various psychological factors such as depression, anxiety, worry, irritability, and panic.

However, by following a few simple tips, one can "achieve" healthy sleep, and in turn a better being. These simple steps are encompassed in a type of approach called "SLEEPHYGIENE".

To assess if you are maintaining these tips of sleep hygiene, place a tick mark in the box provided next to each tip. If you find yourself not following any of these tips, then **START TODAY TO SLEEP BETTER!**

- ❑ Regular rising time and bedtime everyday.
- ❑ Plenty of bright light, especially natural light exposure during the day.

- ❑ Avoiding intake of products containing caffeine and nicotine, eg, coffee, aerated drinks, tobacco, cigarettes, at least 8 hours before bedtime.
- ❑ Avoiding alcohol 4-6 hours before bedtime.
- ❑ Avoiding activities that increase the body temperature, such as heavy exercise, at least 6 hours before bedtime.
- ❑ Avoiding heavy late night meals.
- ❑ Decreasing evening fluids 3 – 4 hours before bedtime
- ❑ Avoiding thoughts or discussions about topics that cause anxiety, anger, and frustration before bedtime.
- ❑ Reserving the bedroom only for sleeping, thus avoiding activities like watching TV in the bedroom, and reading.
- ❑ Minimizing light and noise at bedtime and throughout the night.
- ❑ Napping in the afternoon for not more than an hour, and ending the nap before 3 p.m.
- ❑ Going to the toilet just before sleeping.

If doing all of the above does not help then one can:

- Institute a simple but consistent bedtime routine, such as a bath, or brushing teeth, or a small glass of warm milk, or a light snack.
- Assure a quiet, dark, comfortably bedded, and cool bedroom.
- A light snack at bedtime. Good bedtime snacks include carbohydrates and dairy products.
- Use earplugs if there is environmental noise.
- Don't spend more than 15 minutes trying to sleep. If so get up and do some activity like listening to soft relaxing music or reading a book in a dimly lit environment and return to bed only when sleepy.
- Use satin sheets on the bed or wear satin pajamas to facilitate movement, difficult due to rigidity.



Sleep Diary

- Place a commode next to the bedside, so the required activity and light for nighttime toileting is reduced.
- Ask physician if medications could be causing sleep disturbances, and if any alterations can be made accordingly.
- Maintain a Sleep Diary like the one provided below, so you can assess the kind of sleep disturbance you are experiencing and how you can improve it.

Finally, its best to end by quoting E. Joseph Cossman, “The best bridge between despair and hope is a good night's sleep.”

Navaz Irani – Clinical Psychologist.

Maintain the following diary for the next 4 days, and then make one of your own:

Date	(Example) 28.4.06				
Treatment	No coffee, nap before 3 p.m.				
What time did you turn the lights off?	11:00 pm				
How long did it take you to fall asleep?	15 min				
How many times did you wake up?	6				
What time did you wake up this morning?	7:00 pm				
What time did you get out of bed?	7:15 pm				
How many hours did you sleep last night?	8				
How well did you sleep					
(Scale 1=poor, 10=excellent)	7				

(Adapted from: <http://www.ucsf.edu/brain/pdcenter/sleepmod6.htm>)



Important Details

CERTIFICATE OF DISABILITY & ITS BENEFITS FOR PD PATIENTS.

Certificates of Disability are issued to PD patients, which can provide them with various benefits and concessions in various public service areas.

These certificates can be obtained at the 'All India Institute of Physical Medicine & Rehabilitation' at Mahalaxmi, Mumbai.

Certain specified procedures have to be followed such as submission of a few identification documents and application forms; as well as evaluation by therapists before a certificate is issued.

The services in which benefits can be obtained include the following:

- 1) Railway concessions,
- 2) Air travel concessions,
- 3) Bus travel concessions,
- 4) Income Tax reduction benefits,
- 5) Loan facilities with reduced rates of interest.

All of these benefits are subject to specific state government policies, and differ for each of the above mentioned facilities.

Moreover, there are also certain criteria that have to be met, such as amount of disability and income of the individual for the patient to obtain these benefits.

For detailed information, a copy of the same has been provided to you with MOVEMENT. If you have not received a copy of the same please contact us (refer to last page for our contact details).

A Capsule of events of the PDMDS

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- The second support group meeting at Nair Hospital was held on 4th April '06, with Dr. Neerav explaining the motor symptoms of PD, and giving tips on how to deal with these. Physiotherapist Ms. Sonal Chaudhry then demonstrated some breathing exercises. This was followed by an extremely interesting presentation and demonstration on Speech Therapy, by Speech Therapists, Mrs. M. Sanghi, and Ms. G. Hattiangadi.
- A meeting for the Borivli Support Group was held on 8th April '06, where Physiotherapist Ms. Sonal Chaudhry presented the importance of Physiotherapy to the patients and then demonstrated some breathing and postural exercises, at the same time attending to patients specific difficulties.



PD patients in the Art Therapy class.



Life in Balance for people and families living with Parkinson's Disease

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right now, rather being a broken record that sings I'm feeling awful. I'm not asking you to be dishonest. As long as you set realistic goals, you will find it does two things. It gets your mind off Parkinson's condition. Secondly it is a valuable confidence builder.

Acceptance is Critical: There's no way you can anticipate and react normally to the changes that take place in that tiny mass in your brain called the substantia nigra. Medication will help, Diet will help, Exercise will help, and Attitude will help. But the biggest hurdle for newly a diagnosed Parkinson's person is accepting the idea that your body will not be the same as it was before. How can you be optimistic

under such conditions? Accommodate the disorder but do not surrender to it. Those who do not accept the disease every step of the way are formulating a pathway to frustration, depression and unhappiness.

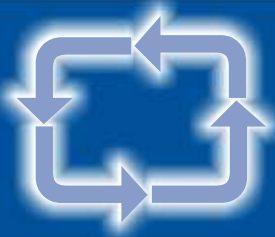
Keep a Sense of Humour: Laugh at yourself. A laugh a day is more important than an apple in keeping the doctor away. Learn to say "no" without feeling guilty. Find easier ways to do things. Determine your

priorities. Eliminate the unnecessary.

"Refuse To Lose": I think "Refuse to Lose" is an appropriate objective for the newly diagnosed Parkinson's person. You may have progressive symptoms over the years ahead, but you don't have to lose your dignity, self-respect or sense of value to your family and community. Don't let Parkinson's take charge of your attitude.

WE did not choose to have Parkinson's, but we can choose how to live it. Join a support group, build your family relationship and friendships, pursue the activities that have meaning to you; there is a life with Parkinson's only you can decide to make it happen. We see people differently now. The healthy ones don't appreciate how fragile their image and their independence are nor do they realize the depth and breadth that still glows in the hearts of the afflicted. Adversity does enrich your outlook

Parkinson's is such a part of me that the inconveniences of the disease seem natural as though I were selected for some strange reason to awaken each day for the rest of my life with the reality that my body has dramatically changed. But I can accept it. If my words change the life and give hope to just one person who has Parkinson's, than I have achieved something worthwhile.



Continued

From the Editor's Desk

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neurochemicals – dopamine. Exercise helps control body weight, improves cholesterol metabolism strengthens muscles, improves flexibility & posture and helps balance, coordination & protects against loss of bone density. However, always remember, we're in the 'slow – lane'.

- Maintain a 'motor – diary'. This is the single most important source of information about your treatment/ titration of drugs. This has been elaborately dealt with by me in an earlier Update.
- Strictly adhere to the titration carefully worked out for you & if you encounter a problem let him
- adjust your dosages.

I have a lot more to say, but considering that you would like to go beyond page 2 of this Update, I refrain! 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.

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

Remember, You're never alone.

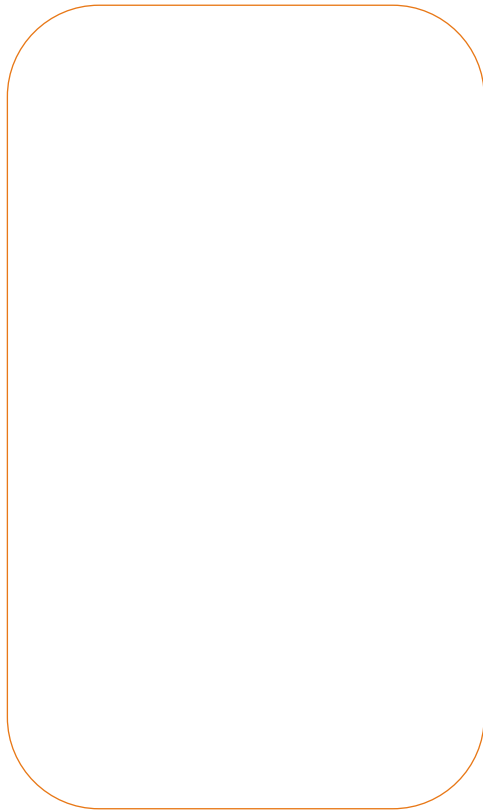
The advertisement is split into two horizontal sections. The top section is yellow and features the text 'In Early or Late PD' in red. Below this is the brand name 'Ropiro' in large purple letters, with 'ROPINIROLE' in smaller black letters underneath. To the right of the name is a dosage table:

0.25
0.50
1
2

. Below the name is the slogan 'Helps your patients prepare ... for an eventful day' in red. At the bottom of this section is the text 'Controls symptoms... Cares always' in green. On the right side, there is a circular inset photo of an elderly couple. The bottom section is light orange and features the text 'THE "STAR" ADJUNCT' in black. Below this is the brand name 'Entacom' in large blue letters, with 'ENTACAPONE 200MG TABLETS' in smaller black letters underneath. To the right is a logo for 'Co Rx WITH LCD' in a white oval. Below the name is the slogan 'Makes mobility an extended reality' in green. At the bottom right, there is a photo of three elderly people playing pool. The 'ASTERA' logo is visible in the bottom left corner.

FOR PRIVATE CIRCULATION ONLY

Book-Post



If undelivered, please return to :
THE PARKINSON'S DISEASE & MOVEMENT DISORDER SOCIETY,
 6, Jasville, 1st Floor, Opp. Liberty Cinema,
 Marine Lines, Mumbai – 400020.

A different journey awaits each one, but our destination is the same.

As the PDMDS moves further forward in this journey, our destination has been to reach out to you. For some of us the journey is through bringing you information, for others it is through answering your doubts, for still others it has been through bringing each of you closer to each other. Similarly, your destination has been to deal with the disease, but the journey through it has been different for each of you. We at PDMDS are extremely keen on knowing what your experiences have been. In a similar vein we would also like to know what you have taken from *movement* – your comments and criticisms; what you would like to see in *movement* – your suggestions and questions. So please write to us.

Besides *movement*, localized support groups, seminars, national and international representation have helped PDMDS move closer towards its goal to “Make the PD World Smaller.” To make it still smaller we invite non-member patients to become a part of our society. Moreover, none of our existing patient-members should have to miss out on being a part of the activities or receiving an update of *movement* because of a change in residence. Therefore keep us informed of any change in address or telephone numbers.

We further invite any organizations or support groups associated with PD & movement disorders, anywhere in the world, to get yourselves enrolled in our mailing list, and we request enrollment into your mailing list.

PDMDS’ consistent goal, being a ‘Charity Society’, has been to make the healthcare system accessible, to spread awareness of tried but dormant ways, and discover new ways of making a difference in the lives of patients and caregivers. It goes without saying that funding is required for these purposes, and therefore we request those well-wishers interested in making donations to our efforts and cause, to contact us.

If you wish to correspond with us for any of the above, or require any information regarding the same, the contact details are given as follows:

Address all correspondence to:
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 Mumbai – 400020.
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