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MOVEMENT DISORDERS CARE IN PAKISTAN

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Earlier discussions about a professional society relating to movement disorders took place about a decade ago and were felt to be a little premature. However PSN nominated Dr Nadir Ali Syed to promote movement disorders related activities. Dr Nadir worked with patients to form a patient centered body, the Pakistan Parkinson's Society which has been quite active in the last several years. Some of the various Parkinson's and movement disorders related activities are listed in appendix A. This is an incomplete list as there is no national professional body dedicated to collate, promote and collaborate in movement disorders activities. The intention is to establish a national Parkinson and Movement Disorders Society (PMDS), a professional body, drawing upon the precedent of other professional domain specific societies previously established focusing on headache, epilepsy, stroke etc. If suitable to PSN the society would work under the PSN patronage and collaboration. The society would comprise of interested physicians, ancillary health care workers, students, patients and caregivers in different classes of membership. PMDS may facilitate activities in three major areas with modifications as per input of members. **Education and professional development.** This includes general public awareness, ancillary health care providers (e.g. nurses, rehab personnel), Medical students, general practitioners, Neurology trainees, neurologists, Rehabilitation specialists and neurosurgeons. **Clinical Service.** Promoting Movement disorders clinics, developing specialized services relevant to movement disorders. Use of information technology to reach out to relatively remote practitioners. **Research.** Promoting highlighting and facilitating research. Strategies for achieving objectives would evolve with input from members but may include;

- Information technology
- Could include developing a repository of online teaching materials, modules, linkages to other websites etc.
- Regular conferences, meeting, workshops
- Patient support groups
- Media
- Development of guidelines/protocols
- Collaboration with other national and international bodies e.g. Pakistan Parkinson's Society, a patient based society active largely in Karachi

On November 29th at the business meeting of PSN in Lahore it was decided to initiate a national movement disorders society aimed at physicians at the March 2016 meeting of PSN. **PSN initiatives related to movement disorders.** Movement disorders related activities in the previous few years - an incomplete compilation but perhaps adequate to demonstrate there is activity enough to provide scope for a national professional body.

- October 3-4, 2015 Pakistan's first National Parkinson's and Movement Disorders Conference was held at Hotel Margala, Islamabad. Organized by Dr Arsalan Ahmed
- Jan 2015, 'National Guidelines for Diagnosis and Management of Parkinson's Disease' published in PJNS, as a collaborative effort of national and international neurologists compiled by Dr Wasay. Subsequently published in a booklet for mass dissemination to GPs. Lead author Dr Nadir Ali Syed
- 28th March 2014 Botox workshop organized as part of PSN meeting by Dr Wasay in Sheraton, Karachi with international experts including Dr Ronald Pfeiffer, Eric Wolters, and Daniel Truong
- MINDS Symposium- Movement disorders Workshop incorporated. well attended May 17-19, 2009 Muzaffarabad in collaboration with GSK. symposium
- Botox Workshops by Dr Nadir Ali Syed in Karachi, Islamabad and Colombo in association with Allergan. Dr Arsalan has organized several botox workshops in Islamabad.

Pakistan Parkinson's Society, formed 2008 by a patient Mr. Haroon Bashir. This is a patient centered society and not a professional society. This has been very successful. They have organized over 50 events, mainly in Karachi but few in other cities as well. Pakistan Parkinson's Society is more of a community and patient based society and does not replace a professional society aimed at. Please check their website at parkinsons.org.pk. **Some of their activities:**

- PPS in collaboration with Dr. Rana Qayyum have published a patient information booklet in Urdu in 2015 and has been distributed to patients

- Held programs for patients in Lahore and Faisalabad under patronage of local physicians but over 95% of activities are restricted to Karachi.
- Dozens of public awareness seminars arranged including on World Parkinson's Day
- Various media presentations on TV, radio to enhance public awareness, dozens of press releases
- Six programs under wellness series held in Jinnah Hospital Karachi for non affording patients
- Patient Support Groups, a successful project, currently meeting on first Thursday of the month and so far over 40 sessions has been held. Non affording patients are welcomed
- Support Group in JPMC, AKUH and South City Hospital launched in September 2012.
- In conjunction with AKUH Rehab Department developed a structured exercise program which was well received.
- Additionally PPS also sourced and invited experts on DBS to create awareness
- PPS from last 4 years have been organizing Parkinson's Unity Walk with the support of Dr. Mughis Sheerani and The Rehab Center AKUH.
- PPS participated on the Parkinson's Global Quilt Program (2011) and galvanized members to submit Quilts.
- PPS over 7 years built relationship with the European and US PD association sourcing latest information material consisting of CDs, brochures and information on teleseminars.
- A fall prevention program has been introduced as a test in Jinnah Hospital, Dow College for Physical Therapy and Civil Hospital Karachi. This is focused on non affording patients.

Pakistan's first National Parkinson's and Movement Disorders Conference

On October 3-4, 2015 Pakistan's first National Parkinson's and Movement Disorders Conference was held at Hotel Margala, Islamabad. This was a highly successful meeting with international and national faculty. It was attended by over 70 neurologists, neurosurgeons and trainees. This was organized by Dr Arsalan Ahmed and there was assistance from Dr Jawad Bajwa (an active movement disorders specialist in Saudi Arabia) for the course materials and speakers through the International Movement Disorders Society. There was considerable discussion in the months prior to the meeting regarding helping the field of Movement Disorders in Pakistan. It was decided to invite during the meeting interested neurologists to determine how the field of Movement Disorders may be developed in Pakistan. This 'strategic' meeting on October 3rd was called by Dr Nadir Ali Syed and attended by Dr M. Tariq, Dr Aziz Sonawalla, Dr Athar Javed, Dr Arsalan Ahmad, Dr Ahsan Numan, Dr Khurram Haq Nawaz, Dr Jawad Bajwa, Dr Danish Bhatti, Dr Asif Bashir, Dr Azhar Saeed, Dr Maimoona Siddiqui and a few others. The agenda of the meeting was to determine how best to move forward in the field of movement disorders in Pakistan. The following points emerged during this meeting.

- Parkinson's Disease and other movement disorders in Pakistan require improvement in clinical care, education and research.
- Although there has been some activity in the field for example the patient based Pakistan Parkinson's Society and good contributions by neurologists across Pakistan but now it is time for a national professional body to be formed, preferably in collaboration with PSN similar to the national headache, stroke or epilepsy societies. This would facilitate education, patient care and research.
- Dr M Tariq suggested making a 2 member committee comprising Dr Nadir Ali Syed and Dr Athar Javed to formulate the initial framework of the society
- The society should be an inclusive body, with recruitment of all interested physicians.
- There is need to promote local human resource development perhaps through developing fellowship training programs, organizing more movement disorders related meetings, use of internet based resources etc. Some participants suggested collaboration with international bodies to facilitate for example brief periods of international exposure at centers of excellence abroad.
- Several neurologists expressed interest in participating in developing movement disorders in Pakistan

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Author's Contribution:

Dr. Nadir A Syed: Concept and design, data collection, data analysis, manuscript writing, manuscript review