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Abdul Malik

*Liaquat College of Medicine & Dentistry (LCMD), [drmaharmalik1@gmail.com](mailto:drmaharmalik1@gmail.com)*

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# NEUROLOGY ADVOCACY IN PAKISTAN

**Abdul Malik MD, DCN, PGDN & MBA**  
*Consultant Neurologist & Assistant Professor of Neurology Department of Medicine,  
 Liaquat College of Medicine & Dentistry (LCMD)*

**Correspondence to:** Email: drmaharmalik1@gmail.com

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Advocacy is an activity by an individual or group which aims to influence decisions within political, economic, and social systems and institutions. Advocacy can include many activities that a person or organization undertakes including media campaigns, public speaking, commissioning and publishing research or conducting exit poll or the filing of an amicus brief. Lobbying (often by lobby groups) is a form of advocacy where a direct approach is made to legislators on an issue which plays a significant role in modern politics (1).

The importance of advocacy for medical professional is being recognized off late, not the least due to complex social and administrative environment. Advocacy includes any activity that gives a voice to patients or creates awareness of pertinent issues. We believe that advocacy can be a helpful tool for neurological patients, their care givers and society. Because of the changing autonomy of patients and their relationship with physicians, advocacy is likely to increase. The issues could be as extensive as the lack of neurologists and neurology residency training programs in Pakistan to as narrow and specific as the prevention of peripheral nerve injury by intramuscular injections.

Neurological disorders are an important cause of disability and death worldwide. Neurological disorders includes stroke, communicable neurological diseases, and brain cancer accounted for 10.2% of global disability-adjusted life-years (DALYs) and 16.8% of all deaths in 2015(2) . Globally, the burden of neurological disorders has increased substantially over the past 25 years. Pakistan is the sixth most populous country in the world, with an estimated population of 210 million (3). Pakistan's absolute numbers and age-standardized rates per 100,000 people for neurological disorders and percentage changes between 1990 and 2015 (2);it is estimated that we are among the highest DALYs (disability-adjusted life-years) rates as mentioned below the change in 25 years i.e. 1990 to 2015 i.e.:

## All-age DALYs (thousands)

## Age-standardised rate of DALYs (per 100 000)

	1990	2015	change	1990	2015	change
Pakistan	6419 (5315 to 7793)	7283 (6255 to 8567)	13.5%	6131 (5327 to 7083)	5005 (4380 to 5716)	-18.4%

Keeping in view the above mentioned highest DALYs (disability-adjusted life-years) rates of neurological ailments we had 200+ neurologists for 210 million (one neurologist per million); the number of patients who need care by clinicians with expertise in neurological conditions will continue to grow in coming decades. Policy makers and health-care providers should be aware of these trends to provide adequate services and expertise development in the field of neurology. Therefore a substantial sensitization in term of advocacy at all levels is required for the speciality of neurology in Pakistan.

In Pakistan neurology started as a department in early 1960 in Dow Medical College (now Dow University of Health Sciences, Karachi) and King Edward Medical College (now KE Medical University, Lahore). Initially having a separate department of neurology was not mandated in medical colleges by Pakistan Medical and Dental Council (3). Till late eighties, we can say the prime advocacy work was the establishment of separate neurology departments primarily in the public sector hospitals. 1990 onwards many neurologists came back from US & UK and the number increased substantially. First graduate of Fellow of College of Physicians & Surgeons (FCPS) Neurology passed in 1995, while first Doctor of Medicine (MD) Neurology was passed in 1994. In late nineties Diploma in Clinical Neurology (DCN) program

was started by the Department of Neurology, JPMC, Karachi.

2001 onwards we can call this tenure as the transformation period in the field of neurology in Pakistan. Subspecialties started establishing i.e. stroke, neurophysiology, epilepsy while movement disorders was still in the stage of infancy. Pediatric neurology was separately recognized; more than 20 neurology training institutes was approved for the post graduate training in the country.

Pakistan Society of Neurology (PSN) had countrywide recognition and was established as the official representative body of the neurology community. Since 1995 PSN is organizing its Annual National Conference every year. In last two decades National Neurology Conference agenda increased from ½ day to three full days with significant increase in number of research papers presented as oral and poster presentations.

In last two decades the neurology specialty evolved a lot in Pakistan; we had established sub-specialties neurological diseases organizations working specifically for the advocacy of that disease. Societies for Stroke, Epilepsy, Headache, Multiple Sclerosis, Parkinson's Disease / Movement Disorders and Myasthenia are working across the country for their specific domain. In last decade, there is overwhelming increase in the awareness about different neurological diseases like epilepsy, stroke, Parkinson disease, dementia/Alzheimer's disease and multiple sclerosis. On the occasion of different neurological days countrywide activities were organized like public awareness seminars, press conferences, walks etc., whereas billboards and posters were displayed not just in the major towns but also in small cities.

A comprehensive neurology training course had been conducted every year by the Department of Neurology KEMU, Lahore. Stroke & Neurophysiology fellowship is conducted by AKU, Epilepsy Mini Fellowship had been organized every year besides consistent epilepsy focus activities by the Comprehensive Epilepsy Control Program (CECP). Annual Neurology Research Day (ANRD) had been celebrated by the Division of Neurology, Shifa International Hospital, Islamabad. This year 12th ANRD was organized in which countrywide budding neurologists as well other neurosciences specialties trainees participated.

In 2015-16 country wide i.e. in all four provinces and Azad Jammu & Kashmir(AJK) 18 stroke workshops were conducted which was endorsed by World Stroke Organization. Almost 1,100 family physicians were trained during these workshops. During 2013-17 we had 21 workshops on headache disorders in 20 cities of Pakistan/AJK. Almost 1,400 doctors were trained. This whole program was endorsed by International Headache Society (IHS). In 2018 Pakistan Society of Neurology started Epilepsy training program for family physicians. There is very strong advocacy campaign about the STROKE i.e. it is a neurological disorder.

Currently we had almost six functional countrywide stroke units and widespread advocacy work for epilepsy. In early nineties Department of Neurology, JPMC conducted Epilepsy in Pakistan: a population-based epidemiologic study; there is dedicated Epilepsy Centre is working. Through consistent awareness in different local languages myths had been reduced much about epilepsy and stroke but misinformation still prevails. In 2018 on completion of its decade Neurology Awareness and Research Foundation (NARF) organized a national conference about the transformation of neurology in Pakistan focused primarily on the advocacy of neurology.

Awareness flyers, booklets and brochures about various neurological diseases like stroke, epilepsy, headache, multiple sclerosis, Parkinson disease, memory and neuropathic disorders/low back pains had been published. Public Awareness videos series for general public had been developed on memory, stroke, headache / neuropathic pains, epilepsy, multiple sclerosis & Parkinson's. These videos not only telecast in electronic media but also uploaded on you tube. Recorded public awareness sound bites about neurological diseases by the leading neurologists in different local languages were disseminated through social and electronic media. Specifically on the occasion of important neurological diseases awareness days like epilepsy, stroke, Parkinson's, Alzheimer's etc. hold press conferences to sensitize overall all component of the society about education, awareness and prevention of these neurological diseases. On the occasion of awareness days leading neurologists of the country also published public awareness articles in national magazines and newspapers about different neurological diseases. Quarterly newsletter is published in Urdu language about neurological diseases and is disseminated across the country. Pakistan Society of Neurology (PSN) had its official face book page and website.

Since 2006 Pakistan Medical and Dental Council (PMDC) and World Health Organization (WHO) Index Medicus for Eastern Mediterranean Region (IMEMER) recognized quarterly Pakistan Journal of Neurological Sciences (PJNS) has been publishing. Pakistan Stroke Society has published Stroke Manifesto i.e. What must be done for Stroke Care in Pakistan. National Guidelines on Epilepsy, Stroke, Parkinson's Disease and Dementia (Alzheimer Disease) have been

published.

For the future roadmap neurology shall be recognized as separate subject in under graduate curriculum of MBBS by PMDC. There is need to start fellowship in neurophysiology, stroke, epilepsy and movement disorders. There is also call for to establish patient support groups for epilepsy, Parkinson's disease, stroke and multiple sclerosis patients. A state of the art dedicated rehabilitation had been planned, but there is severe need to have neurology focus rehabilitation centers. The official representatives of Pakistan Society of Neurology shall coordinate with Provincial Health Commissions for the patients focus neurological care.

There shall be dedicated advocacy campaign to establish Stroke Centers in all teaching and District Head Quarters hospitals of the country. We as community expedite and focus to get approval tissue plasminogen activator (tPA) from Drug Regulatory Authority of Pakistan (DRAP) and its availability on subsidize rates across the country. There shall be availability of anti epileptic medications free of cost in all public sector hospitals.

All of us do act as an advocate of someone or ourselves, sometimes in our life. We need to realize that neurologists can play a very useful role as advocates for the profession of neurology and its beneficiaries, i.e., patients suffering from neurological diseases. If we do not educate the public and governmental officials with regard to who we are and what we do, we may lose the quality of care which we have to provide to our patients. We have to learn the skills to promote the field in order to improve neurology care that is so badly needed in this country.

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**Abdul Malik;** concept, data collection, data analysis, manuscript writing, manuscript review