

## Improving Paediatric Neurological Care in Pakistan

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Neurological disorders in children represent a significant portion of global burden of diseases, mortality, and disability.<sup>1</sup> Burden of neurological diseases in children have reduced over the last few decades in developed countries, however, remains high in developing countries due to high incidence of prematurity, asphyxia, neonatal infectious, consanguinity leading to many metabolic / degenerative disorders and lastly infections of central nervous system.<sup>2</sup>

Among common paediatric neurological disorders epilepsy, neurometabolic disorders, neuro-degenerative disorder, intellectual disability, and autism spectrum disorder (ASD) is more prevalent. Prevalence of intellectual disability varies from 1-3 % globally and documented around 2-8 times higher in low-income countries. It has been estimated to be 1.9 -6.5% in Pakistan and around 10.5% in India.<sup>3</sup> World health organization (WHO) has estimated prevalence of ASD to be 1/160 in paediatric population. It varies between. 1.8-3.6% in US paediatric population and has doubled over past decade but outside the western countries, the number is low.<sup>4</sup> It is probably due to scarcity of high-quality population based epidemiological studies. It has been estimated that 350,000 children are suffering from ASD according to Pakistan autism society while prevalence of autism in India has been documented as 1%.<sup>5</sup> Prevalence of epilepsy has been documented to be 4.5 -5 /1000 in European paediatric population. In southeast Asian countries, prevalence of epilepsy is comparable i.e., 3.28-5.71 /1000. Epidemiological data available in Pakistan has documented higher prevalence of epilepsy, varying from 15.5-23/1000 population.<sup>6</sup>

Paediatric Neurology is one of the largest specialties within paediatrics. Paediatric neurology evolved into a specialty early in the 20<sup>th</sup> century with its base at National Institute of Health, USA. Advances in the neurosciences, particularly in the fields of genetics, molecular biology, metabolism, immunology, and nutrition have greatly advanced understanding of pediatric neurological disorders in last three decades. Expertise in radiology,

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electrophysiology, histology, and immunology have considerably improved the outcome of neurological disorders. These advances have allowed new therapeutic approaches like immunomodulation and gene therapy in the field of epilepsy, neurodegeneration, neurometabolic disorders, infections, demyelinating and neuromuscular disorders.<sup>7</sup>

High prevalence of paediatric neurological disorders in Pakistan can be explained by multiple factors. High infant mortality, maternal mortality, multi-parity, low birth weight and premature deliveries are all due to poor mother and child healthcare facilities and may explain the higher incidence of cerebral palsy and other neurological disorders. Poor perinatal care and high rate of consanguinity are the main causes for cerebral palsy and many other neurological disorders.<sup>8</sup> Pakistan has one of the highest birth rate and proportion of paediatric population. Paediatric neurology services in Pakistan were developed in last quarter of 20<sup>th</sup> century. Child neurology pioneer clinic was established within the Paediatric department of Mayo Hospital/ King Edward Medical College, Lahore and later in Children Hospital and Institute of Child Health, Lahore. Paediatric neurology services in Islamabad and Karachi were established during the same time within the paediatric department of Pakistan Institute of Medical Sciences and Aga Khan University Hospital, Karachi respectively. There are about 20 trained child neurologists in Pakistan. Paediatric Neurology was recognized as a separate discipline by College of Physicians and Surgeons of Pakistan (CPSP) and currently there are three approved training programmes.<sup>9</sup>

Demand of paediatric neurologists will likely increase in coming years for clinical work, training of doctors, training of support staff and research. Even though neurological disorders constitute a major portion of paediatrics, most of paediatric departments have either no or very scarce faculty position for paediatric neurology.<sup>10</sup>

Research in paediatric neurology is another important component. Specialization within neurology is also well-recognized like epilepsy, neuromuscular diseases, molecular genetics, and neurophysiology etc. Paediatric neurology is a multidisciplinary subject with involvement of many support services like rehabilitation, child psychiatry, psychology, occupational, diet therapy and

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speech therapy etc. It seems that this will work at its best when there is a close liaison between the primary physician, paediatric neurologist, and various support staff along with families. The work of paediatric neurology team has huge overlap and there should be joint clinics like cerebral palsy clinic, neuromuscular disorders clinic and ketogenic diet clinic.<sup>9</sup> With the advent of sophisticated brain scans like Magnetic resonance imaging/ Magnetic resonance spectroscopy and whole exome sequencing, the diagnosis and day-to-day monitoring of neurological patients has become quick and more demanding. Prospects for gene therapy are promising after successful launch of Spinal Muscular Atrophy gene therapy approval from Food and Drug Administration, USA.

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