



NEUROLOGY RESEARCH & PATIENT WELFARE FUND

ANNUAL REPORT

JULY 2025 - JUNE 2026

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Neurology Research and Patient Welfare is currently focused on epilepsy, a disorder long neglected by both society and the government. It is among the most common neurological conditions, with an estimated 2.2 to 2.4 million people affected in Pakistan i.e. one percent of the population.

National Epilepsy Centre (NEC) and Epilepsy Support Pakistan (ESP) - the Full Chapter of the International Bureau for Epilepsy (IBE) in Pakistan serve as the two arms of the NGO-run Comprehensive Epilepsy Control Programme of Pakistan, working in close coordination. NEC provides holistic clinical management for people with epilepsy, while ESP leads nationwide awareness and advocacy initiatives.

At NEC, through ESP, every day is an awareness day, with detailed counselling sessions offered to patients and caregivers. These sessions address both medical and non-medical issues, ensuring that concerns are heard, understood, and supported.

The secretariat of Epilepsy Association of Pakistan - the Pakistan Chapter of International League Against Epilepsy (ILAE) is also housed within the NEC premises, enabling seamless integration of clinical services, education, and professional collaboration.

The coordinated functioning of professional and awareness-focused organizations under one roof has yielded highly effective outcomes and is strongly recommended as a model for comprehensive epilepsy care.

As epilepsy activities of NEC & ESP overlap they are being mentioned under the heading of CECP.

COMPREHENSIVE EPILEPSY CONTROL PROGRAMME OF PAKISTAN (NATIONAL EPILEPSY CENTRE & EPILEPSY SUPPORT PAKISTAN).

A. PATIENT MANAGEMENT

Patient Data - 1st July 2025 to 30th June 2026		No of Patients
1	Total Registered Patients since 2007	11,924
2	Follow-Up	11,539
3	Only Consultation	890
4	Monthly ASMs Dispensed	9,998
5	Total EEGs Done since 2007	24,123
6	EEGs of Registered Patients	886
7	EEGs of Outside Referral	288

Drug Bank

A 30 days supply of medicines was provided free of cost to all deserving patients. Some patients who could afford their treatment did not utilize the NEC Drug Bank facility, which is primarily intended for poor and deserving individuals.

The token amount charged represents approximately 5% of the overall patient management cost (excluding medicines). This nominal fee is applied to reinforce the value of the services offered, as the NGO firmly believes that services provided entirely free of charge often risk being undervalued.

EEG Labs

EEG charges at NEC are set at approximately 10% of the commercial cost. All EEGs conducted at NEC include video recording. This gold-standard method of EEG acquisition, first introduced in Pakistan by NEC, is not routinely practiced elsewhere in the country. Only in select circumstances do a few hospitals perform video EEGs, and even then, the cost is substantially higher than standard rates.

Neuroradiology (CT, MRI, MRA)

Radiology services are provided by the Radiology Department at JPMC at highly concessional rates. However, public-sector paediatric hospitals do not extend similar support to NEC patients. As a result, a private radiology centre with highly qualified radiologists in the country offers services for paediatric patients at specially reduced rates.

NATIONAL EPILEPSY CENTRE EXPANSION PROJECT CLOSED

In September 2025, JPMC informed NRPWF of its decision to establish an Opioid Agonist Maintenance Treatment (OAMT) Centre within the National Epilepsy Centre building. NRPWF was initially served with a seven-day notice to vacate the entire premises to facilitate the project. Such an action would have resulted in the closure of the National Epilepsy Centre and the disruption of essential services for thousands of people with epilepsy who depend on the Centre for their continuing care.

Recognizing the serious implications for epilepsy services, extensive discussions and negotiations were held between NRPWF, JPMC, and the Patient Aid Foundation (PAF). While NRPWF fully appreciated the importance of establishing the OAMT Centre, it also emphasized the need to safeguard the continuity of specialized epilepsy services that had been built over twenty years through the generosity of donors and the dedication of healthcare professionals.

Following these discussions, a mutually acceptable solution was reached. It was agreed that NRPWF would retain the ground floor of the building to continue providing uninterrupted

epilepsy services, while the first and second floors would be allocated for the establishment of the OAMT Centre.

This arrangement was formalized through a tripartite Memorandum of Understanding (MoU) between NRPWF, JPMC, and PAF, clearly defining the responsibilities of each organization. Under the agreement, PAF undertook the structural modifications, partitioning, sealing of internal access, and the construction of separate entrances to ensure the complete physical separation and independent functioning of the two facilities. Upon completion of the works, the first and second floors were formally handed over to JPMC for the operation of the OAMT Centre in October 2025, while NRPWF continues to provide epilepsy services from the ground floor.

Although this collaborative solution successfully preserved the continuity of epilepsy care, it also marked the closure of several important expansion initiatives that NRPWF had planned and undertaken for the upper floor. These included the dedicated Video-EEG Telemetry Unit, epilepsy training and education facilities, research infrastructure, and other specialized services that had been envisioned as part of the Centre's long-term development.

It is also a matter of deep regret that significant philanthropic contributions had previously been invested by generous donors in developing infrastructure and facilities on the first floor for the advancement of epilepsy care. As these areas are no longer available for NRPWF's use, the intended benefits of those investments for people with epilepsy could not be fully realized. NRPWF remains profoundly grateful to all its donors whose generosity made these developments possible and sincerely regrets that circumstances beyond its control have prevented the continued utilization of these facilities for their original purpose.

Despite these unforeseen developments, NRPWF remains steadfast in its commitment to ensuring uninterrupted, high-quality epilepsy care. The agreement reached with JPMC and PAF prevented the complete displacement of the National Epilepsy Centre, safeguarding twenty years of dedicated epilepsy services, and protecting the interests of 12,000 registered patients and many new treatment seekers.

B. EPILEPSY AWARENESS ACTIVITIES

CELEBRATING NATIONAL EPILEPSY MONTH, INTERNATIONAL EPILEPSY DAY & NATIONAL EPILEPSY DAY February 2026.

National Epilepsy Month: Highlighting A Framework for Sustained Action

National Epilepsy Month – February 2026 was observed by the National Epilepsy Centre (NEC) and Epilepsy Support Pakistan (ESP) as a series of purposeful, well-structured, and ethically grounded initiatives rather than symbolic activities. Both organizations emphasized that epilepsy awareness must translate into measurable public health outcomes, reaffirming its role as a strategic intervention rather than a ceremonial exercise.

Throughout the month, outpatient services incorporated focused education on seizure first aid, treatment adherence, lifestyle measures, and myth dispelling, with particular emphasis on empowering caregivers, especially mothers, who bear primary responsibility for long-term epilepsy care.

Community outreach included awareness sessions, school workshops, update sessions for primary care physicians and neurology allied fields, interactive dialogues, and distribution of culturally sensitive materials in local languages.

With Ramadan starting in February special awareness activity at NEC was done with patients and family members to ensure safe fasting.

Observed on 9 February, the day aligned ESP and NEC with the global epilepsy movement, highlighting epilepsy as a shared concern. Participation in the 50 Million Steps initiative symbolized commitment to visibility and advocacy, alongside the Epilepsy Pledge reaffirming continuation of integrated services.

Patient interaction sessions were organized, fostering dialogue, reassurance, and shared experience. All patients attending on the day received gifts, while children were given goody bags and balloons, simple yet powerful gestures affirming dignity, belonging, and hope. A photobooth was put up.

broadcasting epilepsy awareness messages every 15 minutes from 7:00 am to 7:00 pm, ensuring repeated exposure across diverse populations. The radio messages addressed seizure recognition, basic first aid, the treatability of epilepsy, and the urgent need to abandon fear and misconceptions, an approach recognized as among the most cost-effective strategies for public attitude change in low-resource settings.

National Epilepsy Day – 28 February: National Conscience and Humanitarian Legacy

National Epilepsy Day, observed on 28 February, served as the culminating focal point of Epilepsy Month. The day carries profound national significance as it coincides with the birth anniversary of Abdul Sattar Edhi, Pakistan's greatest humanitarian, who himself lived with epilepsy. Observing National Epilepsy Day on this date links epilepsy advocacy with compassion, dignity, and service to humanity. The day was marked by a series of high-impact events:

Iftar Awareness Media Meet

In view of the holy month of Ramadan a thoughtfully organized Iftar awareness media meet brought together journalists, editors, opinion-makers with our celebrity guest of honour, Ms. Hina Khwaja Bayat in an atmosphere of reflection and dialogue. Media professionals were sensitized to the realities of living with epilepsy, the magnitude of Pakistan's treatment gap, and the ethical responsibility of stigma-free, accurate reporting.

Celebrity & International Support and Public Solidarity

Public figures and celebrities like renowned actor, anchor and activist Hina Khwaja Bayat and celebrated music composer and actor Arshad Mahmud lent their voices to the cause, amplifying messages of inclusion, dignity, and hope, and extending the reach of epilepsy awareness beyond medical and academic circles. Donna Walsh, CEO, IBE in her message acknowledged the efforts of ESP and stressed the need for national, regional and international collaboration to strengthen the epilepsy awareness mission.

Engagement with Future Doctors

An awareness session with JSMU medical students focused on epilepsy beyond prescriptions, highlighting psychosocial impact, ethical responsibility, and continuity of care – planting the seeds for a more empathetic future medical workforce.

Nationwide FM Radio Campaign

A nationwide FM radio campaign, identical in scale to International Epilepsy Day, ensured high-frequency awareness messaging throughout the day.

Celebrating Patients as Partners

Festivities with patients and families honoured people with epilepsy as active partners in awareness. Gifts for all patients, goody bags for children and a photobooth acknowledged their resilience and the pivotal role their lived experiences play in reshaping societal attitudes.

Visibility, Resilience, and Continuity

Epilepsy advocacy cannot pause for ideal conditions. Epilepsy Month 2026 achieved substantial media and social media visibility despite adverse external circumstances speaks to institutional resilience and moral clarity.

Structuring epilepsy awareness around National Epilepsy Month, International Epilepsy Day, and National Epilepsy Day has created a coherent continuum, from sustained action to global solidarity, to national accountability. The experience of ESP and NEC affirms a simple, enduring truth: epilepsy care succeeds when science, society, and empathy are aligned.

C. EDUCATIONAL ACTIVITIES

Epilepsy Awareness Lecture at ZVMG Rangoonwala Community Centre

Dr. Zarine Mogal was invited to give an epilepsy awareness talk by the Rangoonwala Community Center at their Annual Health and Wellness Session. It was well attended talk by students and volunteers. The audience interaction in the interactive talk was encouraging and created a positive energy required.

Enhancing Competent Epilepsy Care Workshop for Psychiatrists – Multan July 10, 2025

In recognition of the importance of expanding the number of skilled epilepsy care providers, psychiatrists in Multan participated in a comprehensive workshop on the diagnosis and management of epilepsy. Faculty and students from the Department of Psychiatry at Nishtar Medical College also attended. The interactive video session was highly appreciated for enhancing understanding and accurate diagnosis of different seizure types. These workshops are planned to continue nationwide as part of a broader initiative to strengthen epilepsy care across the country.

Workshop on Women with Epilepsy in Reproductive Years - Multan July 11, 2025

As part of an ongoing series focused on addressing the unique challenges faced by women with epilepsy and promoting interdisciplinary collaboration, a dedicated workshop was held in Multan. The event was well attended by both gynaecologists and neurologists, reflecting a shared commitment to enhancing care for this vulnerable population.

Report Prepared By:
Dr. Zarine Mogal