Available Apps: Epilepsy and ASD tools; Apps on ADHD and NMI tools will be available soon


For details, please contact:
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Coordinator, DM Pediatric Neurology Programme
Faculty Incharge, Centre of Excellence & Advanced Research
for Childhood Neurodevelopmental disorders
Department of Pediatrics, AIIMS, New Delhi
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Fax: 91-11-26588641, 26588663
Neurological disorders are one of the most common illnesses with which a child presents to a paediatrician. More than half of the patients seeking pediatric consultations have neurodevelopmental disorders. They encompass a wide spectrum of illnesses.

With improved newborn survival and reduction in under 5 childhood mortality there is a paradigm shift from improving survival to improving quality of life of these children. World Leaders and United Nations have urged global awareness and advocacy for health services of children with neurodevelopmental disorders focusing on the need to implement practical, standardised and affordable management/rehabilitation strategies. Most of these disorders are chronic and require long term management across the entire lifespan. The cornerstone of care is multidisciplinary holistic management.
Child Neurology Division, Department of Pediatrics

The Child Neurology Division at the Department of Pediatrics, AIIMS, New Delhi caters to a significant proportion of in-patients and out-patients. It also runs the first D.M. programme in Pediatric Neurology in South Asia (started in 2004). The Division is also involved in undergraduate and postgraduate teaching and caters to training of National and International long-term and short-term fellows / trainees from time to time.

The Division has continuously produced high quality research in diagnostics and therapeutics aimed at benefitting individual patients as well as the community. It is involved in high quality and cross-cutting research in Neurodevelopmental Disorders in children translating into around 20 publication every year in indexed International and National journals. It actively disseminates awareness and knowledge to health personnel and public in the field of Child Neurology. It is involved in advocacy at National and International level.

Currently the Division has three faculty members, 2 electrophysiology technicians and one specialty nurse as permanent staff. The Division also gets support from the Departmental Psychologist, Nutritionist, Physiotherapist and Social Service Officer. In addition, we have secretarial staff and keeps project staff too which keeps varying with projects.

The Division has 15-18 bedded in-patient unit (as a part of Unit 2) and caters to around 25000 outpatients annually. Apart from twice a week routine morning outpatients, the Division runs 5 specialty clinics on a weekly basis attending to around 6000 patients in a year.

<table>
<thead>
<tr>
<th>Day</th>
<th>Clinic</th>
<th>Room No.</th>
<th>Timing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monday</td>
<td>Development Clinic</td>
<td>5</td>
<td>2:00 pm onwards</td>
</tr>
<tr>
<td></td>
<td>Neurocysticercosis Clinic</td>
<td>11</td>
<td>2:00 pm onwards</td>
</tr>
<tr>
<td>Tuesday</td>
<td>Pediatrics OPD</td>
<td>4,5,14</td>
<td>9:00 am onwards</td>
</tr>
<tr>
<td>Wednesday</td>
<td>Pediatrics Neurology Clinic</td>
<td>3,4,5</td>
<td>2:00 pm onwards</td>
</tr>
<tr>
<td>Thursday</td>
<td>Autism Clinic</td>
<td>12,13</td>
<td>9:00 am onwards</td>
</tr>
<tr>
<td></td>
<td>Room D</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friday</td>
<td>Pediatrics OPD</td>
<td>4,5,15</td>
<td>9:00 am onwards</td>
</tr>
<tr>
<td></td>
<td>Neuromuscular Disorder Clinic</td>
<td>3, 4</td>
<td>2:00 pm onwards</td>
</tr>
</tbody>
</table>

However there is a dearth of expertise for management of these children. The need of the hour is a: State of the Art, Centre for Advanced Research and Excellence for Childhood Neurodevelopmental Disorders which can provide high quality affordable care for all sections of the society, perform high end diagnostic/therapeutic research and act as an education/training hub.
The Division provides EEG, Electrophysiology and Polysomnography (PSG) laboratory services. There are 3 video EEG machines of which one is placed in the ward for longterm overnight EEG recording. In addition, there is an ambulatory EEG machine as well for critically sick children who can't be transported. Two portable combined EEG and EPS machine have been recently installed. The procedures performed in Electrophysiology lab include Nerve conduction studies, EMG, RNST and Evoked potentials. For PSG, patients are admitted overnight. On an average around 3000 EEGs, 450 EPS procedures and 50 PSGs are done in a year. Apart from this, these services are also availed routinely for resident dissertation and projects. Other procedures performed include muscle, skin and nerve biopsies (around 100, 15 and 25 respectively in a year), CSF studies (around 50/year), Neostigmine challenge and Forearm ischaemia test (10 each/year). We are also doing Intracranial pressure monitoring along with the Intensive Care team. In addition various Neurodevelopmental and Psychological tests are being carried out by the Division.

**EEG**

**Routine EEG:** is done in Room no. 12 in Paediatric OPD. The appointment is given after the child has been seen in Paediatric Neurology division.

**Ambulatory EEG:** Is done bedside when indicated for in-patients who cannot be shifted to EEG room.

**Video-EEG:** is performed in C5 ward Video EEG/Sleep laboratory. Short-Term and Long-Term Video EEG are performed as indicated.

**Polysomnography:** Is performed in Video EEG/Sleep laboratory in C5 ward.

**Electrophysiological Studies**

The electrophysiologic laboratory is in Room no. 3057 in the academic block of All India Institute of Medical Sciences. The studies performed herein include Nerve Conduction studies and Needle Electromyography. Ambulatory EPS has also been initiated.

In addition in collaboration with Department of ENT and Department of Ophthalmology, Brain stem Evoked Response Audiometry (BERA), and Oto-Acoustic Emissions (OAE), and Visual Evoked Response are also performed respectively.
Despite the emergence of Neurodevelopmental disorders as a major public health demon, there is a dearth of appropriately trained personnel in India to manage this group of disorders. Delay in timely diagnosis and treatment add further to the existing adversity. AIIMS being the premier institute of the country has an important task of strengthening the knowledge base of every health care personnel to take care of this enormous disease burden. In keeping with this objective, a microsite/website was launched on 3rd December, 2014. The aim of the microsite/website is to augment the level of knowledge, and skills of the Pediatricians and health care professionals all through the country for early detection and intervention of childhood neurodevelopmental disorders. The knowledge and skills gained will be helpful in upgrading patient care at all levels from the primary care facilities to the referral centres and will translate in a more judicious diagnostic and therapeutic approach towards these ailments. Though the information on microsite/website is straightforward and unambiguous, there are often doubts about certain terminologies and procedures, and also many parents have specific queries about their child which may not have been covered. In view of the aforementioned, a platform on this microsite/website has been developed where parents and care givers can post their queries that can be subsequently answered by experts. This will go a long way to ensure “personalized care” for these differently abled children.

**Biopsies**

Skin, muscle and nerve biopsies are done in C5 ward as a day care procedure by Paediatric Neurology residents. The appointments for the same are given on OPD basis.

**Other Day Care Procedures**

Various other diagnostic tests are performed as a day care procedure. These includes:

- Lumbar puncture and CSF manometry.
- Blood/CSF Lactate
- Neostigmine challenge test
- Forearm ischemic test
- Dynamometry
- Oto-acoustic emission.

**Neurodevelopmental and Psychological Assessment Tests**
Envisaged Thrust Areas

With this background, the Division envisages developing a Centre For Advanced Research and Excellence with the following envisioned thrust areas:

- Development of a **National Registry** for Childhood Neurodevelopmental disorders.
- **National Knowledge and Training Centre** for Childhood Neurodevelopmental disorders
- Childhood Neurodevelopmental disorders: **Advanced Diagnostics**
- Childhood Neurodevelopmental disorders: **Advanced and Novel Therapeutics/Rehabilitation**
- Establishment of **Child Neurology Helpline and Tele Consultation Services**

**In fulfilment of this, the following research projects have been planned**

1. **National Registry** for Neurodevelopmental Disorders affecting infants, children and adolescents from 1 month to 18 years of age
2. **National Knowledge and Training Centre for Neurodevelopmental Disorders** affecting infants, children and adolescents from 1 month to 18 years of age
3. Childhood Neurodevelopmental Disorders: **Advanced Diagnostics**
   - 3.1) Etiological profile for acute and/or subacute and/or chronic encephalopathy/encephalitis syndrome affecting infants, children and adolescents from 1 month to 18 years of age
   - 3.2) Clinical and investigative profile in Indian infants, children and adolescents aged 1 month to 18 years with Muscular Dystrophy; a Muscle MRI, Skin biopsy and Exome sequencing based study
   - 3.3) Epileptic encephalopathy in Indian infants, children and adolescents aged 1 month to 18 years; a clinical, electrophysiological and Exome sequencing based study
   - 3.4) Autism Spectrum Disorder in Indian infants, children and adolescents aged 18 months to 18 years; a clinical and Exome sequencing based study
4. Childhood Neurodevelopmental disorders: **Advanced and Novel Therapeutics/Rehabilitation**
   - 4.1) Technology based advanced and indigenous modes of rehabilitation for infants, children and adolescents aged 1 to 18 years affected with Cerebral Palsy and Autism spectrum disorder
   - 4.2) Efficacy of Ketogenic diet for treatment of Electrographic Nonconvulsive Status Epilepticus in infants, children and adolescents aged 6 months to 18 years of age.
4.3) Efficacy of Gluten and Casein free diet for treatment of Autism Spectrum Disorder in children and adolescents aged 2 to 18 years of age: a Randomised Controlled Trial.

4.4) Efficacy of Music therapy for treatment of Autism Spectrum Disorder in children and adolescents aged 2 to 18 years of age: a Randomised Controlled Trial

5. Establishment of Child Neurology Helpline and Tele-consultation services for Neurodevelopmental Disorders affecting infants, children and adolescents from 1 month to 18 years of age.

**Proposed Structure**

<table>
<thead>
<tr>
<th>Core Staff Members</th>
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<tbody>
<tr>
<td><strong>Faculty</strong></td>
</tr>
<tr>
<td>Professor Sheffali Gulati (Faculty Incharge)</td>
</tr>
<tr>
<td>Dr. Biswaroop Chakrabarty (Assistant Professor)</td>
</tr>
<tr>
<td>Dr. Prashant Jauhari (Assistant Professor)</td>
</tr>
<tr>
<td><strong>Speciality Nurse</strong></td>
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<tr>
<td>Mable Jossy</td>
</tr>
<tr>
<td><strong>Technicians</strong></td>
</tr>
<tr>
<td>Mrs. Sushila Yadav</td>
</tr>
<tr>
<td>Mr. Suresh Kumar</td>
</tr>
</tbody>
</table>

**Additionally Secretarial and Project staff**

**Mentors**

*International (alphabetical order)*

1. Professor Brenda L Banwell, Chief of the Division of Neurology, The Children’s Hospital of Philadelphia, Philadelphia, USA

2. Professor Vinod Bhutani, Professor of Pediatrics (Neonatology), Division of Neonatal and Developmental Medicine, Department of Pediatrics, Stanford University School of Medicine and Lucile Salter Packard Children’s Hospital, USA

3. Dr. Harry Chugani, Chief of Neurology, Nemours / Alfred I. DuPont Children’s Hospital and Thomas Jefferson University, Philadelphia, USA
4. Saima Hossain, Licensed School Psychologist, Chairperson, Shuchona Foundation, Chairperson, National Advisory Committee on Autism, Bangladesh; Focal Person for Disability for the Ministry of Disaster Management and Country Focal Person for Disability for UNISDR, Bangladesh; Goodwill Ambassador for Autism for WHO SEARO

5. Dr. Shekhar Saxena, Director, Department of Mental Health and Substance Abuse, World Health Organization, Geneva, Switzerland

6. Professor Michael Shevell, Chairman, Department of Pediatrics, Professor (with Tenure) Departments of Pediatrics and Neurology/Neurosurgery, McGill University Guyda Chair in Pediatrics, Pediatrician-in-Chief, Montreal Children’s Hospital/ McGill University Health Centre (MUHC)

7. Professor Donald Silberberg, Professor Emeritus, Department of Neurology, University of Pennsylvania School of Medicine, Philadelphia, USA

8. Dr. Soumya Swaminathan, Director General, Indian Council for Medical Research, New Delhi; Secretary, Department of Health Research, New Delhi; Appointed as Deputy Director General, WHO, Geneva Switzerland

9. Prof. J. Andoni Urtizberea, Praticien Hospitalier, APHP, Hendaye - France; Head, Summer School of Myology, Paris - France; Chargé de Mission, Filnemus, Marseille - France

10. Professor Donald Wertlieb, President, Partnership for Early Childhood Development and Disability Rights (PECDDR), Professor Emeritus, Eliot-Pearson Department of Child Development, Tufts University, USA

**National (alphabetical order)**

1. Professor M.K. Bhan, National Science Professor, Indian Institute of Technology, New Delhi; President of the Jawaharlal Nehru Institute of Postgraduate Medical Education & Research (JIPMER), Pondicherry

2. Professor A.K. Deorari, Head of Department, Department of Pediatrics, All India Institute of Medical Sciences, New Delhi

3. Professor Randeep Guleria, Director, All India Institute of Medical Sciences, New Delhi

4. Dr. Veena Kalra, Consultant Pediatric Neurologist, Apollo Hospital,
5. Dr. MKC Nair, Vice Chancellor, Kerala University of Health Sciences, Kerala
6. Professor Anand Pandit, Emeritus Professor and Director, Department of Pediatrics; Director, TDH Rehabilitation Center, KEM Hospital, Pune
7. Professor Vinod K Paul, Member, NITI Aayog, National Institution for Transforming India, Government of India, New Delhi; Professor of Pediatrics, All India Institute of Medical Sciences, New Delhi
8. Dr. I.C. Verma, Director, Institute of Genetics and Genomics, Sir Ganga Ram Hospital, Rajender Nagar, New Delhi

National Scientific Advisory Board (in alphabetical order)

1. Prof. M. Gourie Devi, Emeritus Professor of Neurology, Department of Neurology, Institute of Human Behaviour and Allied Sciences (IHBAS), New Delhi, Honorary Advisor for Neurology Research, Indian Council of Medical Research, Former Director-Vice Chancellor, Professor of Neurology, National Institute of Mental Health and Neuro Sciences (NIMHANS), Bangalore.
2. Professor Satish Khadilkar, Professor and Department of Neurology, Bombay Hospital Institute of Medical Sciences, Mumbai.
3. Dr. Ajay Khera, Deputy Commissioner and Head of Child Health, Ministry of Health & Family Welfare, Government of India.
4. Professor Rashmi Kumar, Professor and Head, Department of Pediatrics, King George Medical University, Lucknow.
5. Professor PAM Kunju, Head, Department of Pediatric Neurology, Medical College, Trivandrum.
6. Professor Man Mohan Mehendiratta, Director of Janakpuri Super Specialty Hospital Society-JSSHS; Director Professor, Department of Neurology, Gobind Ballabh Pant Institute of Medical Education and Research, New Delhi.
7. Dr. Vrajesh Udani, Consultant- Child Neurology & Epilepsy, P.D. Hinduja National Hospital & Medical Research Centre, Mumbai.
8. Dr. Anaita Udwadia-Hegde, Consultant Pediatric Neurologist, Jaslok Hospital & Research Center, Wadia Children's Hospital, Mumbai.
The Research Syndicate

Intramural
- Child Neurology Division, Department of Pediatrics
- Department of Pediatrics (other Divisions)
- Microbiology
- Radiology
- Centre for Medical Education and Technology
- Physical Medicine and Rehabilitation
- Pharmacology
- Biostatistics
- NMR

Extramural
- IIT, New Delhi
- IGIB, New Delhi
- World School of Design, Gurgaon
- Nada Centre for Music Therapy
- Bhaktivedant Hospital, Mumbai

Thrust Areas

1) National Registry

Need: The prevalence of Childhood Neurodevelopmental Disorders (NDDs) is on a rise. For understanding etiopathogenesis, epidemiology, clinical features, comorbidities, diagnostic and therapeutic attributes and long-term outcome and formulating policy and advocacy, there is a need for a robust composite database for these disorders. This registry will be the first of its kind in the country paving the way for meaningful research, policy making and advocacy for childhood NDDs in India. It will also act as a ready source for enrolling patients in various therapeutic and rehabilitation trials.

Proposed Methodology: The final structure of the database will be created after face and construct validity by a team of experts comprising of the investigators and mentors. Subsequently, the team of experts will have 6 monthly to annual meetings for periodic appraisals and surveillance of the database. During the first year, the registry will be maintained only at Child Neurology Division, Department of Pediatrics, AIIMS, New Delhi. Subsequently, collaborating sites will be involved, and within a definitive time
period, the data collection will be networked upto the level of District Early Intervention Centres and Hospitals within the catchment area of all the collaborating sites.

2) National Knowledge and Training Centre

Need: Currently in Neurodevelopmental Disorders, there is a skewed patient and health care provider ratio. Additionally there is lack of awareness and knowledge amongst them. Thus it is imperative that augmentation of medical knowledge and practice is done. Information technology based E-learning is emerging as an effective modality of learning. However, the best method of imparting education is still a blend between technology based individualised learning and traditional methods of teaching like didactic lectures. Through this thrust area, it has been planned to conduct symposium cum workshops periodically for health care providers at all levels. It has also been envisaged to augment the existing educational microsite/website and also maintain a web based interactive platform for parents and professionals.

Proposed Methodology: The symposiums will cater to Doctors, Nurses, Physiotherapists, Occupational Therapists, Psychologists, Special Educators, Technicians and Parents. Doctors in all categories will be included in the workshop cum symposia, namely Resident Doctors, Private and Government Pediatricians, Pediatric Neurologists and Neurologists, Medical Officers and Primary Level Physicians. The content of the workshops will vary on a yearly basis to cater to the needs of these various subgroups of doctors. The proceedings of these symposia cum workshops will be uploaded on the microsite/website. From time to time additional educational material in the form of E-learning modules will be uploaded on the microsite/website. The interactive web based platform will act as a supervised technology aided learning tool. The useful and relevant clarifications will also be uploaded on the microsite/website.
3) Advanced Diagnostics

**Need:** This thrust area will dwell on diagnostic aspects of Neurodevelopmental disorders with focus on genetic basis of Autism Spectrum Disorder, Epileptic Encephalopathies and Muscular Dystrophies and comprehensive etiological work up of Acute Encephalitis Syndromes. The genetic tests in the three mentioned disorders would help in antenatal counseling, preventing further birth of affected children in the families and aid in unveiling of newer pathogenic and therapeutic pathways. Antenatal diagnosis of these disorders significantly affect the productivity of a nation as it prevents further disabilities from developing in the population. The role of skin biopsy and muscle MRI will also be explored in patients with muscular dystrophies.

Evidence suggests that in Acute Encephalitis Syndrome scenario upto 60% cases don’t have an identifiable etiological agent. As a result most of the treatment protocols are based on empirical use of antibiotics. This leads to unnecessary usage of antibiotics in many instances, prolongation of hospital stay and emergence of antimicrobial resistance. Moreover, early and appropriate institution of treatment significantly affects long term outcome, thus preventing neurocognitive morbidities. Currently there is no database regarding etiology of Acute Encephalitis in the country. The current initiative will help in formulation of appropriate treatment guidelines, prevent unnecessary use of antibiotics and help policy makers to frame epidemiologically relevant preventive and immunisation guidelines.

**Proposed Methodology:** The genetic testing in the three disorders would employ state of the art, advanced technology like array CGH, Exome and genome sequencing. The etiological work up of Acute Encephalitis syndrome would employ advanced PCR, ELISA and immunofluoroscence based kits for looking at a broad spectrum of etiology (bacteria, virus, fungus, parasites and autoimmune). The various staff required will be senior and junior research fellows, data entry operators and laboratory technicians and attendants.

4) Advanced and Novel Therapeutics / Rehabilitation

**Need:** This thrust area focuses on use of technology aided, latest, state of the art rehabilitation strategies for children with Cerebral Palsy and Autism Spectrum Disorders. The burden of these two disorders is on rise and appropriate, affordable, indigenous rehabilitation programmes for realisation of optimal functional capacity in these children are the need of the hour. This in turn will translate into increase in productivity of the nation as a whole.

**Proposed Methodology:** The primary focus is on appropriate application of textile technology and biomedical engineering in collaboration with IIT, New Delhi in the management of these children. The products include

- Weighted compression vest and lower body garment
- Drooling scarf
- Hand splint
- Virtual reality based play cum therapy rooms
- Posture stabilising
- Augmented Reality
- Communication Boards based Picture Exchange Communication System
- CIMT integrated with Virtual Reality
- Kinetic integrated weight training module
- Smart Card based SMS integrated devices for safety and security

All these products will be first developed, then piloted and subsequently evaluated in clinical trials

Apart from these, complementary and alternate forms of therapy with promising evidence will also be evaluated through clinical trials like Ketogenic Diet in Status Epilepticus, Gluten and Casein Free Diet and Music Therapy in Autism Spectrum Disorders.

5) Child Neurology Helpline and Teleconsultation Services

**Need:** The Child Neurology Division, at the Department of Pediatrics, AIIMS, New Delhi, caters to patients from far off places in the country as well as from neighbouring nations. The travel expenses further increase the cost of treatment in these patients, as most of them require long term medications and access to rehabilitation services. Many times the visits are for small queries, which can be resolved telephonically. Moreover, there is lack of awareness and knowledge of parents and care providers with respect to NDDs. Reliable 24x7 telephonic guidance would help in dispelling myths associated with these disorders. This would further help in decreasing parental work absenteeism and decrease burden on hospitals and lead to optimal utilisation of health care resources. The quality of life of both health care providers and patients their families would improve significantly.

**Proposed Methodology:** With this background, a telephonic helpline was launched on 30-Apr-2015. It is proposed to augment this by providing counsellors to manage this Telephonic helpline round the clock. It is also proposed to provide two toll-free landlines and mobile smartphones for optimal functioning of the helpline. A Registry/Catalogue will also be maintained for all the queries and expert technical assistance will be available from DM Pediatric Neurology residents and Faculty whenever required or indicated.