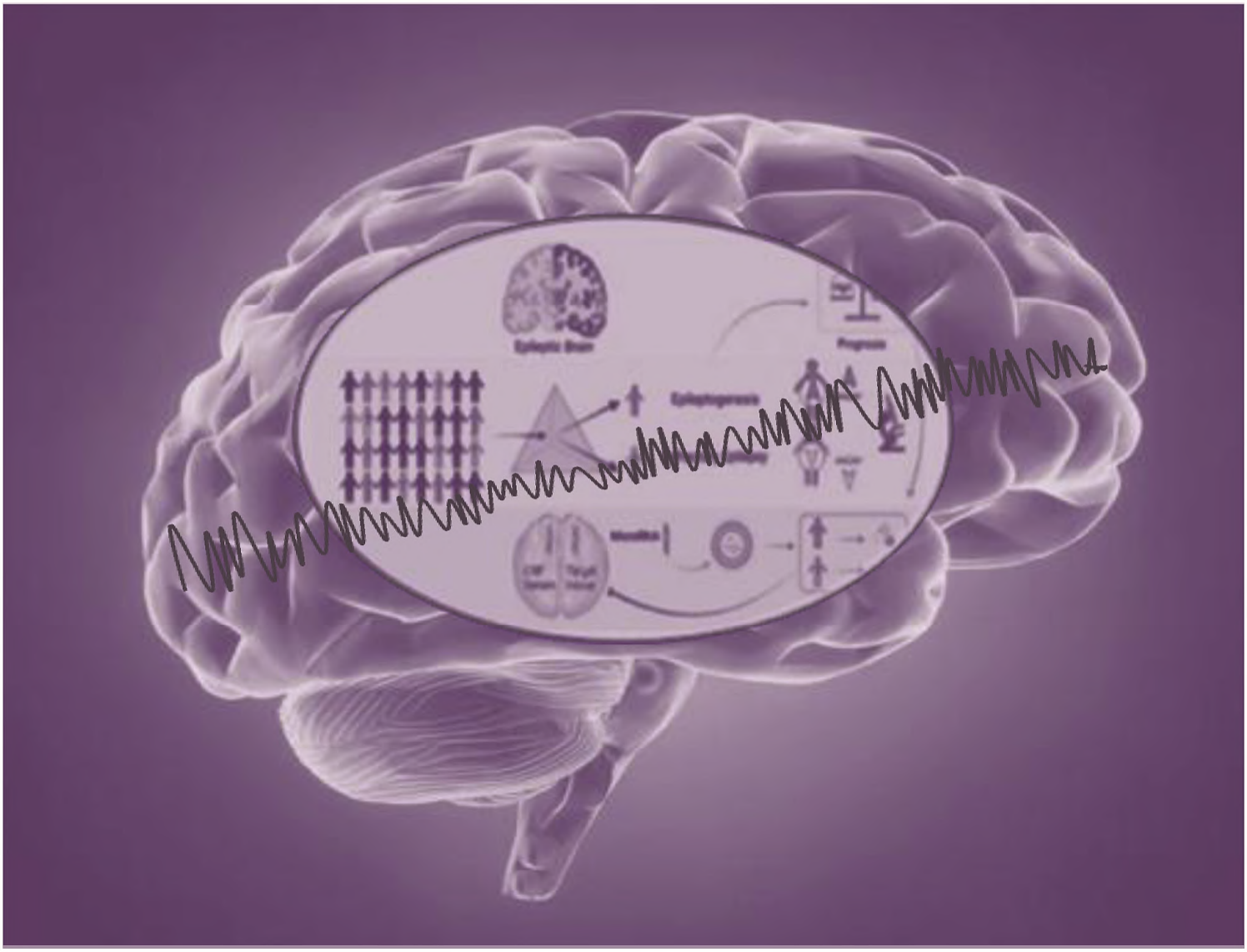
Issue - 1

January – March 2023

Epilepsy India

Newsletter of the Indian Epilepsy Association & Indian Epilepsy Society



Diagnosis of Epilepsy
MicroRNAs as Biological Markers
A
Technological Advancement

CONTENTS

OFFICE BEARERS

EDITORIAL OFFICE :

16-7-129, Ramamurthy Nagar,
2nd Street, Minibyepass Road,
Nellore 524003
neurology.nellore@gmail.com

WEBMASTER :

Dr Atma Ram Bansal

Editorial...

Dr. Bindu Menon

Dr. Chanda Kulkarni

Welcome you all to the first issue of 2023, Epilepsy India, Newsletter

This issue brings to you an overview of a very important type of epilepsy, the sleep related hyper motor Epilepsy presented by Dr. K.S. Anand. He has also described the reason and supportive argument behind the change of nomenclature of this type of epilepsy from nocturnal frontal lobe epilepsy to sleep related hyper motor epilepsy.

We have yet another epilepsy warrior, Miss Apoorva Mahajan from USA, who has shared with us her story. She is presently engaged in motivating and encouraging persons with epilepsy with her success story in the past from her childhood and has briefed on how she diverted her life towards the research in Epilepsy as she grew. Would like to thank this young achiever Apoorva, particularly her positive outlook and insight to move forward. Truly her story is an inspiration to all those with epilepsy. We wish her all the very best in contributing to bring 'epilepsy out of the shadows'. In parallel with this we have an article from Dr. Prahlad K. Sethi and Dr. Nitin K. Sethi on defeating the stigma associated with Epilepsy.

Several international Epilepsy day celebrations were held in February across India and we thank themember associations who have shared their awareness activities. The preparations for annual conference ECON are underway and we hope to have a great academic program in July – 2023. Do stay tuned to read important announcements on the Epilepsy and society in the era of Integrated global action plan (IGAP)

Lastly, the cover page of our newsletter features the technological advancement in the diagnosis of Epilepsy using micro RNA as a biological marker. So we have lots more for us to learn and understand.

Looking forward to meeting everyone at Jaipur for the conference to enjoy the exciting scientific feast!

Thanks and regards

Bindu and Chanda

SLEEP-RELATED HYPERMOTOR EPILEPSY

Dr.K.S.Anand.
Principal Consultant & Professor,
Department of Neurology,
ABVIMS & DR. RML Hospital,
New Delhi.

Nocturnal frontal lobe epilepsy (NFLE) was discovered in Bologna in 1981 when Lugaresi and Cirignotta described five patients with frequent episodes of bizarre movements with tonic posturing of the limbs clustered during sleep, strongly suspected to be epileptic as it responded to carbamazepine [1].

NFLE has been recently renamed as **Sleep-related hypermotor epilepsy (SHE)** by a consensus conference of sleep and epileptology experts in order to recognize the disorder as a distinct epilepsy syndrome.

Issues that justified this change included :

- Firstly, the term "nocturnal" was considered misleading as it implies a chronobiological pattern of seizure occurrence, rather than sleep state specificity of this disorder as seizure can occur at night as well as during daytime naps.

- Secondly, emphasis on localization to frontal lobe was considered misleading astypical seizures may have extra-frontal origin.

- Thirdly, original name did not specify typical clinical semiology – hyper-motor pattern of seizures.

According to the consensus conference, SHE is a rare disease, with an estimated prevalence of 1.8/100,000 individuals, without a gender predominance, and with a peak onset during childhood and adolescence.

Seizures are abrupt in onset and offset, typically brief (2 minutes), highly stereotyped hyper-motor pattern - complex body movements with kicking or cycling of limbs and rocking body movement, accompanied by vocalization, emotional facial expression and asymmetric tonic/ dystonic seizures with or without head/eye deviation.Clustering is characteristic but not obligatory for diagnosis. Seizures occur predominantly during non-REM (NREM) sleep and rarely during REM sleep.

Awareness of seizure is common. More rarely, protracted ambulatory behaviour known as epileptic nocturnal wandering (ENW) - lasting more than 2 minutes, up to several episodes per night.Patients may also complain of non-restorative sleep and excessive daytime sleepiness.

Most patients are of normal intelligence. However, intellectual disability and behavioural disorders have been rarely reported.

Aetiologies of SHE are heterogeneous and include: structural anomalies, acquired injuries and genetic causes. In genetic, sporadic is the most frequent form. Patients with drug-resistant SHE may have a surgically treatable lesion - particularly type II focal cortical dysplasia (TFCD).

Minority of familial cases has a known genetic mutation. Scheffer et al. described a large Australian family with autosomal dominant NFLE (named ADNFLE, now ADSHE). CHRNA4 was the first epilepsy gene discovered, coding alpha4 subunit of neuronal nicotinic acetylcholine receptor (nAChR) [2].

Mutations in genes (CHRNA2 and CHRNB2) coding for other subunits (alpha2 and beta2) of nAChR have been identified – can have associated intellectual disability, neuroregression, depression, psychosis and personality disorder.

Other gene mutations include – sodium activated potassium channel encoded by KCNT1 and DEPDC5 - also mutated in a severe epileptic encephalopathy with migrating focal seizures of infancy (MFSI).

A warning sensation (consisting of fear, associated with epigastric discomfort or déjà vu) and auditory aura seem to be more suggestive of a temporal onset [3].

Patients with nocturnal insulo-opercular epilepsy often reported viscero-sensitive (laryngeal and throat sensations, breathing discomfort, unpleasant or rising epigastric sensations) and somatosensory (unpleasant or electrical paraesthesia, diffused or restricted to a small cutaneous area) manifestations and auditory hallucinations. Visual hallucinations are indicative of occipital involvement.

Patients with an asymmetric tonic or dystonic posturing showed an early activation of supplementary motor area and involvement of posterior mesial and cingulated frontal cortex. Patients with hyperkinetic ictal behaviour showed involvement of mesial-dorsolateral, orbitopolar, opercular or larger lobar cortical regions. The epileptic manifestations characterized by fear and prolonged organized motor behaviours like ENW, involve activation of anterior cingulate, orbitopolar and temporal regions.

Apart from the ictal semiology, a long delay (10–20 s) between the electrical and the clinical onset of motor seizure suggests an extra frontal origin of SHE.

Recently a stereo-EEG study revealed that mean electrographic seizure duration was shorter (38.5 sec vs. 61.8 sec), mean elapsed time from EEG onset to first video detectable movement was lower (4.3 sec vs. 9.5 sec), delay between first movement and onset of hypermotor manifestation was shorter (2.2 sec vs. 11.4 sec) and duration of clinical manifestation was shorter (32.3 sec vs. 52 sec) in frontal than in extra frontal SHE [4]. Once the hypermotor manifestation began, no differences in seizure phenotype were observed.

Ictal motor sequences in SHE reflect release of Central patterned generators (CPGs) - which are innate motor patterns present in all organisms and localized in spinal cord and mesencephalon pons and bulb, essential for survival [5]. In adults, these motor sequences are normally under control of the mature neopallium but may re-emerge during transient loss of neocortical control, such as during an epileptic seizure, cerebral anoxia or parasomnia.

Certainty of diagnosis can be categorized into 3 levels: witnessed (possible) SHE, video-documented (clinical) SHE, and video-EEG-documented (confirmed) SHE.

Majority of SHE's core features have been clarified, some critical issues remain: the semiological overlap between SHE and sleep disorders. The behavioural patterns of NREM arousal parasomnias, REM behaviour disorders and SHE has some similarities. An overview of the differences between SHE/NFLE and NREM Parasomnias is listed below.

	NFLE	NREM parasomnia
Age at onset	Any age (usually before the age of 20 years)	3–8 years
Family history of parasomnias	Possible	Frequently present
Time of occurrence during the night	Any time	Usually during the first third
Sleep-stage onset of episodes	NREM sleep (usually N2)	NREM sleep (usually N3)
Frequency during one night	Several episodes/ night	Usually one episode/ night
Frequency in a month	Almost every night	Sporadic
Duration	Seconds–3 minutes	1-10 minutes
Evolution	Stable, increased frequency, rare remission	Tend to disappear
Triggering factors	Rare	Frequent (sleep deprivation, febrile illness)
Stereotypic motor pattern	Yes	No
Consciousness if awakened	Usually preserved	Usually impaired
Recall of the episode on awakening	Variable	No

Two instruments to help clinicians to discriminate parasomnia from SHE are: Frontal Lobe Epilepsy and Parasomnias (FLEP) scale and Structured Interview for NFLE [6]. The FLEP scale has low sensitivity in patients presenting with ENWs, which were misinterpreted as arousal parasomnias; and in patients with REM behaviour disorder, the scale gave misleading epileptic diagnosis, lowering its specificity.

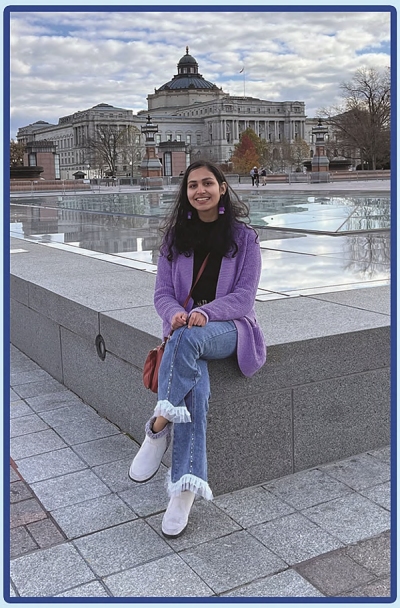
Carbamazepine is effective at low doses in two-thirds of patients with SHE. Drug refractory epilepsy associated with structural causes like cortical dysplasia responds to surgery.

References :

1) Lugaresi E, Cirignotta F. Hypnogenic paroxysmal dystonia: epileptic seizure or a new syndrome? Sleep. 1981; 4(2):129-138.
2) Scheffer IE, Bhatia KP, Lopes-Cendes I, et al. Autosomal dominant frontal epilepsy misdiagnosed as sleep disorder. Lancet. 1994; 343(8896):515-517.
3) Ferri L, Bisulli F, Nobili L, et al. Auditory aura in nocturnal frontal lobe epilepsy: a red flag to suspect an extra-frontal epileptogenic zone. Sleep Med. 2014; 15(11):1417-1423.
4) Gibbs SA, Proserpio P, Francione S, et al. Seizure duration and latency of hypermotor manifestations distinguish frontal from extrafrontal onset in sleep-related hypermotor epilepsy. Epilepsia. 2018; 59(9):e130-e134.
5) Tassinari CA, Cantalupo G, Högl B, et al. Neuroethological approach to frontolimbic epileptic seizures and parasomnias: The same central pattern generators for the same behaviours. Rev Neurol (Paris). 2009; 165(10):762-768.
6) Bisulli F, Vignatelli L, Naldi I, et al. Diagnostic accuracy of a structured interview for nocturnal frontal lobe epilepsy (SINFLE): a proposal for developing diagnostic criteria. Sleep Med. 2012; 13(1):81-87.

Reported By:
Ms.Apoorva Mahajan
Sanfrasisco, California

I had my first seizure when I was just 3 months old. The only symptom - I didn't Blink for a full two minutes. My mother noticed that something was amiss. She rushed to a neighbor's place wondering what had happened to me. However, by the time she took me in her arms, and reached their place in a panic mode, I had recovered. Thus, the very first episode was ultimately dismissed and was taken lightly. But then these episodes (seizures) became very frequent; sometimes occurring twice a day. My parents were scared, they feared whether I would be able to survive in this world. They did all that parents could do - studied about this disorder, joined clubs and forums, discussed with relatives and well-wishers and reached out to all doctors they could contact. They also tried various alternative treatments- homeopathy, Ayurveda, home remedies, and even took me to an ashram in Rhishikesh. I was being fed all kinds of medicines, home remedies, parents took several opinions- from mystics to doctors and friends. But it took time until I had 20+ such episodes later diagnosed as Epilepsy. However, even after the diagnosis, I was subjected to many investigations like - CT scans and MRI's and was treated rigorously with various medicines. Unfortunately, nothing worked!



My mother kept meticulous record of all the symptoms, with date and time of seizures. Most of them were febrile in nature, as they were preceded by high fever. My parents would consult a doctor each time I caught cold or fever although it was mild. My parents were strict about my diet and they ensured that they kept me away from eating junk food, ice cream, soft drinks. Over the years different doctors treated me with a variety of medicines of different brands. I was then treated with Frizium, a new entrant in the market and it worked like a magic. The frequency and intensity of seizures reduced and was doing better. Later on, with the advancement in science and medications, I switched to DIVAA-OD(slow release variant of valproate), this too worked well for me. Recently I have switched to Levipil (Levetiracetam). I am doing much better and well controlled. However, wish to share with those with epilepsy it is important that one should not switch medications on their own but it is important to consult your doctor/neurologist, since these need to be tailored based on the age, gender, and if you are suffering from other health conditions.

Leading a NORMAL life:

I am glad to share with you all that presently I am well controlled and leading near normal life and this was possible because of the strong support from my parents and family. I could excel both on academics and in co-curricular activities.Yet, the journey isn't easy, but makes to stronger to accept and fight to move forward, which has made me brave to lead normal life.

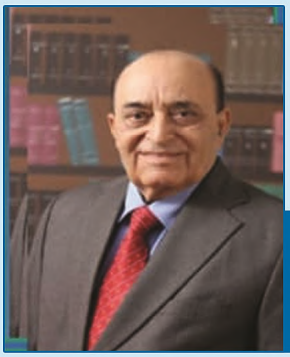
I have now moved to a new city Bangalore for my corporate job and living independently. I wish to share my recent experience -"one of my colleagues in the office suddenly fell from his chair and had a seizure. The entire office staff panicked and surrounded him with no room to breathe. Thankfully, I was around and was able to helped him with first aid and also educated the office staff about epilepsy." This incident made me realize that a lot needs to be done to educate people about epilepsy and the first aid. I also felt that the stigma associated with epilepsy doesn't allow people with the condition to openly talk about it or discuss it in public. Therefore I made my own website, and decided to share my own story and how I could overcame. This effort was appreciated by a lot of people, and encouraged me to start a social media campaign to educate people about epilepsy. This led to #indiagoespurple an Instagram page and an effort to start a purple day campaign all over the country to help people with epilepsy to come together and share their stories. By the time this campaign was shaped up I had already applied to pursue my master's study at the cross section of health, technology and neuroscience at Carnegie Mellon University [CMU], Pittsburgh. I started working remotely with - Grover a research lab and involved them in this campaign. At CMU, I was in a unique place where I could integrate my efforts for I did a lot of research on improving the present-day EEG system and technology and how it could be improved to work for all hair and skin types, I also took a lot of interesting courses to understand how the brain functions. It was here that I developed an interest in the field of brain-computer interfaces and how they could change the world. In one of these courses, I also learned about responsive neurostimulation therapy and how it has benefited people with refractory epilepsy. Thus, when I was looking for an internship, I applied to Neuropace - the only FDA-approved company in the USA that works for RNS systems. My cold emails worked, and I got an opportunity to intern with the company over the summer. As an electrical engineering intern, I got to learn more about the device and helped make automation systems to test the system more easily.

At Pittsburgh – a city which is booming with neuroscience research and startups with the support of my advisor- Professor Pulkit Grover, and encouragement from my friends I also replicated started another campaign CMUgoespurple to encourage students to learn about epilepsy and the kind of cutting-edge research going on in this field. For this event, we saw a footfall of around 150 people that came together to paint the famous CMU fence purple on a purple day. It was truly beautiful. The entire campus turned purple for a day. Post graduating from college I started working at another BCI company called Neurosity which makes EEG recording systems and recommends music to improve the user's productivity. I still work with my friends and colleagues at CMU to keep the CMUgoespurple event going every year as a tradition. This I feel has been my single most cherished achievement to date. Through my story, I want to inspire people like me to keep fighting and never loose hope. Epilepsy is not a limitation, and by coming together we can overcome and conquer it.

Links:

indiagoespurple.org
https://www.instagram.com/indiagoespurple/?hl=en

DEFEATING THE STIGMA OF EPILEPSY



Prahlad K Sethi1, MD
Department of Neurology,
Sir Ganga Ram Hospital,
New Delhi, India

Nitin K Sethi, MD
Department of Neurology,
New York-Presbyterian Hospital,
Weill Cornell Medical Center, New York,
NY, United States of America

The history of epilepsy is connected with the history of humanity. One of the earliest descriptions of the disease is reported in the medical text called Sakikku thought to be written sometime around 1.050 BC by the Babylonians. The word epilepsy is derived from Ancient Greek ἐπιλαμβάνειν, "to seize, possess, or afflict". Even though epilepsy is as old as civilization itself, surprisingly there still exists stigma around this common neurological condition. Despite sustained efforts this stigma persists.The stigmatized are discriminated, ostracized, devalued, scorned, shunned and ignored. In school these children experience social problems and difficulty integrating with peers. Other children are afraid to study or play alongside them. Teachers instead of understanding and treating these children with empathy may ignore them. When these children grow up and enter college, the stigma accompanied them and they experience social isolation leading to mental health disorders such as anxiety and depression. While laws exist to protect against discrimination at work, most epileptics struggle to find a good job despite possessing requisite qualifications.

In India, young women with epilepsy face unique challenges when it comes to marriage and family. In an arranged marriage the bride and groom are primality selected by parents and other close family members. If the girl or her parents reveal the epilepsy diagnosis, the match is rejected by the prospective bridegroom or his family. If the diagnosis is hidden and comes to light after the marriage, it leads to marital discord and at times divorce. The girl and her parents are devalued and scorned.

How can we remove the stigma surrounding epilepsy in India? Education remains the cornerstone but despite persistent collective efforts of various national and international epilepsy associations, the stigma remains. Neurologists, inadvertently may also be contributing to the problem. We publish articles highlighting the psychiatric comorbidities of epilepsy such as anxiety and depression. But these comorbidities are not unique to epilepsy. Any chronic illness which affects a patient's quality of life adversely will cause anxiety and depression. The message we should be sending out consistently is that epilepsy is a highly treatable chronic disease. The vast majority of patients live a normal productive life. We should encourage our patients to live their dreams doing things that make them happy and fulfilled. That you are not alone should be the message. Fyodor Dostoevsky (the great Russian writer), NapoleonBonaparte (the legendary French military commander and political leader), Sir Isaac Newton (physicist, mathematician, and natural philosopher), Leonardo Da Vinci (painter), Agatha Christie(English writer known for her detective novels), Alfred Nobel (Swedish chemist, engineer, innovator, and the inventor of dynamite), Joan of Arc (legendary defender of the French nation) and many other influential people all had epilepsy. These individuals did not let their epilepsy hold them back. Epilepsy is not something to be ashamed of is the message that should resonate.

The LGBTQ community has faced stigma and discrimination over the years. Some even today say that homosexuality is a mental health illness. The gay community though fought back against this narrative. They have emerged from the shadow of discrimination by proudly coming out as gay, holding gay pride parades and celebrating their diversity. Our patients too should emerge from the shadows. Epilepsy is not a curse, nothing to be ashamed of or to hide from friends, family or a prospective bridegroom. While epilepsy casts a long stigma shadow, the time has come for our patients to emerge from it.

ARE YOU AN EPILEPSY WARRIOR

DO YOU WANT TO SHARE YOUR STORY WITH US

PLEASE MAIL TO

NEUROLOGY.NELLORE@GMAIL.COM

BE MOTIVATED, KEEP MOTIVATING

INTERNATIONAL EPILEPSY DAY: JAIPUR CHAPTER ACTIVITIES

Reported By: **Dr. R.K.Sureka**
Professor & Head Neurology,
Mahatma Gandhi Medical College, Jaipur

1. TV TALK SHOW AND EXHIBITION FOR PERSONS WITH EPILEPSY [PWE] AND CAREGIVERS AND CME: MAHATMA GANDHI MEDICAL COLLEGE, JAIPUR

A **T.V. Talk show** was organized with First India TV where Prof. Manmohan Mehendiratta, President - Indian Epilepsy Society and Dr. R.K. Sureka, President of Jaipur Chapter, IEA, responded to queries from PWE and general audience. The objective was to create awareness on myths and misconceptions about Epilepsy. There were around 250 participants, including PWE and students from various departments of medical college. A painting competition was held for PWE and best drawings were distributed the prizes. A poster was released with the theme **"Treat Epilepsy - Prevent Epilepsy"** by the dignitaries.

A CME on epilepsy was organized for faculty and students of Mahatma Gandhi Medical College & Hospital and Prof. M.M. Mehendirattadelivered a educational lecture on epilepsy. Prof Dr. M.L.Swarankar, Chair person MGUMST, was the chief guest for the event. Prof B.S. Sharma, HOD Neurosurgery, presided the event.

2. EPILEPSY AWARENESS EXHIBITION, WALKATHON AND FREE EPILEPSY CAMP: RATANNAGAR VILLAGE, DIST (CHURU), RAJASTHAN.

International Epilepsy Day, was celebrated by hosting 341st free epilepsy camp, at Village Ratan Nagar, Dist. Churu, by Epilepsy Care and Research Foundation, Jaipur (a unit of Triveni Devi Sureka Charitable Trust) and Jaipur Chapter of IEA. This camp was a part of series of free monthly epilepsy camp being held for the last 29 years. Free consultation was offered to 562 PWE and were given free medicines for one month and an exhibition was set up on various aspects of epilepsy. Shri. Sidharth Sihag, Dist. Collector, Churu, was the chief guest who addressed the gathering and distributed the prizes for winners of painting competition. A walkathon was flagged off by chief guest to create awareness and Dr. R.K.Sureka, the Chief Neurophysician and President Jaipur Chapter of IEA addressed the gathering.

Dr. R.K.Sureka, seen delivering Epilepsy awareness Talk Show - on First India TV [left].
Prof .Dr. Mehendiratta and Prof .Dr. Sureka are on Talk Show on First India TV [right]

Inauguration of CME
by Prof. Dr. M.L. Swarankar

Release of Epilepsy Awareness Poster
"Treat Epilepsy - Prevent Epilepsy"

Prize distribution for winners of painting competition by - Dist. Collector Churu (Raj)
who also visited the exhibition

INTERNATIONAL EPILEPSY DAY, NELLORE

Reported By:
Dr. Bindu Menon

International Epilepsy Day 2023

Extempore by students from various colleges on various topics on epilepsy at Sri Krishna Chaitanya Junior college. 100 students participated in the event. Students interacted and cleared their queries. Topics covered were epilepsy and education, sports, marriage, stigma, first aid. Certificates were distributed to all participants.

Thanks to Mr Vara prasad for the coordination.

We interviews Ms Preet Singh on our podcast: NeuroVoice Podcast. Ms Preeti Singh, a person with epilepsy and an author based at Chandigarh who is a true warrior of Epilepsy was a true motivator sharing her experiences

The podcast NeuroVoice is available on Spotify, Gaana, Google podcast, anchor

https://gaana.com/podcast/neurovoice-season-1
https://podcasts.google.com/.../aHR0cHM6Ly9hbmNob3IuZm0vc...
https://open.spotify.com/show/5ujRQpFU5rPuF4gP6NR99G
https://anchor.fm/dr-bindu-menon

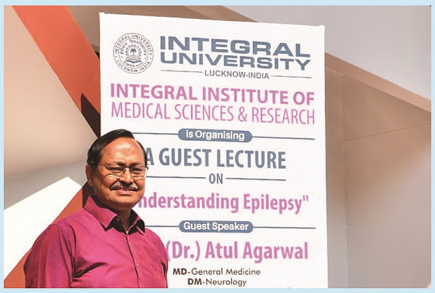
Reported by
Dr Atul Agarwal

International Epilepsy day was celebrated on 13thFeb 2023 at the Medanta Institute of Neurosciences Lucknow. The theme of the day, Stigma in Epilepsy was highlighted after a brief introduction on epilepsy & myths by Dr. A.K. Thacker,Director & Dr. Ritwiz Bihari, Associate Director. An interactive quiz session was organized on the topic with the participants, which included Second Inning Club, Inner wheel club & Rotary club Elite of Lucknow. The group included mainly Senior citizens. The questions and their answers were conducted by Dr. Sudhakar Pandey, Dr. Pradeep Kumar & Dr. Vibhor Upadhyay and the program was highly appreciated. A vote of thanks was delivered by Dr Rakesh Mishra.(Pic 1)

18.02.2023. An interactive Epilepsy Discussion was held with Neurologists & Neurosurgeons of Dehradun in which all aspects of Epilepsy were discussed. Dr Mahesh Kuriyal organised and chaired the meeting. (Pic 2)

15.03.2023. Dr Atul Agarwal was invited for an interactive Lecture on 'Understanding Epilepsy' wit UG's, PG's and faculty members of Integral Institute of Medical Sciences, Lucknow. Prof Abha Chandra, Dean of the institute welcomed Dr Agarwal. The lecture was very well appreciated and included dozens of question in form of Quiz. Director Syed MohdFauzan presented a moment to Dr Agarwal and took him to a tour of Library & institute. (pic 3,4,5 & 6)

!8.03.2023. Dr Atul Agarwal was invited by the Paediatrician Group of Alambagh to drliver a lecture on 'Fever Related Epilepsy'. He was welcomed by Dr Atul Rasogi who chaired the session. (Pic 7)



We invite you to join our full-day, multi-stake holder symposium which will be held on Sunday, July 23rd as part of the 2023 IEA/IES ECON Conference.

The objective of this event is to foster intercultural exchange, cross-country collaboration, person-centred approaches, and durable partnerships towards regional implementation of the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (IGAP) – uniting a diverse group of regional and international stakeholders around the overarching theme of: Epilepsy & Society in the Era of IGAP: Realities and Prospects.

The symposium will be centred around IGAP as a key policy framework for the region, with dedicated sessions addressing the inclusion, treatment, research, and prevention gaps in epilepsy. Sessions will contain a mix of presentations and interactive multi-stakeholder panels, offering global and regional perspectives – including contributions from people with epilepsy, caregivers, healthcare providers, researchers, advocates, and policy-makers.

IBE will also organise an invite-only Policy Advocacy Workshop the day before the symposium, on the afternoon of Saturday, July 22nd. Take a look at our agendas below!

IBE International Bureau for Epilepsy

INDIAN EPILEPSY SOCIETY

Indian Epilepsy Association

Epilepsy & Society in the Era of IGAP

July 22nd and 23rd, 2023 at Marriott Hotel Jaipur, India.

Hosted by the International Bureau for Epilepsy (IBE), the Indian Epilepsy Association (IEA), and the Indian Epilepsy Society (IES)

Saturday, July 22, 2023

15:30 – 16:00	IBE Workshop Registration and Welcome
16:00 – 18:00	IBE WORKSHOP: *Leveraging Policy Frameworks for Epilepsy Advocacy Action in South East Asia and Western Pacific Regions*
19:00 -onwards	**Banquet Dinner**

Sunday, July 23, 2023

Session 1	**09:30 – 11:00 - Epilepsy & Society in the Era of IGAP (Moderator: Graeme Shears)**
09:30 – 09:45	**Opening Address:** The WHO Intersectoral Global Action Plan (IGAP) and Epilepsy Technical Brief: Overview and Significance
09:45 – 09:55	**Personal Testimony:** View from Person with Epilepsy/Caregiver
09:55 – 10:15	**International Perspectives:** Closing the Epilepsy Inclusion Gap – Theory and Practice
10:15 – 10:35	**Regional Perspectives – South East Asia and Western Pacific:** Stigma and Health Literacy Interventions
10:35 – 11:05	**Multistakeholder Panel Discussion with Q&A -** Challenges and Opportunities in the SEA region… *on improving health literacy and reducing stigma*
11:30 – 13:00	**Enhancing Access to Epilepsy Health & Social Care** in Response to IGAP (Moderator: **Man Mohan Mehndiratta**
Session 2	11:30 – 11:45: Opening Address: Access to Care – Problem Overview & Status Quo in South East Asia
11:45 – 12:05	**Panel Discussion of Regional Perspectives – South East Asia and Western Pacific** Strengthening community-based primary care for epilepsy
12:05 – 12:20	**International Perspective -** Closing the Epilepsy Treatment Gap
12:20 – 12:40:	**Panel Discussion of Regional Perspectives – South East Asia and Western Pacific** Fostering Epilepsy Social Care: Regional Examples
12:40 – 13:00	**Multistakeholder Panel Discussion with Q&A** Challenges and Opportunities in the SEA region… *on ensuring equitable access to care*
Session 3	**14:00 – 15:30 - Doubling Epilepsy Research in Response to IGAP (Moderator: Francesca Sofia)**
14:00 – 14:15	**Personal Testimony -** View from Person with Epilepsy/Caregiver
14:15 – 15:00	**Regional Perspectives** - Research Needs in South East Asia and Western Pacific
15:00 – 15:10	**International Perspective -** Mapping Needs Beyond Healthcare: A Global Epilepsy Needs Survey from IBE
15:10 – 15:30:	**Multistake holder Panel Discussion and Q&A** Challenges and Opportunities in the SEA region… *on establishing baseline data for IGAP and building capacity for research*
Session 4	**16:00 - 17:00 - Prevention and Brain Health Promotion in Epilepsy (Moderator: Sebastian F. Winter)**
16:00 – 16:15	Opening Address Optimizing Brain Health Across the Lifecourse: Implications for Epilepsy
16:15 – 16:30:	**Regional Perspective -** Closing the Epilepsy Prevention Gap
16:30 – 16:55	**Multistakeholder Panel Discussion and Q&A** Challenges and Opportunities in the SEA region… *on getting to Global Brain Health: Policy Priorities for the Region*
Closing Session	16:55 – 17:00 Closing Remarks & Future Outlook

INDIAN EPILEPSY SOCIETY

ELECTIONS 2023

NOMINATION FORM for President Elect, Secretary General, Treasurer & Executive committee Members

Name of the Post:

Name and Address of Nominee:

_____

_____

_____

Proposed by

Signature _____

Name and Address _____
_____
_____

IES No. LM_____

Seconded by

Signature _____

Name and Address _____
_____
_____

IES No. LM _____

I, Dr. ……hereby give my consent for my nomination for the post of President Elect, Secretary General, Treasurer of the INDIAN EPILEPSY SOCIETY, the election for which is to be held in 2023.

Signature:

Name and Address:

IES No. _____

Last date & Time for Receipt of Nomination	: June 15th 2023 05:00 PM
Last Date & Time of Withdrawal	: June 22nd 2023 05:00 PM
Last date & Time of Receipt of Ballot Paper	: 18th July 2023 by post/courier before 05:00 PM

P.S. Only members meeting requirements can file in nominations, any member can propose and second the nominee. Please enclose a brief bio-data of the nominee in not more than 200 words.. Send soft copy to secretarygeneralies@gmail.com

Completed Hard and e mail copy of form should be sent to (Hard copy is essential):

Dr. Manjari Tripathi, Returning officer and Secretary General, Indian Epilepsy Society, Professor Neurology, Department of Neurology Room no 705, Neurosciences Centre, AII INDIA INSTITUTE OF MEDICAL SCIENCES, New Delhi, India,110029

INDIAN EPILEPSY SOCIETY: NOTICE FOR ELECTIONS 2023

It is for the information of all members of the IES that **Elections** are due for the posts of **President, President-Elect (PE), Secretary-General, Treasurer and 5 Executive Members**

The election process will be completed as per the Constitution and Byelaws of the Indian Epilepsy Society. The details are as follows:

1. The term of office of the President, President-Elect and 5 executive members shall be 2 years 2023-2025. While for the Secretary-General and Treasurer shall for a period of four years 2023-2027.
2. One complete year shall be counted from one Annual General Body Meeting (AGBM) to the next GBM.
3. Eligibility for various posts shall be as under:

    a) President: 10 years continuous, uninterrupted Membership of IES and should have served for minimum 4 years in the Executive Committee of the IES.
    b) President-Elect: 10 years continuous, uninterrupted Membership of IES and should have served for minimum 4 years in the Executive Committee of the IES.
    c) Secretary-General and Treasurer: 5 years continuous, uninterrupted Membership of IES and should have served for minimum 2 years in the Executive Committee of the IES
    d) Executive Committee Members: 3 years continuous, uninterrupted Membership of IES.

4. Election Procedure:

1. The last date for filing nominations is June 15th 2023 . The last date for withdrawal is June 22nd 2023.
2. Election shall be held by a single non-transferable vote.
3. No member shall concurrently hold more than one post in the Executive Committee.
4. A member elected to any particular post shall complete his/ her tenure of that post before contesting any other post whose tenure starts before the completion of office of the existing post.
5. Any person elected as President shall not contest for any post in future.
6. Ballot papers (if required) will be sent to all IES Members in the last week of June 2023 and shall be returnable to the returning officer by 18th July 2023 by post/courier.
7. The Returning officer shall finalize the result before AGBM July 2023.
8. As per constitution Dr. M Tripathi has agreed to be the Returning Officer.
   Nominations to be sent on the enclosed nomination form by regular or email to
   secretarygeneralies@gmail.com

Indian Epilepsy Association
Election Notice

Notice is hereby given for election to the following posts of the Indian Epilepsy Association:
President-Elect -1
Secretary General – 1
Treasurer – 1

Nominations, proposed and seconded by one member of IEA on the prescribed form available at the IEA website, i.e., https://epilepsyindia.org/

The deadline for receipt of nominations is Thursday, June 15, 2023.
The last date for withdrawal of nominations is Monday, June 22, 2023.
Ballots for the elections will be available subsequently and should be received by the undersigned by Wednesday, July 19, 2023.

Prof. P. Satish Chandra
President-Elect
Returning Officer
Indian Epilepsy Association

ABOUT THE COVER PAGE

MicroRNAs and Epilepsy Diagnosis : A Technological Advancement

Introduction:

The microRNAs (miRNAs) were discovered in 1993, and subsequently evaluated for their physiological and pathological role in humans. Studies are presently targeted to identify these as biomarkers for the diagnosis of epileptogenesis. It is proposed that microRBAs may serve as a useful and cheaper tool to confirm diagnosis of epilepsy compared to present neuroimaging techniques that are expensive.

What are miRNAs?:

MicroRNAs (miRNAs) are a class of small (~19–24 nucleotides in length), endogenous, evolutionarily conserved RNAs that function as posttranscriptional regulators of gene expression. They primarily function by binding to complementary target sequences in messenger RNA (mRNA) and interfere with the translational machinery, thereby preventing or altering the production of the protein product.

The role of miRNAs in epilepsy:

The miRNAs (micro RNAs) are said to be a special kind of RNA, controlling the post-translational gene expressions of various genes and may help in the diagnosis of epileptic foci in persons with epilepsy [PWE]. Studies have shown changes in the expression levels of various circulatory/tissue specific miRNAs may differentiate epileptic phenomena such as epileptogenesis or drug responsive/drug-resistant epilepsy. The effect of miRNAs in humans with epilepsy was first studied in 2010, reporting the up regulation of miR-146 expression in patients with temporal lobe epilepsy [TLE] and hippocampal sclerosis. Early functional studies over several years have revealed that miRNAs are linked to seizure development, neuro-inflammation and changes in neuronal microstructure. It is hence anticipated that they have a potential to enable more effective diagnosis and clinical management of PWE. Further, the development of such biomarker techniques may significantly aid not only in understanding of several changes inside the brain during and between seizures, but may eventually improve diagnosis and effective clinical management of epilepsy. Biology (Basel). 2021 Nov.

Current status of miRNAs in epilepsy:

Supportive evidence till date suggests that miRNAs find their way into the blood stream and hence may enable diagnosis, assessing the risk of developing, monitoring, and treatment of epilepsy. The detection of potential biomarkers once validated appears to be a cheaper and useful tool to confirm diagnosis of epilepsy before the implication of expensive procedures like - MRI, PET, SPECT, and CT scans. While, more research is necessary, it is anticipated that the molecular imaging of the brain miRNAs, holds a great potential and promise in the determination of epileptogenesis and improved clinical management of PWE.

References:

1. Recent Developments in Diagnosis of Epilepsy: Scope of MicroRNA and Technological Advancements. Ritam Bandopadhyay et al. Biology (Basel). 2021 Nov; 10(11): 1097.

2. MicroRNAs: History, Biogenesis, and Their Evolving Role in Animal Development and Disease. M. Bhaskaran and M. Mohan. Vet Pathol. 2014 July ; 51(4): 759–774.