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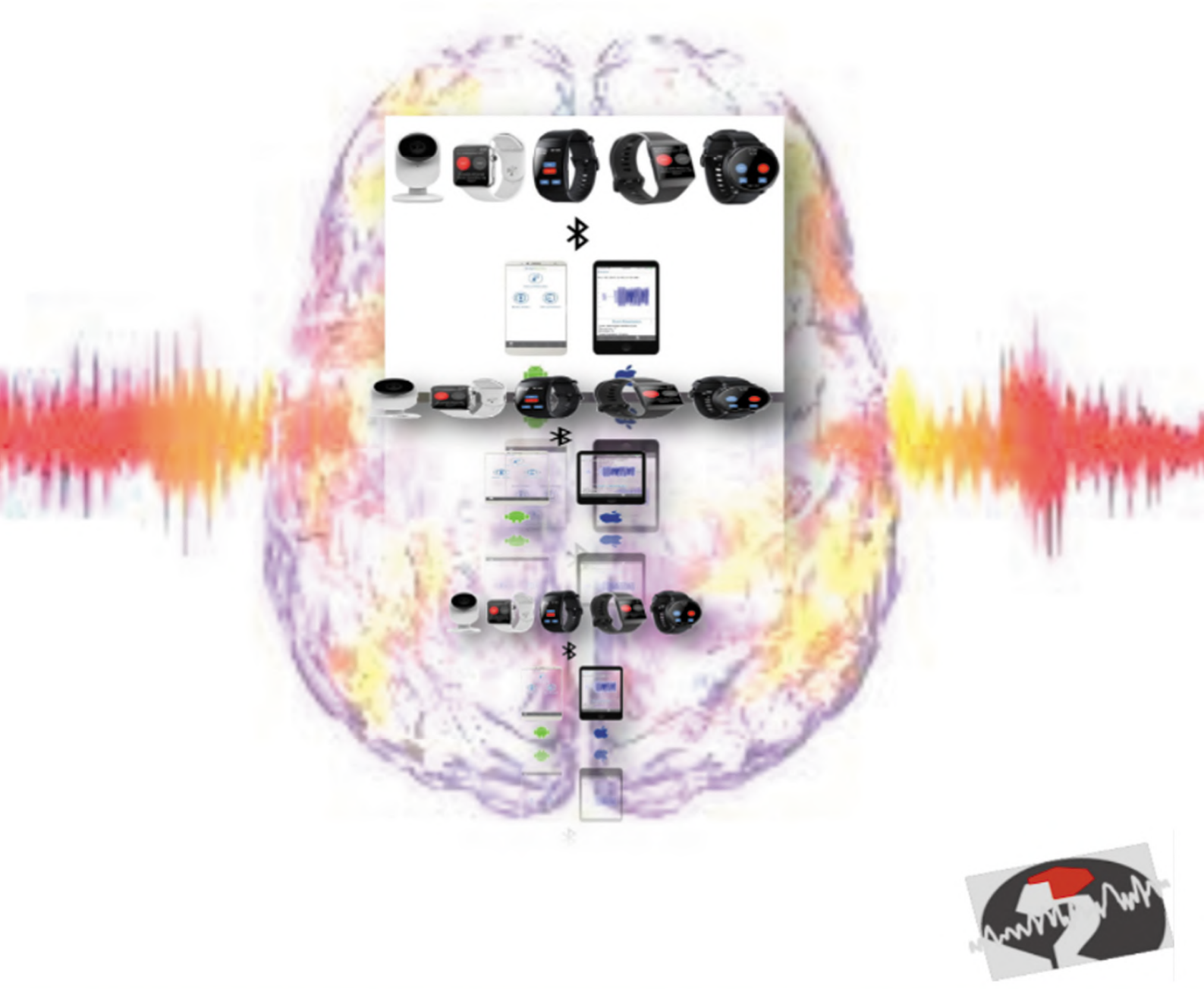

Seizure Detection Devices [SDDs]

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Editorial...

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The Editorial team wishes all its readers and their family a healthy and joyful New Year -2022! While, we enter into the New Year with lots of aspirations and goals, we continue to remain challenged with the ongoing Covid – 19 pandemic. However, we should unitedly ensure that we will face the same with confidence.

The year 2021 has seen the inception of a series of monthly webinars on variety of topics covering important aspects about epilepsy as a part of Golden Jubilee celebrations of IEA. As you all are aware these have national level audience. In this connection we are happy to bring to you in this newsletter the brief summary of reports on these received from- Mumbai, Hyderabad and Bangalore Chapters. The topics so far covered are -factors precipitating seizures, Epilepsy in Children and issues related to driving are summarized here. The webinars had well known experts on the panel from each chapter, isn't it great?In this connection, we request all the members of IEA to kindly share this information with your friends so that the information truly falls under "BEST" webinar series to reach out everyone across to the country to create awareness.

There is an important article from Dr.K.S. Anand, who has given an overview of sleep related hyper motor epilepsy initially known as 'Nocturnal frontal lobe epilepsy'. Also, Dr. Suvasini Sharma and Dr. Prabhjot Kaur, have given us information on'Ketogenic diet' in Pediatric Epilepsy. Ketogenic diet is an option for cling refractory epilepsy. In addition the awareness activities on epilepsy from Jaipur and Rajasthan Chapters are also shared here.

Covid - 19 has been a difficult situation globally and the moment we feel we have waged the wave we have a new variant threatening us! So friends, take care and do continue to take all necessary precautions.

We request persons with epilepsy and their care givers not to hesitate to share their challenges if any which they are facing, during this pandemic. We assure that our experts will guide you in clarifying your concerns to the extent possible!

Stay tuned friends.

Once again wishing you a healthier and a wonderful year ahead.
Best of 2022 to all

Bindu and Chanda

SLEEP-RELATED HYPERMOTOR EPILEPSY

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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 expertsin order torecognize 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 duringnon-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 andinclude: 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 paresthesiae, 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 extrafrontal 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 andonset 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 extrafrontal 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 undercontrol 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 SHEare: 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. Drugrefractory epilepsy associated with structural causes like cortical dysplasia responds to surgery.

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KETOGENIC DIET IN PEDIATRIC EPILEPSY

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Pediatric epilepsy is common in pediatric practice, almost 30% of which have drug refractory epilepsy. The treatment options for refractory epilepsy include epilepsy surgery, vagal nerve stimulation (VNS) and ketogenic diet. Epilepsy surgery is an excellent option for many patients with focal, structural lesions, however is limited in our country by the limited availability of epilepsy surgery centers with good expertise in managing pediatric epilepsy. Moreover, many children are not good candidates for epilepsy surgery. Good quality evidence for use of VNS in pediatric patients is lacking. Ketogenic diet (KD) offers a good therapeutic option for children with refractory epilepsy not amenable to epilepsy surgery.

What is ketogenic diet?

Ketogenic diet is a high fat, low carbohydrate and protein diet. The "ketogenic ratio" refers to the ratio of total weight of fats to the weight of proteins and carbohydrates in the diet. This ketogenic ratio varies in different types of ketogenic diet. The different types of KD currently available are as follows:

1.Classic KD: In classic KD the ketogenic ratio is 4:1 and derives 90% of the total calorie intake from proteins. It is a highly restrictive diet and requires hospitalization at initiation for monitoring of the anticipated side-effects. Diets with ketogenic ratio of 2.5:1 or 3:1 are better tolerated as compared to 4:1 diet.

2. Medium-chain triglyceride (MCT) KD: MCT-KD derives 70% of the total daily calorie intake from fats which are provided in the form of MCT oil. It is less restrictive and more ketogenic as compared to classic KD as the MCTs break down and are absorbed more easily.

3.Modified Atkins Diet (MAD): MAD derives approximately 65-70% calories from fats. The quantity of protein intake is unrestricted. Admission for diet initiation, prior fasting and calorie, protein and fluid restriction is not required. Better palatability and ease of administration makes it a feasible option for pediatric patients.

4. Low Glycemic Index (LGI) KD: LGI-KD derives ~60% calories from fats, carbohydrates with low glycemic index are allowed and high glycemic index carbohydrates are restricted. Although ketosis is lesser as compared to other diets, efficacy has been found to be similar to other KDs.

Mechanism of action of ketogenic diet :

Though the exact mechanisms of anti-epileptic effect of ketogenic diet remain elusive, there are many postulated mechanisms of action. Being a carbohydrate deficient diet, KD produces ketosis in the body. Ketosis is hypothesized to result in potassium channel activation thorough hyper-polarization, potentiation of GABA-enegic activity with gultaminergic inhibition in the brain and reduced synaptic excitability in the long term. KD also results in increase in levels of polyunsaturated fatty acids (PUFA's) like arachadonic acid, docosahexanoic acid and ecosapentanoic acid. PUFA's are known to activate peroxisome prolife rator-activated receptors (PPAR-α) which may have anti-seizure effects. Alterations in the gut microbiome and pro- and anti-inflammatory mediators may also have a role to play in the anti-epileptogenic effects of KD.

Indications of KD :

1. 1st line therapy for epilepsy with cerebral glucose transporter deficiency type 1 (GLUT-1) and pyruvate dehydrogenase deficiency

2. Refractory epilepsy associated with:
   a) Otaharra syndrome
   b) West syndrome
   c) Lennox-Gastaut syndrome
   d) Dravet syndrome
   e) Tuberous sclerosis
   f) Epilepsy with myoclonic-atonic seizures
   g) Non-syndromic refractory epilepsy
   h) Acute onset, refractory status epilepticus

Contraindications of KD

Absolute contraindications

- Carnitine palmitoyltransferase I or II deficiency
- Carnitine translocase deficiency
- Primary carnitine deficiency
- Pyruvate carboxylase deficiency
- Medium & long chain 3- hydroxyacyl-coenzyme A dehydrogenase deficiency
- Short, medium & long chain acyl dehydrogenase deficiency
- Porphyria

Relative contraindications :

- Non-compliance
- Definite surgical focus
- Propofol use

Pre-requisites for KD initiation

1. Parental counseling for parental education and understanding financial, socioeconomic and parental moti vation for KD initiation.

2. Nutritional assessment by a nutritionist for evaluation of dietary requirements, looking for any allergies, practicability and social issues prior to KD initiation.

3. Baseline investigations include complete hemogram, liver and renal function tests, lipid profile, serum electrolytes, serum vitamin D levels and serum acylcarnitine levels. Additional investigations as required per case basis may be ordered.

Basic protocols for KD initiation

There is increasing shift towards domiciliary KD initiation protocols of late. Previously hospital admission with 12-24 hours fasting prior to KD initiation was recommended. Currently liberal approach without fluid and calorie restriction in followed. KD can either be initiated at 1:1 ratio and built up to 4:1 ratio or be directly initiated at 4:1 ratio. The direct initiation of 4:1 KD has not be found to have significantly higher side effects with a similar efficacy. MAD and LGIT diets can be initiated on out-patient basis. Initially patients are called back at short intervals, which are gradually prolonged as parents become confident in managing KD at home. The international KD study group recommends daily supplementation with oral calcium, vitamin D and multivitamins for children on KD.

Follow-up and monitoring

Frequent follow-up is required at time of initiation of KD. Measurement of daily serum ketone (beta-hydroxy butyrate) levels is ideal. Patients should be followed up monthly initially followed by 3 monthly. Note should be made of seizure frequency (preferable using a seizure diary), ketosis, compliance with diet and issues faced by parents in preparing and giving the KD. KD related issues must be adequately addressed and KD suitably modified to ensure continued compliance. Detailed clinical examination should be done at each visit with emphasis on anthropometry and signs of nutritional deficiencies.

Laboratory monitoring includes hemogram, liver and renal function tests, serum calcium, magnesium, phosphate levels, fasting lipid profile and vitamin D levels. These should be done 3-monthly in the 1st 6 months and can be subsequently spaced out. Kidney ultrasound for renal calculi, EEG and serum acylcaritine levels may be done less frequently.

Side-effects of ketogenic diet

1. Metabolic alterations like hypertriglyceridemia, hypercholestrolemia and decreased low-density lipoproteins may be seen.

2. Gastrointestinal side effects can be seen in almost 50% of children initiated on KD. These include vomiting, diarrhea, constipation, gastro-intestinal reflux and pain abdomen.
3. Renal complications like renal calculi may be present in 5-7% cases. The risk is reportedly decreased by

administration of oral citrate; however, it has not been equivocally proven.

4. Growth: The long-term effect of KD on height is not clear, both decreased and normal growth rates have been reported. Hence, height should be monitored at each visit.
5. Osteoporosis has been reported in children on long term KD.
6. Cardiovascular: Prolonged QTc interval and cardiomyopathy have been reported with prolonged KD, however, long term effects have not been well studied till date.

Discontinuation of KD

International KD consensus guidelines recommend a trial of KD for at-least 3 months for evaluation of efficacy. In children who have responded with >50% reduction in seizure frequency should be continued on KD for 2 years following which it can be tapered and stopped. KD discontinuation has to be tailored for each patient. Short therapy for 6 months may suffice for west syndrome patients, whereas prolonged KD may be required for GLUT-1 deficiency. Classical KD is gradually tapered over 4-6 weeks. The 4:1 KD is modified by gradual addition of carbohydrates into diet prior to stopping. It can be re-initiated any time seizure frequency worsens. Around 80% children are reported not to have a recurrence of seizures once KD is stopped.

Indian Experience of pediatric ketogenic diet

Results of Indianized version of ketogenic diet using socially accepted foods was published by Nathan et al in 2009, using a ketogenic ratio of 4:1 – 2:1. They reported > 50% reduction in seizure frequency in ~80% of children with refractory epilepsy; of which 37% achieved 100% seizure control and 22% had seizure reduction between 90-99%. Subsequently, KD with ketogenic ratio 4:1 for children older than 18 months and 3:1 in <18 months was reported to result in >50% seizure frequency reduction in 48 % and seizure freedom in 15% at end of 6 months by Sharma et al. KD with ketogenic ratio of 2.5:1 was found have similar efficacy to 4:1 KD in an open label randomized control trail by Raju et al, with similar rates of side effects. An RCT comparing simplified MAD with no KD reported a significantly higher proportion of children with >50% reduction in seizure frequency in the MAD arm (56.1% vs 7.5%, $p < 0.0001$) as well as proportion of children with 90% seizure reduction (19.5% vs 2%, $p = 0.09$). A recent RCT by Sondhi et al comparing KD, MAD and LGIT did not find significant differences in the change in seizure frequency after 24 weeks of intervention, however non-inferiority of LGIT and MAD to classic KD could not be proven. Lower ketogenic ratio KD, MAD and LGIT had a better side effect profile and were better tolerated as compared to classical KD in most studies.

Conclusion

KD offers an effective and feasible option for drug refractory epilepsy in children. Considering that there is good evidence to support the use of less restrictive diets which are better tolerated and are associated with fewer side effects, these should be offered to suitable candidates for KD.

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SEIZURES PRECIPITATING FACTORS

REPORTED BY
CAROL D'SOUZA

MUMBAI

To celebrate the completion of 50years, the Indian Epilepsy Association decided to have a series of epilepsy related webinars conducted by its various chapters. On 19th September, **Samman, the Mumbai chapter of the Indian Epilepsy Association,** hosted a program on **Seizures: Precipitating Factors.** After an introduction and welcome by the IEA President Dr. Vengamma and Secretary General Dr. Gagandeep Singh, the **Moderator Neuropsychologist Dr. Urvashi Shah (US)** introduced the panelists: Neurologists Dr. Pravina Shah, Dr. Sangeeta Ravat, Dr. Jayanti Mani, Dr. Joy Desai, Psychologist Carol D'Souza, and Entrepreneur Pooja Nandi. The panel discussion then proceeded as follows. After each panel member spoke the moderator gave a summation, which has not been mentioned here below.

US: Dr. Pravina Shah (PS) can you tell us what is meant by seizure precipitating factors? Patients often ask whether it refers to the cause of seizures?

PS: There are multiple causes or reasons for epileptic seizures. Whatever the cause, there is in some part of the brain a seizure focus or epileptogenic zone. With anti-seizure medicines we try to keep this focus quiet so that there is a normal rhythm and normal brain function. While some patients have their seizures under fullcontrol,othersget only partial control. Everyone has some sustainable seizure free period with optimum dosage of medication. But at times there are external factors which try to provoke these foci into behaving abnormally and then quite unexpectedly one has a breakthrough seizure. These external factors are known as Precipitating Factors or seizure triggers. From a detailed history of the patient and family it is possible to identify these triggers. Some are general and some are patient specific. With proper understanding one can avoid them to achieve better seizure control and a better quality of life. So, it is important to discuss them in detail.

US: we asked our members who have epilepsy to send us videos and tell us about their seizure triggers. And this was the video sent by Pooja Nandi (PN) who after a very successful stint in the corporate world has started her own business.

PN: Hello friends, I Pooja, have been getting seizures for the last 35 years of my life. Over the years I have found that there are 4 main factors that trigger my seizures. One is skipping medicines – if I have missed a dose or two, I am likely to get a seizure. The second is lack of sleep – so if I have not slept well the previous night, again there is a higher risk of getting a seizure the next day. Third is work-related stress: for instance, in a really high-pressure situation, my body may just give up. And finally, the 4th one is related to my period cycle. These are mutually exclusive or they could overlap. I try and avoid these triggers and my health has improved and the number of seizures has gone down.

US: Dr. Jayanti Mani (JM) can you tell us about the importance of taking medicines regularly? Can one miss a dose or even stop taking medicines?

JM: One should never miss medicines, but if it does happen, then as soon as you realize you have missed a dose you can take it, and then space out equally the next 2 doses or keep at least 4 hours before your next dose.

Abruptly stopping medicines can be extremely dangerous. We (neurologists) have seen patients, especially pregnant women abruptly stop medications, also some patients cannot come to terms with taking medicines daily, so they stop. Another reason for stopping medication is because of the experience of side effects. Also, some patients may feel they are doing well so they have no need tocontinue taking medicines.

I tell people with epilepsy to not consider themselves as'patients', they should know that taking medicine is like taking insurance. You take it because it lowers the risk of having a seizure. If you have concerns about taking medication, discuss these with your doctor. Doctor visits are not only for changing medicines, it is also to discuss all the concerns you may have.

US: Inadequate sleep is seen as another big seizure risk – Dr. Joy Desai (JD) how important is the timing and quantity of sleep?

JD: Yes,sleep is very important. I see patients who are doing extremely well on appropriate medication, suddenly report seizures when they have an important project or submission going on which involves staying awake till 2-3 in the morning. And they feel when they are taking their medicines on time this should not be happening. One needs to know that sleep is not a passive process, the brain is actually doing a lot of work – we have science that showsthatbrain cells talk to each other duringsleep. There are some cells that are cleaning up the space between 2 cells in the brain which accumulate neurotransmitters like potassium glutamate and this happens only at night. And if you have too much potassium glutamate in this space it creates the background for a seizure.

Another concept not understood by most is that the brain is wired to sleep about 4 to 4 ½ hrs after sunset and wired to wake up after sunrise. The whole benefit of sleep is optimum only when we are in synchrony with this. That is our biological wiring. In our part of the world, it means sleeping at around 10.30 pm and waking at 6.30 am. If we can manage that, then that is a very optimum sleep hygiene and the benefit of sleep will come through. So, if a patient asks can I sleep at 1 am during an exam – I say no – if the other students start

studying for final exams in January, you please start studying from November. Timing, quantity and the discipline which one observes, is most important.

US: Women with epilepsy complain that during the menstrual cycle, they have more seizures. Dr. Sangeeta Ravat (SR) can you tell us what can be done to avoid this ?

SR: During menstruation there are a lot of hormonal changes in a woman's body. Estrogen is epileptogenic and progesterone is protective against seizures. During menses estrogen goes high and progesterone goes down. Those affected by this are said to have catamenial seizures. If you have catamenial seizures, contact your doctor who will recommend that you either have an additional tablet or may increase the dose of anti-epileptic drugs you are on for 6 to 7 days of your menses. Rarely one might have to take hormonal treatment to control catamenial seizures.

US: Does epilepsy itself cause menstrual irregularities?

SR: When you have temporal lobe epilepsy, from the temporal lobe the seizure discharge goes to the hypothalamus from where hormones are secreted. So,one may have irregularities due to epilepsy itself. Secondly anti-seizure medicationespecially Valproate can have an effect on the ovaries which may cause Polycystic Ovarian disease. So, if you have something like this contact your gynaecologist as well as your neurologist and jointly, they can manage this problem.

US: We will now show you the video sent by Shenaz Haveliwala (SH) who is an entrepreneur as well.

SH: Hi, I have epilepsy since the last 15 yrs. It all started out of the blue, I was in college and suddenly got a convulsion. I have tried everything from brain surgery to the keto diet, I am on a very high dose of anti-epileptic drugs. My main triggers I would say is an overwhelming feeling, any sort of anxiety or excitement, I will get a seizure. Then another thing would be stress. I have my own business and I have to do everything from scratch. And it is not the work, it is the deadlines – having to do work fast, under pressure, is what causes a problem. I have also noticed that when brisk walking or sometimes jogging, I could get a seizure. It is strange because when I do it cardio at home, I am perfectly alright. I am very particular about having good sleep and taking my medicines – so no problems there. I have found that stopping dairy has helped me. And sometimes when I go out, I have a little coffee which helps me.

US: Dr. Pravina Shah, do you think that certain kinds of diet, as Shenaz mentioned, are important and affect seizures? Also, would alcohol consumption increase seizures?

PS: Everyone should have a good balanced diet. Taking food at regular times and intervals is certainly helpful to prevent seizures. There should be no fasting. Reactions to particular foods like milk as suggested by Shenaz,is more person specific. However, it may be that the indigestion and bowel movements the milk caused can give discomfort and this indigestion may precipitate a seizure. Very often Gujaratis say that channa or kaddhanya is not suitable to them. Again, this may be causing indigestion which may precipitate a seizure.

The Ketogenic diet of course is a very specific treatment for epilepsy.

Regarding alcohol, at times when one wants to socialize, one or two drinks are ok. When one has too many drinks for a long period it can make him or her a chronic alcoholic. And when these are withdrawn, seizures appear as part of the withdrawal symptoms. Even sometimes a person may fall due to being in a drunk state and this causes a head injury which can result in a subdural hematoma and seizures may follow.

US: Stress seems to be a common trigger and most people talk about it, even if there is excessive happiness, that can also precipitate a seizure, so Carol D'Souza(CD) can you tell us how this can be better managed and why is this happening?

CD: When people talk about managing stress what they are really saying is how do I manage my life better. It is not that people with epilepsy do not know they have to take their medicines on time, eat on time, exercise, sleep well etc. But they somehow don't do that; because it is very easy to value other things. It is very easy to value one's job because it brings food on the table and gives the person a sense of self-worth. It is very easy to value digital entertainment because it brings immediate satisfaction. All this cuts into your sleep. And you do this once or twice, it may not have any effect on you so you are encouraged to do it more often and then one day you get a seizure. So, it is time people with epilepsy asked themselves "what am I valuing? what am I giving priority to?" and honestly evaluate what changes they can make.

The second thing is Acceptance – accept your epilepsy – we hear so much about being epilepsy warriors that we think we have to fight every time. In fact, what you resist, persists. But really, before anything else if we first accept what is, it clears the mind and we are better able to make decisions and take action.Even if you fight your condition, eventually you may take the same action but it would come after a lot of unnecessary suffering and pain.

The third thing is that one gets seizures mostly because of a combination of factors. So, if you are under stress, say you have exams going on or a heavy work load which has you staying up late then please see that someone in your family sees to it that you have your medicines – not just keep it in front of you but also sees that you take it. Because it is very easy when your mind is full of other stuff to forget about your medication. Even if the medicine alarm is kept, you tend to say to yourself "yes, yes, I will take it" and then forget to do so.

Also, during times of stress, please do not engage in any mental drama – say you have exams going on – just focus on your studies and don't think about what would happen if you don't get a certain percentage – or what would your parents say etc. etc. This will just cause you additional stress which can trigger a seizure.People with epilepsy should remind themselves that at best they can handle one thing at a time – so please no mental drama. And if you are just looking at your books and not assimilating anything, then it is better you sleep. Because sleep is very important; get up early instead of staying up late.

The last thing that needs emphasis is that people with epilepsy always feel they are being told not to do this and not to do that and they begin to resist. The way it can work is if from young, as soon as the child becomes a teenager, the parents have to give the decision making to their child. The parent could inform what could happen if one stays out late – which of course the child already knows, but a blanket ban is not a good thing. Your child might get a seizure if he stays out late but he could also get a seizure if he is angry about not being allowed to go for a party. Have the same rules you would have for your other kids – say going out only if the next day is a holiday – once or twice a month. Parents cannot and should not protect their children so much that they do not allow them to grow. Being exposed to different experiences

and going through pain and suffering after making one's own decisions is what builds inner resources. If parents do have kids who listen all the time, that kid is not going to make a decision on his own when he needs to.

US: The last video we have comes from AnkushT. (AT)who works as a Chartered Accountant.

AT: Hi, today I can tell you that improper sleep hygiene, lack of emotional awareness and not spending enough 'me time' is what precipitates my seizures. In order to deal with these, I make sure to sleep on time, I have become more self-aware and have grown up mentally and emotionally. Importantly in order to spend more 'me time', I incorporated my commute to work on my bicycle which helped me spend more time by myself and on my passion. I hope you are keeping well just as I am.

US: As Ankush said 'Me Time', 'Emotional stability' and 'Self-awareness' is important to think clearly and take appropriate action. Pooja as a professional can you comment on this - how did you manage the stress in the work place? And how did you face reactions from colleagues and peers to epilepsy?

PN: Targets and deadlines do cause high pressure and stress. Working in a corporate set up is high pressure. But what really can affect one is getting a seizure at work, after which one needs to go back to work the next day and face the same team. What Ankush spoke about is having me time and clearing one's head. What happens is when we get a seizure, it is a physical thing, our IQ does not change. We just have to gather our thoughts and go back to work the next day. Yes, there will be some murmurs and sympathy and people will ask if all is well. I firmly feel if we say and show we are fine then people start saying "Oh wow, she is good – she can continue to do the work". We have to continue to prove ourselves which is true for normal people as well. Accepting that epilepsy is just a part of my life and does not define me, helps me to deal with it much better. There will be times when colleagues will say, "she has epilepsy, she will get a seizure, itna stress mat de usko, girjayegi". I have laughed with colleagues when they have said this. And proven myself inspite of it – that really works. I also think parents and siblings also plays a very important role. No one made me feel special, positively or negatively – everyone treated me as normal – and most of all I choose to lead a normal life.

US: Fever is often seen as a trigger for seizures especially in children, Dr. Mani what should parents do when the child has a high fever?

JM: It is true that some kids, even when they do not have any other illness, can have a seizure with fever, but usually it is one or two times during their childhood from 6 months to 5 years. And really nothing much needs to be done other than the first aid measures. If you know your child has had seizures with fever in the past, just take extra precaution to keep the fever down. And if you child keeps getting seizures with fever then talk to your doctor about medicines you can take intermittently during the fever.

Very rarely even in adults, fever may trigger a seizure, so if you feel this happens with you, take rest, don't pack your day, take your medicines on time and don't get into risky situations!

US : Dr. Joy Desai, people do a lot of screen time these days – how much can one safely watch without precipitating a seizure?

JD: Very simply if exposure to screen time is more than 4 hrs in a 24 hour cycle, then there is a good chance that there is exposure to excess blue light emitted from your screen and blue light is an inhibitor for melatonizaton. Melatonin as we know helps us sleep. If you've had a lot of screen time, then it is likely your sleep will be shallow and very likely your sleep will be delayed. One could get a screen guard which shuts of blue light or better still one could limit screen time.

US: Dr. Pravina Shah, do the phases of the moon precipitate seizures?

PS: There are certain random reports and random studies which indicate that the lunar phase affects the physiology in certain people, especially on a full moon day. This is actually more obvious amongst animals. But it does happen to affect some people, not all. There are also reports that there are changes in behaviour, for example one becomes more angry or more aggressive or more emotional during this time which could precipitate seizures. For some, getting a seizure on a full moon day could simply be coincidental. However, there is no concrete research or results so far in this regard, but I do feel there is some truth in this.

Questions from the Audience were then taken up by the moderatorDr. Urvashi Shah as follows:

US: Prof. Satishchandra could you comment on how water acts as a seizure trigger?

Prof. Satishchandra : There are individual trigger factors which vary from person to person. It could be flickering lights, hot or cold water or even music, all these are broadly classified as Reflex epilepsy i.e. reactions to certain sensory stimuli which result in a seizure. Hot water epilepsy is much more common in the southern part of India where people come to us and explain that when they put hot water on the head they get a seizure. It happens to them because there is a sensitivity to thermal temperature and the way they pour the water over the head. We suggest not to use very hot water and if they must – they could also take a tablet and then enjoy a hot water bath. There are many other sensory factors that may act as triggers such as eating food. For any of these always speak to your doctor / neurologist and together you can find a way to avoid or prevent these or cope with them appropriately.

Dr. Manjari Tripathion other seizure triggers – in our population there is widespread use of balms which contain eucalyptus oil and application of these balms to the surface or inhalation can cause a seizure – and it is quite common. Then again use of over-the-counter medication which act as pro-convulsants is quite common in our country. So always a history of concomitant medicine intake should be taken when one reports a seizure.

US: Can a woman who gets seizures take medicines to postpone her period?

Dr. Srinivas: As mentioned estrogen is a trigger factor, one can take a medicine which contains a high dose of progesterone to postpone the period.

US: If we are in the hostel alone by ourselves how do we ensure we take our medicine?

Dr. Jayanti Mani : It is a good point as many young teens are travelling out and staying without parents – I always advise keeping a flatmate or roommate and, in this day, and age it is always possible to have someone phone you or you can keep a reminder on your phone.

Dr. Srinivas: Right from the age of 7 I tell parents to train their kids to take their own tablets. Other problem is the Hindu wives, giving the husband water and tablet. And then when the husband travels he forgets to take his medicine. So, it is important for the patient to take his own medicine. He can keep the tablets along withthe food he places on the table.

US – what difference does environmental setting make on seizures?

Dr. Vengamma – I think environmental setting can definitely make a difference – say a new environment can increase stress and as we know stress is a trigger factor. **Dr. Bindu Menon:** Say if it is too hot, too bright, certain smells too can trigger seizures for some people. Environment can also make people depressed.

US – are certain types of food involved in eating epilepsy, what can be done in such cases

Dr. PK Sethi - the patient can tell you if certain foods trigger their seizures.

US : How has covid affected epilepsy?

Dr. Manjari Tripathi – During Covid many have not been able to obtain medicines. The lesson learnt is to always keep a stock ready – just as you buy 'atta' before your stock gets over. Similarly, always keep 2-3 weeks medicines on hand and make sure they are within and not nearing expiry.

Covid was very mild in 80-90% of the people with epilepsy who got affected. It was necessary of course, to avoid all medicines which could promote seizures. Regarding vaccines, I recommend that they be taken and thatCovaxinwould be better than Covishield for people with epilepsy

The meeting ended with Dr. Gagandeep& Dr. Vengamma thanking Samman, especially Moderator Dr. Urvashi Shah for a wonderfully conducted and informative session.

The next session will be conducted by Bangalore chapter Oct 17 Sunday at 5 pm and they will be discussing 'Driving & Epilepsy'.

EPILEPSY AND DRIVING

REPORTED BY
DR KALYANI DILIP KARKARE

BANGALORE

On the occasion of 50th year of Indian Epilepsy Association, BEST (Beat Epilepsy Stay Informed) webinar series arranged by central chapter IEA, had its third webinar on "Epilepsy and Driving" on October 31st, 2021, hosted by IEA Bangalore Chapter. The eminent panelists included senior neurologists Dr PV Rai, Dr P. Satishchandra, Dr G.T. Subhas, and Mr Shivaraj Patil - retired Additional commissioner for transport; with Professor Joga Rao - Advocate and Healthcare consultant, Bangalore. The President of IEA Bangalore chapter Dr Suresh, Secretary Mr Chandrashekhar, Treasurer Mr Janardhan and Senior Neurosurgeon Professor Malla Bhaskara Rao actively particpated in the session. Dr Gagandeep Singh- secretary IEA and Dr Manjari Tripathi – executive meber of IEA and Secretary IES were few other distinguished attendees.The session was skilfully moderated by Dr H V Srinivas, senior neurologist and a crusader for social reforms in the lives of persons with epilepsy.

At the outset, Dr Suresh welcomed all and evoked the memories of late Dr Mani, "Father of Epilepsy" in India. Mr Chandrashekhar introduced the panelists. Dr Srinivas kickstarted the session with a small introduction about the current status of "Driving and Epilepsy" in India. In the interest of public awareness, Dr Satishchandra elaborated the definitions of seizure and epilepsy and enumerated the causes of provoked and unprovoked seizures. With the impact of diagnosis of epilepsy on the prospects of driving, it was well emphasized by Dr Subhas that only a neurologist should certify the diagnosis of epilepsy. The current scenario has any Government Doctor (MBBS minimum) signing the form for fitness for driving license as pointed by Mr Patil which was rigourously discussed in the panel. Mr Patil pointed out that amendments for driving license authorisation has been achieved in the past through constitution by voting for disabilities like mono-ocular visiosn loss (one eye blindness). On this, the panel emphasized that "Epilepsy is not a disability" and thus same rules can't be applied to it. Mr Joga Rao insisted legal reform in this aspect is necessary.

As the discussion progressed, various aspects of epilepsy and law were discussed. Dr Rai explained how seizures are the least of all the causes to cause accidents. The top most reasons are drunken and rash driving. Eye witness and CCTV footage may throw some light on the actual occurrence of event at the time of accident. Dr P Satishchandra discussed important issues regarding employment and epilepsy and medical insurance in persons with epilepsy.

The discussion also touched upon the day to day practice of neurologists which was elaborated by Dr Subhas. In a first unprovoked seizure, with low risk for seizure, it was discussed that driving can be resumed after 6 months of seizure free period and one year in those with high risk. The practical tips like avoiding late night or early morning drive and appropriate saferty measures like helmet on a two wheeler and seat belt in a car was emphasized by Dr P Satishchandra.

Giving an alternative job in professionl drivers with epilepsy is an option but the chances of acceptance from patient is variable and sometimes the suggestion may pose threat to the treating doctor as expressed by Dr Manjari Tripathi.

The idea for digital health card and its link to Aadhar card to facilitate the process was brought forward. The time interval to revoke license in a person who already has license and develops seizure later, was discussed.

Alongwith Prof Joga Rao, everybody agreed upon the necessity of a public interest litigation under "Right to equality"- section 14. It was discussed that the association should take steps to approach ministry of transport and ministry of health to pursue "safe driving rights" for persons with epilepsy with well controlled seizures.

Unique concepts like crash avoidance system in the anticipation of an accident were discussed too.

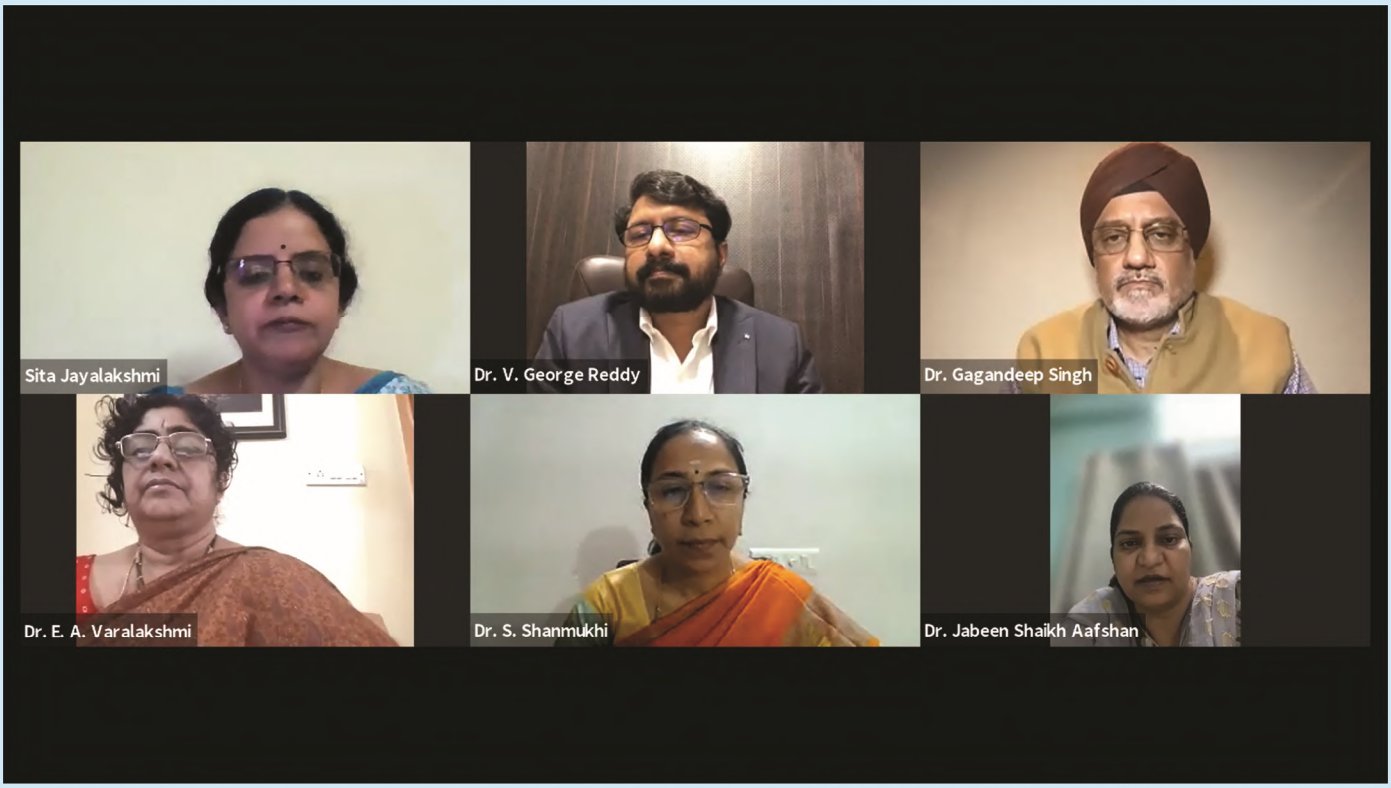
All and all, it was a fruitful, comprehensive, extensive discussion among the panelists from various fraternities which was concluded by Vote of Thanks by Dr P Satishchandra.

A drive for driving! Think and drive !!

EPILEPSY IN CHILDREN: BEHAVIORAL AND COGNITIVE ASPECTS

REPORTED BY
DR. SITA JAYALAKSHMI

SECUNDERABAD



The 4th webinar in the instrumental Beat Epilepsy Stay Informed series was conducted on Sunday, November 21, 2021, 05:00 – 06:00 PM by the Secunderabad chapter. Following the National epilepsy day celebrated on 17th November, it put another step forward in spreading awareness regarding epilepsy this time focusing on the topic of children with epilepsy.

Being with a child with epilepsy is definitely stressful for the parents and caregivers. Lot of myths and mis-concepts are still prevalent in our society partly due to lack of awareness and partly out of pure apprehension. So, this webinar did open a window of opportunity to reach the public across the nation.

Dr. Gagandeep Singh, Secretary of IEA started the session with warm welcome and a brief introduction of the topic. He generously introduced Dr. B Vengamma, President of IEA who highlighted the importance of reaching out large number of people and imposing the need for early detection and right treatment of children with epilepsy. Dr. E. A.Varalakshmi President of IEA Secunderabad Chapter then gave the opening remarks, discussed the unmet needs and burden of childhood epilepsy and the potential consequences on their growth and development. This was followed by Dr.Sita Jayalakshmi, senior neurologist, KIMS Hospital, Secunderabad starting the panel discussion with brief introduction of the panelists. Several questions were discussed during the sessions. Dr.LokeshLingappa, Paediatric neurologist from Rainbow hospitals described the possible etiologies for childhood epilepsy and seizures, also the mimics that are frequently mistaken for epilepsy. He also shared his views on precautions to be taken by school authorities and safety precautions during sports for children with epilepsy. Dr.Ramesh Konanki also a Paediatric neurologist from Rainbow hospitals elaborated the do's and don'ts for managing children with epilepsy.

He also shed light on the common notions of heredity in epilepsy. Dietary aspects and epilepsy were reviewed during the panel discussion. Dr. Jabben Shaikh consultant neurologist from NIMS, succinctly discussed various investigations and available treatment options for children with epilepsy. She also addressed to doubts raised about the safety and need for anti-seizure medications. Dr. Shanmukhi from KIMS hospitals elaborated about the behavioral and cognitive co-morbidities associated with epilepsy. She also advised on better handling and providing psycho-social support and allaying parental stress for epileptic young and adolescents. This was followed by Dr. George Reddy consultant neuro-psychiatrist addressing the impact of disorders like autism and hyperactivity on and due to epilepsy. He did put efforts in diminishing the stigma associated with and importance of initiating timely treatment on behavioral and psychiatric disorders associated with epilepsy. Dr. Anuja Patil from KIMS hospitals discussed about the need for long term care and compliance with treatment in epilepsy along with transition of care in in adolescents and young adults.

The entire session was instrumental in clarifying the commonly raised doubts and queries by parents. It reviewed zealous response of over a hundred participants from across the country. The queries raised during the online meeting were taken up by the panelists and keenly answered. Many parents and a few people with epilepsy themselves were forthcoming in sharing their ideas, also their concerns from the treatment aspects to impact on educational and career options.

It was a gratifying experience on part of the entire Epilepsy association of Secunderabad team. It is moments like these that bring us closer across all barriers in spreading awareness and enlightening not just people with epilepsy and their care giversbut society as a whole. The pandemic and its after effects has still locked us down us far off, yet brought us together just at a click’s distance.

It was one of its kind of webinar in the BEST series, which till now has cast light upon various facets of epilepsy and staying true to its name been a best informative series. Future similar events digital or in person as per the need for the time, will definitely prove to be encouraging.

REPORTED BY
DR. R.K.SUREKA

JAIPUR

A) AWARENESS TALK, EXHIBITION& RELEASE OF BOOK "HANDBOOK OF EPILEPSY – A PRACTICAL GUIDE "FOR FACULTY & STUDENTS, ANDGENERAL PUBLIC AT MAHATMA GANDHI MEDICAL COLLEGE, JAIPUR

An awareness talk and an exhibition depicting various facets of Epilepsy, myths and false beliefs prevalent in this part of the country, was organized jointly by Neurology Department of Mahatma Gandhi medical College, Jaipur and Jaipur Chapter of IEA in the foyer of hospital. It was attended by medical superintendent, faculty members and students of various departments of medical college and epileptic patients.

Chief Guest of the function was Prof. Dr.B.S.Sharma, Former Head of Department of Neurosurgery, AIIMS and presently PHOD Neurosurgery, MGMC. He launched the book "Handbook of Epilepsy – A Practical Guide "written by Prof. Dr. R.K.Sureka, PHOD, Neurology Department, Medical College.

Dr R K Sureka, was the main speaker who emphasized that pregnant epileptic women should register in the pregnancy and epilepsy registry of the hospital for safe delivery and proper management of pregnancy. He also threw light on various topics like epilepsy and marriage, epilepsy and driving and epilepsy and insurance. Prof Dr. B.S.Sharma brought about the various recent advances in surgery for epileptics. The other faculty members also addressed the gathering about epilepsy in children.

Photo 1: Inauguration of Exhibition on Epilepsy Awareness at Mahatma Gandhi Medical College, Jaipur by Chief Guest .

B) FREE EPILEPSY CAMP IN VILLAGE RATANNAGAR (DIST CHURU), RAJASTHAN

A free epilepsy and awareness camp was organized by Epilepsy Care and Research Foundation and Jaipur Chapter of IEA at CHC of Village Ratannagar ,Dist Churu (Raj) where about 552 patients attended the camp. In the camp, facilities of Neurologist, Psychiatrist and Physician and Pediatrician was made available for the patients. All patients were clinically examined and given free anti Seizure drugs for full one month. A counselling service for epileptics was also available in the camp and hand bills were distributed for awareness about epilepsy.

Photo 2: Examination of patients by Dr. R.K.Sureka , in the free epilepsy camp at Ratan Nagar Village, Dist. Churu

REPORTED BY
GCS SHREEMAL

GULABPURA, RAJASTHAN

The monthly camp on 23rd November 2021, sponsored by people from our society. Dr. RK Sureka along with his team of doctors visited our hospital and successfully examined 120 patients. Further, as usual, medicines were given free of cost.

On this auspicious occasion we have started following activities:

1) 45 minutes digital presentation on Epilepsy was presented on a large TV screen to all patients and society members.The presentation has received very positive feedback from patients and will be shown every day at the hospital.
2) Drawing competition was organized for patients aged between 6 and 15 years. 18 patients participated and prizes were given.
3) Exhibition hall was inaugurated by Dr. RK Sureka. In this hall various types of posters and flexes were displayed giving all relevant information about epilepsy. The digital presentation was also given in this hall.

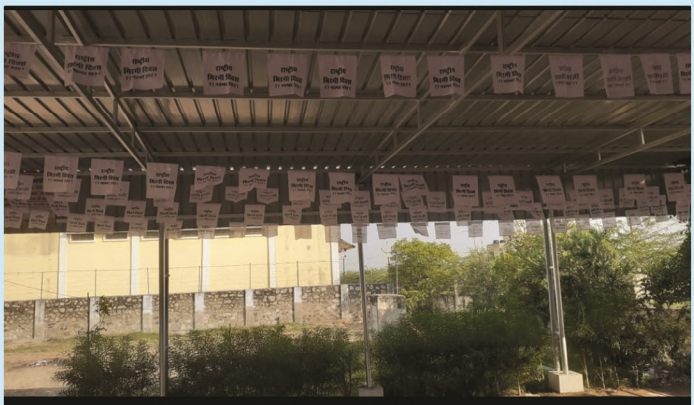
In addition to above activities, we would like to provide the exceptional progress our hospital has made during the COVID 19 pandemic period, i.e. April 2020 to March 2021:

1) Average number of patients per month during the year: ~1870.
2) Average number of patients attending monthly camps (held whenever feasible): ~48.
3) Number of new patients added during the year: ~1500.
4) Medicine distributed last year (free of cost): ~70 lac tablets.

This is the primary way our epilepsy hospital is serving patients and the community which consists of mostly poor families. Since it was established in 1978 ~48,500 patients have been registered and a computerized record of ~18,000 patients is available today. Records include patient name, address, treatment details, medicine received and others.

Inauguration of the camp


Sponsors attending the camp



Spreading epilepsy awareness through pamphlets

Dr. RK Sureka counselling patients

On the right, exhibition hall is visible

Digital presentation about epilepsy to the patients

Counselling given to patients on Epilepsy Day

Epilepsy children participating in drawing competition on Epilepsy Day 23 Nov 2021

ABOUT THE COVER PAGE

Seizure Detection Devices [SDDs]:

The anti-epileptic drugs [AEDs] are the main stay in the treatment of persons with epilepsy [PWE]. A proportion of them however are resistant to AEDs and need both AEDs and surgery. Further, the unpredictable course of this disorder adds to psychosocial impact on PWE. It is reported that there is at least one serious injury related to Generalized tonic-clonic seizures [GTCS] including focal-to bilateral tonic-clonic seizures [FBTCS]. Further, a study shows each year 25% of patients with GTCS experience injury which cause disability or require hospitalization or surgical intervention. As the number of GTCS increase per year there is increase in risk for injuries compared with PWE who only have one seizure per year (Salas-Puig et al., 2019). Therefore, this group particularly in the absence of an eye witness need early detection to safeguard themselves for necessary intervention.

SEIZURE Detection Devices [SDDs] hence appear to have made a breakthrough in the management of epilepsy through early detection and hence in early intervention. In particular several wearable SDDs – like wrist watch; wrist band; heart rate based mobile devices etc. are presently under continuous evaluation and are considered to be of significant benefit in detecting convulsive disorders. With advancement in technology the SDDs are being redesigned to suit individual requirement as wearable devices which help take prompt and necessary preventive measures in addition to using implantable AED delivery systems.

The Clinical Practice Guidelines [CPG] have been developed based on the methodology proposed and developed and are endorsed by the international bodies- The International League Against Epilepsy (ILAE) and The International Federation of Clinical Neurophysiology (IFCN) Guidelines Working Group. It is anticipated that technologically improved automated, wearable SDDs may soon provide promising option to reduce seizure related morbidity and mortality among PWE.

Reference: Clinical Neurophysiology; Volume 132, Issue 5, May 2021, Pages 1173-1184? Automated seizure detection using wearable devices: A clinical practice guideline of the International League Against Epilepsy and the International Federation of Clinical Neurophysiology.