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Epilepsy India



Newsletter of the Indian Epilepsy Association & Indian Epilepsy Society



Albert Melvin Grass

Father of first ELECTROENCEPHALOGRAM
[EEG] machine for - Epilepsy



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Dr. Bindu Menon



Dr. Chanda Kulkarni

Hello everyone,

We trust our readers and their family are safe and in good health.

It is with a heavy heart we mourn the loss of Dr. Vinod Saxena. He left for his heavenly abode on July 20th 2020. We all fondly remember him as an extremely cheerful, cordial and helpful person apart from being a well-known leader in the field of epilepsy. Dr. Saxena was the initial Editor of Epilepsy India newsletter and has played a pivotal role in the growth of IEA & IES. His passing away has left a huge void and we all look forward to fulfilling his dreams for the cause of epilepsy. May his soul rest in peace and pray God to give strength to his family to bear the loss.

The editorial office has received many reports on various epilepsy related outreach and awareness activities and we are happy to share the same in this issue.

The “Intra and Inter-regional synergy in Epilepsy” was conducted by Professor M M Mehndiratta in Delhi. This event has fostered Intraregional Synergy by inviting neurological experts at a national level and a web-conference for persons with epilepsy within India as well as Inter-regional experts. You will read on the various aspects covered in this programme. Congratulatory to the whole team for addressing the most important issue in epilepsy.

There is also a report from Mr. G.C.S. Shreemal, of Bhilwara, on the activities of Shri Pragya Mirgi Rog (Epilepsy) Centre. The centre is reported to offer its untiring services to persons with epilepsy for more than two decades. The vision and mission of this centre in accomplishing the patient centric goal for the cause of epilepsy needs to be applauded. A brief report is presented.

We are sure that many such activities have been carried out across the country and we encourage everyone to kindly share these activities as a brief report and as an inspiration to those working in the field of epilepsy.

Once again we wish you all good health

INTRA AND INTER-REGIONAL SYNERGY IN EPILEPSY - OUTREACH AND AWARENESS

Reported by

Dr. (Prof) Man Mohan Mehndiratta

Vice President IBE (South East Asia)

Member CAO ILAE

Secretary-General IEA Delhi Chapter

Epilepsy affecting more than 70 million people worldwide and around 23 million people in Asia (with around 50% of the global population) makes it one of the most common neurological diseases [1] Epilepsy treatment and care requires to be patient-centric and personalized. A holistic approach is required, which includes adequate medical treatment, psychosocial behavioural therapy, rehabilitation, etc. [2] People with Epilepsy (PWE) and their caregivers need to have accurate information of Epilepsy. This can have significant impact on their Quality of Life (QOL). PWE, their caregivers, and even healthcare workers need to be made aware of many aspects surrounding Epilepsy. These aspects include –

- Impact on socializing role such as regular schooling, marriage, children and employment
- Comorbidities or the cognitive, emotional and behavioural difficulties and disabilities associated with epilepsy.
- Risks and restrictions on activities such as driving and sports
- Laws pertaining to Epilepsy in the country and worldwide
- Misconceptions, negative attitudes, and stigma prevailing in the society surrounding epilepsy

These need to be addressed for an improvement in the QOL of PWE. [1,3]. Janakpuri Super Speciality Hospital Society ((JSSHS) an autonomous envisaged post-graduate institute under Govt of NCT Delhi, India) empathises with PWE and addressed this issue. JSSHS created a platform to answer all the above aspects in an attempt to demystify the current epilepsy care and treatment. JSSHS organized International Epilepsy Day on 11th February 2020 (under the aegis of Patient Awareness and Education Series (PAES) in line with International Epilepsy Day being observed globally on second Monday of February every year to raise awareness about epilepsy.

This event here had wide participation of PWE and their caregivers (~250 in number) as well as the health care workers (~100 in number) from JSSHS, Delhi and (~100 in number) Bombay Hospital, Mumbai. Participants also attended this event, from Japan through Video conference. For maximum benefits this was organized bilingually (Hindi and English) and patient education materials (PEMs) in the form of handouts with simple comprehensive easy-to-understand information about Epilepsy were given to the patients. This was organized under the able guidance, leadership and chairmanship of Dr (Prof) Man Mohan Mehndiratta, Director, Professor and Head of Neurology JSSHS, Current President Indian Epilepsy Association and Vice President International Bureau for Epilepsy (IBE)-South East Asia.

One of the key themes of the session was Synergy (Greek word *sunergos*) which signifies 'working together'. Synergy helps in sharing perceptions, experiences, insights, and knowledge. Synergy brings in multiplicative benefits and converts the sum of parts to be greater than the individual parts acting independently.

The sessions in this event were used to brainstorm better health care decisions and to find creative solutions. Wisdom and concepts across borders were combined to achieve only one objective – better human life. [4] This event fostered Intraregional Synergy by inviting national neurological experts and web-conference with PWE within India as well as Inter-regional synergy through Indo-Japan International Web Conferencing. Its aim was to involve people from the city, state of New Delhi, from the country and one of the developed countries like Japan.

At the onset, promoting Intra-regional synergy, Dr (Prof) Man Mohan Mehndiratta briefed about mission and vision of the institute. The vision aligns with helping improve QOL of patients, inclusivity, empathy towards patients, and synergy of working with teams across the globe. This was followed by an overview of services for PWE being given at JSSHS in New Delhi. He discussed some challenges being faced by PWE and laws pertaining to PWE.

Past President Indian Epilepsy Association, Dr Vrushali Nadkarni, from Indore, Madhya Pradesh (Central India) followed-up with an expert lecture. She revealed an affordable model of treatment of Epilepsy in private set-up, the awareness programmes being conducted in Indore, since 1970's and the way forward.

Renowned Neurologists, Dr (Prof) Lakshmi Narasimhan Ranganathan, Director and Professor, Institute of Neurology, Madras Medical College, Chennai, Tamil Nadu and Dr K Mugundhan, Professor of Neurology at Stanley Medical College, Chennai, attended the sessions as invited dignitaries. They shared their valuable insights and inputs.

The role of surgery in Epilepsy was discussed by Dr Subodh Gupta (in-charge Neurosurgeon Deen Dayal Hospital, New Delhi). Role of psychological support was discussed by Dr Dweep Chand Singh, Professor of Psychology from Amity University, Noida, Uttar Pradesh. Dr Nirmal Surya, Founder trustee & Chairman of Epilepsy Foundation, India and Senior Consultant Neurologist at Bombay Hospital, Mumbai shared a rural model of epilepsy in Maharashtra and how this Model can be considered on a larger scale across India and for other developing countries as well.

Yoga is an age-old traditional Indian psycho–philosophical–cultural method to alleviate stress, induce relaxation. It is known to provide multiple health benefits to the practicing person. For PWE it can help in seizure control and many factors dealing with overall QOL issues. However, Yoga can't be used as the sole method of intervention. It can be an add on to Anti-Epileptic Drugs. [5] A young yoga expert Ms. Diwyasiny Sharma from Mumbai who is herself a PWE, showed the positive effects of Yoga in Epilepsy. She demonstrated few "Asanas" along with the audience.

Indo-Japan International Web Conferencing (2nd in the series) was coordinated by President of Japanese Epilepsy Society and Chair of Commission Asia Oceania Affairs, Dr (Prof) Akio Ikeda from Kyoto University Graduate School of Medicine and was also attended by PWE from Kyoto Japan. They shared their views and ideas through live online video interaction. They also shared their queries related to special schools for children with Epilepsy such as accommodation for children with epilepsy in school, treatment, social support systems, laws related to driving and marriage, and rehabilitation. medical expense support system for

epilepsy as well as participation plan in AOEC2020, Fukuoka. It was established that PWE from Japan are better placed in terms of social and legal reforms. It was also noticed that these reforms are gradually being rolled out in India as well.

Dr (Prof) Martin J Brodie(President, International Bureau for Epilepsy), Dr Zarine Mogal (President, Epilepsy Association of Pakistan), Dr Muzharul Mannan (Consultant Neurologist, Dhaka, Bangladesh, General secretary, Bangladesh Epilepsy Association, SecretaryIBE Regional Executive Committee for the South East Asia) were also invited. They could not participate but they sent their good wishes for the success of this event.

This was an interactive event where the attendees raised questions and queries which were immediately answered. To motivate the participants, a post-session quiz was organised. This was followed with a token of appreciation to the winners and high tea for all the attendees.

Medical Superintendent JSSHS, Dr Ashok Kumar concluded the event with a vote of thanks. The entire event was smoothly coordinated by Conveyer PAES, Dr Amrita Tiwary Vyas, Specialist Nuclear Medicine JSSHS

The event hence created a platform which helped in sharing epilepsy experiences and helped the PWE and their caregivers boost self-esteem, better socialization, improve psychological health and quality of life, and hence better epilepsy control and care. Also parents of Children with Epilepsy (CWE) reported improved knowledge about epilepsy and less stress related to the disease and that they are capable of better handling their children. It helped in motivating people to seek accurate knowledge about epilepsy and will definitely benefit in reduction of stigma. PWE and their caregivers gave a positive feedback and appreciated the program. There is a great demand for additional awareness programs. [2,3]

References

1. Trinka E, Kwan P, Lee B, Dash A. Epilepsy in Asia: Disease burden, management barriers, and challenges. *Epilepsia*. 2019;60 Suppl 1:7-21. DOI:10.1111/epi.14458
2. Mehndiratta MM, Alam A, Pandey S, Singh E. Assessment of quality of life in Indian adults with epilepsy and their caregivers. *International Journal of Epilepsy* 2015; 02(01): 011-018
3. Herrmann LK, Welter E, Berg AT, Perzyski AT, Van Doren JR, Sajatovic M. Epilepsy misconceptions and stigma reduction: Current status in Western countries. *Epilepsy Behav*. 2016;60:165-173. DOI:10.1016/j.yebeh.2016.04.003
4. Mehndiratta MM, Kaji R, Wong KS, Ng PW, Gulati NS. Asian and Oceanian Congress of Neurology 2014: intraregional and interregional synergy. *Neurology*. 2015;84(12):1269-1271. DOI:10.1212/WNL.0000000000001388
5. Yardi N. Yoga for control of epilepsy. *Seizure*. 2001; 10: 7-12



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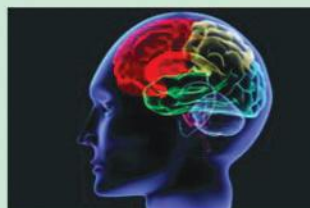
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सार्वजनिक जागरूकता और शिक्षा श्रृंखला

World Epilepsy Day February 2020

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Epilepsy an overview for patient awareness & education
मिर्गी व दौरे के रोगी की जागरूकता कार्यक्रम के लिए एक पत्रिका



Legends. A: Dr (Prof) Man Mohan Mehndiratta and Dr (Prof) Akio Ikeda, President of Japanese Epilepsy Society and Chair of Commission Asia Oceania Affairs, Kyoto (Japan) addressing the attendees through video conferencing. B: Dr Vaishali Nadkarni C: Dr K Mugundhanand Dr (Prof) Lakshmi Narasimhan Ranganathan, D: Live video session with Dr Nirmal Surya. E: Onsite Yoga session by yoga expert Ms.Diwyasiny Sharma, Mumbai. F:Group photograph of faculty Members JSSHS and invited guests.

EPILEPSY CARE FOR THE POOR

Reported by

Shri. G.C.S. Shreemal

Secretary, Shri Pragya Mirgi Rog NiwarakSamiti
P.O. Gulabpura, Dist. Bhilwara

Shri Pragya Mirgi Rog (Epilepsy) Centre is a charitable and self financed institution. It has been serving People with Epilepsy (PWE) since 1978 and has made a mark in epilepsy care in the region. Our mission is “better life for these patients with good control of seizures and free from myths and stigmas to all sections of the society with a focus on economic weaker segment”. Our values are services with Empathy, Respect and Trust.

Vision : Our future plans are to hold awareness and treatment camps at other cities, frequent medical camps at the centre, installation of a CT scanner, rehabilitation services, and to develop a model of epilepsy care in resource poor area collaborating with national and international institutions.

This centre has an independent spacious building with big lawns at front and backyard with three consulting chambers, two emergency beds, EEG room, pharmacy room, administrative office and investigation room equipped with EEG machine & air-cooled large waiting cum demonstration area with LED TV. Every day films on Epilepsy is screened to educate the patients and caregivers. This year we have constructed a night shelter with basic amenities within our campus. On an average 180 new patients and 2195 old patients visit the centre every month. During the year 2019-2020, a total of 28512 (old- 26342, new-2170).visits have been made by our patients. Approximately two third of visit is done by the patients below 30 years of age. These patients are coming from nearly 71 district of India, covering more than 12 states i.e. Rajasthan, Gujarat, M.P., Chhattisgarh, Punjab, Delhi, Maharashtra, U.P., Bihar, Haryana, Tamilnadu and Assam. In addition to medical checkup and consultation, they are provided with free antiepileptic drugs. An Epilepsy diary (30 pages) in Hindi is given to each patient who has complete information about epilepsy treatment, with doctor's perception & next date of his visit.

Dr RK Surekha and his team from Mahatma Gandhi hospital Jaipur continues with their monthly epilepsy camp. In which on an average 176 patient visited the camp. During these monthly camps we also organize Yoga Practice and Presentation by a Yoga Expert & Counseling by counselor for about 30 minutes each session for 45 minutes. Dr. RK Chandak (MD), Dr. GL Gupta (MD), Dr. Meena (MBBS) and Dr. Rathore (MBBS) from local area have been extending their regular services.

Services during COVID-19 : In this pandemic with long lockdown, we are serving the patients by sending the medicines to patients through courier and providing them with advices on telephone. We hope that situation will improve soon.

We invite all readers of Epilepsy India to visit this unique centre and bless us with your inputs.



OBITUARY - Dr. Vinod Swaroop Saxena



Dr. Vinod Swaroop Saxena
(17.07.1942 to 20.07.2020)

Dr Vinod Swaroop Saxena was born on July 17, 1942 in Lahore (now in Pakistan) to a doctor father (Bihari Lal Saxena) and a doting mother (Kalawati Saxena). He was the only brother amongst four siblings and was the apple of everybody's eyes.

He had his initial schooling in the famous Bishop Cotton School at Shimla, one of the oldest boarding schools for boys in Asia. After having topped in the undivided Punjab state in Matriculation examination, he was the state topper in Intermediate examination also. In 1959 he joined the Maulana Azad Medical College, New Delhi and obtained the MBBS degree in 1964 with distinction and a gold medal in Social & Preventive Medicine.

Soon after graduation in 1964, he chose to join the Indian Army and saw action in 1965 Indo-Pakistan war. He left the Army in 1969 after 5 yrs of exemplary service to begin a long career in the pharmaceutical industry and joined Sarabhai Chemicals, moving on to work with May and Baker in 1970. He then joined Reckitt and Coleman as a Medical Advisor in late 1977, which resulted in his moving with his family to Calcutta where he enjoyed a stay of 14 long years. While working with Reckitt and Coleman, he was the man behind introduction of sodium valproate not only in India but also in the neighbouring South-East Asian countries. He joined Sanofi in 1997 for a brief stint but soon left Sanofi and dedicated rest of his life to the cause of Epilepsy. In between, he was an adviser to a few pharma companies.

Dr Saxena played a pivotal role in the formation, growth and development of the IEA-18th IEC TRUST ever since its formation in 1993, and over the last almost three decades made it a vibrant organization. Under his stewardship the IEA-18th IEC Trust has been involved in various epilepsy awareness programs, dissemination of guidelines of management of epilepsy in India to physicians and neurologists through

publications, supporting members of Indian Epilepsy Association and Indian Epilepsy Society to attend international conferences and even funding research projects.

Dr Vinod Saxena served with distinction both the Indian Epilepsy Association (IEA) and the Indian Epilepsy Society (IES). He worked as the Secretary General and the President of both the organizations during his long stint as an office bearer. He was also a founder member of the IES.

He led an exceptionally disciplined and fit lifestyle enjoying his time listening to music, watching musical productions, discussing politics and reading voraciously! Dr Vinod Saxena also enjoyed his travels extensively across the world and shared anecdotes with friends and family members. When he was free from his work, he enjoyed his club life with the family and friends, played golf and swam during the weekends.

Those close to him would know of his being a connoisseur in food and drink. Had he chosen to be a Gourmet, he could have given a lot of food critics a run for their money. Having enjoyed his company on so many occasions in all parts of the world, I can vouch that he was also a wonderful host.

Unfortunately just 3 days after I last interacted with him, he contracted COVID-19 possibly while attending to the migrant labourers at a construction site across his home where he often donated supplies! He spent almost 40 days in the ICU before his departure on July 20, 2020 just 2 days after his 78th birthday. It was a great relief that his son Saurabh managed to make it against all odds from Singapore to be able to spend the last few days with him. He fought COVID like a warrior but failed to win the battle against the dreaded sepsis during his prolonged stay in the ICU.

With Dr Saxena's death, an era of refined leadership defined by consensus, humour, charm, wit, vision, intelligence and humility comes to an end not only in the Indian context but also in the Epilepsy scenario globally.

Our condolences and prayers go to his wife Shobana, children Saurabh (and his wife Vandana), Surabhi and Laltu, and the grand children who have been devastated by his untimely passing away.

Om Shanti!!

On behalf of the IEA-18th IEC Trust

Dr. BC Bansal
Dr. M Gourie-Devi
Dr. Devika Nag
Dr. Satish Jain

ABOUT THE COVER PAGE

ALBERT MELVIN GRASS [1910 -1992]

ALBERT GRASS was born in Quincy, Massachusetts in 1910. In 1935, he built first 3-channel EEG machine at the Harvard Medical School and was the first one to design & produce commercially available ink writing multichannel EEG in the USA. He held many patents for invention of medical instruments for which he was awarded honorary doctorates by American Academy. Albert was a graduate of MIT & worked on developing radar during world war II. As technology advanced, he with his wife Ellen Robinson **Grass** formed the **Grass** Instrument Company in 1945. Clinical research to epilepsy was in those days dominated by EEG technology.

GRASS for many years was a leading supplier of EEG machine in the world which led to rapid advancement in clinical application of EEG. Albert Grass is reported to have had a distinguished career as a - scientist, engineer and inventor. He was recognized as a self-disciplined individual with thirst for knowledge and was identified as an interesting personality right from his childhood. At the age of 11, he built a crystal radio, & at 15 a vacuum tube radio.

Ellen Grass became popular as a major figure in ILAE & a co-founder in IBE. Specialized departments soon were established across countries. In 1958 international 10-20 system was developed to standardize recordings & classify based on clinico-EEG correlation. In 1965, Talairach and Bancaud introduced stereotactic EEG implantation, & mid-1970s, a long-term recording of video-EEG was introduced internationally. In recent years, developments in EEG have been technology driven, with computing synthesized data reduction and processing and automated analysis allowing vast datasets of information to be recorded. EEG today can be seen to have set the conceptual parameters of epilepsy & has dominated its investigation & classification including in-vitro portable devices. Although its demise now is often predicted, Zifkin and Avanzini wrote: 'This simple yet revolutionary method of studying brain function will likely continue to benefit from advances in technology that are yet to come. Its theoretical limits may not have yet been reached'.

References:

1. Charles E Henry. In Memoriam – Albert Melvin Grass. AMJ EEG Technol. 32, 183-185. 1992