Editorial

Dear Friends

“Epilepsy Care and Research Foundation (ECRF)”, a non-profit non-government organization, was established under the auspices of Triveni Devi Sureka Charitable Trust and is dedicated to the care of people with epilepsy. The aims of the foundation are to achieve holistic goals of providing best possible management options for epilepsy, to impart education and awareness on epilepsy and to remove stigmas and social rehabilitation for patients of epilepsy with special emphasis being laid in the rural areas of Rajasthan. The goals of ECRF are to help patients gain control of seizure and optimize their quality of life. The purpose of the Foundation is to address various issues faced by patients of epilepsy across all age-groups including children and their guardian, women and elderly patients who have been afflicted and ravaged by the prevalent misconceptions and phantasms about epilepsy. Free medical care including drugs to the poor, financial support to epileptic students and explorative research in neural dynamics of epilepsy are main hallmarks and attributes of ECRF. Monthly camps are organized by the foundation on a regular basis in the district of Churu, Rajasthan to realize the aims and goals so formulated. It is a step taken and an effort to educate, manage, rehabilitate and make the patients of epilepsy and their attendants look at life from a different perspective.

The present newsletter is an attempt to bring in awareness and impart education in the neurophysiological, neuropharmacological and epidemiological perspectives of epilepsy. The discourse details the aims and objectives of the foundation and various errands ECRF has undertaken inclusive of disseminating knowledge regarding various myths and facts related to epilepsy. The foundation celebrated the National Epilepsy Day on November 17, 2011 and has been organizing camps on a regular monthly basis and effort has been made to explore and evaluate the interesting finding and observations that were made in the epileptic patients who attended the camps so organized.

Dr. R. K. Sureka
(Editor-in-Chief)
इमारा परिचय

भारतवर्ष के जनसंख्या के उत्तरस्त्री 25% है जिसमें से करेंगे 0.5 से 0.9 प्रतिशत जनसंख्या मिस्री रोग के साथ है। भारत की 70 प्रतिशत जनसंख्या गांव में रहती है जो 70 प्रतिशत विपिनकर शरीर में अभी रहता है। युवराज्यों के विशेष बढ़ते शरीर में ही उपन्यास है।

मुख्य उद्देश्य

- आर्य स्वास्थ्य से झरनों की जीत करना, मिस्री रोग को निर्मल निवारण प्राप्त करना।
- रोगी रोगों को समृद्ध हृदेंत्र से शुरू करके नियंत्रण करना, रोगियों पर नियंत्रण करना की पूरे शरीर की दर्दी रोगियों के लिए सुयोग के साथ उपलब्ध कराना।
- मिस्री रोग के बारे में यथायोग्य अकादमियों व गतिरोध के अनुसार करना, जिससे लें समय-समय पर चर्चा समाप्त हो जाए।
- राज्य स्वास्थ्य एवं वित्तीय मुद्दों का मतलब करना।

उपलब्धियाँ

मुख्य विकासकृत एवं विविध विधियों को तकनीकी अनुसार तथा 212 शिविर हो चुके है। इन शिविर में करेंगे 42000 मिस्री रोगी जीवन सुविधाओं जैसे हो सकता है। चंद्र, विश्व, उत्तराखंड, बिहार व बंगाल से उपराज्य लेने आए। इन शिविरों में सभी रोगियों की जीवन एवं मिस्री रोगों की साथी है। इन रोगों को अनुसार करना है एवं वेबसाइट पर निर्माण करना का कार्य करना।

17 नवम्बर को हर वर्ष 'राष्ट्रीय मिस्री विश्व' के अवसर पर विशेष रूप से अनुकूलण कार्यक्रम आयोजित किया जाता है एवं विभिन्न विभिन्न विभिन्न कार्यक्रमों का आयोजन किया जाता है।

रोगियों एवं उनके परिवारों के लिए मिनरल वॉटर एवं नियुक्त भोजन की व्यवस्था की जाती है।
Epilepsy Awareness Program 2011

The Jaipur Chapter

An epilepsy awareness programme was organized on 17th Nov, 2011 on the occasion of the National Epilepsy Day by Epilepsy Care Research Foundation at JMA Hall, SMS Medical College, Jaipur. The function was inaugurated by Chief Guest Dr. Ashok Panagariya (Professor Emeritus Neurology and member of State Planning Board (Health)) and was attended by leading neurologists, epileptic patients, and relatives.

On this occasion, the Secretary of the Foundation and Professor of Neurology at SMS Medical College Dr. R.K. Sureka emphasized the need of awareness of epilepsy and the role of health education and removal of prevailing myths and beliefs about the disease in general masses. A poster depicting the causes, precipitating factors and the Do’s and Don’ts was released by the Chief Guest Dr. Ashok Panagariya along with Dr. Subhash Nepalia Principal SMS Medical College. Also, a video prepared by Dr. Sureka in Hindi about epilepsy awareness was launched on YouTube and on website www.epilepsycrf.com. On this occasion students also took out a rally with awareness posters about Epilepsy and a message regarding misbeliefs was also relayed on FM 94.3.

The Ratan Nagar, Churu Chapter

Epilepsy Care and Research foundation is working for the welfare of epileptics in rural areas of Rajasthan since last 18 years. Professor Dr. R.K. Sureka, reports that this foundation is holding free monthly rural camps at Ratan Nagar, Churu in Rajasthan.

The 200th camp was held on 8th November, 2011 at Ratan Nagar where National Epilepsy Day was celebrated. As reported by Dr. R.K. Sureka, an Exhibition depicting the various facets of Epilepsy was organized and visited by residents of the village and about 590 patients and their relatives where people were educated about Do’s and Don’ts. Similarly an audio visual film was also run for the Epileptics. A painting competition was also held for Epileptic children below 16 years of age and best five paintings were rewarded. The chief guest on this occasion was the M.L.A. Churu, Shri. Maqbool Mandelia who flagged the march “Fight against Epilepsy” in which about 50 school children participated and who carried the message of “Control Epilepsy, Fight against Epilepsy” to the masses.
Epilepsy Research Activities

According to the chief Neuro-Physician of ECRF, Professor (Dr.) R. K. Sureka about 212 free camps have been organized as per schedule at Ratan Nagar, Churu and around 4200 odd patients from across the nation namely, Haryana, Punjab, Delhi, Uttar Pradesh, Bihar and West Bengal have been registered in the camps as of this date. Free medicines and free investigations are carried out in these camps and about 60 to 80% of the patients have become seizure-free as a consequence of such a focussed and concerted effort. Besides imparting education, awareness and effective management to epilepsy patients, the camps give the team of Medical professionals the right impetus, data and ground work for exploratory research in field of various seizure disorders. The various research papers published under the able tutelage of Professor R. K. Sureka and his team are as follows:

Professor (Dr.) Sureka reported the Clinical profile and spectrum of epilepsy in rural Rajasthan in the Journal of the Associations of Physicians of India in 1999 (47, 608 – 610), wherein the side effects of anti-epileptic drugs (AED), role of education and the clinical profile of epilepsy in sample population and their attendants were evaluated for a period of one year. About 80% of the patients had generalized tonic and clonic seizures with a preponderance of male patients with the mean age of onset of seizure being 10 years. Around 70% of the patients could be fully controlled with pharmacotherapy and were seizure-free. It was concluded from the study that epileptic patients could be managed in the rural scenario without the need for sophisticated investigations.

The Prevalence of Epilepsy in Rural Rajasthan was a evaluated during the period of January 2005 to October 2005 as door to door survey [Journal of the Associations of Physicians of India in 2007 (55, 741)], the first of its kind done in Rajasthan, a total population of 1,72,442 was evaluated through the means of a well-structured and validated questionnaire. The prevalence rate of active epilepsy was reported as 3/1000, with the male: female ratio being 1.1:1. Generalized seizure was the most common (78%) type seizure that was observed in the survey. The survey was an effort to document the load and menace of epilepsy and was undertaken to sensitize the community and government to mobilize resources for the needful.

Another paper entitled Knowledge, attitude and practices with regard to epilepsy in rural north-west India was published in 2007 in Annals of Indian Academy of Neurology (10, 160 – 4). The prospective longitudinal study stretched through four years from 2000 to 2004 and it was observed that generalized seizures were the most common type (84%) of seizure that was reported followed by partial seizures (9.4%). The most common and effective AED used was phenytoin followed by phenobarbitone. Ayurvedic treatment was the most common alternative therapy used. Evil spirits were believed to be the cause of the disease by 26.4% of the patients in 2000, but with intervention and education the percentage declined to 11.2% in 2004. Faith in scientific and logical management of pharmacotherapy increased from 18% in 2000 to 59% in the year 2004 and polytherapy regimens (60%) in 2000 could be effectively converted into monotherapy regimen (45.6%) in 2004. The findings reiterated the fact that education, awareness and logical management of epilepsy can effectively remove the mis-concepts of epilepsy and make life better for the epileptic patients.

Professor (Dr.) Sureka and his team investigated the Dermatoglyphic pattern in epileptic patients and their interesting findings were published in 2012 in the Journal of Anatomical Societies of India (61, 26 – 29). Statistically significant difference could be appreciated in the dermatoglyphic traits of a – b ridge count, lateral deviation, c – line, palmar pattern and finger-tip pattern in patients of epilepsy as compared to that of the controls. The study further underscored the relevance of antenatal factors in the etio-pathogenesis of epilepsy and opened newer avenues for research and diagnosis.
### गलत धारणाएं और सच्चाईयां

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<tr>
<th>गलत धारणाएं</th>
<th>सच्चाईयां</th>
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<tr>
<td>मिमी का पूरा कीमार है।</td>
<td>मिमी की जीवांका एक व्यक्ति से पूरा व्यक्ति तक नहीं जीना होता।</td>
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<td>मिमी का पूरा पढ़ने पर मरीज के हाथ में चारवाँ पकड़ल का पांझा या मंदा जुड़ा संयोग करता है।</td>
<td>मिमी के दीवार पढ़ने प्राथमिक चिकित्सायुक्ति उपचार उपलब्ध है।</td>
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<td>मिमी का मरीज न तो मरीज कर सकता है और न ही समय के बाद धारा कर सकते हैं।</td>
<td>मिमी का मरीज एक समय दिन भी मरीज कर सकते हैं। मरीज करते हैं और परिवार का पति जीना कर सकते हैं।</td>
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<td>मिमी का एक तह वास्तविक शैक्षणिक या दैनिक विचारधारणा का निर्माण करती है।</td>
<td>मिमी का एक अधिक उपयोग है जिसमें अंतर्गत जीवांका दीवार प्रकाश के अपने तह भी जीना होता है।</td>
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<td>मिमी का उस्तन व्यक्ति का उस्तन अकसर होता है और वह काम कर सकते हैं। मिमी के दीवार प्रस्तुत प्रजानिक है: सुकृतिशील, निर्मलता दोनों, अभ्यास तथा समाजवादी मिमी के दीवार।</td>
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### मिमी का दीवार पढ़ने पर

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<td>मिमी को जीवांका पढ़ने से पहले अनुशासन की आदेश समझा।</td>
<td>मिमी के मुंह में जीवांका या अन्य कोई चीज न हारी। इससे संभाल लेने में सहायक हो सकती है।</td>
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<td>सर को नीचे फिराक रखे।</td>
<td>मरीज के आसपास बिज्जा न लगाए। मरीज के हाथ पर दांतों होने के बाद योग्य नहीं हो पिघलाने का समय नहीं है।</td>
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### मिमी के दीवार आने पर क्या करें

1. **प्रतिभा**
   - मिमी के दीवार को पूरा सुनाएं और दीवार कर हो जाए।

2. **प्रतिभा**
   - मिमी के दीवार नहीं - चेतन नव दीवारों की प्रतिभा से होए।

#### वास्तविकता
- मिमी का दीवार मुत्ता - जीवांका की प्रतिभा से होए।
- मिमी का शरीर भिड़ न लगाए।
- मिमी के दीवार को दो किलो में रखें।
- मिमी के दांत को निपटाएं।
Novembev 17: The National Epilepsy Day

National Epilepsy Day is observed every year on November 17 to sensitize the public on various issues concerning and to address the need for people living with the condition to be given a fair opportunity in every aspect of life. The objective is to raise epilepsy to a new plane of acceptability in the public domain ans social fabric and to increase public awareness of epilepsy as a universal and treatable brain disorder. In order to create awareness about epilepsy, the Epilepsy Care and Research Foundation (ECRF) is undertaking various initiatives. Some of the highlights of this awareness campaign include educating people about dos and donts and myths and facts of epilepsy, to ensure timely help to such patients, and special initiatives have been undertaken by the ECRF to fight the stigma associated with epilepsy, especially in rural India.

Purple Day – The Global Epilepsy Awareness

Epilepsy affects over 50 million people worldwide or approximately in 1 in 100 people, a figure that outnumbers multiple sclerosis, cerebral palsy, muscular dystrophy and Parkinson's disease combined. Purple Day, celebrated annually on March 26th, is an international grassroot effort dedicated to increasing awareness about epilepsy across the globe. Purple Day was founded in 2008 by a nine-year old girl, Cassidy Megan, of Nova Scotia of Canada with the help of the Epilepsy Association of Nova Scotia (EANS). The colour purple was chosen after the international colour for epilepsy, lavender. The lavender flower is often associated with solitude, which often is representative of the feelings of isolation many people affected by epilepsy and seizure disorders often feel. Purple Day India started in March 2011 by the Anita Kaufman Foundation.

Recent Advances in Epilepsy Care and Management

New Drug for Epilepsy

Epilepsy research has entered an exciting phase as recent advances have supplemented in vitro and in vivo electrophysiologic and phenotypic characterization. Fycompa, a selective, non-competitive AMPA receptor antagonist, has been approved by the US Food and Drug Administration (FDA) on October 22, 2012 as an epileptic drug that effectively controls epileptics seizures and has been found to be superior to its counterparts.

Vagus Nerve Stimulation

A new area that has garnered much attention of late is the use of brain stimulation to treat epilepsy. This area perhaps started with vagus nerve stimulation many years ago, but has recently grown rapidly to include brain targets. Vagus nerve stimulation (VNS) is designed to prevent seizures by sending regular, mild pulses of electrical energy through pacemaker to the brain via the vagus nerve.

MRI Guided Laser Therapy

Recent advances have shown that drug intractable epileptic seizures are amenable to MRI guided laser therapy, which can correct deep seated brain lesions. The laser ablation technique reduces the risk of complications of more invasive procedures like craniotomy.

Ketogenic Diet

Diet therapy in epilepsy in children has also been recently addressed. The ketogenic diet which is high in fat, low in carbohydrates and full of adequate proteins with omega 3 PUFA supplementation has been hypothesized to be effective in uncontrollable refractory seizures in children.

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