

Indian Epilepsy Association **Bombay Chapter**

**E-Cell**

The Indian Epilepsy Association (IEA) was registered in December 1971 as a Public Charity Trust with a mission to raise epilepsy awareness, increase acceptance of persons with epilepsy and provide relief and rehabilitation to patients and their families. It started with 16 chapters, Bombay being one of them, and today we have 22 chapters all over India with a total membership of 1597. The office bearers of the Bombay Chapter are:

President: Dr. B.S. Singhal, Vice Presidents: Dr. Arun D. Bhatt, Carol D'Souza, Kavita Shanbhag, Hon. Secretary: Dr. Pravina U. Shah, Jt. Secretaries: Dr. Sangeeta H. Ravat, Dr. Urvashi R. Shah.

The activities of the Bombay Chapter can be classified as follows:

<b>Patient &amp;</b>			
<b>Family Welfare</b>		<b>Education &amp; Awareness</b>	<b>Training/Work-</b>
<b>Shops/Conferences</b>		<b>Information Material</b>	

- Support Group
- Yoga
- Counselling
- Special Education
- Sheltered Work
- Special Programs
- Medicine Subsidy
- Excursions
- Entertainment

- At Schools
  1. Epilepsy education
  2. Epilepsy Quiz
  3. Essay competitions
  4. Poster competitions

- 5. At Public Places
  1. Malls
  2. Promenades
  3. Railway stations
  4. Hotels

- For Educators/Para Professionals

1. Epilepsy Educator workshop
2. Comprehensive Epilepsy Care

3. For Patients
1. Early Intervention
2. Life Skill Training
3. Cultural Programs

4. Conferences
1. National
2. International

- Newsletter
- Films
- Epilepsy Facts booklet
- Pocket Calendar Cards
- Conquering Epilepsy book

- **Patient & Family Welfare at our Center ‘E–Cell’**

**Support Group ‘Samman’:** Loneliness or lack of companionship is a major problem for people with epilepsy. Our support group meetings give our members an opportunity to make friends and learn from each other how to cope with the disorder. Professionals are also invited to attend meetings to interact with our members and educate them on various aspects involving their health care. Every 2nd and 4th Saturday we have support group meetings from 2:30 to 4:30. 5th Saturday, if there is one, is reserved for an excursion.

Yoga helps in a large way to alleviate the stress felt by people with epilepsy and their family members. Every 1st and 3rd Saturday we have yoga classes.

**Medicine Subsidy:** For 30% of people, epilepsy becomes chronic. The high cost of medication, which needs to be taken life long, and investigations increases their financial burden. We therefore offer at E–Cell, anti–epileptic medications at a reduced rate.

**Counseling:** The unpredictability of seizures leads to overprotection of people with epilepsy. This consequently leads to a lot of behavioural problems which is taken care of through individual, family and group counseling at E–Cell with prior appointment.

**Special Education:** Children with epilepsy having difficulties are helped to improve their studying methods through special education. The special educator also trains family members to use innovative methods to train their children – This service is rendered at E–Cell

with prior appointment.

**Sheltered Work:** We obtain orders for sheltered work in order to provide an opportunity for people with epilepsy who are normally kept at home learn, earn and socialize with others.

**Cultural Programmes:** The need to build confidence amongst people with epilepsy was felt and this has been achieved, among other things, by training our members to take part in various cultural programmes: dance, drama, skits. On National Epilepsy Day our members perform before large audiences. Skits have also been performed at national and international epilepsy conferences and public forums.

**Special Programs/Workshops:** Once or twice a year, during the holidays, we hold a workshop. Successful workshops we have had include the E–Camp: 4 day in–house personality development workshop, Epilepsy Phone–in–Program where eminent neurologist answered questions from patients and others about epilepsy, E–Remedial Programme which focused on proper child development and behaviour remediation, ‘Umang’ – one week dance and drama workshop and workshops on ‘Epilepsy & Employment’ and ‘Epilepsy & Marriage’.

**Entertainment:** We also celebrate Religious festivals such as Diwali and Christmas and once a year have a puja and a picnic.

- **Awareness**

Due to the stigma associated with epilepsy, there is a strong need to educate people about the disorder. As young minds are more open to new ideas, most of our awareness programmes take place in schools. The child with epilepsy also needs to be nurtured in a supportive environment to maximize his/her potential. These programmes besides educating children and teachers about epilepsy also serve to make known our organization and the services we provide.

Education helps increase acceptance of people with epilepsy which needs to take place at all levels, not only at schools, but also in the neighbourhood, and very importantly at the time of employment and marriage where stigma is greatest.

- **Training/Workshops/Conferences**

*For paramedicals and those working with people with epilepsy*

As epilepsy education is an ongoing process and the need to educate is large, it is important that we have workshops to train the trainers. So far we have had two such workshops : The Epilepsy Educators Workshop in 1998 and Comprehensive Epilepsy Care in 2002.

**Early Intervention & Life Skill Training Programmes:** Approximately 25–30% of people with epilepsy do not have their seizures under control and this hampers their education and coping skills. Worldwide it is acknowledged that the earlier the intervention the better the prognosis. Our early intervention programme, which started in 2004–2005 revealed that children who had cognitive or learning difficulties attending mainstream school needed one–on–one remedial education which we offered on Saturdays. Those who were homebound due to uncontrolled epilepsy were taken on a daily basis and taught functional literacy and socially acceptable behaviour. The main factor that hampered the progress of this program was the long

commuting distance for the participants and their caregivers. We have now started a Life Skill Training programme in 2006 to cater to the needs of the teen–adult age group. Conferences: Participating at conferences gives our members an opportunity to interact with other people with epilepsy living in different cities/countries and learn more about the disorder and how to cope with it.

### - **Information Material**

**Newsletter:** We publish a quarterly newsletter 'Epilepsy Care' (started on Oct–Dec '05) which is distributed to doctors and patients all over Maharashtra. For 3 years prior to that we published 'Epilepsy India' the national newsletter of the IEA. Pocket Calendar Cards giving basic information about epilepsy and our services has been printed in large numbers and is distributed at all our awareness programmes.

**Films:** We have made 5 films so far, our latest one 'Samman' is used at our school awareness programmes.

**Epilepsy Facts booklet:** This has been authored by Dr. Pravina Shah and is available in English and Hindi.

**Conquering Epilepsy:** this book is a compilation of life stories of people with epilepsy, which has been edited by Carol D'Souza.

### **You can support our activities by:**

- *Becoming a member of the Indian Epilepsy Association.* Life membership Rs.1000/–. Yearly Rs.100/–. Membership forms available at the E–Cell Tel: 65057751/23850563.

- *Donations in favour of the 'Indian Epilepsy Association, Bombay Chapter'.* (All donations are exempt under section 80G of the Income Tax Act 1961).

- *Sponsoring medications.*
- *Volunteering.*

All the activities above have been made possible with the help of donations from various philanthropists. Services are offered to members free of cost.

Websites: 'Indianepilepsyassociation.org', 'leasamman.org'

### **E–Vision**

- To increase the affordability of epilepsy medication on a large scale.
- To reduce the stigma of epilepsy so that each person who deserves a job is able to get one and people of marriageable age are able to get married.
- To increase independence and self sufficiency of all people with epilepsy.
- To raise the quality of life of people with epilepsy and their families.

**For up–to–date information on our activities & events log on to ' [ecellin.wordpress.com](http://ecellin.wordpress.com)**