

## **EPICADEC NEWS**

No.16 October 2000

**Biannual newsletter of the Foundation Epilepsy Care Developing Countries  
Editorial**

---

This year's topic for our special issue is "Children and Epilepsy". On the African continent, south of the Tropic of Cancer, after South Africa, Kenya probably has the best developed organization for the care of people with epilepsy.

The late Dr. P.A. Dekker wrote a very useful manual for medical and clinical officers on epilepsy and her successor, Dr. Cecilia Bartels, highlights how the relationship between malaria and epilepsy has an impact on epilepsy care. She also emphasizes that, notwithstanding the excellent work by the Kenyan Association for the Welfare of Epileptics, much remains to be done in Kenya. Although India, certainly urban India, may be a step ahead, Geeta Rangan and Vijaya Prema point to the great numbers of people who do not have adequate drinking water, sanitation, transport or educational facilities. Nevertheless, there is a dynamic force at work that is providing children with epilepsy with equal opportunities in the form of the Indian Epilepsy Association, the well-established chapter of the International Bureau for Epilepsy and the recently formed Indian Epilepsy Society, a chapter of the International League Against Epilepsy.

The editors thought it would be appropriate to acquaint the readers with a reflection by a neurologist taking care of children with epilepsy in a quite different part of India. For many years Goa has been a Portuguese enclave, but it is now a state of India with some 1,2 million people, 4,600 hospital beds (60% of which are government funded) and one doctor per 855 people.

One story that comes from England is concerned with a boy from Pakistan who has epilepsy according to medical doctors, but not according to his parents. This is a conundrum that is common in many parts of the world. Christine Miles shows how she helped span the cultural gap, which has allowed the child access to antiepileptic treatment without violating the beliefs of the parents.

Also from Europe are the observations of an anthropologist from Bangladesh. Although the interviews concern adults with epilepsy, the editors have included this report as it reflects on the fact that children of parents who have epilepsy in a sense also belong to the topic "Children and Epilepsy". Finally, we hope our readers will find the information collected from Medline useful. If you are of the opinion, however, the space available in Epicadec News can be better utilized than by republishing information available from the internet, places, do not hesitate to inform us.

We make an exception, however, as regards information about the ILAE/IBE/WHO Global Campaign against Epilepsy, even though it may be retrieved from other publications, because Epicadec is of the opinion that this campaign is of utmost importance for the improvement of epilepsy care in developing countries.

Harry Meinardi

## ***Epilepsy and Convulsions***

DR CECILLA BARTELS  
KENYA ASSOCIATION THE WELFARE OF EPILEPTICS  
NAIROBI, KENYA

### **Epidemiology**

Epilepsy is highly prevalent in Kenya, although exact data are not known. The prevalence varies from place to place, depending on the environmental and social circumstances, which are important, e.g. rural areas, which have fewer health care facilities, hence more morbidity. Research in some areas puts the overall estimate on 15-20:1,000 (1,2). This means that of a population of 28 million (3), 500,000 people will have epilepsy. This ratio is slightly higher in areas where malaria is endemic, such as in the western and eastern provinces and on the coast.

Despite this high number of presumed epileptic patients, only a minority admit to their symptoms. Generally, traditional beliefs surround seizures, such as witchcraft, evil spirits, a bad eye from neighbors, etc, which vary from tribe to tribe. Due to these traditional beliefs, people with epilepsy are often stigmatized, isolated and ostracized from their communities. Fits are often not recognized or are misinterpreted by the relatives, resulting in delay in getting treatment, which in turn leads to increased severity, which then becomes very difficult to control.

The parents of children with seizures are the most likely people to come forward for advice or treatment. The seizures observed are mostly febrile convulsions, especially in the endemic malaria areas, where the seizures are seen as cause of malaria and therefore "legalized" in the eyes of the parents. Malaria is simply the most common cause of fever in children under five. Cerebral malaria is more common in young children because their resistance has not had a chance to build up. This is the same for travellers, who have no resistance against malaria at all. Since the incidence of malaria in Nairobi is low, children traveling up country can develop severe malaria more easily.

### **Clinical experience**

During my three-year stay in a rural hospital in western Kenya, where I worked as a medical officer, I had the following experience. This hospital is situated in an endemic malaria area where 35% of all admissions were due to malaria (children under five, 46% of admission). The type of infection is mainly plasmodium falciparum. A child comes in with high fever and in serious cases the parasitaemia reaches between 500 and 1,000 rings per field. The high parasitaemia does not necessarily indicate cerebral malaria, nor does it seem to correlate with the occurrence, of seizures (4).

Generally, the higher the parasitaemia, the higher the anemia and hypoglycemia. The children are often in a bad condition as malaria also causes a loss of appetite and is often combined with gastroenteritis, which causes dehydration and thus an electrolyte imbalance. In a rural settings,

though, this is not tested routinely not only because of the lack of means but also as the treatment will not change tremendously. If a child has not already had several seizures before arrival to the hospital, it can develop them during this malaria episode. The reason might be the fever itself; it also may be caused by the electrolyte imbalance and hypoglycemia, or in the case of cerebral malaria, by the encephalopathy caused by the malaria infection itself.

The malaria, or the quinine, or the quinine, or the combination both may cause hypoglycemia. The general practice for children under five in western Kenya is to administer quinine intravenously, especially with high parasitaemia, severe anemia or cerebral malaria. Nearly all patients also receive on admission 5 cc dextrose 5%, as well as half-strength Darrow's solution during admission in order to treat the hypoglycemia.

Seizures are initially managed with Diazepam, which is administered rectally with a nasogastric tube, since rectioles are not available in a rural setting. Phenytoin i.v. also is rarely available. If the seizures do not stop or if they reoccur Diazepam is repeated after 20-30 minutes. If a satisfactory response is lacking, phenobarbitone is gradually introduced intravenously. To prevent suppressed respiration Diazepam or phenobarbitone are cautiously administered, especially in anemic children. If meningitis is suspected, with or without lumbar puncture results, antibiotics are also given intravenously.

From my experience, the first seizure in children is nearly always a generalized tonic-clonic seizure, which happens in 3-20% of acute *falciparum* infections (5). This first seizure is probably a febrile convulsion.

Essentially, the seizures may be febrile convulsions in an uncomplicated case of malaria, whereby consciousness is regained rapidly after a seizure. If the children develop a convulsive status epilepticus, with seizures persisting for over 30 minutes, or if seizures become cluster attacks without regaining consciousness in between, we often see that the pattern of the seizures changes. These seizures – complex febrile convulsions (4), which are seen in cerebral and in non-cerebral malaria-become partial, or present themselves as hemi-convulsions. These partial convulsions are probably caused by the brain damage, which is the consequence of the status.

Repeated or prolonged fits sometimes lead to neurological sequelae, such as spastic or flaccid hemiparesis. There is still the question, however, of whether these sequelae are caused by the seizures or by the malaria encephalopathy.

Initially it is often very difficult to differentiate if you are dealing with cerebral malaria or with complex seizures due to non-cerebral malaria. Seizures may have occurred repeatedly at home, where they are normally first managed by traditional healer. These children may arrive at the hospital late as a result in a similar clinical condition: high fever (40<sup>0</sup>C-42<sup>0</sup>C), severe headache, delirium and go from stupor to a non-arousing coma.

### **Immediate follow –up after admission**

After the acute phase we continue with antiepileptic drugs mostly (phenobarbitone) and refer them after discharge to our special epilepsy clinic. To follow up on these children is difficult, as it is hard to persuade the parents to come to the epilepsy clinic. There is also the traditional taboo associated with the clinic and extreme poverty also plays a part. In families with more than 10 children, epileptic children do not have a priority over the healthier ones. In severe cases these children often have mental or physical disabilities. Their parents would rather go to traditional healers or witch doctors for treatment. They finally come to the epilepsy clinic when fits reoccur, the attacks mostly being described as generalized tonic-clonic seizures or hemi-convulsions. These are the main fits they can recognize and only through history taking may reveal a focal onset.

As seizures reoccur, even after the age of six, the parents are still convinced that malaria is to blame. They will tell you that fever is always the first symptom, and give the children anti-malarials, without consulting medical practitioners, thinking it is malaria even if the seizures occur five times a month. As malaria is the most common disease in which febrile convulsions occur, it is not surprising that this connection is made. For the parents it is a satisfactory explanation for a scary and incomprehensible event.

From my experience, children who have had complex febrile convulsions with or without neurological sequelae develop epilepsy later in life. As many of these patients have complex partial seizures, the brain damage and anoxia as a consequence of a status epilepticus during the malaria episode may lead to a focus.

### **Rural epilepsy clinics**

I am currently working in epilepsy clinics in various parts of the country on a more primary healthcare basis. In these areas both the traditional beliefs and the incidence of malaria varies. Within the different regions patients may or may not find it easy to come forward with their problem. If the patient's previous medical history indicated a hospital admission with malaria and seizures, their current fits mostly appear as complex partial seizures. Again, one may only diagnose these after thorough history taking, since the relatives can only describe the (secondary) generalized convulsions. Strange behavior in advance or other "partial" signs may not be recognized.

Patients can also rarely describe an aura. Many will tell you "*ninaumwa kichwa*", which means in Kiswahili "I have a headache". To specify which kind of headache is difficult. Is it a real headache, a kind of dizziness, a clouded consciousness?

It is also difficult for relatives and bystanders to accurately describe the duration of the fit. They might indicate that it takes three hours and on the other hand short seizures, such as absences, are rarely observed.

Looking at the differentiation of seizures, following the International Classification of Epilepsies (6) the impression is that generally more partial seizures than generalized seizures ( $\pm 70\%$  to  $30\%$ ) are seen. Comparative studies done in other developing countries (7) see a similar spread. A majority of the partial seizures are complex partial seizures, which seem to

generalize easily. This view is based as the complex partial seizures are not easily recognized; in many of those partial seizures a specific cause can be indicted.

In the malaria zones, especially, it seems that malaria with repeated or prolonged febrile convulsions is often the cause. In the group of generalized seizures the most often seen are the generalized tonic-clonic seizures. Absences are only rarely diagnosed, but myoclonus in combination with other seizures are not rare.

In rural areas one can only rely on the history and the physical examination. Electroencephalography is rarely done as in most areas there is none available and most patients cannot afford such an examination. In cases where a pseudo seizure is suspected we always try to do an EEG – although this is not a foolproof method of ruling out epilepsy. Surprisingly, we often do see pseudo seizures.

### **Social restraints**

The social impact for children with epilepsy is that in many cases they are expelled from school and sometimes even neglected by their relatives. I have seen cases where the child is left on his or her own or where they are chained in the hut. Children who have suffered severe brain damage, either due to a cerebral infection or a status epilepticus, show regressed milestones, with impaired psychomotor functions. Occupational therapy is indicated, but rarely available. Their seizures are difficult to control, especially with the limited range of antiepileptics.

As epilepsy is a chronic disorder, it is a heavy burden on the patients, not only financially but also socially. This is especially true in rural areas, where people are poor and not very well educated; the policy within our clinics is to provide accessible, available and affordable epilepsy care. The antiepileptic drugs currently being used are phenobarbitone, phenytoin and sometimes carbamazepine. These drugs are commonly available throughout the country and are not very expensive. Although they have side-effects the patient sometimes finds the financial burden more of a “side effect” than the medical ones. If the patients do come forward about their epilepsy, it is generally not easy to keep them on regular treatment. The biggest problem is non-compliance, which is made worse by giving them expensive drugs that are not readily available. Financial burden as well as a lack of trust in modern medicine, exacerbate non-compliance. And the latter also encourage default if there is no immediate response to treatment.

The prevailing opinion is that if the seizures are rather well controlled, the patient feels that he or she is cured and they stop their medication. Counseling is of major importance and compliance has to be emphasized all the time. In the view of the objectives of the WHO: “Epilepsy out of the shadows” there is still a lot to be done in rural Kenya. If levels of awareness are raised and patients do come forward, epilepsy care and knowledge has to be available and accessible. Only then we can offer them a better life.

### **References.**

1. Kaamugisha Y, Feksi AT. Determining the prevalence of epilepsy in the semi-urban population of Nakuru, Kenya. *Neuroepidemiology* 1988; 7:115-128.
2. Baldwin S, Asindua S, Stanfield P. Survey of childhood disabilities within a community-based programme for the rehabilitation of the disabled in Kibwezi Division, Kenya. Nairobi: African medical and research foundation (AMREF)/Action Aid, 1990.
3. Census 1999.
4. Waruiru CM, Newton CRJC, Forster D, et al. Epileptic seizures and malaria in Kenyan children. *Transactions of the Royal Society of Tropical Medicine and Hygiene* 1996;90:152-155.
5. Bittencourt PRM. Relationship between epilepsy and tropical diseases. *Epilepsia* 1994; 35 (1):89-93.
6. Commission on Classification and Terminology of the International League Against Epilepsy. Proposed revision of clinical and electroencephalographic classification of epileptic seizures. *Epileptic* 1981; 22: 480-501.
7. Danesi MA. Classification of the epilepsies: an investigation of 945 patients in a developing country. *Epilepsia* 1985; 26(2): 131-136.

## ***Problems in the Management of Epilepsy in Children in India***

DR GEETA RANGAN\* AND MS M. VIJAY PREMA, B.Sc. B.ED.\*\*

\*CONSULTANT EPILEPTOLOGIST

\*\*HOD PSYCHO-EDUCATIONAL DEPARTMENT

THE SPASTIC SOCIETY OF KARNATAKA, BANGALORE 560 038, INDIA

### **Introduction**

On May 12,2000, the population of India crossed the symbolic figure of one billion. Taking the prevalence of epilepsy as five to six per 1,000, there are **five to six million persons with epilepsy** in this country.

A door-to-door epidemiological survey was conducted for epilepsy in Yelandur Taluk, a region with 69,000 people, of Karnataka state from 1 April 1990 to 31 March 1991 and patients were followed up regularly for the next five years (1). 1,060 cases were screened from 1 April 1990 to 31 March 1994 and of these 573 had a definite seizure problem. Of these 293 (51%) were children, i.e., aged 18 years or less. Projecting this figure to represent the incidence in the entire country would be erroneous, but one can safely surmise that India has around two and a half to three million children with active epilepsy.

The figures for the prevalence of epilepsy in urban areas appear similar. In a private neurological practice in Bangalore, 10,561 patients were seen between August 1978 to 31 December 1999. 3,386 had epilepsy and 1,408 were aged 18 years or were younger (41.5%). Thirty-one per cent were girls in the rural set-up while in the urban group 40.8 per cent were girls. In the rural set up, 228/293 (77.8%) had no other complaints besides epilepsy. 65/293 (22%) had other disabilities besides epilepsy. Of these, 39/293 (13.3%) were clinically mentally handicapped; 13 (4%) had behavior or learning problems, and only one child was formally tested for learning disability in a specialist center. In the urban set up 812/1408 (59.5%) had no other complaints besides epilepsy. 252/1408 (18%) had obvious leaning disabilities. In addition 313/408 (22%) had some form of learning disability or a behavior / psychiatric problem. Information was unknown in 31 (1%).

The percentage of severe learning disability is the same in both the urban and rural sector but minor gradations of disability are more common in the urban area, with 22 per cent versus four per cent indicating a greater awareness and greater intellectual expectations from urban children than from rural children.

In summary, we have about **two and a half to three million** children with epilepsy. Twenty per cent of these, i.e., **500,000-600,000** children would have obvious learning disabilities and another **equal number** would need special educational facilities for learning and behavior problems. Management of epilepsy, especially in children, often needs a multi-specialty set-up consisting, ideally, of epileptologists, psychologists, counselors, occupational therapist, physiotherapists, speech pathologists, and social workers. Even a child with well controlled seizures may need counseling over the years to adjust to the restrictions imposed by drug therapy and hospital visits, besides the constraints imposed by epilepsy itself – namely prohibitions associated with some games, late nights and alcohol. A child with mental and physical disabilities needs a gamut of people working in tandem to see that the child achieves his or her full potential. In both instances, the careers have to be involved with continued counseling besides, possibly, financial or other forms of assistance.

## **PROBLEMS IN MEDICAL CARE**

### **Availability of medical services**

Pediatric neurologists or epileptologists are the specialists who handle children with epilepsy. In India, qualified pediatric neurologists are few. There are four in the State of Karnataka with a population of 44.8 million. General pediatricians, general practitioners, internists and neurologists primarily deal with these children. There are about 500 qualified neurologists and pediatric neurologists in the country to treat two and a half to three million children, i.e., one specialist for five to six thousand children with epilepsy. Most, if not all, the specialists are based in towns catering to 25.73 per cent of the population, while the remainder of 74.27 per cent are in far-flung villages needing five to six hours of travel by road to reach the specialist in either practice or government service. The specialist in turn is so overburdened that the patient can get only a few minutes of attention. The result is often a prescription for medication with little else.

### **Illiteracy/poverty**

The percentage of literacy is 52.2 per cent as per 1991 Census a level of 44.69 per cent in rural populations and 73.8 per cent for urban populations (3). The medium of television has greatly improved awareness (the majority are aware of epilepsy and know that allopathic medicine gives relief).

However, the careers need quite extensive and repeated counseling to convince them that the therapeutic methods advised will be effective. It is commonplace for a patient to change doctors if the first prescription did not stop the attacks. Magic potions, injections and drugs are expected. Exercise, training, education are all too time consuming for the impoverished and intellectually challenged parent. An estimated 30 to 40 per cent of the population lives in poverty, four-fifths being in the rural areas. It is usual in the villages for a spastic child with learning disabilities and with uncontrolled epilepsy to be left untreated. Parents who are poor and daily wage earners

find it difficult to find the time and money to care for such a child. The urban population is more aware and literate but there is very little difference in the expectations from therapy. If maintaining a diary and giving drugs regularly is a problem that interferes with the day-to-day running of the household the affected child's problem is put on the back burner. In an urban slum where the Spastic Society has an outreach facility and the neurologist visits the facility once a month, 11/19 (58%) of children with epilepsy are not brought for follow-up and treatment. In a neurological clinic in an urban neurological practice 40.8 per cent (715/1408) had a follow-up of two years and more. Twenty-four per cent (575/1408) did not return after the first consultation in spite of detailed counseling. Seventy-four children with epilepsy were registered in two years in the epilepsy clinic of the Diagnostic and Research Center of the Spastic Society of Karnataka. Forty (54%) did not come back for follow-up. This was in spite of subsidized treatment associated with counseling and training rendered by a group of therapists.

### **Drug availability**

Phenobarbitone and phenytoin are now freely available in even the remote villages, the cost of therapy being reasonable and medications are given free or subsidized in certain places. This gives relief to about 70 per cent of those affected. Carbamazepine and valproate therapy are expensive. Only two patients in the Yelandur study could afford to purchase carbamazepine and valproate on a long-term basis. Thus, the treatment gap is large in this group of children with epilepsy and mental handicap. In urban areas, the per capita income is much higher. Fifty per cent can afford sodium valproate or carbamazepine. Three to four per cent can afford the newer antiepileptic drugs.

### **Investigatory facilities**

The electroencephalogram has become commonplace and is available in the smaller towns. Also, the test is not expensive and many get it done taking it as a one-off expenditure. Similarly, CT scans are readily conducted. However, MRI is expensive and not that freely advised. PET and SPECT scans are not available.

Biochemical facilities for detection of metabolic problems and the screening test for neonatal infections, namely toxoplasmosis, rubella, cytomegalo virus and herpes are freely available. Chromosomal studies and molecular genetics are also available in a specialist center in Bangalore.

### **Surgery**

Surgical work for epilepsy in children is still in a very nascent stage. Video EEG facilities are now available in three centers in a town such as Bangalore with a population of six million, but surgical expertise is restricted.

As the Sri Chitra Thirunal Institute in Thiruvanthapuram, Kerala, surgery for temporal lobe epilepsy has been on for the past three years. In no other neuroscience center around the country has surgery for epilepsy been taken up in a planned way.

To summarize the problems in medical treatment:

- Specialists are few. We may need three to four times the present number and distribute them to the smaller towns to make expert services available.
- Investigatory facilities appear adequate.
- Drugs are available but the wherewithal for purchase is grossly restricted. With the advent of medical insurance things may improve but this does not appear to be realizable in the near future.
- About half a million children with epilepsy are left uncared for because of poverty, illiteracy and total absence of support from the government.

## **ARAMEDICAL CARE FOR THOSE WITH EPILEPSY AND OTHER DISABILITIES**

### **Comprehensive intervention**

The Spastic Society of Karnataka started a diagnostic and research center for developmental disorders, which became operational from June 1998. This center is the brainchild of Ms Rukmini Krishnaswamy, who took over as director of the Spastic Society of Karnataka in the 1970s and started this center to offer all possible facilities for not only the spastic child, but also for all other children with varied types of disabilities under one roof (2). The services are given at a subsidized rate, or without charge for the needy. The center has been built, equipped, and is being maintained from donations. These are from corporate firms are actively and regularly involved in the running of the institution. The monthly expenditure is around 600,000 Rupees (US\$11500) half of which is met by service charges and a grant from the government. The staff is a dedicated group working for an honorarium, while some are working as volunteers.

#### *a) early intervention program*

Trained physiotherapists and occupational therapists carry this out. A social worker provides counseling for the parents to exercise and stimulate the child, to aid the development of milestones. Visits are planned once or twice a month. As the child grows toilet training, sitting or walking aids, speech therapy are introduced. The center has registered 700 cases in the past two years.

#### *b) education*

The psycho-educational department has assessed 363 children since June 1998. Referrals are made from the in-house home management

department, schools both normal and special schools as well as pediatricians and neurologists, to this department for assessing children who have problems in school. Psychologists and special educationists handle the references, supported by speech/occupational therapist, medical social worker, and family counselor.

The social worker takes a detailed medical and developmental history, family history, educational history, and socio-emotional behavior.

The psychological tests include the:

- Binet-Kamath test for intelligence,
- Wechsler Intelligence Scale for children, or the MC Bhatia modification for Indian conditions,
- Vineland social maturity scale – Indian adaptation.
- Bender Gestalt test (for developmental age and emotional aspect),
- Susan Harter self perceptual test for the child's self-concept assessment.

The testing is tailored to suit the individual and in the child with severe disability, or the very young child, testing could often be observational only. Attention deficits or behavior problems could extend the testing time to separate sessions.

The educational assessment tests include:

- the Dolch sight word list,
- diagnostic reading scale for word recognition,
- Gates MacGinite reading tests for word meaning and vocabulary,
- informal testing materials for oral learning, comprehension and written expression,
- Schonnel's achievement test for silent reading comprehension and spelling,
- curriculum based materials for mathematics,
- Brigance Diagnostic Inventory of basic skills and early development.

(The tests have been adapted to meet Indian school norms.) Referrals to this department were school age children and those without obvious disabilities. Therapy was given depending on the problem area and its severity. This could be a home-based or institution-based remedial teaching program or a resource room for learning in the center itself, while the parallel education section of the school also managed some children. Others were advised to join the government sponsored open school program, in which the children could pass the varied subjects at their own pace with home-based teachers. Those not considered educable were referred to centers with special education programs concentrating on teaching social skills or occupational therapy units in those who had acquired social skills. Of the 363 children assessed in the period June 1998 – June 2000, 35 (9.6%) had active epilepsy and were on medication.

Of these children with epilepsy:

- 16 (45.7%) had global deficits and had learning disabilities with an I.Q. of between 40 to 65
- 15 (42.8%) were slow learners, their I.Q. varying between 70-90. Only three had an average IQ and the disability was secondary to extraneous factors
- four (11%) had a learning disability, either in language or numerical.

Twenty (57%) had attention deficient disorder with or without hyperactivity or emotional problem. There were no cases of autistic or psychotic children with epilepsy during this period. The therapist concerned handled behavior and varied aspects of attention deficit disorders.

### *c) Other therapies*

These include speech therapy and sensory integration programs. Children with auditory and visual handicap are referred to the concerned special schools. A special educator from this center pays periodic visits to regular schools and schools for children with development disabilities to give educational aid.

Besides our center the parents' association for people with learning disabilities runs centers, where the child with epilepsy could also be accommodated, either for schooling or vocational therapy. There are 106 centers, all in the major towns, registered throughout the country and the charges are nominal. These centers do not provide diagnostic facilities, and medical advice is from the nearest government or private hospital. A few residential facilities are coming up for the total care of such children, but these are expensive.

**There are no centers, which take only children with epilepsy and disability, and there is no government program to cater to the educational needs of children with epilepsy or any other development disability.**

If each center can handle about 200 children (the Spastic Society of Karnataka has 180 on its rolls) the facilities provide for about 40,000 children with any type of neurological disability.

Considering that this country has about one million children with epilepsy and disability, our facilities are woefully inadequate. The proportion of learning disabilities appears small from our figures, just 10 per cent of those referred. As cognitive testing is not the norm in schools, children who cannot cope get shifted to less demanding schools and, quite often, especially in the rural areas, courtesy passes until the seventh grade are often the norm. The rural girl is often married even before she reaches 18. The boys are assimilated into the family agricultural operations or businesses and continue their lives in a protected atmosphere. In urban areas, education becomes important as there is an immense competition for jobs. Managements of good schools are mainly interested in training the bright children for name and fame and tend to ignore children with a disability – who become a drag on the services – rather than providing the suitable facilities or guidance. A country like India appears two faced. One aspect is the booming information and technology sector, as well as super hospitals with all facilities on a par with the developed world, and the other face is the teeming masses with

inadequate clean drinking water, sanitation, transport or educational facility. The divide is certainly narrowing but we still have a long way to go before we see the day when all children get equal opportunity.

### **Literature**

1. Mani K.S, Rangan G, Srinivas HV, Kalyanasundaram S, Narendran S, Reddy AK. The Yelandur Study: a community based approach to epilepsy in rural South India. *Seizure* 1998;7:281-288.
2. Rukmini Krishnaswamy, director Spastic Society of Karnataka. Helping children with learning disabilities. A guide for class room teacher and parent.
3. The Census of India website <http://censusindia.net>.

### ***A Letter from India***

DR. RAJENDRA B KENKRE, MDFRS  
S-2 ASHWINI BUILDING, SECOND FLOOR, CARANZALEM  
GOA, 403 002, INDIA.

I have looked through the data on children with epilepsy in my practice and would say that the principle I adhere to is that of total care (holistic care), with, where need be, new antiepileptic drugs prescribed. I would say that from this survey of my data the majority of the parents were of the lower and middle classes, either salaried or with small businesses. Although cost was a factor in introducing sodium valproate and carbamazepine, for instance, my impression was that patients' parents, specifically, wanted their children to be given best possible care and they did not complain at all about the cost of the drug or the cost of investigations such as anticonvulsant level monitoring, CT scan and EEG. It is my practice to look into the cost-benefit of a therapy, and although it was difficult for me to know the exact socioeconomic status of the parents, they were not coerced into specific pharmacological therapy and investigation with newer imaging techniques, such as MRI. I have seen significant numbers of children with epilepsy.

The follow-up period of such children has been significantly long, extending, sometimes, to five years after the last fit.

In my understanding phenobarbitone has been promoted as a cheap anticonvulsant rather than for its anticonvulsant efficacy. However, there were a lot of behavioral and learning disabilities in children who were either on phenobarbitone monotherapy or phenobarbitone as an add-on therapy particularly in the age-group of one to five years. This was explained to the parents, and where necessary carbamazepine and sodium valproate were substituted. I had to refer only a few cases to the Medical School Hospital with a letter addressed to the physician, neurosurgeon or pediatrician to offer best possible care for these patients. This was principally due to the economic factor, rather than due to availability of specialized services at the medical school. I followed up on some of these children and found that there was a significant difference in the prescribing of anticonvulsants. Phenobarbitone, carbamazepine, phenytoin and, more recently, sodium valproate have been freely prescribed. I could not influence the long-term management of such children as they fell into the province of public health officialdom.

Most children have responded well to medication. However, this is a city population; according to the All India Epidemiological Study of Epilepsy, as a disease entity the estimated number of epilepsy patients as per the projected population for 2001 would be 5,1 million of which 4,1 million would be in rural areas' and of these 75 per cent of the total would not be getting any specific treatment as per the present standards (1). In my opinion India should also contribute to new insights on the possible mechanisms operating in epilepsy in infants and children. From the age of three months to four years major changes occur in the physiology of the brain. There is maturation of synapses, deposition of myelin and increase in birth weight. At the end of this period a child's brain is more or less characteristic of an adult brain. Newer imaging modalities of the brain are being used to study the process of development of the brain in the neonatal and post-neonatal period. Hitherto, febrile seizures, which commonly occur after the age of three months, but can occur after the age of five, have been little understood, but possibly they can be looked into with the same viewpoint as those types of seizures which are now being classified as genetic epilepsies.

This may have some bearing on the prognosis of febrile seizures, which in later life may lead to epilepsy, and also on the likely treatment of such febrile seizures with non-pharmacological therapy, but with genetically primed drugs. These actually target the hyperexcitable neuron at the molecular level, and we can then be reasonably certain of the idiopathic nature of such febrile seizures in children, which may after all not be due to environmental factors, such as toxins, radiation or infections (2,3). We are not aware of follow-up studies of neurological diseases in test tube babies over a period of time, looking specifically for illnesses such as febrile seizures, and comparing them with normally conceived and normally delivered babies, although follow-up studies of such children from infancy to adulthood have been published elsewhere in Europe. So far, there has been some confusion as to how new genetics should help us to understand and study a disease such as epilepsy. Genetic studies have only stressed inherited epilepsy, in particular common forms, such as juvenile myoclonic epilepsy,

childhood absence epilepsy (4). Although McKusick referred to the human genome, the inborn errors of metabolism, such as lysosomal diseases and other storage diseases, should not be included in the present entity of epilepsies under discussion, as the epileptic syndromes and other neurologic abnormalities in these cases arise from deficiency of a known lysosomal enzyme (5).

It was interesting to notice that the Delgado-Escueta group is looking into the linkage studies in epilepsies emphasizing the value of large family groups (6). Whether the birth control policy of the Indian Government has influenced the family size I cannot say. In India, Maheshwari and his team at the All India Institute of Medical Sciences, New Delhi, recently reported on the occurrence of epilepsies in relatives of 1,219 probands with different epileptic syndromes (7). Their study, however, is mainly aimed at establishing a genetic database of a large number of families, with familial cluster of various epileptic syndromes, possibly to form an alternative hypothesis of genetic contributions in the pathogenesis of these epileptic syndromes.

My impression is that mice being closest to humans in genetic make-up, we have to take seriously the report of Puranam and McNamara "*Seizure disorders in mutant mice: relevance to human epilepsies*", in which they refer to 1994 as a cut-off year when only a single mouse with identified gene defect was linked to a phenotype of cortical epilepsy. Since that time over 40 single gene mutations have been linked to an epileptic phenotype (8).

In general terms we have to unlike auto-immune mechanisms, such as those proven to be true only during the past five years in a rare form of human epilepsy, Rasmussen's encephalopathy.

I think, frighteningly that there is definite and a precise attack on the neuron at the chromosomal level, which alters the gene expression the cell. The mechanism of resultant damage could involve the modulators and the potassium and sodium ion gate channels.

Environmental factors, rather than inheritance, are possibly involved in this genetic manipulation. It may be that just as there is a positive and a negative ion, similarly there are diametrically opposing forces acting on the cell, which alter the genetic expression of the neuron and thereby provoking a seizure. In such a situation pharmacological therapy and human gene therapy devised to counteract the seizure pattern or patterns would need to be precise. At the present moment, there are major deficiencies in our understanding of the mapping of the human genome and, indeed, gene therapy. But there is also lack of knowledge about the long-term effects of pharmacotherapy.

We know some of the anticonvulsants alter the immune status of the person with epilepsy. It is unlikely that improvement in cognitive functions of the persons with epilepsy after therapy is purely due to the effect of the anticonvulsant properties of the drug on the neuron, although there may be actual improvement in the synaptic potential long term by what we refer to as plasticity of the neuron. Indeed, a recent report makes interesting

reading, overturning the long-held dogma that damage to the mammalian central nervous system is irreparable (9).

Here again studies in mice are opening many possibilities of looking at this ancient disease epilepsy in an entirely different light in humans.

## References

1. Sridharan R, Murthy BN. Prevalence and pattern of epilepsy in India. *Epilepsia* 1999;40(5):631-636.
2. Evans GA. The human genome project: applications in the diagnosis and treatment of neurological disease. *Arch Neurol* 1998;55(10):1287-1290.
3. Dubrova YE, Plumb M, Gutierrez B, et al. Transgenerational mutation by radiation. Brief communication. *Nature* 2000;405(6782):37.
4. McNamara JO. Emerging insights into the genesis of epilepsy. *Nature* 1999;399 (6738Suppl): A15-22. Review.
5. McKusick V A. The anatomy of the human genome. *Am J Med* 1980;69(2):267-276.
6. Pietsch SG, Weissbecker K, Delgado-Escueta A V. Importance of developing countries in genetic studies of the epilepsies. *Epicadec News* November 1996:7-10.
7. Jain S, Padma MV, Puri A, et al. Occurrence of epilepsies in family members of Indian probands with different epileptic syndromes. *Epilepsia Digest* April 1997; Vol 2: Number 1.
8. Puranam RS, McNamara JO. Seizure disorders in mutant mice: relevance to human epilepsies. *Curr Opin Neurobiol* 1999;9(3):281-287.
9. Weiss S. Pathways for neural stem cell biology and repair. *Nat Biotechnol* September 1999; Vol 1.

### ***Imran's Djinn***

CHRISTINE MILES, BSc, PGCE, MP.HD(ED)  
WEST MIDLANDS, UNITED KINGDOM.

## Introduction

The following report was promoted by the paper by Susanne Weingart "*Illness-Experience of Moroccans with Epilepsy*" in *Epicadec News*, April 2000. It concerns a Pakistani boy with epilepsy who went with his family to Britain where his father works. It is a practitioner's account of accepting family beliefs about disease causation, while giving the family time to think about a different aspect of epilepsy and the treatment to use for it.

### **Taking Imran's Djinn seriously**

After 22 years in Britain, Mr. Ahmed decided to bring his wife and six of his children to join him. His eldest son was 20 years old, and the youngest just three. Two daughters were married, so they stayed in Pakistan. He hoped the eldest son would find work and there would be school education for the others, but he did not know what could be done for 13 year-old Imran, though he had heard there were special schools for children like him.

It was difficult for the family to manage Imran in the small, two-bedroom house in the cold, West Midlands city. Back in his own village, Imran had been used to being outside almost all the time, and he had always been given his food outside the house, so it did not matter how much mess he made. But he had not played with the other children of the village they had often thrown stones at him. Now, in the British city, he did not like being confined indoors. He was not used to being in a room with ornaments and electrical goods that should not be picked up and dropped; he was not used to anyone telling him to do this or that.

Mr. Ahmed found a special school, and took Imran along to see if he could get him enrolled. Although Mr. Ahmed had been in England for many years, he had little English, so I was called in to talk to him and interpret. There is usually a long assessment procedure before children can enter a special school, but we managed to arrange an emergency enrolment within a month, the assessments being done within the school.

I interpreted for Mr. Ahmed for interviews with psychologists, social workers and doctors. One pediatrician asked whether Imran had ever suffered from epileptic fits. I translated this with the usual terms used in Pakistan, and Mr. Ahmed said "No". In school I worked with Imran, helping him learn acceptable behavior at mealtimes, advising his teachers on how he could learn to use the lavatory, and developing language programmes. I made visits to the family at home, often with the social worker, who was keen to help them – especially when we realized that there would soon be another baby in the family.

The social worker tried several times to encourage the family to take up an offer of "respite care", whereby Imran could stay in a special hostel for a few days every month. The family always refused, but finally Mr. Ahmed felt he was being impolite by continuing this blank refusal, so he agreed to make a visit to the hostel, as long as I would accompany them.

On the way to the hostel, Mr. Ahmed said that he wanted to tell me something which I should not translate to Ann, the social worker. I agreed. He told me that it was impossible for him to let Imran stay overnight at the hostel or anywhere else. I assured him that nobody could force him to send Imran away from home, but would he like to say why? Yes, he would, but only if I would keep it to myself. He knew I had lived for a long time in Pakistan, and respected Pakistani customs and beliefs, but I should not tell any of the "white" people, because they did not know "the things we know". I agreed to this. Mr. Ahmed then explained that at night a spirit often came to Imran. When this happened, all the family had to rush to his bed and pray and read the Qur'an until the spirit went away. If Imran were to spend the

night away from his family, nobody would be able to help him when the spirit came, and it would be dangerous for him. I asked Imran's father to say what happened. He told me that Imran would go rigid, his eyes rolled back and then started to "shake". Sometimes it began with a scream, but at other times the first they knew was when they heard the bed begin to shake. Imran always wet the bed when the "spirit" was there. Mr. Ahmed emphasized that this was definitely not an illness, they were quite sure it was a spirit. There was no point in arguing about this, as the existence of djinns is a well-attested part of Muslim belief. Instead, I hoped to try another approach.

First, I assured Mr. Ahmed that I would not tell the social worker and doctors, and that it was certainly no ordinary "illness" which affected Imran. Then, very tentatively, I suggested that there was another possible explanation. Some children with this sort of "spirit" had been found to have problems with "electricity" in their brains, and it was possible to test for this. If it was an electricity problem, a treatment could be found. This was a new idea to Mr. Ahmed, but he did not dismiss it. Electricity has a somewhat magical quality about it – not just one of these white-people's illnesses. I said he should think about it, and, if he was willing, I would speak to the pediatrician and we could arrange to have Imran's brain electricity tested. Mr. Ahmed agreed to think about it. Our visit to the hostel then proceeded. Mr. Ahmed expressed his amazement at the quality of the services offered, and his regret that, at this time, he would not be able to allow Imran to make use of them. Over the next few weeks I discussed the issue of "testing Imran's brain electricity" several times. The family was anxious that, by such a test, they might interfere with the spirit and cause it to do something more damaging, or to afflict another member of the family. I assured them that the tests were completely non-invasive, and described the process to them. Eventually, Mr. Ahmed agreed, and I spoke to the pediatrician. She arranged for an EEG appointment, which came within a month. I accompanied them to the hospital, and held Imran's hands and talked to him through the procedure. The results were clearly abnormal and medication was prescribed. Now the family was seriously worried. Imran's mother was afraid of the consequences for her family if the spirit decided to take other action. We talked it through several times, and finally the family decided Imran should try taking the pills. The first night, the family members sat up all night praying. Nothing bad happened. For several more nights they took turns at continuing the prayers through the night. Imran had no fits, and nothing else went wrong. The family began to relax. Everything seemed to be okay. Well, after all, that was electricity in the brain, and it was treated by taking little pills. Yes, and Imran must keep taking the pills, or the bad electricity will come back. Within a fortnight it was "Can you phone Ann, the social worker, and see if there are still places in the respite hostel?" Soon Imran was taking as many respite breaks as the social services department could find the funds for.

*NB. The names of people involved have been changed.*

### **A reviewer's comment**

This case history shows that by respecting people's beliefs, and making a point of contact or a bridge across to another way of looking at the situation,

it is often possible to provide help according to methods scientifically proven to be effective, even though at the start they do not seem compatible with the culture of the person in need. Mr. Ahmed's family belief about Imran's djinn may seem rather peculiar, and they cause a good deal of worry to the family members, but they are still human size, and under the control of Allah (who is perceived as Merciful). The djinn calls forth a compassionate family response, which is within the capacity of the family, and for which they are rewarded by seeing the djinn withdraw, at least until the next night. By comparison, modern science, technology and social change are widely perceived as threatening and beyond the control of the single family; their only refuge is Allah, with whom (to some extent) they are familiar, and who makes (usually) quite reasonable demands, e.g., that they should lead honest, decent lives, and say their prayers regularly. However, it is not always necessary to confront religious theories and explanations to have people try out the effectiveness say antiepileptic medication.

The fragility of social interlinking and civil society has become increasingly apparent in Britain, is not so surprising that many people seek security in religious systems of thought, which have been around for much longer than "modern scientific" systems, and which have developed a great deal of flexibility to accommodate near "scientific" facts (which themselves, in the health field, often seem to have rather a short shelf life...).

The occasional puzzling piece of evidence, such as the effectiveness of a regular pill to control "brain electricity", is unlikely to affect adherents of the major monotheistic religions, or the non-theistic belief systems, or any system where unseen forces are believed to operate outside the statistical probabilities of physics. The modern information supermarket encourages people to have a repertoire of modes of thinking, to suit all situations. Rationality is only occasionally called for.

### ***Some Aspects of Epilepsy Care in Russia***

DR A B GUEKHT AND DR E GUSEV  
NEUROLOGY CLINIC OF THE FIRST CITY HOSPITAL  
RUSSIAN STATE MEDICAL UNIVERSITY, MOSCOW 117049, RUSSIA

The problem of epilepsy in Eastern Europe is very important and it deserves special attention, especially in the framework of the ILAE/IBE/WHO Global Campaign against Epilepsy "Out of the Shadows".

*The problem of children with epilepsy, however, has to be seen against the background of epilepsy care in general.*

There is an established system of epilepsy care in Russia. We do not have a medical specialty of epileptology, so the physician treating epilepsy patients is a neurologist, psychiatrist or pediatrician with special knowledge of epilepsy.

An adult patient with epilepsy is treated by neurologists or psychiatrists, either in the outpatient department (polyclinic) or (in more severe cases) in the psycho-neurological clinics (a kind of outpatient department), where there are physicians (usually psychiatrists) with special knowledge of epilepsy. In these departments a patient can obtain prescriptions for antiepileptic drugs free, or with significant discount (often it is the cheapest treatment).

With the help of these departments a patient can receive a pension for disability, some social benefits, etc.

*Pediatricians, child neurologists and child psychiatrists perform the care for children with epilepsy.*

Besides, in psycho-neurological clinics and in polyclinics there is usually a physician, who is in charge of teenagers. The patient can be referred to one of the epilepsy centers that exist in the big cities and regional centers. Departments of neurology and psychiatry of medical schools and top neurological hospitals also serve as referral centers for epilepsy patients. For example, the Ekaterinburg Regional Center serves the city and a region with a population of 4,600,000 people in the Ural, at the border between Europe and Asia. 25,000 adult patients (17,000 in the city of Ekaterinburg and 8,000 in the small towns and urban area) and 8,000 children (2,500 in the city and 5,500 in the small towns and rural area) with seizures were examined and if necessary, treated there, 42% of all the pediatric patients of the Center and 17% of the adult patients being referred by psychiatrists.

Epidemiological data on epilepsy in Moscow suggest a lower prevalence than in Western Europe. Age and gender trends are similar. Quality of life and social status deserve particular attention and should be improved. The prevalence was 2.23 per 1,000, higher among men (3.3 per 1,000) than among women (1.78 per 1,000), and lower in young adults (1.39 per 1,000) than in the other age groups, where values varied from 2.4 to 2.9 per 1,000, increasing in the elderly.

The most important a etiological factors of epilepsy were: brain trauma (37.7%); stroke (12.3%); alcoholism (5.6%); tumor (2%); perinatal pathology (8%) and infection (7.4%). No cause was found in 27% of epilepsy patients. The proportion of office/professional workers was more than two times lower in epilepsy patients in comparison with the whole population, but in industrial workers it was 1.4 times higher. 38% of epilepsy patients were disabled.

Worst quality of life scores were seen in disabled epilepsy patients compared with working, and in patients with partial epilepsies compared to those who have generalized epilepsies.

Data from several other regions of the country (in European and Siberian parts) also show that the overall prevalence of epilepsy is lower, compared with Western Europe, but the difference is more pronounced when the prevalence in middle-aged and elderly patients is compared.

*The prevalence in children, teenagers and young adults is closer to the data from Europe and North America. Approximately 25-40% of cases are of unknown a etiology; perinatal pathology is responsible for 8-13% of all the epilepsy cases.*

Treatment of epilepsy in the best medical schools and university hospitals, as well as in the best regional epilepsy centers, is rather close to European standards. Still, in some regional centers, in many the outpatients departments and in psycho-neurological clinics, the treatment is inadequate.

Polytherapy is used in 40-50% of patients in the European part of the country and in 50-70% in the Siberian part, and unfortunately, in most cases Phenobarbital or phenytoin is one of the drugs. Inadequate supply and difficulties in obtaining the most suitable drugs free of charge can explain such kinds of treatment. In many regions approximately only 20-30% of patients can in reality receive an adequate dose of proper first-line drugs (valproate and carbamazepine) free of charge. Probably the disproportionate high percentage of treatment with Phenobarbital and phenytoin is responsible for the rather high level of cognitive disorders and difficulties in education in many patients with epilepsy. Among epilepsy patients (in Ekaterinburg, for example) at least 30% were diagnosed to have emotional changes, 50% had changes of memory and cognition and 10% had disorders of behavior. The necessity of further development of continuous medical education is obvious. In fact, physicians in psycho-neurological clinics were trained rather long ago and are not well acquainted with modern ways of treatment. The Russian League against Epilepsy, together with the Ministry of Health, the All-Russian Society of Neurologists, and Eureka (European Epilepsy Academy, an ILAE project) are doing a lot in the field of education, but there is still much to do, especially in distant regions of the country. Different aspects of diagnosis and treatment of epilepsy are included in the courses for postgraduate training of physicians; sometimes they occupy the leading place in the program of these courses. As well as this, special educational symposiums on epilepsy with the special attention to medical and social aspects were, or will be, performed this year. Among them Eureka approved educational courses and/or lectures in more than 10 big cities of the country (these are two certified Eureka trainers in the country), an educational course during the Men and Medicine National Congress, the third Russian-American symposium on medical and social aspects of epilepsy, and an East European conference on epileptology and clinical neurophysiology.

It is important to mention that the number of physicians is quite sufficient in different regions of the country (110-130 neurologists and 40-80 psychiatrist per 1,000,000 population in many regions). Now there is a growing

tendency to shift the treatment of epilepsy from psychiatrists to neurologists. More and more neurological departments all over Russia become specialized in epilepsy together with the development of epilepsy centers in large cities.

It is important to underline that the most important problems concerning the epilepsy care are:

- the need to educate physicians and nurses,
- improvement of the quality of equipment (paperless EEG machines, video-EEG, MRI),
- improvement of the system of drug supply,
- further development of the system of social care for epilepsy patients.

Development of a system of social care for epilepsy patients has to focus both on adults and children. It should be based on the following principal positions:

- respect for the individual, patient and career
- individual needs assessment and needs-based care
- continuation of care, follow-up, analysis of results
- multi-disciplinary approach
- improved communication and information skills
- involvement of people with disabilities and their careers in the programmes for professional development
- changing attitudes in the community
- co-ordination of care and services.

Among adults in different regions of the country about 30-40% of adult people with epilepsy are on disability schemes, for the following reasons: first, because of inadequate or sub-adequate treatment (if proper treatment would be used about 70% of patients should be seizure-free); second, there are difficulties in finding adequate work; third, there is the fact that to be on a disability scheme gives additional social benefits, which a patient with epilepsy cannot get without disability status.

In pediatric epileptology the education of children with epilepsy is very important and having epilepsy still causes a lot of problems in regular schools. Another important aspect is the education and management of children with developmental disabilities and epilepsy. There are several clinics with outpatient departments that provide adequate investigation and treatment of children with epilepsy. Most of them are in Moscow and St. Petersburg, and located in the neurological departments of medical schools or scientific institutes. Recently, several centers with special programmes of education and rehabilitation of children with developmental disabilities and epilepsy were opened and the results of their work are promising. Cooperation with families, especially with parents is also an essential aspect and many of our leading clinics work in a close contact with the patient's organizations.

Information and services to help people with disease/disabilities should include:

- support for patients and families
- educational books, brochures, posters, visual aids, newsletters
- information about treatment and rehabilitation services
- information about appliances and resources
- education
- recreational and social service.

It is important to remember, that patients and their family caregivers want to be:

- respected and understood by the professionals providing services for them
- given an accurate diagnosis and prognosis
- involved in the planning and decision-making about their care and services.

In conclusion, we would like to thank epileptologists from different regions of Russia for the information about epilepsy care presently available, and emphasize the fact that the system of management of epilepsy patients in Russia should be developed in accordance with the ideas of the Global Campaign and the Heidelberg declaration, with special attention paid to the health-related Quality of Life issues and its three principal dimensions (O. Devinsky, 1996).

- Physical health: daily functions, general health, seizure frequency and severity, medication side-effects, pain, strength and endurance.
- Mental health: emotional well being, self-esteem, perceived stigma, anxiety, depression, and cognition.
- Social health: social activities and relationships with family and friends.

# ***Reproductive Life of Dutch Women with Epilepsy***

PARVEEN NAHAR (MMA)  
DHAKA, BANGLADESH

## **Introduction**

This paper is part of the outcome of an explorative and qualitative study in partial fulfillment of the requirements for a master degree in medical anthropology at the University of Amsterdam. Its purpose was to establish the way in which women with epilepsy perceive and experience the influences of their illness on their reproductive life and self-image. Data were derived from, among others, in-depth interviews with 12 women with epilepsy. Most had both major and minor seizures varying from a few seconds to several minutes. One has been seizure free for five years; one for eight years but had a seizure again five months before the interview; one, who had been seizure-free for two and a half years had just suffered a relapse a month before the interview, and one has been seizure-free for six months. Eight still had seizures regularly with frequencies varying between one every three months, once per month to four to five times per month.

The study has been performed in the Netherlands, a country which is highly developed; there is only 10 per cent illiteracy (which includes mentally handicapped), most people have access to the internet and there is almost complete coverage by health insurance. Most chronic diseases, epilepsy no exception, have support organizations of which patients, their families and other interested people can become members.

## **Menstruation**

Nine out of twelve respondents mentioned that they have problems with menstruation and that this is related to epilepsy one way or another. Three of the respondents saw a direct link between their first menstruation and first epileptic seizure. The rest of the respondents said they observe a relationship between their menstruation and their seizures. One observed that the frequency of her seizures becomes higher around the time of her menstruation; another said she will always get a seizure just before her menstruation. While one respondent mentioned that whenever her menstruation comes later than the due time she gets relatively more and heavier seizures.

To reduce their seizures two of the respondents had to undergo forced menopause on the advice of their doctor, one through medication and the other by ovariectomy. Only two respondents said they do not have any problems with menstruation.

## **Contraceptives**

Contraceptives in the Netherlands are paid for by health insurance and need a doctor's prescription. One did not take the Pill "because she did not want to have so many hormones in her body" (see below "A physician's comments"). Another tried a normal pill combined with a non-enzyme inducing antiepileptic drug, but that is reputed to give more side-effects. For fear of this she discontinued this combination. Three used copper-T intrauterine devices. One of these discontinued and switched over to

condoms. However, another who uses condoms says she is uneasy with the condom because she does not feel 100% secure with it. Among the rest, one uses the safe-period method and the husband of another chose vasectomy.

### **Partner selection/marriage**

The selection of a partner and marriage are important components of women's reproductive life. It appeared from the life stories of the respondents that their selection of partners and their marriages are affected by epilepsy in many ways. For some of the women it was difficult to make friends at a young age because they were very concerned about their epilepsy. One of the respondents said she was very shy during adolescence: "I was shy because of my epilepsy, also my mother was very preoccupied with epilepsy. She said to me 'when you get a boyfriend I want to talk to him first, before you tell him about your condition....' I was also very preoccupied and always thought that men do not want me...." Two of the respondents said they were so busy with epilepsy during their teenage years that they did not have time to look for boyfriends. One said: "I had no time for boyfriends. I was busy at that time. Not with my study, but with my epilepsy. I was just looking for help and was trying to get rid of it." Another said: "I had less contact with people because for a couple of years I used to be so tired due to my epilepsy that I just used to sleep."

One social worker said that he had seen many people with epilepsy who are depressed and suffer from low self-esteem and that, as a result, they fail to make contact with other people, all of which affects their selection of partners.

Epilepsy creates problems in the marital situation as well. One respondent said: "Yes, I am not married because of this epilepsy. I am single. I had a relationship and I was also having many seizures at that time and the man did not like that, so the relationship broke down." However, there are happy stories, too. Two respondents said that their partner is well aware of the situation and has accepted it. "The most important thing is that you love each other. It does not really matter if someone has epilepsy or any other disorder."

### **Sexuality**

Most of the respondents expressed their concern about sexuality and epilepsy. Some respondents said having a seizure during lovemaking is the most horrible thing that can happen to a woman. One woman who experienced a seizure during sexual intercourse two or three times in her life said she felt most vulnerable at that time. This feeling intensified when the encounter was in a relatively new relationship. In some cases she did not tell her partner that she has epilepsy and the men did not react well. They thought may be she was drunk, or a drug addict, or crazy.

Some also mentioned that as there is a fear of having a seizure during lovemaking the sexual feeling as such is interrupted. One respondent said her boyfriend was always afraid that she might have a seizure during lovemaking; as a result their sexual pleasure was hampered. According to one respondent, intercourse might trigger a seizure because seizures usually come after stress. It happened to her one day. Just after having sex

she had a seizure, which lasted a long time, so that her boyfriend got worried and called the doctor. The doctor asked what she had been doing immediately before having the seizure and she had to tell the doctor about their lovemaking. This was embarrassing for her and she considered it a loss of her privacy.

Another respondent considered the problem from a different angle. She said when she gets a seizure during lovemaking her boyfriend took the seizure as an excuse to be overprotective to her, which, while she doesn't like this attitude, she can't avoid it. Another woman brought a different dimension to the problem. Because of her regular medication she feels very tired in the evening, as a result even if she wants to have sex in the evening she cannot. She has to look for other times of the day to have sex, which is sometimes very inconvenient. However, one respondent said it could happen during sex. She thinks it is a fun time, so when one has a good time she will not get a seizure. Another woman said, in contrast, that she would feel secure if she had a seizure during lovemaking because her husband will be with her, and he would take care of her. None of the respondents said they feel any difficulty in their sexual desire or arousal.

### **Pregnancy**

The narratives of the respondents revealed that epilepsy influenced their pregnancy or choice of becoming pregnant in various ways. Because of epilepsy some women had to give up their plan to be pregnant, some could not have the desired number of children, some had to delay their plan of pregnancy, and again, some became pregnant earlier than they wanted to.

It is clear from the interviews that the decision-making process developed and changed over the years. For example: "Yes, there was a time that I wanted to have a child, but not any more." This is a woman who loves children and always wanted to have a child but only when she was little older than 30. She even became pregnant, but that was unplanned; moreover, it was a tubal pregnancy and had to be surgically removed. When she reached the age at which she had decided to have a baby she faced problems in her relationship and found herself without a boyfriend. Meanwhile, she was continuously taking antiepileptic drugs and she grew older. "Because of the medicine combined with my age – I am 37 now – I have more chance of getting a handicapped child. So it is too much altogether". The fear of the consequences of epilepsy for their pregnancy and for their unborn child was evident in all the responses.

One woman said she had to limit the number of her children to only one because of her medication. She said: "We wanted to have more children but the specialist said no, no more. They said this was because of the medicine I was taking for epilepsy. It is no good for me and not good for the child either." In another case a woman was told to delay her plan of having a baby. "I could not have a baby now, because the dosage of the drug that I have to take for my epilepsy is too high. It is planned that in the year 2000 I will reduce the medicine and then I will have to talk to my doctor whether I can have a child. I really do not know when I can get pregnant."

For some respondents, pregnancy increased the severity and intensity of their seizures. And, for some, delivery was problematic. Moreover, the

decision of the location of the delivery was also affected by their epileptic condition; while most women preferred home delivery, which is common in the Netherlands, they all had to undergo hospital delivery because of the need for special monitoring. Asked whether they thought the child could inherit the epilepsy from the mother, four do not think this was so and three believed there would be a possibility; three other women expressed their uncertainty about this issue. Two of the respondents said that even if the child inherits epilepsy they were not worried about it because they know how to live with it and they would be able to teach their children. On the other hand, two of the respondents mentioned that they would feel guilty if their children inherited the illness.

### **Breast-feeding**

Out of the six women having children two did not breast-feed according to the advice of their neurologists. One, who was seizure-free for eight years, started having seizures within two weeks of starting breast-feeding. Two women did not have medication during the period of breast-feeding. However, one woman continued medication during breast-feeding because she thought that, as she took medicines during her pregnancy, her baby was already adapted to the medicines through being in the womb.

### **Child rearing**

Rearing the children is another dimension of women's reproductive life. As the Netherlands is a socially and technologically advanced society there are supportive institutions and agencies for rearing children. Men and Women share responsibilities in this. However, it is a general feeling among the women that in practice, child rearing is still mainly the responsibility of women. As one respondent said: "I think taking care of the child is still a big thing for women here. It is more important than doing a job. Raising children is more women's responsibility."

If there is the case, what happens with the woman with epilepsy who has children? Some believe it depends on the type of seizures, that is: some of the individuals have seizures that are so big and frequent that they have to remain at home. It is therefore a big burden for them if they have to take care of the children at home. However, some respondents think that whatever form of seizure they have, women with epilepsy cannot take care of the baby properly. The unpredictability and uncertainty of seizures is a big problem for a mother with small children.

One of the women described an incidence, which reflects the danger of the condition: "Everything is so uncertain. One day I had a seizure. I was unconscious for three hours. She (her daughter) was two years old. It is not nice when your daughter finds you with blood (she cut her tongue during the seizure) and other kind of stuff. You cannot move and your child is next to you in a little blanket. I had it again a few months ago with my little daughter (youngest) in my hands. I fell down over my daughter. My husband found us quickly otherwise she would have stopped breathing. She could not cry, she could have died. It was dangerous."

Some women spoke about the danger of bathing the baby in the bathtub. They feared that if they have an attack during the bath the baby might drown. They therefore ask others to help or they bath the baby when others

are around. The women also mentioned various day-to-day problems. For example, one day one of the respondents was taking her child to school and while she was crossing the road, she stopped in the middle of the road. She thought she was walking but actually she was not, she was seeing things double. It was a dangerous situation because cars were all around her. She had this effect because of her medication. Another women said her children would like to go to the beach but they do not want to go with her because she has epilepsy. Also, she could not take her children for outings and as a result the children had to stay at home.

Some women with epilepsy, however, have a positive attitude towards child rearing. As one woman said: "I have taken responsibility for my own life with epilepsy, I will definitely be able to take responsibility for my child." One key-informant stated that decades back it was a common thought that women with epilepsy should not have children. It was thought that people with epilepsy could not raise children. However, things have changed. She mentioned that, understandably as there were not many antiepileptic drugs available people had lots of seizures, therefore, it was usual to have such ideas. Now people think that if the mother with epilepsy follows some practical advice she can rear her children as easily as any one else. But all these assurances do not always make women feel confident in themselves. One of the women with epilepsy has carried this image with her all her life: "When I wanted to have a baby, I could only imagine one picture in front of me. I see I am having a seizure, people are putting me in the ambulance and the child is alone in its buggy just in the middle of the street..."

These statements show hoe the uncertainty of seizures is a great threat to proper mothering and the practical difficulties faced by the women with epilepsy in child rearing. On the other had the statements also indicate that women with epilepsy also differ in the type of problems experienced and in their coping strategies.

### **Conclusion**

The sensitivity and acceptance of one's own limitations, the awareness of human equality, the parallel concept of female gender role and sick role, the value of struggle, probably contribute to the typical Dutch attitude towards this illness. The contribution of different Dutch organizations working in the field of epilepsy is also significant, because unlike other organizations elsewhere they pay equal attention to the clinical and social/psychological aspects of epilepsy. But, though Dutch women with epilepsy maintain a positive image of life, the actual suffering still exists. Some of these sufferings and concerns are very specific to women. The various social organizations that are working on epilepsy do provide some counseling on female reproductive matters, but if we consider women's reproductive life in the broader context of the issues discussed above, it is obvious that the service is inadequate. It is therefore recommended that these organizations should focus more on reproductive and gender-sensitive issues.

### **A physician's comments**

The paper by Papreen Nahar highlights several important points. First, in the light of the comparatively good social position of Dutch women, this study warns us that equal gender relations should not blind us from gender differences in the meaning of epilepsy for one's life and well-being, and the

different coping mechanisms that are available to men and women. Second, in the Netherlands, if there is an illness help is invoked from a medical source. It is nowadays emphasized that medical care should not be restricted to making a diagnosis and prescribing a treatment and/or a change in lifestyle. As much as possible explanation is offered about the disease itself, its prognosis and the choice of treatment. This is further supported by the wide availability of written or even multimedia information. Notwithstanding all efforts this communication is bound to be deficient.

Evidence which supports biomedicine is based on statistical analysis of varied individual reactions to the particular environment. The concern of a patient is with just one element, him-or herself, and this single person may be on one of the extremes of the Gauss lan distribution. For such a person, explaining the average situation is not within their experience. This is clearly reflected in the narratives presented by Papreen Nahar. Many studies have tried to establish whether recurrent seizures follow a pattern, perhaps related to specific syndromes. Such studies have failed; yet individuals may be under the impression, or can even show on a chart of seizures and events, that there are relationships between, for example their menstrual cycle and the occurrence of seizures. Also, such a relationship has never been statistically proved; on the other hand, it is well known that progestagens reduce and oestrogens increase neuronal excitability. And, indeed, fluid retention, which may accompany the menstrual phase, can also lower seizure thresholds.

That antiepileptic drugs may interact with contraceptives increasing the speed of elimination of the hormones, therefore necessitating a higher dosage, is well known. Nevertheless, among the respondents, one did not take the pill "because she did not want to have so many hormones in her body".

A narrative sometimes contains too little information for the reader. For example one women said: "We wanted to have more children but the specialists said no, no more children. They said because of the medicine I was taking for epilepsy, it would be no good for me and not good for the child, either." This is clearly not a general consequence of having epilepsy or taking antiepileptic drugs, but there may have been an individual reason, which is unknown to the reader and, perhaps, even to the woman who was advised not to have any more children.

The value for a physician reading these narratives is that they highlight that the image people have of their illness may differ on a few or several points from what the health-care provider with whom they communicate may think and that a greater effort should be made to discover and understand these discrepancies.

## ***From the Literature***

### **ON SAFARI IN MEDLINE**

The editors have considered whether a literature review based on Medline would be interesting for our readers. True, this information is presently available to anyone who has access to the internet. However, although internet accessibility is widespread in developing countries the costs of keeping telephone lines open or frequent breakdowns of telephone services may impede use when need be of the Medline service. We have therefore decided to make a personal choice of recent papers, and publish their abstracts as they appear in Medline. As the postal address of the authors is included readers can ask them for reprints if a paper appears particularly interesting. What was considered a key-sentence by the editors has been underlined. We would be pleased to get feedback whether you feel this to be a useful utilization of the available space of *Epicadec News* or whether you would prefer other types of information.

*Ann Neurol* 2000 Aug;48(2):140-7. *Predictors of multiple seizures in a cohort of children prospectively followed from the time of their first unprovoked seizure.*

*Shinnar S Berg AT, O'Dell C, New stein D, Moshe SL, Hauser WA.*

*Department of Neurology, Montefiore Medical Center, The Albert Einstein College of Medicine, Bronx, NY, USA.*

The objective of this study was to assess the risk of multiple recurrences after an initial seizure recurrence in childhood. In a prospective study, 407 children were followed for a mean of 9.6 years from the time of their first unprovoked seizure. Data regarding each seizure recurrence were obtained and analyzed using statistical methods for survival analysis. The cumulative risk of a second seizure was 29%, 37%, 43%, and 46% at 1, 2, 5, and 10 years, respectively. Of the 182 children who experienced a second seizure, 131 (72%) experienced a third seizure, 105 (58%) have had four or more seizures, and 52 (29%) have experienced 10 or more seizures. The cumulative risk of a third seizure was 57%, 63%, and 71% at 1, 2, and 5 years, respectively, after the second seizure. After a third seizure, the cumulative risk of another seizure was 69%, 72%, and 81% at 1, 2, and 5 years, respectively. After a second seizure, factors associated with an

increased risk of additional recurrences included a remote symptomatic etiology (rate ratio = 1.7) and the occurrence of a second seizure within six months of the first seizure (rate ratio = 1.7). After a second seizure, the risk of subsequent seizures was greater than 50% even in the lowest risk group. With the exception of etiology, factors associated with an increased risk of multiple recurrences after the initial seizure were different than those associated with multiple recurrences after a second seizure. Factors associated with multiple recurrent seizures may be different than those associated with an initial recurrence. As most patients who experience a second seizure experience further seizures, these data suggest that two seizures are a sufficient epidemiological criterion for the definition of epilepsy.

*Epileptic Disord 2000 Mar;2(1):45-51. Treatment of children with "ordinary" epilepsy. Camfield PR, Camfield CS. Department of Pediatrics, Dalhousie University, Nova Scotia, Canada.*

Many children with epilepsy have a relatively benign clinical course with eventual remission of their seizures and no further need for medication. It is not easy to be sure who these children are at the time of diagnosis, but they do not have catastrophic epilepsy. Epilepsy is best defined as two unprovoked seizures. Not all of these children require treatment and treatment is motivated by fear of brain damage, injury, death, kindling of additional seizures, and social consequences. None of these fears provides an absolute indication for treatment. The decision to start medication should be considered on an individual basis. The choice of a first AED is arbitrary with most AEDs having equal efficacy.

Follow-up schedules have not been well studied. However, there is fairly convincing evidence that routine blood and urine screening for toxicity is of no benefit, if the child is a symptomatic. Serum drug levels are of little clear benefit.

Once the child has been seizure-free for six months to 12 months, it is reasonable to consider stopping medication. Only rarely does seizure control fail to return if there are recurrences without medication.

*Epileptic Disord 2000 Mar;2(1):3-13. Neuropsychology of childhood epilepsy: pre-and postsurgical assessment. Lassonde M, Sauerwein HC, Jambaque I, Smith ML, Helmstaedter C. Department de Psychologie, Universite de Montreal, Que. Canada. Maryse. [Lassonde@umontreal.ca](mailto:Lassonde@umontreal.ca)*

Childhood epilepsy is one of the most prevalent forms of chronic and disabling childhood disorders. Because it disrupts brain maturation, it has long been thought to produce non-specific consequences such as mental deficiency and behavioral problems. However, advances in medical knowledge have shown that childhood epilepsy should not be considered as a single disorder, and it is now becoming apparent that various clinical entities have different cognitive expressions that yet need to be specified.

The purpose of this paper is to provide an up-to-date analysis of this multifaceted pathology.

The first section is devoted to the characterization of the neuropsychological profile that accompanies focal epilepsies, as defined by the site of the epileptic process. We report the first group study of children with frontal lobe epilepsy. The results indicate that frontal lobe epilepsy produces symptoms (deficits of planning, attention and motor dexterity) that are akin to those found in frontal-lesioned adults. Similarly, like in adults, temporal lobe epilepsy produces memory impairment in children as well as behavioral and academic disturbances. Occipito-parietal lobe epilepsy is rare in children and its effects still need to be specified. The second section deals with the neuropsychological techniques used in presurgical evaluation. Finally, the various neurosurgical procedures that are increasingly being used as part of the arsenal of epilepsy treatment are described along with the neuropsychological findings that are associated with these interventions. It can be concluded that the beneficial effects of epilepsy surgery (callosotomy, hemispherectomy, temporal and extra-temporal resections) by far outweigh the few cognitive deficits that are occasionally reported following these interventions.

*Neurol India 1999 Sept; 47 (3):210-3. Factors of error involved in the diagnosis of juvenile myoclonic epilepsy: A study from South India. Murthy JM. Department of Neurology, Nizam's Institute of Medical Sciences, Panjagutta, Hyderabad, 500 082, India.*

The study was aimed at finding possible factors for delay in the diagnosis of juvenile myoclonic epilepsy (JME) in a developing country. Data was analyzed retrospectively through the medical records and prospectively through a re-evaluation of the history and EEGs of patients with JME registered in a university hospital in south India. Of the 131 patients, 23 (17.5%) patients were seen by neurologists before registration in the clinic. Diagnosis of JME was established in 118 patients at the time of registration and in 13 (10%) patients during follow-up in the clinic. The mean interval between onset of disease and the diagnosis was  $6.8 \pm 6.3$  years. In 20 patients the diagnosis was established 10 years after the onset. The mean interval between the first evaluation and diagnosis was 24.2 months in the 13 patients in whom the diagnosis was established during follow-up in the clinic. Lack of familiarity with the clinical syndrome was probably the factor for delay in the diagnosis in 108 patients seen by practicing physicians. The factors for delay in the diagnosis in patients seen by neurologists included failure to ask about myoclonic jerks resulting in misinterpretation of EEGs in 28 patients, misinterpretation of absences and/or unilateral jerks in four patients, and failure to ask about myoclonic jerks and misinterpretation of focal EEG abnormalities in four patients. This study suggests that the possible factors of error in the diagnosis of JME among the neurologists were similar to the observations reported from the developed countries; whereas the factor for delay in the diagnosis of JME among practicing physicians was lack of familiarity with the epileptic syndrome.

*Lancet 1998 Jan 3; 351 (9095) : 19-23. Randomised controlled trial to assess acceptability of Phenobarbital for childhood epilepsy in rural India [see comments]*

*Pal DK, Das T, Chaudhury G, Johnson AL, Neville BG. Neurosciences Unit, University College London, UK. [D.pal@ucl.ac.uk](mailto:D.pal@ucl.ac.uk)*

**Background:** The use of phenobarbital for childhood epilepsy is controversial because of reported behavioral side-effects; however, whether this research can validly be extrapolated to developing countries is not clear. We undertook a randomized comparison of phenobarbital and phenytoin to assess the acceptability and efficacy of phenobarbital as monotherapy for childhood epilepsy in rural India.

**Methods:** Between August 1995, and February 1996, 109 unselected children aged 2-18 years with partial and generalized tonic-clonic epilepsy were identified by population screening. 15 families declined to take part. 94 children were randomly allocated treatment with Phenobarbital (1.5 mg/kg daily for 2 weeks; maintenance dose 3.0 mg/kg daily; n = 47) or phenytoin (2.5 mg/kg daily then 5.0 mg/kg daily; n = 47). Children were followed up for 12 months.

The primary outcome measure was the frequency of behavioral side-effects; behavior was assessed by the Conners parent rating scale for children aged 6 years and older, and by the preschool behavior screening questionnaire (BSQ) for those aged 2-5 years, at 12 months or at withdrawal from treatment. Analysis was by intention to treat.

**Finding:** The mean log-transformed scores on the behavior rating scales did not differ significantly between the Phenobarbital and phenytoin groups (Conners 2.64 [SD 0.71] vs 2.65 [0.89],  $p = 0.97$ ; n = 32 in each group: BSQ 2.12 [1.31] vs 2.18 [1.02],  $p = 0.94$ ; n = 4 vs 3). The odds ratio for behavioral problems (phenobarbital vs. phenytoin) was 0.51 (95% CI 0.16-1.59). There was no excess in parental reports of side-effects for Phenobarbital. We found no difference in efficacy between the study drugs (adjusted hazard ratio for time to first seizure from randomization 0.97 [0.28-3.30]).

**Interpretation:** This evidence supports the acceptability of Phenobarbital as a first-line drug for childhood epilepsy in rural settings in developing countries.

**ILAE/IBE/WHO**  
**Global Campaign against Epilepsy**

Gradually the Global Campaign is realizing its objectives, Europe, Africa (in French and English), and Latin America have issued a *Declaration on Epilepsy*, India and North America will soon follow. As an example, the English text of the African Declaration follows.

*African declaration on epilepsy (final version, 6 May 2000)*

Under the aegis of the Global Campaign against Epilepsy of the International League Against Epilepsy (ILAE), the International Bureau for Epilepsy (IBE) and the World Health Organization, a meeting “Epilepsy: A healthcare priority in Africa” was held in Dakar, Senegal, Africa on 5 and 6 May 2000. Professionals from Health and Social Sciences sector and representatives from universities coming from every African Region unanimously agreed to the following Declaration:

Considering that:

- epilepsy is the most common serious chronic brain disorder, estimated to affect at least 50 million people in the world of which 10 million live in Africa alone, irrespective of race, religion, sex, age or socioeconomic groups,
- epilepsy is not an infectious disease and seizures are not contagious,
- all people with epilepsy can be effectively and inexpensively treated.
- $\frac{3}{4}$  of people with epilepsy in Africa have no access to healthcare provisions and are not appropriately treated,

- general information about epilepsy, trained expertise, diagnostic facilities, antiepileptic drugs and surgery are not available to – or affordable by – the majority of people with epilepsy, for geographic, financial or cultural reasons,
- beliefs in supernatural causes and traditional treatment of epilepsy in Africa contribute to the under-utilization of the medical health services, to discrimination and social isolation,
- because of these factors, disability and mortality are greater in Africa than elsewhere,
- epilepsy has serious physical, psychological and social consequences for the afflicted and their families,
- the impact of epilepsy is most severe in children and adolescents,
- in Africa preventable causes of epilepsy are most frequent than elsewhere, including infectious diseases, head trauma, insufficient perinatal care and consanguinity,
- epilepsy does not receive adequate attention in existing national health plans.

### **We proclaim the following:**

Epilepsy is a healthcare priority in Africa requiring every government to develop a national plan to

- address the needs with respect to epilepsy in terms of access to trained personnel, modern diagnostic equipment, antiepileptic medication and surgical treatment, information communication, prevention and social integration,
- educate and train healthcare and other relevant professionals about epilepsy,
- educate those affected by epilepsy and the general public about epilepsy as a universal neurological, non-communicable and treatable condition,
- eliminate discrimination in all spheres of life, particularly at school and the work place,
- encourage incorporation of prevention and treatment of epilepsy in national plans for other relevant healthcare issues such as maternal and child health, mental health, infections, head trauma, neurovascular diseases and community –based rehabilitation programs,
- encourage the public and private sectors and NGOs to get involved in the local activities of the Global Campaign against Epilepsy,
- promote interaction with traditional health systems,
- encourage basic and applied research on epilepsy,
- proclaim a National Epilepsy Day,
- encourage regional and continental co-operation.

### **Demonstrations projects**

Next to these measures, to heighten awareness, the Global Campaign also envisages to start demonstration projects in several regions of the developing world with the aim to prove the feasibility of managing medical conditions requiring a low technological approach at a primary healthcare level. This includes the management of the convulsive forms of epilepsy. Convulsive are usually relatively easy to diagnose and the majority of people will respond to simple treatment schedules with drugs in the WHO's List of Essential Drugs. These demonstration projects at the same time will allow

the collection of hard data on incidence and prevalence of epilepsy and the burden epilepsy imposes upon the population. In this respect further information will be collected about the impact of knowledge on attitudes and actual practice in the behavior of the population with respect of their fellows who have epilepsy.

Preparations are on the way to start demonstration projects in China, Zimbabwe, Senegal and in Latin America. Some brief notes will be presented regarding the China project, and in the first issue of 01 details about this and other projects will be given.

### **The Global campaign demonstration project in China**

The People's Republic of China is stated in the east of the Asian continent. It has the size of 1,00,000 km<sup>2</sup> and is divided into provinces, seven autonomous regions and four municipalities. They contain 335 districts (cities, prefectures), 2,858 counties (county's cities, banners, region); 48,000 towns, and 822,000 villages.

According to the statistics in 1998, China at the continental part has a population of 1.25 billion of 56 nationalities. The urban population amounted to 37.9 million (30.4%), the rural population came to 86.9 million (69.6%). The Chinese gross national product (GNP) was 7,955 billion RMB. In 1998 the urban resident net income was 5,425 RMB; the rural resident net income 2,160 RMB.

The Chinese government makes great efforts for the attainment of the goal of "health for all". The epilepsy project will be carried out in Mulin and Dongning counties of Ningxia Province, Wuzhi county of Henan Province, Zezhou county of Shanxi Province; and Hanjiang county of Jiangsu Province. The setting of the demonstration project will be the primary care level of health attention run by local Public Health Bureaus, Neurologists of local medical universities or general hospitals and local Public Health Bureaus will be in charge of this project.

Phenobarbital, a drug in the WHO's List of Essential Drugs, is the mainstay of treatment for epilepsy particularly in the developing countries in view of its wide-spectrum of action, cost, availability and reliability. In the People's Republic (PR) of China, Phenobarbital is widely available and its use is considered to be safe and practical. The ministry of Health of the PR of China and the Chinese neurological community consider this drug to be a realistic first option of treatment for epilepsy in rural areas of the country.

### **Aims**

#### **Overall Aims:**

1. To generate procedures that will improve the identification and management of people with convulsive forms of epilepsy in rural and semi-rural areas of the country within the existing primary health care system and with community participation.
2. To develop a model of epilepsy treatment at primary health level that can be applied nation-wide.

#### **Specific Aims:**

1. To assess current management practices (identification; treatment, and follow-up) of patients with convulsive forms of epilepsy cases in rural and semi-rural areas of the country.
2. To estimate the prevalence of active forms of convulsive epilepsy and of the treatment gap via an active case finding methodology and changes the project may bring to these figures in the study area.
3. To ascertain the knowledge, attitudes and practice of epilepsy amongst health practitioners at the primary health level prior to the study and after they have undergone training for epilepsy.
4. To develop technical norms for the identification, education, treatment, and follow-up of patients with epilepsy at a primary health care level.
5. To carry out a feasibility study of the treatment of convulsive forms of epilepsy using Phenobarbital by primary health care doctors.
6. To develop a program for continuous professional education on epilepsy for primary health workers.
7. To promote public awareness about epilepsy via an educational program aimed at the community.
8. To develop local advocacy and support groups for people with epilepsy.
9. To reduce the economic and social burden of epilepsy in the study areas.

### **Methodology**

This demonstration project is composed of three parts:

1. Epidemiological Estimation – this will provide a realistic estimation of the prevalence of untreated active epilepsy in the study areas.
2. Service Delivery (Intervention Study) – this will cover the issues of diagnosis, Phenobarbital treatment, follow-up and referral networks.
3. Educational, Social and Community Intervention – this will cover the educational and social aspects of the project.

### **Duration of the project:**

This project will last five years. During the first year, the following activities will be carried out:

- Preparation of training modules
- Design of instruments including the screening questionnaire
- Compose training material and work menu
- Validation of screening questionnaire
- Door to door survey
- Training of “Trainers”
- Training of all rural physicians and a number of village doctors
- End of first year assessment

During the next four years patients will be recruited into the intervention study. As the study will finish after five years and the final assessment of the patient is carried out 12 months after maintenance dose has been reached; the last patient will be recruited into the study by the end of the third quarter of the fourth year. In view of the effect of the pool of prevalent cases most patients will be recruited over the first year of the study.

### **Conclusion**

Gradually, it looks that it is no longer only those confronted with epilepsy and its consequences directly who become convinced that an improvement of epilepsy care in the developing world is cost-effective and long overdue.

People with epilepsy should, in particular, be grateful for the recognition given to their plight by the World Health Organization. Now the ball is in possession again of people with epilepsy, their families and friends as well as of the ILAE and IBE chapters and associates. This is the best opportunity ever to improve epilepsy care nationally and globally. That is finally to get the ball into the goal that seemed so difficult to penetrate.



## Events

### 11-13 November 2000

New Delhi, India

3<sup>rd</sup> Congress of Asian Oceanian Epilepsy Organisation (AOEO)

e-mail: [satjain55@hotmail.com](mailto:satjain55@hotmail.com)

info: [www.aoeocongree.com](http://www.aoeocongree.com)

### 1-6 December 2000

Los Angeles, California

54<sup>th</sup> Annual Meeting of the American Epilepsy Society

e-mail: [info@aesnet.org](mailto:info@aesnet.org)

info: [www.aesnet.org](http://www.aesnet.org)

### 12-17 May 2001

Buenos Aires, Argentina

24<sup>th</sup> International Epilepsy Congress

e-mail: [anajuan@anajuan.com](mailto:anajuan@anajuan.com)

info: [www.anajuan.com/epne](http://www.anajuan.com/epne)

### 16-20 May 2001

Buenos Aires, Argentina

XV International Congress of Clinical Neurophysiology

e-mail: [anajuan@anajuan.com](mailto:anajuan@anajuan.com)

info: [www.anajuan.com/epne](http://www.anajuan.com/epne)

**Colophon:** *Epicadec News is a biannual publication of the Foundation Epilepsy Care Developing Countries.*

*Address: c/o Leyden University, Department of Physiology, P O Box 9604, 2300 RC Leiden, The Netherlands,  
tel. +31-71-5276763,  
fax +31-71-5276782,  
e-mail: [meinardi@wxs.nl](mailto:meinardi@wxs.nl)*

*Editorial Board: A.M. Harting, H. Meinardi, R. Reis, P.H.A. Voskuil.*

*Copy editor: H. Paviour The next issue will appear in the spring of 2001. Final date of submission of articles: 15 January 2001. We would like to receive names and addresses of people in developing countries who do not (yet) receive Epicadec News directly, and who would like to receive it on a regular basis. Please, send this information to Epicadec News at the above address.*

