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**ADVOCACY-Need and its importance  
WCN 2013**

**Advocate 2007  
&  
Advisor 2009  
PALF-American Academy Of Neurology**

**What is Advocacy &  
Why is it important?**

**2013 WCN  
Advocacy Training  
Workshop**

**What is Advocacy and Why is it  
Important?**





# Disclaimer

**No conflict of Interest**

## Plan of My Talk

- **What is Advocacy and its need?**
- § **Brief Video clips of grass root advocacy**

# Overview

- **What is advocacy?**
- **Why is it needed?**
- **Importance of Advocacy**
- **Key components**

# What is Advocacy?

*Advocacy is the pursuit of influencing outcomes including public policy and resources of decision decisions within political, economic, and social systems and institutions. -David A. Auerbach, "The Current State of Advocacy" (2004)*

Moreover, advocacy can be defined as an individual or organization's effort to mobilize and influence the political process in order to create or influence public policy or to bring about social change. -Barbara J. Loefer, "The Role of Advocacy in the Political Process" (2004)

Moreover, advocacy has many definitions and meanings. For example, it can refer to the act of speaking out on issues of concern in order to exert some influence on public policy or the social. -Barbara J. Loefer, "The Role of Advocacy in the Political Process" (2004)

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# Definition

- Support for or recommendation of a particular cause or policy
- The act of pleading or arguing in favor of something
- Advocacy is a political process by an individual or a large group which normally aims to influence public-policy and resource allocation decisions within political, economic, and social systems and institutions

# Types

- Self Advocacy –an individual advocating on his or her own behalf
- Individual Advocacy –one person works with and/or “represents” the interests of another
- Collective Advocacy –the involvement and action by a voluntary group/network/coalition to promote its needs and rights
- System Advocacy – the process of advocates promoting policy and system change to address systemic causes of problems



[Gandhi 30.09.2010.wmv](#)

**Gandhi's Non-Violence and Non-cooperation Advocacy.wmv**

## Need

- **Formal advocacy support can make a real difference to the lives of disabled and disadvantaged people**
- **Advocacy brings your perspective to the attention of policy makers, funders, and stakeholders**

- **Advocacy is necessary at a national level to promote improvement of health care delivery at all levels**
- **Advocacy is important on an individual level to enable us to provide the best possible care for our patients**
- **Grassroots advocacy is the most powerful way of influencing important decision makers**

## Campaign Survey of IBE Members – Conclusions

- The survey reports on responses from 39 organisations, (35% of IBE's total of 110 members).
- 'Using the Press', 'working with other organisations' and 'advocacy' are the most common campaign methods.
- The general public, people with epilepsy, the families of people with epilepsy and journalists are the most common campaign targets.



**26th IEC Paris August 2005**

# Resources

- What are the components of advocacy?
  - Strategy, planning
  - Stakeholders
  - Resources
  - Channels

# Strategy Development

- What is the problem?
- What is the solution?
- Who has the power to make change?
  - Stakeholders
- Who/What is needed to apply pressure for change?
  - Resources
- What message would convince others to act?



? **The mean number of people with epilepsy per 1000 population ranges from 7.99 in the high-income countries to 9.50 in the low-income countries.**

? **In spite of huge burden of epilepsy especially in Asia-Oceanian and Pacific region the awareness about epilepsy is quite low.**

- **In most of the countries in ASIAN OCEANIAN REGION epilepsy is surrounded by poor public awareness, social stigma and myths. Diagnostic resources are limited and treatment gap is huge.**

**AOEA Presentation 16.11.2006**

**M.M.Mehndiratta.ppt**

# Epilepsy services in Asia: patient management

1. Socio-economic cultural diversities in Asia
2. Government health benefits or insurance
3. Treatment gap
4. Subsidized and new AEDs
5. Imaging and neurophysiological investigations
6. Is phenobarbital affordable?
7. Surgery
8. Comprehensive care
9. Use of complementary and alternative medicine
10. Community control of epilepsy

## WORLD POPULATION

The total estimated world population is around 6.5 billion and population of Asia is approximately 3.7 billion.



**Asia+Africa= 4.5 billion**

Asia is the largest and most populous continent or region, depending on the definition. It covers 8.6% of the Earth's total surface area, or 29.4% of its land area, and it contains more than 60% of the world's human population, while the peoples of Africa currently make up only 10% of the world's population. .

# Developed countries

- The term developed country is used to categorize countries with developed economics in which the tertiary and quaternary sectors of industry dominate.
- This level of economic development usually translates into a high income per capita and a high **Human Development Index (HDI)**. Countries with high **Gross Domestic Product (GDP)** per capita often fit the above description of a developed economy. However, anomalies exist when determining "developed" status by the factor GDP per capita alone.



■ Countries described as high-income and advanced economies by the WB and IMF

# Tapping the resources

- **Pattern of Neurological Disorders and inherent difficulties attached**
- **Magnitude of problems**
- **Administrators / Policy Makers**
- **Politicians**
- **NGO**
- **Print & Electronic Media**
- **Philanthropists**

What is the current status?  
One billion population,  
1000 Neurologists, 1 /Million,  
40 trainees/year

Neurological  
Association  
Government  
Press

Most  
concentrated  
in Urban areas

Improving  
neurological care  
in India

**Epilepsy**  
Discrimination  
Myths Social  
Stigma  
AD Old age

Poor awareness  
& accessibility  
Of neurological  
Services













# FROM HOSPITAL TO HOME



# **M. M. Mehndiratta, MD, New Delhi, India**

## **Advocacy Goal:**

- A. Establish advocacy wing in the Indian Academy of Neurology, patterned after American Academy of Neurology**
- B. Improve neurological care for Indian Patients**

## **Strategies**

- Place this issue as an agenda item before the full Governing Council of the Indian Academy of Neurology**
- Get the issue endorsed by the general body of the Indian Academy of Neurology**
- Conduct four workshops on advocacy in collaboration with AAN in India to promote advocacy policies**

## **Roadblocks/Barriers**

- Apprehension among members about the advocacy wing**
- Initial reluctance to accept change**

# Cont' d...

## Strategies Used to Overcome Roadblocks/Barriers

- To show them the AAN model of advocacy and its success in improving the care of patients
- To conduct workshops and invite neurologists of various age groups and seniority
- To start subsection of advocacy wing and symposium during the annual conference of IAN

## Relevance to Neurology

- The advocacy wing of the Indian Academy of Neurology can encourage neurologists to take up the issue
- This policy will help neurologists focus on their areas of interest to improve diagnostic and therapeutic care
- To convince the administration to improve the infrastructure and financial funding for neurological disorder



# Cont' d...

## Resources and/or Partnerships

- Persuaded Indian Academy of Neurology to start advocacy wing
- Holding meetings of advocacy wing during the annual conference of the Indian Academy of Neurology
- Preparing workshops in India to understand the concept of advocacy with the help of experts and finding from American Academy of Neurology

## Outcomes

- Approval from General Body Meeting of Indian Academy of Neurology
- approval to establish advocacy in India
- Collaborating with American Academy of Neurology

*Established advocacy wing in the Indian Academy of Neurology based on the American Academy of Neurology*

*To Conduct workshops in India to understand the concept of advocacy with the help of experts and funding from American Academy of Neurology*

# Strategy Stakeholders Resources

- **What are the components of advocacy?**
  - **Strategy**
  - **Stakeholders**
  - **Resources**
  - **Channels**



# IEC / AOEC Encouragements





# Teaching and awareness through print media

**EPILEPSY INDIA**  
 INDIAN EPILEPSY ASSOCIATION & INDIAN EPILEPSY SOCIETY

*N e w s l e t t e r*  
 October - December 2010 Issue 4, 2010

*Editorial*

**Dear Friends**


**"Happiness of Giving"**  
 Two of the world's wealthiest, Bill Gates and Warren Buffett (net worth \$54 and 46 billion resp) want to share all they have with the needy. Gates a workaholic who slept under his desk to save time and to nurture Microsoft left it at age 52, not to play golf which he found time wasting for its good. What was the great retirement plan he and Melinda his wife had? Apart from picking up kids, 14, 11 and 8 and taking them for excursions, they are busy fighting malaria, rotovirus, HIV/AIDS and concerns on agriculture and environment. He feels giving money to his children will neither be good for them nor be fair to the society. Could he find something with an incredible impact? His vaccine program cost him, \$30 billion but he says it has benefited 250 million poor children making a difference between their living or dying. Buffett owns 80 major companies but is a model for decades for a simple life, in a 50 years-old 3-bedroom house, drives his own car, travels in commercial airlines though he owns a company of executive jets. In laissez faire management, he writes only one annual letter to each of his company chiefs. Buffett and Gates were always philanthropic but arrived at their biggest decision while dining on burgers and milk shake in a nondescript fast food joint in Omaha airport. Following that meeting, in May 2009, behind closed doors in a house in New York, these two met Rockefellers, George Soros, Bloomberg, Oprah Winfrey and some others whose combined net worth was a large slice of US\$600 billion. Their sole objective: to start giving away their wealth. "How much do us and our family need for ourselves" Buffett had once famously said "Leave your kids enough to do anything, but not enough to do nothing." Gates does not want to launch a dynasty which Warren Buffett calls 'Lucky Sperms Club'. A quick consensus came up as most confirmed that their children did not need anything. Buffett pledged away 99% of his wealth. Gateses confirmed to give more than 95% of theirs. The other families also confirmed at least 50%. All this was behind news to the world until June 2010, as they did not wish to lose the focus. Now they have approached other billionaires. Paul Allen - Microsoft has pledged at least \$13 billion. One from China donated all his \$ one billion and others are following. However, no Indian yet, despite having three in the top 10 billionaire list. What moves these happy givers? It is the trust in people of the community beyond your own. Respect for community, rules, regulations and ethics. These great givers have earned money out of businesses but give value to what is earned, saved, invested or spent. Real value is for the greater good of the greatest numbers. Trust has even a neurochemical explanation. Oxytocin and vasopressin bring positive emotions in lowly fish, mammals and in humans trust and generosity for even perfect strangers. Perhaps these individuals possess the right amounts of the chemicals. The subcontinent could do well with some local philanthropy (see page 4). A sociologist-academician Dipankar Gupta terms this as our natural reluctance to give to public causes (Parsi industrialists are honourable exceptions). We of course happily contribute to religious symbolisms towards 'philanthropy'. We all seek happiness and its dimensions in life by moving up the scale from comfortable, pleasant to good. However, creatively enhancing life for a higher purpose could make it more meaningful as some have realized. Greetings for happy festivities and celebrations in the coming season.

**Dr VS Sasena**  
 Editor



A Billionaire in Bihar: the personage

**INDIAN EPILEPSY SOCIETY**  
 Guidelines for the  
**Management of Epilepsy**  
 in India



**INDIAN EPILEPSY ASSOCIATION-  
 18th INTERNATIONAL EPILEPSY CONGRESS TRUST**



# Workshops Organized



# Teaching for epilepsy experts & Decision making Boards



# Advocacy Workshops





## Teaching Programs, Fun after work and Public Awareness



11<sup>th</sup> Joint Annual Conference ECON 2010 at Indore



09.06.2010 GBPH, New Delhi

# **Public Awareness**

## **New Delhi-India**

- **What is a Epilepsy?**
- **How common is the problem?**
- **The Myths**
- **Most common symptoms**
- **HOW IS Epilepsy DIAGNOSED ?**
- **WHAT CAUSES EPILEPSY?**
- **WHICH AED AND HOW LONG?**



# Booklet on Epilepsy



सहायता प्राप्त करें।

- ★ दौरे के पश्चात मरीज थका हुआ या चिड़चिड़ा हो सकता है। अतः उसं सांत्वना देकर शांत करने की कोशिश करें

### अभिभावको के लिए सलाह

- ★ मिर्गी के रोगी के साथ एक साधारण रोगी की भांति व्यवहार करना चाहिए
- ★ मिर्गी के रोगी को चाहे वह बच्चा हो या व्यस्क उसकी बीमारी के बारे में पूर्ण जानकारी दें। उसे रोग सम्बन्धी जांच व इलाज का महत्व बता कर नियमित रूप से दवा रखने के लिए प्रेरित करें।
- ★ मिर्गी के मरीजों में असुरक्षा की भावना, विश्वास की कमी, चिड़चिड़ापन व अनिश्चितता की भावना आ जाती है। अतः उन्हें निरंतर प्रोत्साहन व सहयोग की जरूरत होती है।
- ★ मिर्गी से प्रभावित बच्चों को अध्यापकों का सहयोग प्राप्त होना चाहिए व अध्यापक को इस विषय में जानकारी होनी चाहिए ताकि अचानक आवश्यकता पड़ने पर अध्यापक स्थिति को संभालकर बच्चों की सहायता कर सकें।
- ★ मिर्गी के रोगी को जरूरत से ज्यादा महत्व न दें ताकि व स्वयं आत्म निर्भर बन सकें।
- ★ ध्यान रहे रोगी नियमित रूप से दवाई लेता रहे। दवा लेने में अनियमितता बरतने से दौरे पुनः पड़ सकते हैं व इसके गंभीर परिणाम हो सकते हैं।
- ★ रोगी को परिवार व समाज में सामान्य जीवन जीने के लिए प्रेरित करें। ताकि वह स्वयं को लोगों से भिन्न व असुरक्षित न समझे व एकाकी न बने।

सचिव  
आई. ई. ऐ., दिल्ली चेपटर  
डा० एम. एम. मेहन्दीरता  
प्रोफेसर, स्नायु रोग विभाग  
गोविन्द बल्लभ पंत अस्पताल नई दिल्ली

प्रेसीडेन्ट  
डा.० मीना गुप्ता  
विभाग अध्यक्ष, स्नायु रोग विभाग  
गोविन्द बल्लभ पंत अस्पताल नई दिल्ली

# Strategy Development

- **What is the problem?**
- **What is the solution?**
- **Who has the power to make necessary change (stakeholders)?**
- **Who/what must be mobilized to apply pressure for change (resources)?.**
- **What message would convince those with power to act for change (key messages)?**

- Resource Mapping
- Exploring social resources and alternatives
- Integration of resources into overall strategy
- Stake holder analysis. The participants will be equipped with conceptual and practical tools to operationalise advocacy strategy.

# Resources needed

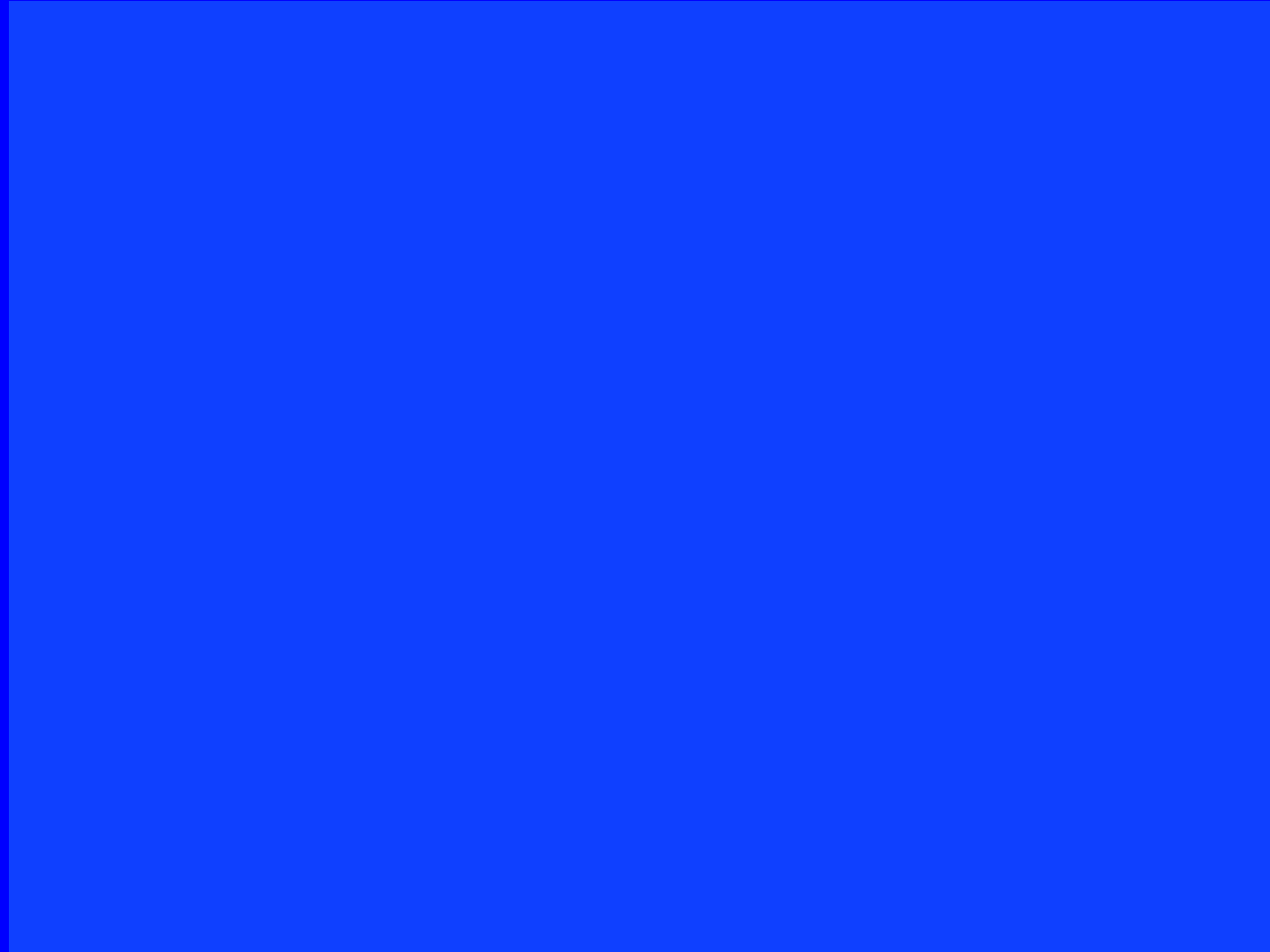
Think about people you might need to contact, information you might need to gather and materials to be developed and distributed

- What tools and personnel resources might be needed
- Listing of legislators, key decision-maker and media outlets

# Realistic Approach

## Objective (s)

- Yours objective is the targeted result of your efforts.
- Objectives should be SMART
  - S= Specified
  - M= Measurable
  - A= Attainable
  - R= Realistic
  - T= Timely
- A more succinct statement of why you are undertaking your advocacy efforts
- The rationale can be used as a motivation tool during low energy times when you are implementing your plan



[Advocacy through Invictus.wmv](#)



## Advocacy-I

ONE TEAM ONE COUNTRY

## Advocacy-II

Secretary: It is Political Calculation

No

IT IS A HUMAN CALCULATION

His people needed a leader. He gave them a champion

# **CARRY HOME MESSAGE**

- **Selection of Achievable Goal**
- **Focused Approach**
- **Clarity of mind**
- **Determination**
- **Perseverance**
- **Evaluation and assessment**

Thank you!

Questions/Discussion