

MINUTES OF THE APPL 's MEETINGS /PRESENTATION ON 'A QUALITATIVE STUDY ON THE STATUS OF JE/AES VICTIMS'

Date-December 28,2010

Time- 11:00 am

Venue- conference hall Hotel Shivoy,Gorakhpur,(U.P.)

The meeting was chaired by APPL's executive trustee: **Dr A. K. Srivastava**, who welcomed all the distinguished delegates/participants from invited Government officials, BRD Medical college, National Viral Institute, leading NGOs/Civil society, WHO, UNICEF, Academicians, Journalists, both from print and electronic media, medical practitioners, Social workers/volunteers, other stake holders besides APPL's own officials.

It started with individual introduction of the representatives of different organizations and institutions.

1.0 Dr A. K. Srivastava (Executive trustee APPL Trust):

Dr. Srivastava gave a brief account of objectives and activities of APPL, generally in the fields of Primary health and primary education, with special emphasis on the on-going projects of extensive Studies & Research on status of victims of Japanese Encephalitis and A.E.S. over the past five years, in this eastern part of Uttar Pradesh,(generally termed as Purvanchal), comprising the districts under the Gorakhpur and Basti commissioner(s). He informed about the scope and objectives of the present study, which was an extension of previous studies on the subject, undertaken by APPL. The results of the current-study entitled, '**A qualitative study on the status of J.E. and A.E.S. victims**' was to be presented during the meeting. The scope of the current study was based on the data and information collected during informal interaction with the victims of JE/AES at their respective residences, who were previously admitted and treated at BRD Medical college, through a 40 point questionnaire covering various important aspects such as socio-economic status, the reach of the resources, quality of drinking water and sanitation, living standards and habits, water logging in their area, their health status in the past few years etc. Keeping in view the background of victims and their families, APPL collected some of these information through story telling mode, which was found to be very effective. The data was collected for the victims, by visiting their respective places, some 10-15 KM away from the main roads, and those already admitted in the BRD Medical college, on a random basis, during APPL's regular visits to the BRD Medical college on each Monday and Thursday of a week, for a period of about 11 weeks, when the problem was highly manifested. The findings of the current study were based on the scientific analysis of the collected data and also the information collected by a panel of scientists, academicians, doctors, health activists and researchers. The presentation of the study was captioned as '**LIVING ON THE EDGE**', which APPL's trustee: Dr Sanjay and the main author of the problem, was requested to present.

2.0 Dr Biplav Srivastava: I.B.M. Senior Research Scientist and also associated with the APPL Trust, on the Advisory Board.

Dr. Biplav gave a bird eye view of the various charitable projects undertaken by various MNC's world-wide and its impact on the society. Dr. Biplav wanted to put his point for the information and kind comments of all of the delegates present. He informed that all the

studies on JE/AES done by APPL 's team and their findings along with details of all the other general activities of APPL were duly available at the APPL 's official web-site: [www:http://appltrust.Org](http://appltrust.Org) . Currently APPL 's web-site have had hundreds of hits from across the world, including about 22 countries covering U.S.A., U.K., France , Japan, China, Germany, Philippines, Canada, U. A.E. etc.

3.0 Dr. Sanjay Srivastava: Trustee, APPL Trust

After a warm welcome to all the esteemed guests, Dr. Sanjay explained about the scope, methodology adopted, the results obtained, strong & weak points, recommendations, etc. of the current APPL 's Qualitative Study based on the primary data collected and other information gathered from the twenty families of the victims of J.E./A.E.S. The findings of the study were as follows;

3.01 APPL 's study/analysis shows that 80% of the affected victims were found to be under weight and under-nourished.

3.02 The primary symptoms of the affected –victims varied in the following manner :

--As such 20% of the affected showed the symptoms of high fever with diarrhea,

--Another 20% of the affected showed the symptoms of high fever with breathlessness.

--Next 20% of the affected showed the symptoms of high fever with seizures and unconsciousness.

--Next 20% of the affected showed the symptoms of high fever with altered mental status.

--Next 10% of the cases showed the symptoms of high fever with altered mental and physical status.

--Balance of 10% of them showed mixed symptoms.

Only two victims (out of the total twenty patients studied), found with varied symptoms, were tested J.E. Positive. The vectors involved could not be characterized in the rest of the eighteen cases, as they were unknown.

During the presentation **Prof. D. K. Srivastava: Head Of the Department, Social & Preventive Medicine. B. R. D. Medical college, Gorakhpur**, interrupted and said that this was an interesting data and that this fact could be kept in mind, along with others, while diagnosing the future patients of JE/AES. He said that it was noticed that the patients showed the primary symptom of only fever in the first three to seven days, there-after it did start also creating different complications. All the cases were initially taken up as A.E.S. cases.

3.03 It was found that the most vulnerable age group was the children from 1-10 years which was found to be 70% of the total effected victims.

3.04 The most probable vector other than culex might be an other species which affects the patients through contaminated drinking water, on which the experts are having an eye. APPL 's study pointed out to the fact that all of the affected victims were consuming water from shallow sources. In 65% of the cases the affluent-water was collected in a pit, nearby the main water source which could be the primary cause of the contamination in the drinking water.

3.05 It was found that only 15% of the affected victims reached BRD Medical college, the designated super-speciality facility in the region by the Government, within 1 day, 30% of the affected reached the medical college within a week, 30% of the affected reached within 10 days and the rest 25% reached after ten days. The time taken to reach to the specialized facilities at medical college counts and also decides the degree of the affect in the victims.

3.06 It was found that most of the affected families preferred, mainly due to economic considerations, public transport to bring the patient to the medical hospital. They were brought by motor bikes, auto-rickshaws, busses etc. This directly related to the seriousness and negative impact on their health, as they were not kept in a right posture.

3.07 Our study showed that 80 % of the affected preferred local quacks for the primary consultations/treatment. Our analysis showed that the seriousness of the patient was found directly proportional to the delays/ no. of days to reach the medical college (the patients reached at an average of after seven days for specialized medical facilities.) The lack of awareness seems to be the primary cause as 80% of the affected victims did not know about the Encephalitis and its seriousness.

3.08 JE/AES GAREEBON KI BEEMARI (Disease of Poor)

Our study pointed out the fact that 50 % of these patients came from the low income group of less than Rs.3000/ per month, 60% of them lived in kuccha(Tiled/thatched) houses, this relates it to poverty, mal-nutrition, and poor immune-status.

As widely presumed that this disease had a direct relationship with the nearness of paddy fields /water bodies, our study showed that in the majority of the cases there was no relation to the above mentioned reasons.

Sri Narendra Mishra: a prominent Researcher associated with the study:

QUALITY OF CARE: The quality of the care provided to the victims needed to be checked and reviewed. Almost 70% of the patients attendants were not satisfied with the services rendered to them at the BRD Medical college. In majority of the cases the patient's attendants were females, whereas the male counterparts were often out to manage the funds/procuring the medicines/other sundry things. The fact was that the female attendants were partially educated or uneducated and were not capable to even read the prescription, mostly written in English language (some of the attendants /patients were found to recognize the medicines only by the color of the rapper). Also they were not counseled properly and briefed about the right dozes, sequence of the medicines prescribed, hence there was always a great possibility of giving improper dozes of medicines to the patients. To provide free medicines was a great help to them but to tell them about the proper dozes is more important and it should be insured. The attending doctors and nourishing staff were over burdened as they had to look after most the times more than 150 critical patients at a time. This factor should be looked upon and the numbers of attending staff should be increased to improve the quality of care.

4.0 RECOMMENDATIONS OF THE STUDY

4.01 Awareness programs about JE/AES should be redesigned and strengthened.

4.02 Quality of care should be improved by increasing the staff-strength and volunteers.

4.03 Because this disease is said to be directly related to animals, birds and mosquitoes the veterinary doctors ,human medicine doctor and scientists should also be consulted and involved in planning and implementation of the preventive measures as joint venture for a long time i.e. 10 to 15 years

4.04 Measures to be taken to minimize the time lapse for specialized medical help.

4.05 Measures should be taken to strengthen the medical facilities at the grass root level so that the timely referral of the patient could be assured.

4.06 To restructure and strengthen post medical follow-up.

4.07 Measures should be taken to improve and assure safe drinking water.

4.08 To insure proper drainage for used /effluent water, to avoid main drinking water contamination.

4.09 Existing facilities at the BRD Medical college should be modified/improved to cater to multifunctional needs of rehabilitation, efficient utilization of resource and quality day-care in the vulnerable areas.

After the presentation was over, the topic was thrown open for discussion. Some tea and snacks were served.

Dr. M. Gore : Senior Scientist and Director, National Institute of Virology Gorakhpur(U.P.) :

Dr. Gore offered to thank the team of APPL Trust for the wonderful work they had been doing for the past few years. He opined that this study had pinpointed some of the facts and left a way out for the next step. He said that they also had been closely monitoring the source of drinking water, water logging and sanitation, drainage et, which had also been closely and efficiently monitored in the APPL 's study. It's a challenge for all of us how to minimize the effectiveness of this serious hazard. Also he agreed that the quality of care should be improved and all the agencies should work positively in this direction.

Dr D. K. Srivastava: H.O.D. S.P.M., B. R. D Medical college, Gorakhpur(U.P.):

He opined that this study had brought up some interesting facts and the efforts would help us all in the fight against this disease. The recent data showed that the Japanese encephalitis cases have been minimized. There were only 13 out of 100 cases showing J.E. symptoms. Rest of the cases were of A.E.S. The probable etiology is still not known .His team have been constantly monitoring the drinking water quality the drainage and water logging. He assume that the contaminated drinking water may be the root cause. This study has come up with the data regarding the same which would help us to move in the right direction.

Dr. B. L. Srivastava: C.V.O., Govt. of U.P., Deoria

The CVO said that he would like to thank the APPL 's team for their sincere efforts, which at least had provided the starting points to the people concerned. He hoped that all these efforts would help us to fight this deadly disease and save lives of the people. He felt that as an veterinarians they have an important role to play but was sorry to say that there was a lack of coordination between veterinarians and the other Government health agencies. This should be sorted out.

Dr Vijay Mishra : Primary school teacher

This was a serious issue and these small efforts could bring a change. As a teacher he had been constantly in touch with hundreds of families and he constantly tried to educate them about the cleanliness ,health and the health facilities. There was a lack of awareness in the villages.

Sri Utkarsh Sinha: Renowned social worker and consultants in India/Abroad and Director of Center For Contemporary Studies And Research, Lucknow, India (CCSR) :

Sri Sinha liked to discuss about the recommendations made in this study, First of all the lack of awareness was a prime concern and he would like to say that the government machinery was not well efficient .We should collectively find out the way and should contribute for the same.

He also agreed that since this disease was directly related to animals, birds and mosquitoes the veterinary doctors and scientists should also be consulted and involved in planning and implementation of the preventive measures. Some of our veterinarian friends were present here and they had already shown concern over this issue.

Sri R.P.SHAHI: C.C.S.R., LUCKNOW

APPL Trust has been constantly working in this field for the past five years and we had been closely associated in the planning and research of some of their efforts. Definitely the efforts made were appreciable and they have managed to bring up some of the hidden facts about this disease. He wished APPL all the best and their support whenever needed

Prof. (Dr.) Harsh Sinha: Senior Journalist and Academician

He remembered in the year 2007, when he was present at the same venue at the presentation of APPL Trust's first study on the disability of the J.E. victims. He said it was an absolute eye opener and brought many hidden facts, the pain and sufferings of the victims to the light. Since then this organization (APPL Trust) had been constantly working in this field .He admired the spirit behind APPL 's work and the level of dedication. This qualitative study has also brought in light some start up points, which he hoped the people concerned should go through it and pave the way out

Dr. Amulya K. Srivastava , Clinical Psychologist and CEO 'Achintya' Foundation'

He opined that J.E/A.E.S. was probably the biggest problem in this part of Uttar Pradesh. In spite of all the efforts we are not finding way or solutions. These efforts are genuine efforts and we appreciate them. He offered from his side that he would be always available when he was needed for this cause

BESIDES THESE THE DELIGATES FROM P.G.S.S., P.G.V.S, SEVA BHARTI ALSO EXPRESSED THEIR VIEWS.

LIST OF PARTICIPANTS WHO ATTENDED THE MEETING

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The details of the presentation were given here separately on the APPL' s web-site .
