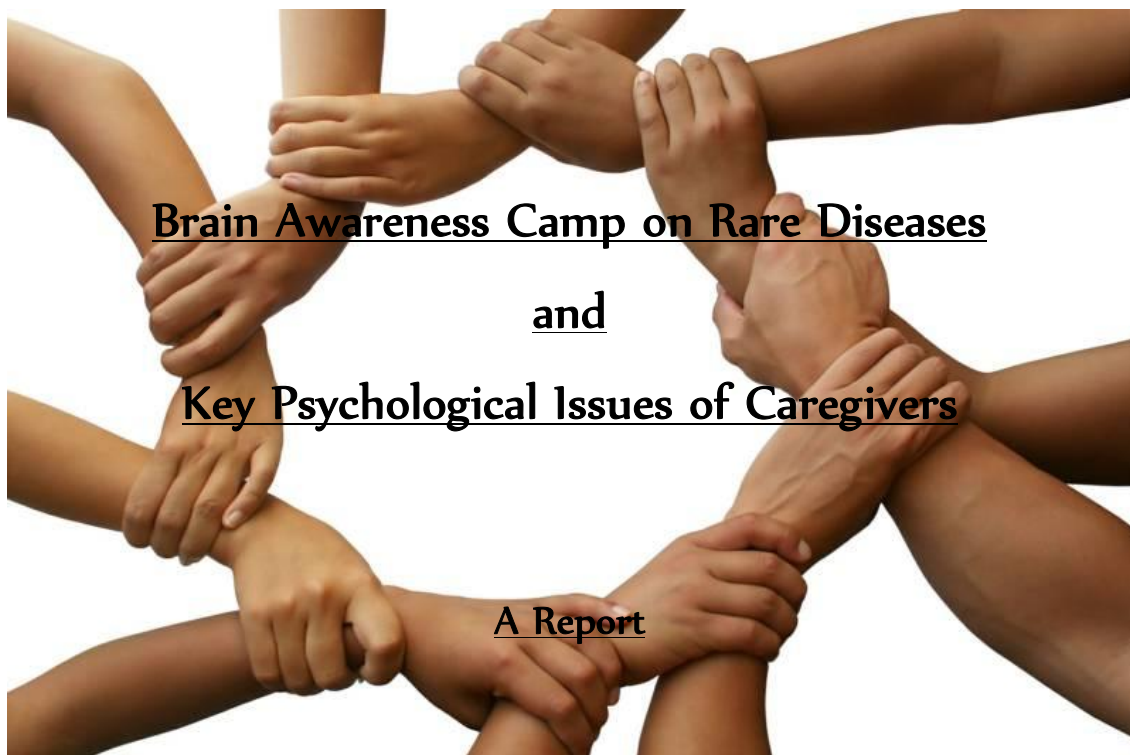




Brain Awareness Camp on Rare Diseases

and

Key Psychological Issues of Caregivers

A Report



An awareness camp on rare diseases was organised by Seek a Miracle Ataxia Group (S.A.M.A.G) in association with National Brain Research Centre (N.B.R.C) in Indore on 1st March 2015. The camp was attended by over 100 people and arranged at Nath Mandir, Indore. The participants included patients of MS, MD, Ataxia and spinal injury, care takers and general public. Even though the intermittent and unexpected rains poured all day, the participants' excitement and spirit was gushing all throughout the program.

The registration process was open all round the event. Patients themselves filled most of it (with few exceptions). The program started with welcoming all the speakers with flowers and memento which were presented by patients.



Ms. Swasti Wagh, President – SAMAG Indore Chapter, inaugurated the camp by addressing the audience, welcoming the speakers and motivating the patients to take little but constant steps towards little but important everyday chores and stressed the importance of helping oneself.



She also thanked all the patients and care takers, who had arrived from as far as Nagda and Shajapur for taking extra efforts and attending the meet despite heavy rains.

Speakers

Dr. Apurv Puranik

One of the key speakers of the event, Dr. Apurv Puranik is a well known neurologist based in Indore. He emphasised on the need of awareness and education of rare diseases among the population and linked the former to advocacy groups of these diseases which work seamlessly in western countries. He said that patience is one of the most important virtues required because an avalanche effect cannot be expected out of the efforts the groups put in. It is a step by step process but definitely culminates into success if pursued hard. He suggested periodic meetings, media reporting and writing memoirs in forms of diary or blogs as few ways to spread awareness in a fruitful way and cope with the disease. He stressed that although patients with diseases like Aphasia, Ataxia, and Dyslexia etc. are few in absolute number, but the sheer non – development of any kind of treatment calls for a penetrated level of public awareness about these. With examples of “The theory of everything” and “ALS ice bucket challenge”, his speech

also stressed the need of skill development of the especially abled. He also encouraged public to think about starting and helping sheltered workshops (like the ones in Europe and USA) in India to help make the patients of rare diseases financially strong and independent.



Mrs. Tapati RoyYadav

A psychologist by profession, Ms. Tapati's speech focussed on the nature of psychology and what basically goes through the minds of patients and caretakers specially. She emphasised on how important mobility and entertainment for both is. She said the two parameters keep the patients and caretakers happy and motivated every day. She asked the patients to follow a diet and chart out what they ate, drank and did. A good diet helps in thinking positive. Socialising was also suggested as a means to keep one oriented positive. She said that self respect and loving oneself is very important and every task that the patient thinks of taking or doing next should be first thought of in the mind with a creative bent and then executed.



Mr. Prathmesh Desai

National Secretary, Viklanga Sahayata Seva of Bharat Vikas Parishad, Mr. Desai gave an insight to the programs they have conducted and upcoming for specially abled patients. He said being positive is the only requisite to lead a happy life. He appreciated the efforts of all the care givers present and said that their motivation and unconditional support drives the patients' happiness and life but it should always be kept in mind to

not do all the tasks by themselves. Some of them should be done by the patients as it will boost their spirit and motivate them to do tougher tasks next.

Mrs. Kirti Dike

Mrs. Kirti heads the women's division of Lions Club Indore. She shared the problems and issues she faced with her daughter who is suffering from spinal bipedia (a degenerative neurological disease) herself and had to be operated on the day of her birth itself. She motivated all the care givers and family of patients by giving examples from her day to day life and how with the constant support of her family that her daughter is now working in an MNC and how after so many operations, it was her and her family's constant motivation and positive energy that brought her daughter out of her condition.

A quiz competition was organised for all the participants. The questionnaire and answer sheet were distributed along with the registration kit, the answers of which were scattered along the presentations and speeches. Top three scorers were given prizes. All the patients were encouraged to ask as many questions to the speaker panel and a discussion between the care givers and speakers took place. A few videos on themes of attitude, psychology and motivation were also shared. Refreshments were served at the end of event.

