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LUPUS INITIATIVE KOLKATA (LIK)

Lupus initiative was incepted 10 years ago in 2010 with the goal to empower the patients suffering from this multisystemic disease. This idea started in the outpatient department of the Rheumatology clinic at IPGMER, Kolkata and has now materialized into a busy, functioning office in Kolkata run by Mrs. Subhra Ghosh and 3 assistants who themselves are lupus patients. It is a platform where these patients can interact with other patients of SLE and the doctors to deal with their disease at a more personal level- beyond the mere prescription of medications. In our country, the social, economic and emotional aspects of a disease are very commonly overlooked, and this forum is to address those issues- where the patients can share their anxieties, happiness, and sadness with one another. It gives the patients a lot of moral support to be able to talk to other people who suffer from the same disease in this otherwise difficult, lonely and sometimes fatal battle. They bring up problems they face while dealing with the disease- social, personal, monetary and especially for our female patients- problems related to pregnancy and motherhood.



The family has grown from having just a handful of members 10 years back to over 450 patients currently. Each patient has a Lupus ID card and gets their medicines at a largely subsidized cost from the Lupus Initiative, Kolkata office. Their essential investigations are also done at a subsidized cost from renowned laboratories. There are mental and physical health specialists to take care of the patients' needs with regular workshops. LIK organizes outreach camps in rural parts of the state and involves the local practitioners who often come in contact first with our patients. This opportunity is used to educate the patients and their families about their illness. The families of lupus patients also require counseling as they frequently experience caregiver's burnout which is addressed in these programs.



Every year in January, a scientific meet on Lupus is conducted which invites Lupologists from India and abroad to discuss challenges and advances in this field. Every year, World Lupus Day, on May 10th is celebrated with cultural performances by the patients. This year's Lupus Meet was held on 11th and 12th January 2020. It was graced by the presence of Dr. David d 'Cruz and Dr. Anisur Rahman, notable rheumatologists in the UK with significant contributions in the field of SLE along with specialists from different parts of the country.

With each year, this family grows and our aim is to be able to include all lupus patients in this initiative and address their medical and non- medical problems. We also hope that this initiative is taken up at other places to help lupus patients all across India.



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