

## A Report: Inauguration of Jananeethi Help Desk & Release of Information Kit

Held at 5 pm on 25<sup>th</sup> March, 2011, at Kerala Sahithya Academy, Thrissur



Health is a common concern of all people of all times in all communities. The first phase of Jananeethi's Study on Clinical Drug Trials revealed that the mandatory global standards and best practices in clinical drug trials were rampantly violated by those who conduct the trials. Statutory norms and policies designed to check unethical practices were not yielding any significant result. The society in general and institutions in particular were not concerned, nor were they conversant with the ethical standards and statutory norms with respect to clinical drug trials. Jananeethi's fight against corruption and unethical practices in clinical drug trials has brought some sporadic but significant changes in the approaches of institutions and medical practitioners with regard to the rights of human participants in drug trials. However, the general public remained abysmally ignorant about the present scenario, especially of the rights of human participants of clinical drug trials. Our experience in the first phase of the Study indicates that this ignorance among the general public results in gross breach of laws and wide spread corruption that go unnoticed in the field of clinical drug trials. Sensitization among various sections of society regarding the mandatory norms and ethical



standards, and creation of a critical mass in society that demands strict adherence to rules and best practices is the need of the hour.

Therefore, a second phase of the Study focuses predominantly on mass awareness building programmes on the impending threats to public health across the State of Kerala as it was proposed by the independent assessor of the phase 1 activities, and provision for tangible services to victims of unethical and corrupt practices in medical research. A Help Desk, to achieve the afore mentioned aims, was proposed at Jananeethi to monitor and keep



vigil on clinical drug trials from March 2011 onwards. Jananeethi Help desk will function as a public utility hub for providing correct information to people with regard to clinical drug trials. It will investigate into and act upon complaints regarding unethical and corrupt practices in the area of clinical drug trials. Help desk will also extend legal aid and counseling to the victims and their family members of clinical drug trials. The Help Desk will also have a collection of comprehensive data on court orders, international documents, scientific studies and study reports that are relevant to clinical drug trials on human participants. Further, the Help Desk will contribute monthly news reports to the column in



Jananeethi magazine. To strengthen the services of Jananeethi Help Desk, we also have prepared an Information Kit for distribution among general public. This kit contains information regarding the Rights of human participants, various services available at Jananeethi Help Desk, ICMR Guidelines and contact details respective statutory authorities in case of emergency (in Malayalam).

Jananeethi Help Desk was formally inaugurated at a public function by the honourable District Collector, Mr. P.G.Thomas I.A.S. on 25<sup>th</sup> March 2011 at 17.00 hours organized at Kerala Sahithya Academy Hall and in the presence of a galaxy of invited dignitaries, friends, benefactors and members of Jananeethi Family. The meeting was presided by Dr.V.K.Ramankutty, Principal, Jubilee Mission Medical College, Thrissur. The Collector, as head of District Administration, applauded the initiatives taken by Jananeethi



for phasing out of the unlawful and unethical trends in medical research that have become truly detrimental to the interests of the large masses. Advocate Sunilkumar.P, project co-coordinator, welcomed the honourable guests and dignitaries and further presented a blue print of the ongoing study and its ramifications in Kerala society. As part of the function, the Information Kit that covers exhaustive information on clinical drug trials and a detailed description of the services of the Help Desk was formally released by Dr.V.K.Ramankutty giving the first copy to Shri. Joy Mannur, President of the Press Club, Thrissur. The function was felicitated by Dr.K.G.Radhakrishnan, Assistant Professor of Government Medical College, Thrissur. Advocate Ms Faritha Ansari, Law Officer and in charge of the Help Desk of Jananeethi, proposed vote of thanks.

Small, but elegant and erudite, the audience was very keen on the issues and concerns presented and that many of them had no knowledge of the colossal manipulations and violations of rights as currently prevail in the area of clinical drug trials on human participants. The participants urged the early formation of District Health Watch Groups as proposed by Jananeethi for the second phase of the study.

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