

Decision to form Patients' Rights Forum in Pune

On 9th May 09, in a meeting of about 30 representatives of various organizations and concerned citizens, a decision was taken to form a 'Patients' Rights forum' or 'Rugna Hakk Samiti' in Pune. In the meeting convened by Jan Arogya Abhiyan-Pune, several of the participants expressed concern over the lack of any mechanism to ensure dialogue between medical professionals on one hand and patients, carers and concerned citizens on the other hand. The lack of redressal mechanisms and widespread dissatisfaction with lack of proper communication and the kind of behavior that patients often receive in private hospitals and nursing homes was also shared. The fact that the 'Standard Charter of Patients' Rights' as part of the BNHRA draft rules have remained on the Health department's website since nearly three years without receiving final approval from the Health Minister was also a point of major dissatisfaction among health activists. It was deplored that the efficiency showed in issuing the ordinance to give protection to doctors from violent attacks is totally wanting when it comes to protecting Patients' Rights.

It was discussed that today an ordinary patient who suffers from any kind of rights violation has no public space to even express his or her grievances, and hence faces a lonely ordeal. It was felt that there is a need for some kind of review system, wherein patients and their carers could communicate any negative experiences, and the Patients' rights forum could periodically review such complaints and then dialogue with concerned hospitals, thus putting in place some kind of feedback and accountability mechanism. It was discussed that the forum would basically focus on issues of patients' rights violations, while not dealing with issues related to levels of charges in various hospitals or cases of malpractice and negligence. However the issue of Trust hospitals not providing free beds to poor patients and the need to monitor this was raised.

It was agreed that there is need for widespread awareness activities to educate common citizens about their health rights. It was felt that the emerging forum should reach out to not only middle class citizens, but should address issues faced by poorer patients and special categories of people such as persons living with HIV/AIDS who may suffer exceptional rights violations in private hospitals. The need to actively involve mass organizations working among various sections of working people in Pune was emphasized.

Keeping various suggestions in mind, the following decisions were taken:

- a. A patients rights' forum at Pune level with the name 'Rugna Hakk Samiti' will be launched
- b. A background note about the forum, along a 'Charter of patients' rights' will be finalized during the next discussion on 30th May
- c. A patients' rights convention will be held in July (tentatively 19th July), where the finalized charter will be released and discussed with a wide spectrum of citizens, including interested doctors and hospital representatives
- d. The circulated e-petition on patients' rights will now be signed by large numbers of people
- e. A process of citizens education on patients' rights will be carried out by means of

- bringing out leaflets etc. and by involving various mass organizations
- f. A system of review of patients' rights will be initiated. Here people experiencing rights violations in private hospitals will be encouraged to report such issues to the forum. The forum would meet periodically (say on a monthly basis) to review such complaints, and would give relevant feedback to concerned hospitals with an expectation of corrective action
- g. The mass media would be actively involved in this entire process. As part of this, the blog on patients' rights should be publicized and people should share their experiences on the blog.

Organizationally, it was decided to have a number of convenors, to take the process forward. Organizations and persons who volunteered to work as convenors included:

- MASUM (Anupama Pathak)
- Aarogya.com (Dwijen Smart)
- Kagad Kach Patra Kashtakari Panchayat (Surekha Gadekar, Neha Kagal)
- Lok Vidnyan Sanghatna (Ravindra Soman)
- Saheli (Tejaswi Sevekari)
- Joseph Lobo
- Makarand Sathe
- Yogesh Soman
- Anant Phadke (Jan Arogya Abhiyan)
- Abhay Shukla (Jan Arogya Abhiyan)