

File 1

Increasing Awareness

One of the major problems in rare diseases is lack of awareness - not only among the general public, but also clinicians and researchers. We plan to make a concerted effort to increase awareness amongst different stakeholders of the rare disease community. Some of the strategies are:

- Development of training/information modules for the public, teaching institutions, doctors/specialists, other practitioners, health care providers, policy/law makers etc.

- TV, radio and newspaper articles that depict and explain rare diseases.

- School and college students across the country should be made aware through mechanisms formulated by CBSE and NSS.

- Introducing suitable content for MBBS/MD/ other specializations through Medical Council of India (MCI), attending different medical conferences, publishing editorials and review articles in Indian medical journals, organizing CMEs for clinicians and regular workshops for researchers.

If you have experience or interest in drafting and formulating training materials, if you work in any area which is related to the above, if you are a doctor who attends medical conferences where materials could be distributed, or if you are a student or person willing to take time out to raise awareness physically and across social media, please do contact us.