

## **Enhancing Quality of Life and Providing Support to Diagnosed Patients**

Newly diagnosed patients and families face many challenges including coming to terms with a diagnosis. Generally lack of knowledge and understanding of genetic disorders compound the problem. Doctors may not have the time to continuously counsel patients through the initial phases after a diagnosis. We are providing support to newly diagnosed patients and need your help to continue and increase these efforts. For instance you could help us in starting a 'buddy programme', organize group meetings etc. If you speak a regional Indian language or an international language and have some experience or the willingness to counsel and support patients, please do contact us.

Most of the rare diseases lead to progressive disability. In GNE Myopathy, it starts from the distal muscles, eventually spreading through the body and a patient becomes a wheelchair user in a few years. Assistive devices help in enhancing quality of life. We would like to provide appropriate devices to patients who cannot afford the cost of these devices. Your money could go a long way towards making a patient's life much easier.