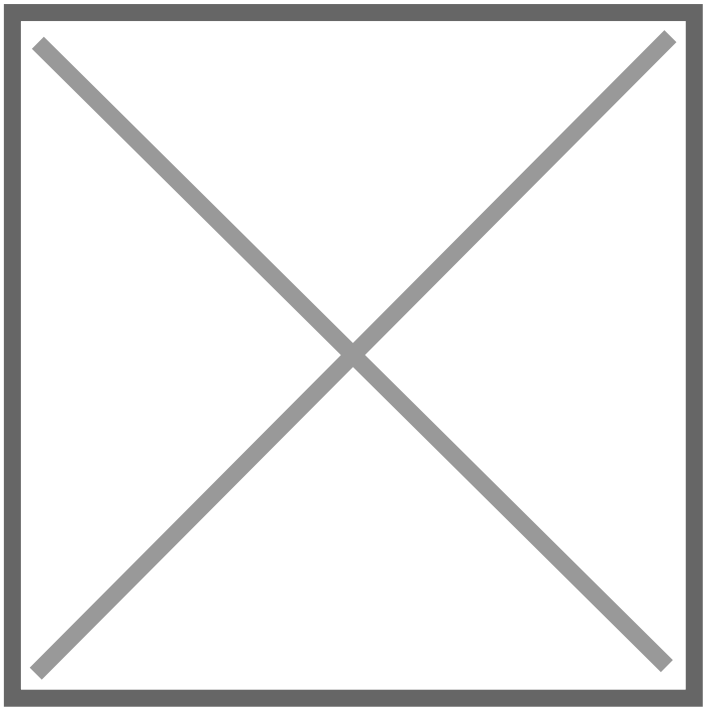
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Biotech Cos hesitant to invest in rare disorders R&D

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"We have the talent and the money, however, it is not coordinated into actual deliverables. We have the largest biotech companies here. Many are interested in investing in rare disorders R&D. But the moment they think in terms of marketing and business, that is where the hesitancy is," she commented.

Many biotech and pharma companies seem to invest millions in cancer research. "Rare diseases affect patients throughout their lives. Treating rare diseases is life-long. That's where we can see potential business opportunities," she said.

"Treated children suffering from rare diseases can live a normal life like everyone else. They are not mentally retarded. But they do have some physical disabilities," she opined.

Enzyme replacement therapy or ERT is critical to improve the quality of life for patients suffering from rare genetic disorders. "Without treatment, there is progressive accumulation of partially degraded compounds which stealthily leads to multiorgan dysfunction," Dr Bhat revealed.

The government of Karnataka made a historic decision to include treatment of rare diseases children in Karnataka, and made a budgetary provision in 2014-15 to set up a special unit at Indira Gandhi Institute of Child Health.

"Treatment for LSD is beyond the reach for most patients. Government support in terms of funding is imperative to help them lead a normal life. We urge the Karnataka government to release funds already allocated in the state budget for the treatment of rare diseases without any further delay so that patients get timely treatment," said Mr Manjit Singh, president, Lysosomal Storage Disorder Support Society (LSDSS).