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Shaking hands with the devil. Why a “For profit” stakeholder is a potential game changer in the rare disease ecosystem

The emergence of start-ups deploying digital crowdfunding platforms (DCP) in India for financing of rare disease (RD) treatment in India is a relatively new phenomenon. For these start-ups, commercial success is often measured by the ability to attract investors and investment making this space extraordinarily successful in that regard for them (Table 1). When we compare their success with the government driven DCP, it clearly shows the impact (1000x) of a “for profit” incentive stakeholder in the rare disease ecosystem (Table 2). India has also seen such start-ups actively promote media awareness of a rare disease (Spinal Muscular Atrophy), fund six patients with a potential curative therapy, and through engaging celebrities’ do more for disease awareness in a few months than any other intervention has done in the last decade.

Therefore, we believe that healthcare systems and public health authorities should actively support and encourage such companies through partnerships, easy access to data, tax incentives and other measures to allow them to consistently grow profitably. This will encourage them to further invest in disease awareness, diagnosis, genetic testing, new born screening and research into treatments as all these interventions are fully aligned to their commercial success.

In this presentation, we will critically examine the commercial model of these companies for scalability and long-term sustainability as well as how their “for profit” motivation can address the needs of the rare diseases community and better serve public health interests.

We propose that partnerships by the other stakeholders like healthcare professionals, hospitals, diagnostic centres and the government with them would be a game-changing approach to address the unmet needs of the rare disease community

in India.

Company	RD focus	Funding from investors	Investors
Impact Guru (IG)	Very high	\$4.5 Mn	7
Ketto	Medium	\$1.4 Mn	9
Milaap	Low	\$0.8 Mn	13

Table 1

DCP	Patients registered	Number of donors	Money raised
For Profit (IG)	1200	1.2 Mn	USD 18 Mn (14 months)
Non Profit (Government)	275	0.12 Mn	USD 0.001 Mn (6 months)
Milaap	Low	\$0.8 Mn	13

Table 1

Biography

Sanjay Somasundaram co-founded a technology start-up Eichiba Inc (USA) and learning’s from there helped him closely understand the commercial model of such companies. As a physician, he has experience in the pharmaceutical industry across clinical medicine, research, marketing and access. He was lead for the rare disease access program in Pfizer for five years. He and his co-author have extensively interacted with all stakeholders in the rare disease ecosystem including governments, public health experts, regulators, doctors, caregivers and patients to develop deep insights into their unmet needs and look for potential solutions.

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