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Harsha K Rajasimha, Androl Gynecol: Curr Res 2017, 5:3
DOI: 10.4172/2327-4360-C1-004

3rd Annual Congress on

RARE DISEASES AND ORPHAN DRUGS

October 30-November 01, 2017 San Antonio, USA

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Rare diseases and orphan drugs: Passion and compassion or growing market with career opportunities for scientists and technologists?

The words rare and orphan often generate a compassionate response from those affected but rarely generates any excitement among scientists or technologists or entrepreneurs. The progress in diagnosing or treating a disease has been largely driven by patient advocacy groups fighting against specific diseases. While this continues to be a driver, numerous recent trends indicate a thriving orphan drugs market with over 4000 orphan designations and ~600 orphan drugs approved by FDA since 1983. Until recently, only a handful of countries had a formal national policy on rare diseases or umbrella organizations advocating patients' interests, clinical research involving rare diseases and patients registries to engage the biopharmaceutical industry. A number of new national and international organizations are spurring innovation and creating opportunities for collaboration and progress never before possible. The international consortium for rare diseases research, international collaboration of rare diseases, rare diseases international are examples of international organizations. The organization for rare diseases India (ORDI) and Chinese organization for rare diseases are examples of umbrella organization representing the collective voices of all stakeholders of rare diseases in the most populous countries. Technology trends in clinical-speed, low-cost genome sequencing is enabling diagnosis of thousands of genetic diseases in a single test, BigData integration and analysis technologies are enabling unprecedented global patients access, wearable devices and real world data extracted from EMRs are empowering patients with a 360o view of their health data and mobile apps are enabling them to participate in drug discovery and clinical development process. Collectively, these trends point towards a very promising area of research and development for young scientists and engineers to pursue as career options with much hope for patients globally. I will present how ORDI is tapping into these opportunities for India.

Biography

Harsha K Rajasimha is internationally recognized in the field of life sciences consulting, systems biology, healthcare IT systems integration, BigData analytics, genomics of rare diseases and precision medicine. He is currently the global Head of life sciences R&D at Dell Healthcare and Life Sciences (acquired by NTT DATA Inc.), Founder President of Jeeva Informatics and Founder Board Member of the non-profit organization for rare diseases India, Affiliate Faculty and Co-Director of the Center for Metabolic and Rare Diseases at George Mason University. He was the global Vice President at Strand Life Sciences, a precision medicine company that develops genomics based clinical lab developed tests for cancer and inherited diseases. In collaboration with Rare Genomics Institute, he has received the Sanofi Genzyme's rare diseases Patient Advocacy Leadership award in 2016. He has authored over 15 peer-reviewed articles and is often invited speaker at conferences. He has earned Baccalaureate degree in Computer Science from Bangalore University, Master's in Computer Science and Doctorate in Genetics, Bioinformatics and Computational Biology from Virginia Tech.

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