

# Doing Well Through Doing Good: Investing in Rare Disease Drugs



## **Les Funtleyder**

*Portfolio Manager - Healthcare, E Squared Capital Management*

Les was recently the CEO of Applied Therapeutics, an Orphan disease company which was acquired by Circle Therapeutics. He is also a Healthcare Portfolio Manager at E Squared, where he is responsible for conducting fundamental and valuation analysis of public and private companies within the healthcare industry. Prior to E Squared Les was the Director of Strategic Investments for Opko Health and a healthcare strategist portfolio manager for the Miller Tabak Health Care Transformation Fund (Symbol: MTHFX). He joined Miller Tabak after managing a healthcare portfolio for Provident Advisors. Before joining Provident, Les worked as a medical device analyst at UBS Warburg. He also covered Biotechnology stocks at Bigelow and company.



## **Jack Kalavritinos**

*Founder & Principal, JK Strategies*

Jack Kalavritinos is a Washington-DC based public affairs veteran having served at the White House and three different federal agencies. Jack and his team focus on advising companies and national trade association in the life sciences and infrastructure areas and he serves as a speaker for investor groups, trade association conferences and as a contributor on national and Washington-DC based cable and broadcast news programs. Jack has served on the Trump Administration Transition team in 2016-17 and as a senior official at U.S. HHS and at the U.S. Food and Drug Administration advising the HHS Secretary and FDA Commissioner. He founded the public affairs firm JK Strategies representing clients and two coalitions: the Washington Health Innovation Council and the Construction Leadership Council.



## **Craig Martin**

*Founder & CEO, Orphan Therapeutics Accelerator*

Craig is a deeply experienced executive, advisor and board director, with extensive background in biotech and health technology fields. His focus in emerging innovation in areas of high unmet need has led to a longstanding commitment and extensive experience working in rare diseases. Craig has led for-profit and non-profit organizations focused on advancing and expanding access to treatments for rare, genetic conditions and is a frequent speaker and commentator on overcoming challenges facing innovators in rare diseases. He has worked extensively on the advancement of new technologies and treatment modalities – including gene editing and gene therapy, mRNA and microbiome-based treatments, genomic sequencing and molecular diagnostics, as well as in wearables and other aspects of digital health.



## **Bibhash Mukhopadhyay** (*moderator*)

*Entrepreneur/Firm builder, Asset Manager,  
Investor and Advisor to Biotech Companies*

Bibhash is an investment fund manager, investor, company builder and board member with almost 2 decades of experience in biotech. He is the CEO of Sapient Biotech, which is currently building a sector-specialized investment fund that invests exclusively in biotech companies, both private and small-cap public, with a fundamental, bottom-up, absolute-return strategy. It is also building a fund focused on rare diseases with a double bottom-line mandate for return on mission and return on investment. Through DW Wealth Management, he also advises various Family Offices and Disease foundations on investing in the healthcare sector. Previously, he was a co-founder and GP in Sound Bioventures and an investor with the biotech practice of a large, diversified venture fund, NEA.



## John Parker

Trustee, Charles H. Hood Foundation

John Parker is a family member and trustee of the Charles H. Hood Foundation, a Boston-based private foundation that has supported pediatric research since 1942. The foundation reflects a philanthropic legacy established by his great-grandfather, the son of the founder of HP Hood & Sons, the largest dairy business in New England, which the family owned for more than 130 years. In addition to being a trustee, John established and manages the Foundation's direct investment arm, which invests in life science and healthcare companies addressing significant challenges in children's health.

Investment portfolios in Family Offices are geared towards protecting first, and then growing generational wealth. This is typically achieved with a traditionally diversified capital allocation approach where a small fraction of discretionary allocation is towards mission-driven outcomes that the family principals are passionate about in spaces or areas they want to make a difference in.

Historically these spaces have spanned affordable housing, alternative energy, women empowerment, global health, health equity, racial equity and the like, where the power of company building through solutions architectures and impact measurement frameworks are well articulated and relatively mature frameworks for evaluation of outcomes of the investments made, already exist. No one has really shined a set of headlights in the rare disease space. Historically they have been neglected because they are not considered to be "big enough" by themselves i.e. each of these thirty thousand or so rare diseases afflict a small number of patients, but cumulatively, they impact one in every ten Americans.

The moderator, Bibhash Mukhopadhyay, has been working on constructing an unique investment fund structure and an associated ecosystem of capabilities bespoke to rare diseases drug development. This effort would integrate both philanthropic and for-profit sleeves of capital and construct a portfolio of systematic and consistent returns and measure the impact with a novel scale enabling a double-bottom line approach where Return on Mission AND Return on Capital are equally pertinent. This was the nucleating theme of the panel discussion.

The participants were carefully curated with representation from a private mission driven foundation, venture capital investor, an operator in a biotech which underwent M&A to deliver return to its investors, a leader who developed a novel model for rare disease development and a matchmaking marketplace for such treatments and a rare disease policy expert, with close ear to the ground on how the government thinks about rare diseases.

John Parker, a trustee of the Charles Hood Foundation that supports scientific advancements and innovation in pediatric diseases, as well as Founder of Springhood Ventures, provided background on the barriers perceived by the pharmaceutical industry and how a new model for drug development is needed. Being uniquely positioned both as an investor as

well as closely affiliated with a private foundation, he shared his perspective between goals advanced by the philanthropic approach versus those advanced by a for-profit intent and how the two can co-exist with a common mission.

Craig Martin, CEO of the Orphan Disease Accelerator, a nonprofit biotech focused on expanding development and commercial access to promising rare disease treatments, highlighted the CGTexchange. This platform will enable a crowdsourced model of rare disease drug development, where a match-making process will be performed between capital and projects. The projects seeking financing will be listed for individual investors, who are mission-driven to find a cure, to peruse and provide capital for.

Les Funtleyder, who until recently was the CEO of Applied Therapeutics and previously a fund manager investing in healthcare, opined on how an evergreen fund focused exclusively on rare diseases can be an attractive "financial product" in any asset allocators' portfolio. He walked the audience through the journey in Applied Therapeutics through the ups and downs of both the drug development process and the financial markets, and how ultimately, he was able to generate a return for his investors through acquisition of the company and fulfil an implicit compact with patients who need the drug that they were developing by appropriately resourcing the effort.

Finally, Jack Kalavritinos, drawing on his deep expertise in public affairs and health communications highlighted how new regulatory pathways are being formed and existing ones reinforced. Despite what is claimed in the popular press about political and policy uncertainty, this "ground reality" in the FDA, CMS and HHS, should assuage the concerns of a generalist investor, who at the outset perceive of investing in biotech and rare diseases, as risky because of the regulated nature of the industry.

The key takeaways from the discussion harped back to underlining rare disease drug development as a space that is ripe for consideration of investment from impact-oriented Family Offices and UHNWIs. Being able to put a smile on a child or a parents' face is priceless. And if one can make money while doing it brings that added layer of satisfaction.

**For more information, please contact:**  
Bibhash Mukhopadhyay - [bmukhop1@sapientbi.com](mailto:bmukhop1@sapientbi.com)

