

# **Navigating the Emotional Landscape of Parenting a Child with an Ultra-Rare Disease**

## **A Father's Journey**

**Dr. Sumira Riaz and Jonathan Bracey**



In the realm of rare diseases, the focus often lies on medical advancements and practical solutions. However, the psychological and emotional challenges faced by caregivers, particularly parents, are equally significant.

**This article delves into the profound experiences of Jonathan, a father navigating the complexities of caring for his son, George, diagnosed with an ultra-rare disease.**

Through his candid reflections, we explore the emotional toll, coping mechanisms, and the relentless pursuit of hope and solutions.

## The Diagnosis: A Bolt Out of the Blue

Jonathan's journey began in August 2023 when his son George was diagnosed with a rare form of cancer, rhabdomyosarcoma, in his bile duct. This diagnosis was a shock, as there was no family history of cancer. The biopsy revealed a tumour, shattering the initial belief that it was merely a blockage. The subsequent genetic sequencing uncovered two rare diseases: Silver Russell syndrome and mosaic variegated aneuploidy (MVA) syndrome, the latter being extremely rare and associated with a predisposition to cancer.



## The Fight Mode: Resilience and Determination



Faced with these daunting diagnoses, Jonathan and his family adopted a proactive and decisive approach. *"You fall into two different response mechanisms, you know, it a kind of flight or fight type of thing and we landed in the fight mode"* Jonathan recalls. Their journey through chemotherapy and innovative treatments, including nano-knife technology, exemplifies their unwavering determination to find solutions.

## Emotional and Psychological Impact

The emotional impact of George's diagnosis was profound. Jonathan describes it as "*a bolt out of the blue*," leading to a high level of anxiety and a relentless drive to find treatments.

The psychological toll was immense, yet Jonathan's background in the army and pharmaceutical industry provided him with resilience and self-belief.

He emphasises the importance of his son, stating,

*"If I can't put everything, I've got behind sorting him out, then I think I'd be doing him a disservice as being a dad."*

## Coping Mechanisms and Support Networks

Jonathan's coping mechanisms are rooted in traditional values and a strong support network. He relies on friends from various walks of life, engaging in conversations and activities like running the London Marathon. The MVA society, founded to advocate for George and others with the same condition, serves as a crucial outlet for his energy and anxiety.

Jonathan's approach is encapsulated in a quote he resonates with: "***It's not the destination that's important. It's the journey that's important.***" He often turns to his friends for emotional support, engaging in conversations and social activities that provide a sense of normalcy and relief. "*I talk to my mates, have a beer, and talk some more,*" he shares. This camaraderie and the ability to discuss his feelings openly with trusted friends have been invaluable.

Physical activities play a significant role in Jonathan's coping strategy. Running, in particular, has been a therapeutic outlet for him. He participated in the London Marathon, which not only helped clear his mind but also provided a sense of accomplishment and purpose, "Pounding the streets clears your head and makes you feel good," he explains.

## Impact on Personal Relationships

The journey has inevitably impacted Jonathan's personal relationships. The year-long hospital stays, often alone, strained his relationship with George's mum, Rachael. Despite these challenges, their differing approaches—Jonathan's focus on advocacy and Rachael's desire to return to work and normalcy—complement each other. Jonathan acknowledges the galvanising effect on friendships, revealing the true nature of support from those who stood by them.

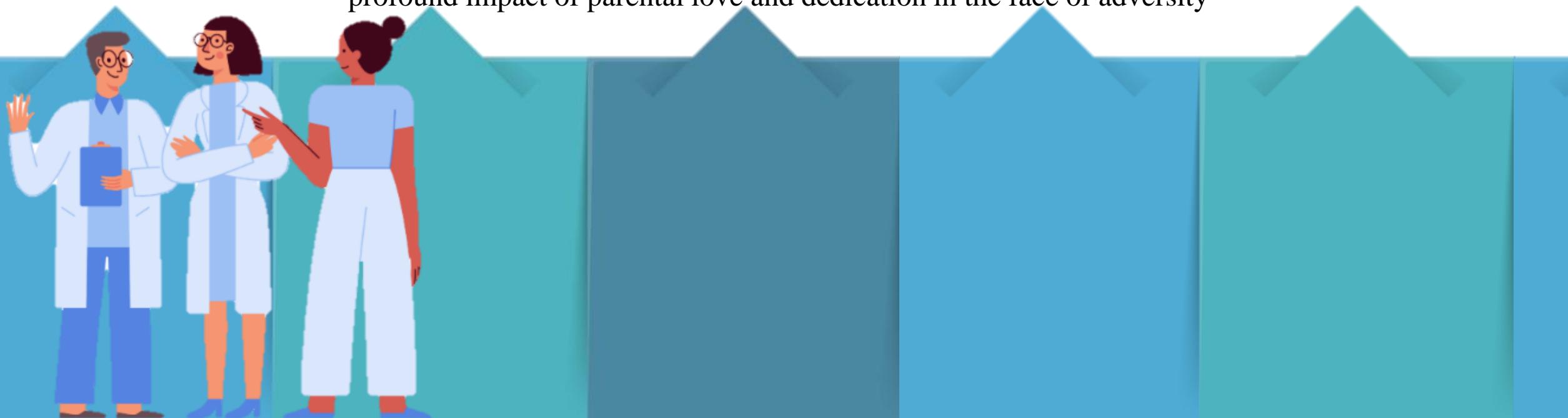


## Balancing Hope and Reality

Jonathan's hopes for the future are intertwined with his dedication to the MVA society and spending time with George. His employer's support has been invaluable, allowing him to balance work and caregiving. Jonathan's focus remains on progressing the MVA society, supporting his family, and finding moments of respite.

**Jonathan's journey as a parent of a child with an ultra-rare disease is a testament to resilience, determination, and the power of hope.**

His story highlights the emotional and psychological challenges faced by caregivers, emphasising the need for support networks and advocacy. Through his unwavering commitment to George and the MVA society, Jonathan exemplifies the profound impact of parental love and dedication in the face of adversity



# About the authors



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Dr Riaz is a health psychologist and a patient engagement consultant and founder of Unboxed Psychology; a behaviour change consultancy. Unboxed Psychology focuses on behaviour modelling and formulating clinical and health interventions to support the development of robust and strategic interventions for patients and healthcare professionals. Sumira works directly with patients, focusing on therapeutic interventions involving pain management, mental health care, and psychological support for people living with chronic health disorders.

Contact Unboxed Psychology by visiting our website [www.unboxedpsychology.com](http://www.unboxedpsychology.com) to learn more about enhancing doctor-patient communication using health psychology.



**Jonathan Bracey**

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Jonathan is the Founder of The MVA Society, Executive Vice President of Corporate Development and Managing Director in the UK at Tanner Pharma Group and George's Dad. MVA Society is a dedicated patient advocacy group establishing a focus on the ultra-rare genetic condition Mosaic Variegated Aneuploidy syndrome with a mission to find a cure. Jonathan has a very personal connection with MVA Society as George's Dad. Jonathan has worked in pharma for twenty years, including branded, generics and specialty pharma and during the pandemic supported the Governments COVID Task Force.

Contact MVA Society by visiting our website [mvasociety.org](http://mvasociety.org) to learn more about MVA and supporting those affected.