**DEAR LILY (A DIARY ENTRY)**

*March 2050*

Dear Lily, I remember meeting you at five years old—bright eyes, quiet resilience, and the weight of a rare metabolic disorder. Your parents had spent years searching for answers, only to be met with confusion and hopelessness.

Lily, I remember the fear in your mother’s eyes as she navigated a healthcare system not designed for the rare. Back then, as a young doctor, I saw firsthand the gaps in care for rare disorders. The fragmented pathways, the lack of research, the overwhelming burden on families. It was clear that medicine needed to do better, and I committed myself to being part of that change.

One of the biggest challenges has always been ensuring timely and accurate diagnosis. The reality is that many rare disorders masquerade as more common conditions, leading to misdiagnosis or years-long diagnostic odysseys. In the early years of my career, I worked closely with geneticists and researchers to integrate whole-genome sequencing into standard paediatric assessments. It was an uphill battle—cost, accessibility, and physician training were constant hurdles. But persistence paid off, and now, in 2050, genetic testing is a routine part of newborn screening, offering families the answers they deserve far earlier than before.

Lily, I remember the day your parents received the call. The relief, the grief, the unbearable weight of knowing and not knowing all at once. But diagnosis was only the beginning. Treatment remained another major obstacle. For many rare disorders, treatment options were either non-existent or prohibitively expensive. I worked alongside advocacy groups, including ‘Rare Disorders New Zealand’, to push for better government funding and pharmaceutical incentives. It took years of lobbying, policy discussions, and clinical trials, but we saw real progress. In 2038, a breakthrough initiative enabled targeted gene therapy subsidies, establishing a care pathway for rare disorders, including diagnosis and genetic testing for individuals with uncommon, undiagnosed symptoms.

I remember your mother telling me how alone she felt—how no one truly understood what they were going through. Perhaps the most difficult challenge has been addressing the emotional and social toll of rare disorders. The isolation that families face is profound, and for a long time, the support networks were scarce. This is why I dedicated much of my time to establishing peer support programs and online communities where families could find solace, guidance, and connection. These networks are now an essential part of holistic care, ensuring that no one has to walk this path alone.

Lily, 25 years later, you stand on the other side of a seemingly impossible future. You are a young woman, living a life your parents once feared you would never have. Looking ahead, I hope that your story will continue to inspire the next generation of doctors and researchers. It is true that medicine constantly evolves, but the need for advocacy, innovation, and empathy remains timeless. Your journey shows us why this work matters.

Thank you, Lily.