

# **ONE FALL, A MILLION CLIMBS**

MY LIFE JOURNEY WITH POMPE

**ALYASGHAR HEBATULLAH**

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**ISBN-13: 979-8541-28-061-6**

Published and Printed by **Elong'o Publishers**

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## **DEDICATION**

This book is dedicated to my beloved family for their kindness, devotion, and endless support during my daily struggles.

To miss Maryze Schoneveld van der Linde, who is constantly working to help other patients and inspiring us to help others.

To Sanofi Genzyme for providing medicine and putting their unaltered effort into patients like us.

Also, to the Sanofi Genzyme Humanitarian Program, for the ultimate opportunity given me to be one of their beneficiaries.

And all those patients with rare diseases, especially Pompe patients.

And to the whole team of Doctors and Nurses at Agakhan Hospital for putting their best efforts during the ERT.

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## **PREFACE**

"ONE FALL, A MILLION CLIMBS" is a book based on a real-life story expressing my life battles with a rare kind of disease called Pompe.

I wrote this book to create awareness of the existence of rare diseases, more specifically Pompe. I want people to understand more about it and know what people with this kind of disease go through and how they should handle them.

The book encourages anyone with any rare disease to live their lives and achieve goals because having the disease is neither the end of life nor the world.

My inspiration for writing this book is my life journey, how I struggle to come to terms with the disease, how I handled it after, and the secret behind living an everyday life despite not knowing what tomorrow holds.

## **FORWARD**

### **FATHER**

Alyasghar, my 29 years son, has gone through such a difficult life fighting against Pompe disease. He is such a fighter who doesn't depend on anyone for survival.

My son has been his own doctor, doing thorough research and digging deep into computers while consulting various specialists. I have never heard him complaining or crying over his disabilities. Still, instead, he has worn his armor and made his state as conducive as possible for him to live happily like any other Normal being. He has amazingly raised his two daughters besides running the family business, which was beyond expectations from someone whose health has taken a toll on them.

I wish Alyasghar a happy life and pray that he continues his fight and live for many years to his old age.

### **WIFE**

Life has been of great adventure ever since I met my husband, Alyasghar, and I am sure more is to come with the power of Allah. I consider Alyasghar a healthy person because he gets his way around things perfectly well and does not depend on anyone whatsoever. He has accepted Pompe as a lifestyle and embraced it with open arms.

It is usually evident that any person is scared of any strange disease, and so was my husband before diagnosis. Even though it has been years since we got married, I know little about his past except for the ones he told me about, and I can't even imagine how difficult it was for him.

It has been eight years since I met him through an arranged marriage, and I must admit it has been the best years of my life with him by my side. The first time I met him, I hardly realized anything amiss except that he was thinner than his mates. However, what caught my attention was his gentle, caring, and native voice, which made me fall head over heels in love with him. We went on few dates before I could notice the difficulty in his walking, but then that was never a hindrance to anything he set his mind to do. At some point in our many dates, he informed me about his health issues. I sought to satisfy my curious immature self for the rest of the dates by keenly finding his limitation. I must admit it was never easy since Alyasghar was an ordinary person in the making. I must say I wasn't mature enough then to understand the seriousness of his health condition, and neither was he, or so I thought.

Even with the limitations, I was madly in love with my then-husband for his gentle, loving, caring, and hardworking family-natured personality. If I can describe in detail, Alyasghar is all in one package.

The whole process of understanding this disease later posed to be a challenge to me at first. There was a strict diet, daily exercises, not forgetting daily doctor's visits among many

medical prescriptions, which by the time I got to understand, and it became part of my life, and I did it with pleasure.

On any everyday occasion, managing a person with any rare condition is not a bed of roses. Despite Alyasghar's hardworking nature, some activities are unsuitable for him, and he must adhere to them. He also faces many challenges like the constantly changing diet, the struggle to sleep at night, keeping up with a strict exercise schedule, making sure he is not stressed, trying to balance his time to fit the family, work, and his health needs; all this needs my support.

He has had difficulties coping with physical activities, but the third power has done wonders to us. It has been a year since he started his medication with Genzyme company, whom I owe them a great deal of gratitude and not forgetting Allah sent an angel Maryze Schoneveld who was our guiding star to this far. The medicine has restored his health, and I am grateful and happy to have found them.

If I must say, my husband is a great person who is loved and respected by both young and old in our family for his personality. He is an inspiration and a role model for his siblings despite the pressure from his health. I am grateful I met Alyasghar, who has been my pillar of support in a way I think nobody else could have been and a loving father to our two princesses. He has stood by my side irrespective of his challenges, and I promise to love him till death do us part.

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## **INTRODUCTION**

My name is Alyasghar. I am one of the unfortunate people born with one of the extremely rare diseases called Pompe, but then lucky enough to have lived this long to tell a tale. Pompe is a rare disease that happens when your body cannot make a protein that breaks down complex sugar, called glycogen, for energy. Too much sugar builds up and damages your muscles and organs. It causes muscle weakness and respiratory difficulties.

It approximately infects 1 in every 140,000 infants and 1 in every 60,000 adults in the world's population, and I happened to be one of those infected.

Growing up, I honestly had no idea that anything was wrong with me physically. Realizing years later that Pompe is a progressive disease made it hard for me to understand myself at the early stages. Having no source to compare how my body should have been made it

challenging for me to realize any worrying changes besides seeing significant differences in others.

Going back to my past, I remember I was always weak in sports, which was always coming last or second last in a race and other physical activities. Eventually, I started thinking beyond and developing the sixth sense, which showed me the more accessible paths in everything I did—finding loopholes while playing sports to fit in and be an ordinary person.

It never occurred to me that I might have a rare disease or any general weaknesses of such kind. To me, it was just that I was slow and not good at sports.

My body was also thin, thighs and arms were 30-40% thinner than my friends. Unnoticeable at that time, my appetite was also not as the one for 10-15yrs old. All these I realize when I am 30.

As I recall today, it all began in my first year at the University of Al Jamea Tus Saifiyah, located in Surat Gujrat, India. It was in the year 2006 when I was walking along uneven grounds. I unexpectedly collapsed when my knees suddenly lost control. It never raised any alarm because, to me, anyone can fall, especially on uneven surfaces like that. It was no big deal; however, sometimes, due to the bumpy ground, It got me injured with stones and other objects, bruising my legs badly on several occasions and afterward living with that pain.

The falls became consistent until it was time to crack the nut. One day, I decided to go to my uncle, Al-Mudaris Ahmedali, a teacher at the same University (Al Jamea Tus Saifiyah). I informed him about my condition and can recall his face being mixed-up of surprise and concern. The next day he decided to take me to a family doctor Dr.

Jambarwalla. After the examination, the doctor affirmed that diagnosis wasn't possible in Surat, which made me travel to Mumbai. Now it got me a little worried that my condition could be severe.

By that weekend, after visiting Dr. Jambarwalla, I was on my way to Mumbai as my parents used to live in Mumbai at that time, which meant easy access to medical practitioners. My parents were distraught but also happy about my arrival. We started calling Saifee hospital and asked for a neurologist, we booked an appointment with one, and a few days after, we went to him together with my Parents. My medical journey began from there.

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