ROAR FOR RARE: THE UNHEARD VOICES

Commemorating 20 years of Sanofi Specialty Care in India

sanofi
Specialty Care

DISEASES THAT ARE RARE
NEED MUCH MORE CARE.

INTRODUCTION

Rare diseases are serious, chronic, debilitating and life-threatening diseases that require long-term and specialized management. Their health expenditure is so high, that it would eventually impoverish the affected patients and their families. The fundamental 'Right to Health' rests on the foundation of equal rights and opportunities for all, where *no one* gets left behind.

Sanofi Specialty Care, since its incorporation in India in 2007, has been working towards enhancing awareness of rare diseases and capacity building of clinicians through innovative programs like Fellowships in Clinical Genetics; in collaboration with Society of Indian Academy of Medical Genetics and CSIR - Institute of Genomics and Integrative Biology.

Since 2013, a free diagnostic support program has been ongoing, to aid timely diagnosis of patients with rare diseases.

Sanofi's India Charitable Access Program (INCAP) is part of Sanofi Specialty Care's global humanitarian program, through which we provide free treatment to patients in India affected with Lysosomal Storage Disorders (LSDs) – Gaucher, Pompe, Fabry and Mucopolysaccharidosis. The humanitarian program in India began in 1999, even though Sanofi Specialty Care did not have a local presence, then.

Globally, more than 900 patients from 50 countries are on the Humanitarian Program today, out of which around 130 patients are from India.

ROAR FOR RARE
THE UNHEARD VOICES

With this collection of real patient chronicles who are on our humanitarian program, as well as those supported by government/institutional funding; we have attempted a glimpse into how the lives of people suffering from such debilitating disorders, have *transformed*.

This would not have been possible without the partnership and alliance of other partners like the States of Karnataka and Kerala, the Employee State Insurance Corporation (ESIC), the Indian Army and many such, who rose to the occasion and supported the treatment for a few of the children living with these rare diseases.

Sanofi Specialty Care is committed to stand strong as a health journey partner – Bringing 'hope' to those who think they have none.

BRINGING HOPE | TRANSFORMING LIVES

#EveryLifeIsPrecious

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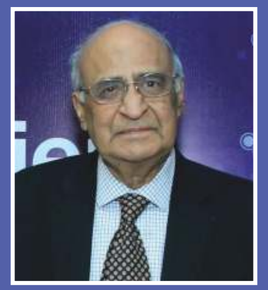
BRINGING HOPE | TRANSFORMING LIVES

#EveryLifeIsPrecious

FOREWORD BY
Dr. I. C. Verma



Professor and Senior Consultant
Advisor, Institute of Medical Genetics and Genomics
Sir Ganga Ram Hospital, New Delhi, India

I feel honored and privileged to be asked to write the foreword for this delightful book, sensitively describing the improved life of those patients of Lysosomal Storage Disorders, lucky enough to fall under the umbrella of Sanofi Specialty Care's India Humanitarian program. The Enzyme Replacement Therapy (ERT) they received transformed their lives, enabling them to fulfil their desires and ambitions. These stories are not only inspiring, but a testimony to what modern science and technology has made possible for those who have the will to succeed. Sanofi Specialty Care in India deserves accolades for their generous support to this program to help patients suffering from LSDs, who otherwise cannot afford this expensive therapy.

Of course, patients with Gaucher disease achieved the best results, growing from children with bloated tummies to smart adults, to becoming engineers and scientists. Patients with Mucopolysaccharidosis Type 1 were able to flex their joints and muscles and benefitted from increased movement. Those with Fabry disease kept their hearts and kidneys strong and avoided dialysis and kidney transplantation, while those with Pompe disease strengthened their hearts and the older ones increased their mobility. Overall, each one improved the quality of his/her life.

The stories of these patients also remind us of their brethren who were not able to obtain enzyme therapy. This starkly points out the intransigence of the authorities in denying therapy to patients of LSDs, because of cost. Admittedly the enzymes are expensive, but these are not beyond the resources of the Government of India. These case histories are a remarkable demonstration of what appropriate therapies can do, and hopefully will make the authorities realize their duties towards the Constitution and towards the Father of the Nation, Mahatma Gandhi, who famously remarked that the state of our society will be judged by how we treat the poorest of the poor who lack the means of supporting themselves.

The other lesson we learn from these case histories – is that the earlier the diagnosis is made and earlier the treatment with ERT is started – best are the results. Once the physicians know that treatment would be available for those who need it, they would surely make an early diagnosis for early start of therapy, to ensure best results for their patients. They have the necessary clinical skills, but they have not felt any compelling reason to exercise it.

In the end, I congratulate Sanofi Specialty Care for initiating and continuing the Indian Humanitarian Program and showcasing these stories of hope and success.

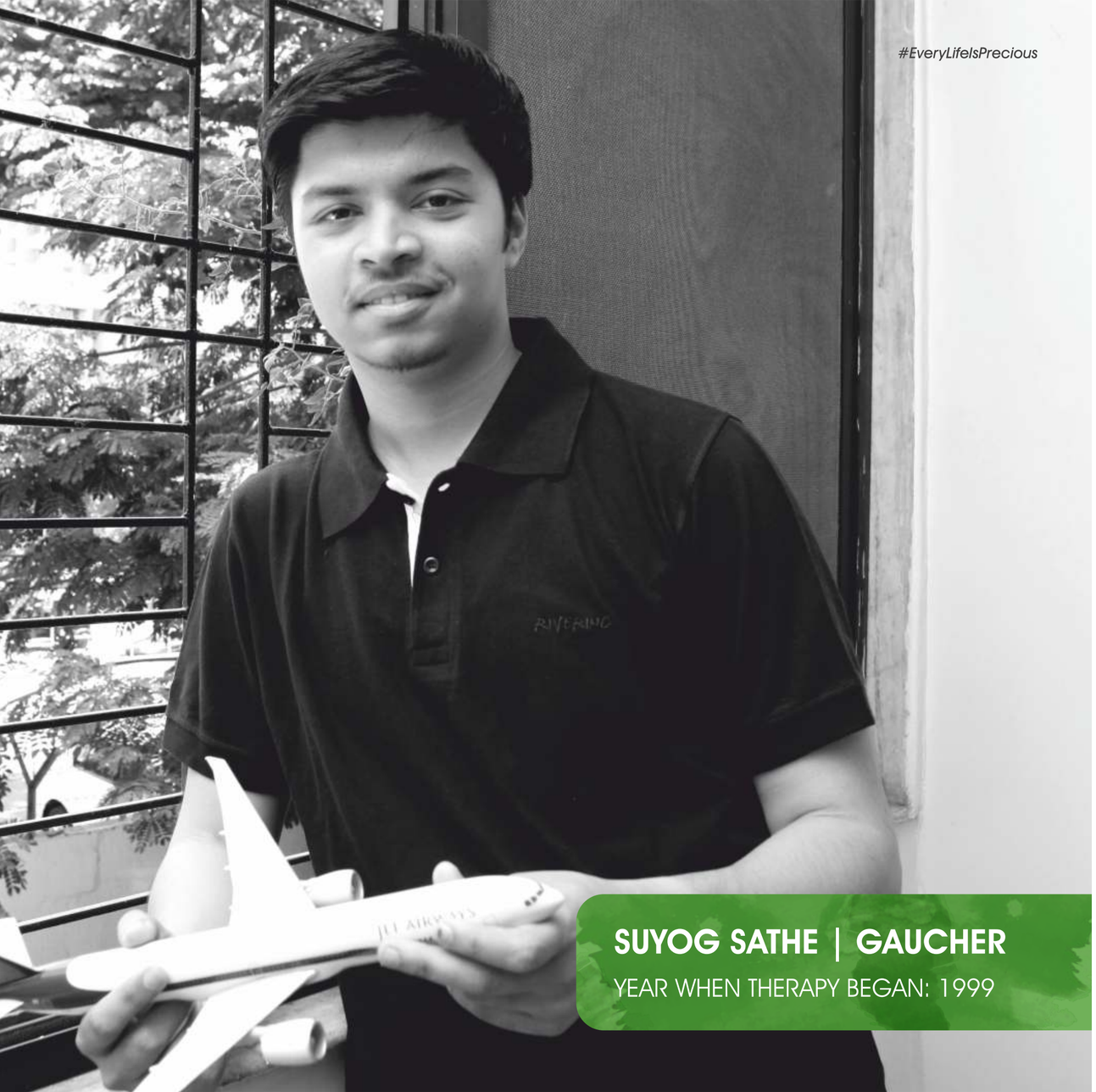
Ishwar Verma
Chairman, Indian Medical Advisory Board,
India Charitable Access Program (INCAP), Sanofi Specialty Care

OUR
GAUCHER FIGHTERS

Standing Together for a Healthier Tomorrow

#EveryLifeIsPrecious

#EveryLifeIsPrecious



SUYOG SATHE | GAUCHER

YEAR WHEN THERAPY BEGAN: 1999

SUYOG SATHE

Two-and-half-year-old Suyog was severely anemic and abnormally pale. Nothing improved for him, even after a blood transfusion. It was only in 1997, when his blood sample was sent to Manchester, that he was diagnosed with Gaucher disease. By this point, his liver and spleen had swollen considerably, and he had difficulty in breathing.

Many internet searches later, his parents heard of and wrote to Genzyme USA pleading for their son's life to be saved through the enzyme replacement therapy. They were delighted to hear back that their son would not only receive treatment assistance, but that it would be completely free.

By early 1999, Suyog's therapy began and he was the first recipient of this treatment from Sanofi Specialty Care in India.

Today, Suyog leads a healthy life. He is an electronic engineering graduate and works at an IT firm in Mumbai. He also works as a Regional Manager – South Asia, for the International Gaucher Alliance.

He aspires to climb the corporate ladder, while he fuels his hobbies of travelling, music and photography.

VILOL MALAVDE

At the age of three, when treating Vilol for high fever, doctors also detected a swelling on his liver, by chance. After many more tests and examinations, he was diagnosed with Gaucher disease.

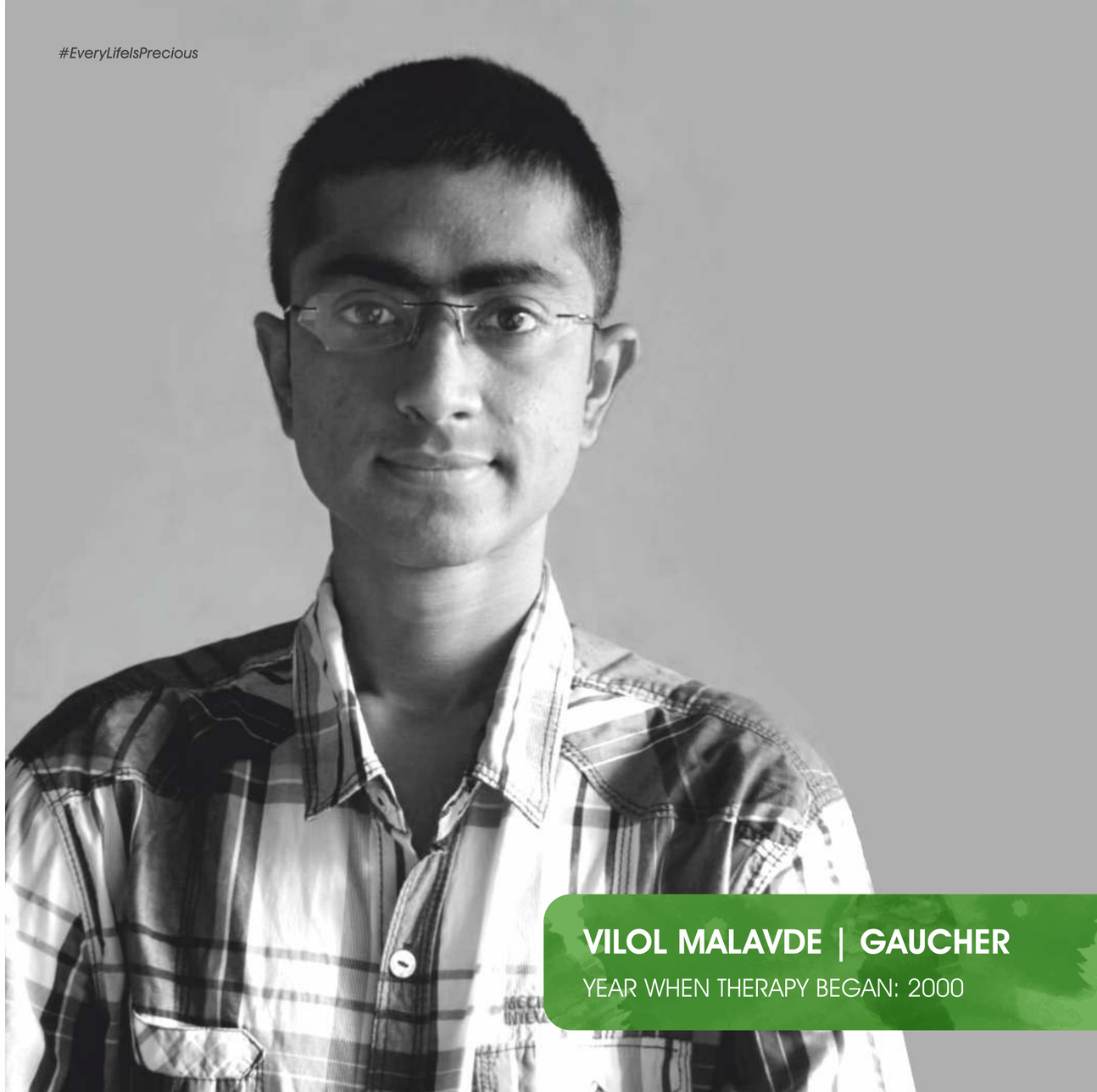
As Vilol grew older, his condition worsened. Following a severe pain in his legs and joints, bleeding from the nose, and vomiting blood, he had a brain hemorrhage. This left him in a coma for three days, and doctors feared that he would not survive beyond three months.

Lying on a hospital bed, when young Vilol asked his father if he would survive, his father knew he was going to do everything in his capacity to save his child.

Fortunately, Vilol recovered from coma, but his health kept deteriorating. The struggle continued until he received an infusion at the age of 13. Since then, Vilol has lead a near-normal life. He completed his education on time and currently works in Mumbai.

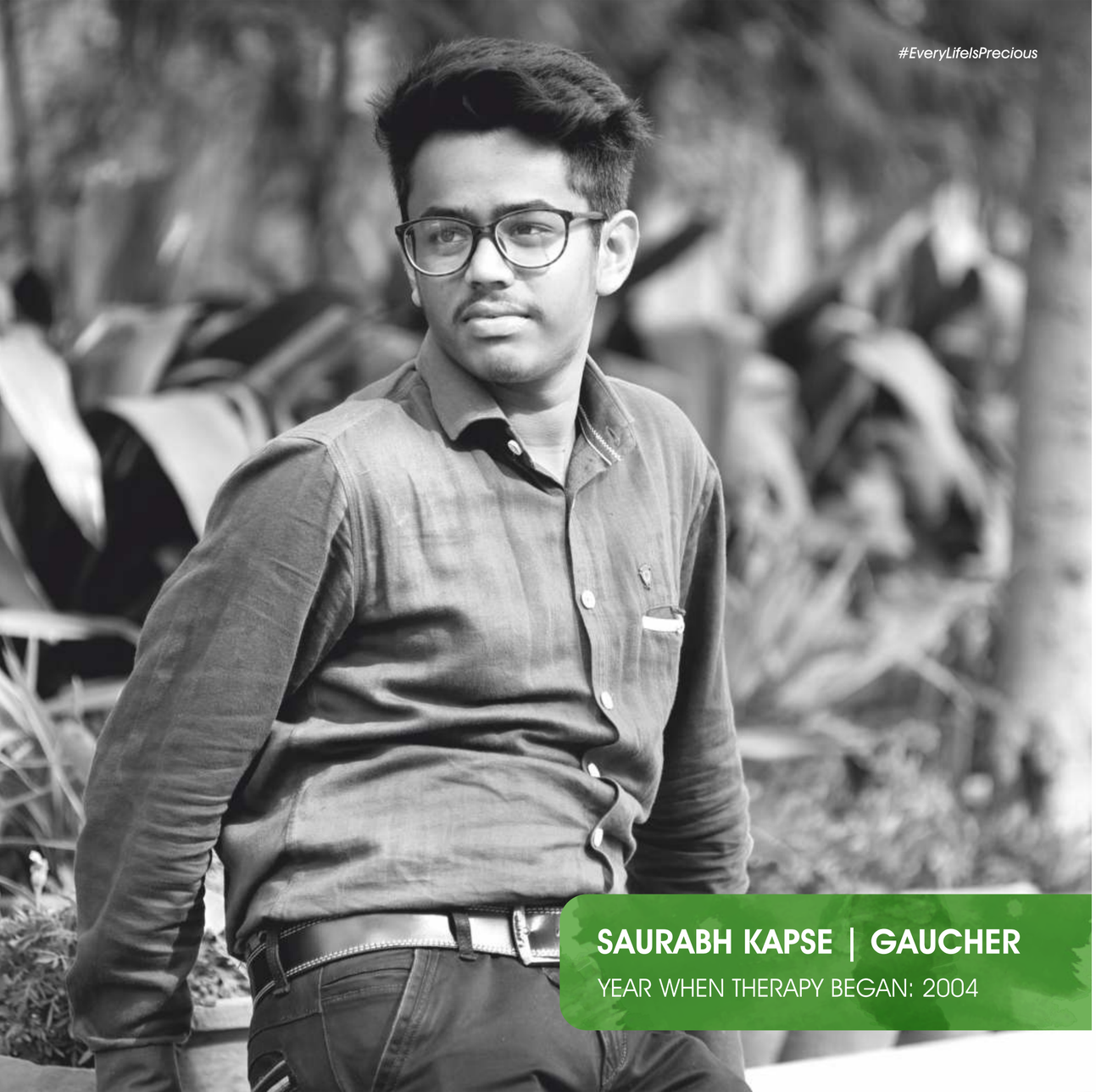
He is happily married and wishes to lead a fulfilling life with his wife and family. He also hopes to help other Gaucher patients through counseling, to ease their anxiety and pain.

#EveryLifeIsPrecious



VILOL MALAVDE | GAUCHER

YEAR WHEN THERAPY BEGAN: 2000



SAURABH KAPSE | GAUCHER

YEAR WHEN THERAPY BEGAN: 2004

SAURABH KAPSE

Three-year-old Saurabh had an abnormally sized stomach due to liver and spleen enlargements. His blood tests showed low counts of hemoglobin and platelets. He frequently experienced nosebleeds and developed an aversion to food, due to indigestion.

His family doctor noticed soon that both his sister Aishwarya and Saurabh were showing similar symptoms. Due to poor bone health, their height wasn't increasing, either. He referred them to a pediatrician.

The pediatrician suspected his condition to be a rare genetic disease and referred both siblings to the Ganga Ram Hospital in Delhi. After thorough medical tests, they were diagnosed with Gaucher disease in the year 2000.

Since no treatment was available in India then, they underwent splenectomy and were on an antibiotic regime to avoid any susceptibility to infection. Finally, in 2004 they started infusion therapy. He has been on treatment, ever since.

Saurav recently graduated as a Mechanical Engineer. He loves the outdoors, plays cricket and football and works out at the gym to keep fit. He has won numerous awards as an athlete in college and is an avid science-fiction reader.

AISHWARYA KAPSE

Aishwarya was all of one-year old when she started showing initial symptoms such as an enlarged stomach, weakness, loose motions, indigestion and low appetite for food.

Till 2000, her treating physicians were clueless about the reasons behind her worsening health condition. She was on symptomatic treatment based on recommendations of various specialists. She underwent splenectomy for interim relief, but it was all in vain. Her condition continued to worsen until she, along with her brother who showed similar symptoms, were referred to the Ganga Ram Hospital in Delhi. There, both siblings were diagnosed with Gaucher disease.

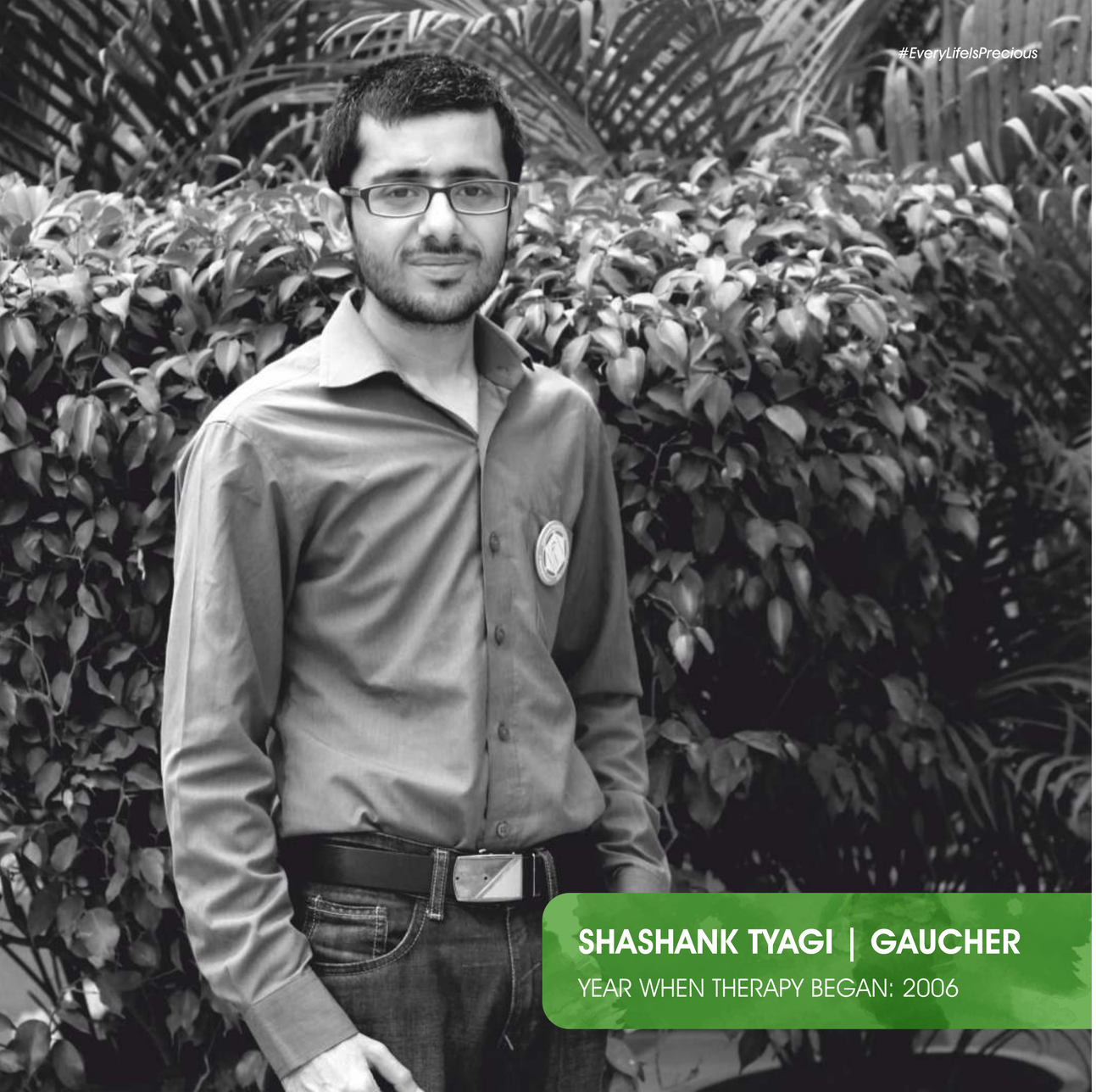
Aishwarya's treatment began in 2004, along with her brother Saurabh's. Looking back now, no one can tell she is the same child that suffered such a traumatic journey of misdiagnosis and delayed treatment.

Currently, an Electronics and Telecommunications Engineer, Aishwarya continues her search for work opportunities in the Information and Communications Technology space. She swims and cycles to stay fit, enjoys reading novels and continues to keep her passion for baking and cooking alive.

#EveryLifeIsPrecious

AISHWARYA KAPSE | GAUCHER

YEAR WHEN THERAPY BEGAN: 2004



SHASHANK TYAGI | GAUCHER

YEAR WHEN THERAPY BEGAN: 2006

SHASHANK TYAGI

Shashank recalls his journey of a decade full of misdiagnosis through never-ending medical screenings and tests. It all started when he was four years old. He used to throw up whatever little he ate, could not digest any solid foods and was growing lower on energy and immunity with each passing day.

He was always tired, physically drained and on a constant liquid diet, due to which, his life was very inactive when compared to other young, bubbly, energetic children of his age. And that he wasn't growing tall as per his age, made him sadder.

Through these ten tumultuous years, his family and he went through immense emotional ordeal, fear and hopelessness. Shashank was even put on various alternative therapies, but nothing improved his condition. His health was worsening, and his liver and spleen were enlarging.

Finally, in 2004, he was diagnosed with Gaucher at AIIMS, Delhi. Two years later, he received his first infusion through CMC, Vellore. His body started responding to the therapy. He started eating better and his body started regaining the strength it needed. He could run, cycle, play football and go to school like all other children of his age.

There has been no looking back, ever since. Currently, Shashank lives a near-normal life and is now an MBA graduate.

He's a Pan India coordinator of the Lysosomal Storage Disorder Support Society and is raising awareness on rare diseases and also works as a Regional Manager - South Asia for the International Gaucher Alliance since 2018. Shashank aspires to work at a corporate firm soon and wants to live his dream of bungee jumping and paragliding.

SHREYA SETHI

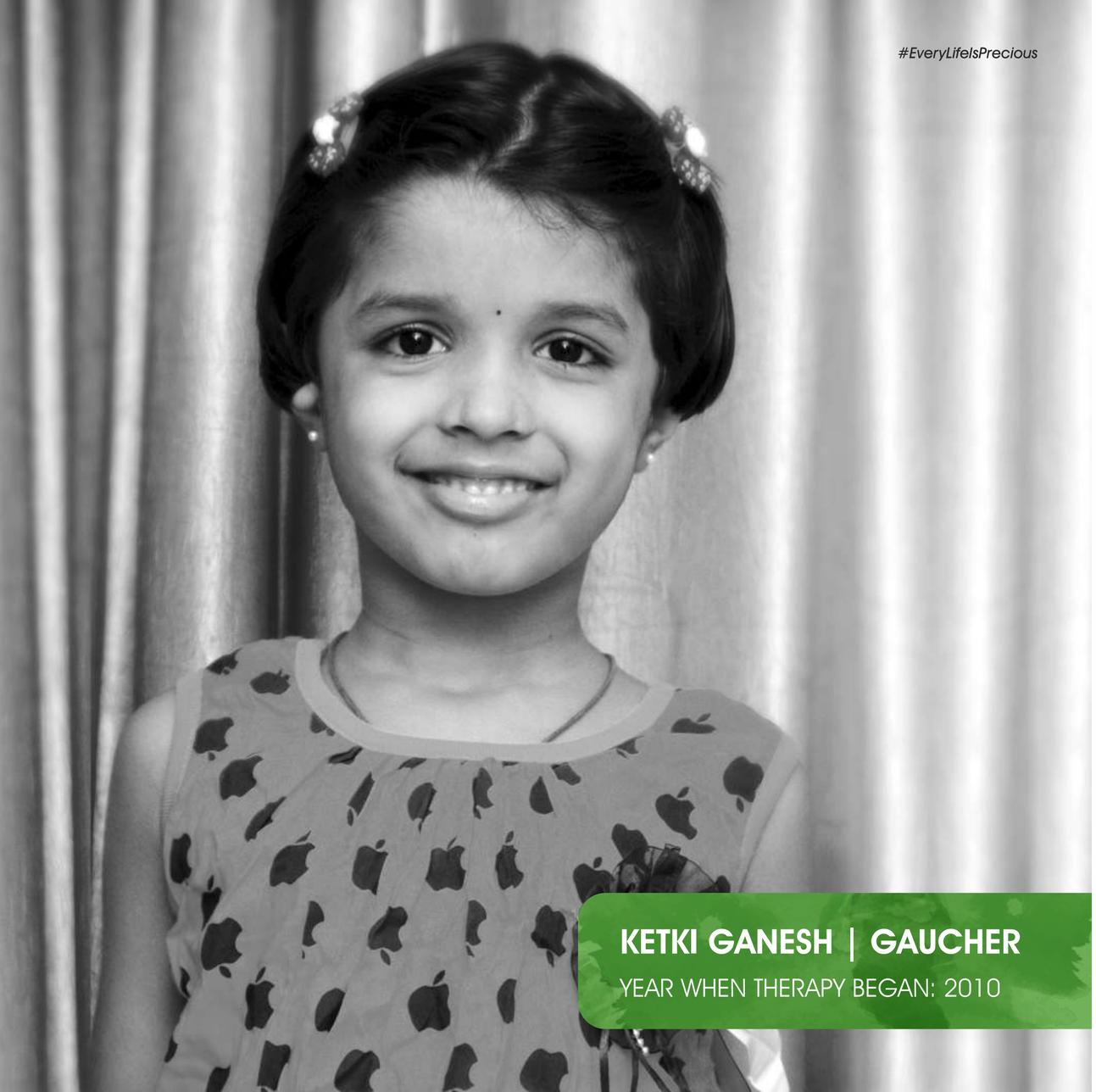
Shreya's birth was like a dream come true for her parents. The couple had a boy earlier, and with a baby girl, their family was 'complete'. But their happiness seemed very short-lived, when doctors reported major health concerns for Shreya.

Her spleen was enlarged and her hemoglobin kept dropping, persistently. She was admitted to the ICU for blood transfusion, twice. It was only when her blood samples were tested for rare genetic disorders, that the family found out she had Gaucher disease.

Her health kept deteriorating for a year after her birth, constantly indicating near-nil chances of survival. The family was heart-broken but determined. Various internet searches later, they approached Sanofi Specialty Care in 2011, requesting any possible assistance with their daughter's treatment.

A response in the affirmative ensured their joy knew no bounds. As soon as Shreya started receiving therapy, her condition stabilized – her blood count improved, and her spleen and liver reduced to normal size within two months.

Now Shreya attends school regularly and is academically sound. She loves watching movies and spends her time cycling, creating craft and, at times, grooving to her favourite



KETKI GANESH | GAUCHER

YEAR WHEN THERAPY BEGAN: 2010

KETKI GANESH

When 2-years old, Ketki's family noticed that she had an abnormally hard and strangely large abdomen for an infant. The puzzled but suspicious family immediately visited a specialized hospital for children in Pune to get her diagnosed.

Fortunately, Ketki's pediatrician correctly diagnosed it as a form of rare disease. After her bone marrow and blood tests, it was confirmed that she was suffering from Gaucher. The classic symptoms of a large spleen and low hemoglobin count reaffirmed their diagnosis.

Her pediatrician immediately connected the family to Sanofi Specialty Care, seeking treatment and humanitarian assistance. Within six months of her diagnosis, Ketki received her first infusion.

Now in school, Ketki is a diligent student. Her brother and she are inseparable, always together, curating new child-like mischief. She aspires to be a teacher. Her parents commend her patience, bravery and smiling spirit all throughout her therapy infusions.

GIRIJA KUMARI

Girija's parents lost their older son Ganesh to a condition they were unaware of. When Girija was born, she started displaying the same symptoms that Ganesh had too – an enlarged stomach and low hemoglobin.

Girija's brother passed away even before his condition was diagnosed, but her doctor and her parents were not going to allow history to repeat itself.

They ensured all necessary tests were undertaken in time and as expected, Girija too, was diagnosed with Gaucher within six months of birth – a disease her parents later realized was the cause of death for Ganesh, too.

In 2011, Girija's doctor facilitated the process for her first infusion within six months of her diagnosis.

Girija attends school regularly now. She is an avid watcher of dance shows on TV and loves making new friends. The little girl is a bundle of joy who aspires to become a doctor someday and heal the world.

GIRIJA KUMARI | GAUCHER

YEAR WHEN THERAPY BEGAN: 2011

DEEPESH KUMAR | GAUCHER

YEAR WHEN THERAPY BEGAN: 2015

OUR GAUCHER FIGHTERS NOT GOING DOWN WITHOUT A FIGHT

At the tender age of 12, when most teenagers are out and about, making new friends, cultivating a hobby, exploring relationships and savoring the joys of finishing childhood, Deepesh started falling progressively ill. What began as a mild fever, soon turned chronic.

Over time, his condition worsened. Various doctor visits and multiple medical tests later, he was diagnosed with a potentially debilitating condition – Gaucher.

Luckily, Deepesh and his family did not suffer too long. In 2015, his treatment began soon after a year of diagnosis. He feels fortunate that he did not experience the suffering of either spleen enlargement, or other physical deformities, thanks to the timely availability and accessibility of treatment.

Today, Deepesh leads an almost-normal life. He enjoys regular schooling and is extremely passionate about dance.

OUR GAUCHER FIGHTERS NOT GOING DOWN WITHOUT A FIGHT

It was strange and perplexing for seventeen-year-old Sangeetha and her parents to notice that she was finding it difficult to gulp down food. Never had she faced a problem like this. It took the family a few more complications to realize that there was something more serious than what met the eye.

Sangeetha's spleen started swelling up and as a result, her stomach began protruding. In addition, she had loose motions, headaches and low hemoglobin levels. It took two years of several consultations and a series of medical tests, for doctors to diagnose her with Gaucher disease; this was in 2016. The ordeal didn't end there for Sangeetha & her family. They struggled for two more years to get treatment, even post diagnosis.

Finally, her treatment began in 2018. With regular infusions, her health started to gradually stabilize and even improve.

While due to her failing health Sangeetha had to discontinue her studies from the first semester of B.Sc, she now hopes to pick it back up and complete her degree.

SANGEETHA M. | GAUCHER

YEAR WHEN THERAPY BEGAN: 2018

OUR **POMPE WARRIORS**

Warring Ahead with Faith and Resilience

#EveryLifeIsPrecious

GOVIND M. | POMPE

YEAR WHEN THERAPY BEGAN: 2011

GOVIND M.

Govind's parents lost their older daughter Sarika, to a condition they were unaware of. When Govind was a young child, he started displaying the same symptoms that Sarika had – frequent cold, respiratory issues and acute pain in his joints. His sister unfortunately passed away even before her condition got diagnosed, but his parents and doctors were not going to allow the same fate for Govind.

When Govind was just five years old, the doctors ran a battery of tests. Soon, they were able to diagnose him with Pompe disease. His therapy began quickly.

As a teenager, Govind realizes in retrospect, how big a support his family was to him. He is grateful they did not lose hope after losing their daughter. Instead, they remained positive and ensured that their son got the treatment he needed.

With timely diagnosis and regular infusions, Govind leads a near-normal and happy life. His walk and run are as normal as anyone else's – something that patients with Pompe disease are not usually able to do. In fact, onlookers can hardly tell he suffers from Pompe disease.

Govind is a big fan of football and plays it with his younger brother, Manu Krishna. He aspires to become a policeman and serve his country someday.

MADIHA MAKANDAAR

While Madiha was born as a healthy child, it was not until she was about eighteen months old, that she started facing health challenges. When her parents found that she struggled to eat and even breathe normally, they rushed her to the local hospital in the small town of Bijapur. She was misdiagnosed and treated for Tuberculosis then.

With no improvement in her health, Madiha's parents consulted a child specialist in Bengaluru. While he correctly diagnosed her with Pompe disease, he was skeptical about her survival.

Not ones to lose hope, Madiha's parents enquired persistently and searched extensively online, hoping there's a treatment available for Pompe disease. Fortunately, in 2012, they learned that there was.

From the age of two, with all these years of treatment, Madiha now lives a near-normal life. She loves going to school, enjoys drawing and actively participates in games and races. She aspires to be a teacher when she grows up.

#EveryLifeIsPrecious

MADIHA MAKANDAAR | POMPE

YEAR WHEN THERAPY BEGAN: 2012

FAJANSA

For most women, pregnancy and motherhood are amongst the most joyous experiences of their lives. For Fajansa, it was no different when she was pregnant in 2012. But unfortunately for her, things changed for the worse.

She started experiencing severe muscle pain which she misunderstood to be a part of her pregnancy. Post her delivery, she also experienced unusual breathing problems. Three years and several tests later, doctors diagnosed Fajansa with Pompe disease.

Fortunately, Fajansa's parents came to her aid and reached various avenues to get her treatment started by 2014. She was twenty-nine years old, then.

Today, things are finally looking up for her, thanks to her treatment. She lives a happy life with her daughter. Like any other woman, she too aspires to be a role model mother to her. Fajansa is happy that she can now fulfil all the dreams of her daughter.

Her daughter wants to become a doctor and find a cure for Pompe disease, so she can treat many like her mother, in time.

DILNA N.

For Dilna's mother, the demise of her son was the most shattering time of her life. Later, with her daughter Dilna, the family saw a silver lining. But, for not too long.

As an infant, Dilna showed signs of poor health that were believed to have taken her brother's life. Experience, they say, is life's best teacher. There was no way her mother was going to give up on Dilna. When she saw her little daughter increasingly suffer from severe cough and difficulty while walking, she ensured all the relevant medical tests were done in time. It was then that Dilna was diagnosed with Pompe disease, at the tender age of two and a half years.

Dilna's treatment started soon after her diagnosis in 2015, when she was about three years old. Timely diagnosis and treatment have stabilized Dilna's health condition and enabled her to lead an almost normal life.

The ever-so-lively and vibrant Dilna has won competitions for singing and reciting poems in school. Her dream is to become a police officer when she grows up.

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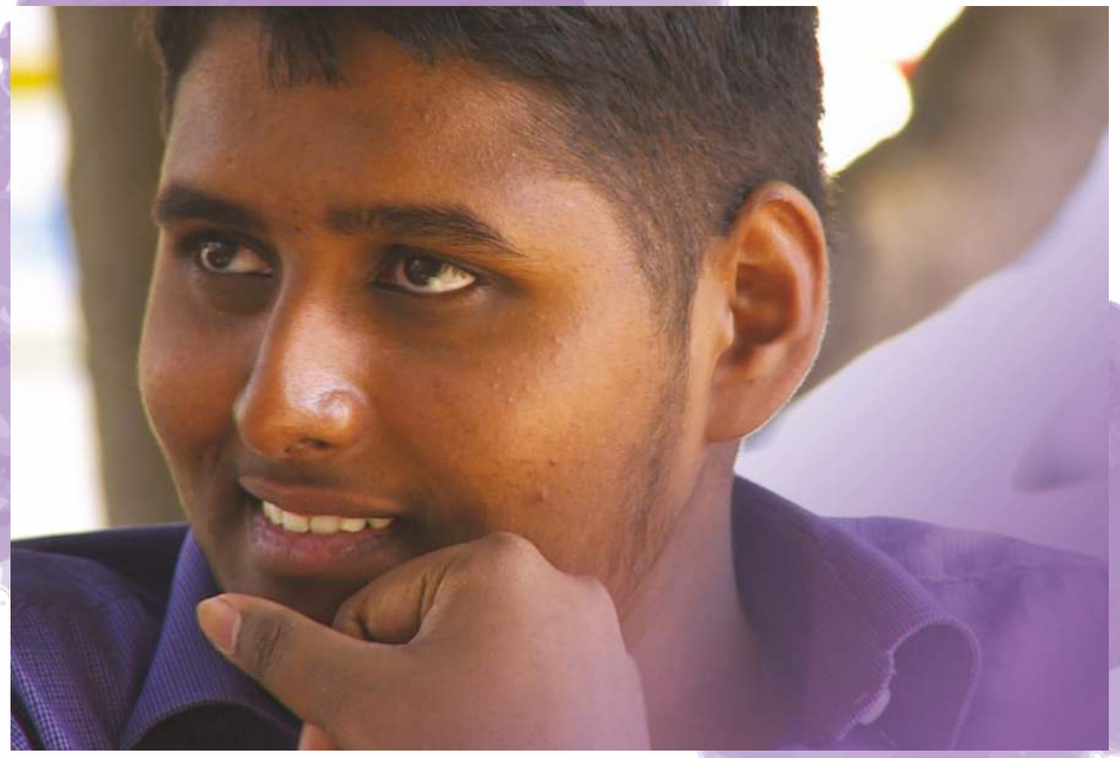
DILNA N. | POMPE

YEAR WHEN THERAPY BEGAN: 2015



GEORGE THOMAS | POMPE

YEAR WHEN THERAPY BEGAN: 2010

OUR POMPE WARRIORS WARRING AHEAD WITH FAITH AND RESILIENCE

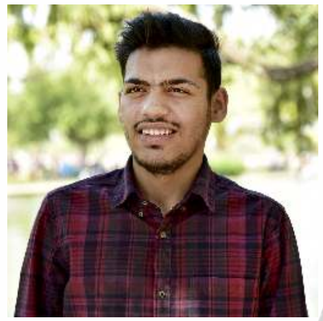
At an age when a young boy should be running around and playing with his friends, George was running from pillar to post with his parents, consulting doctors for his puzzling health condition. In 2003, when he was about seven years old, he developed nodules in his knuckles and elbows, started gaining a lot of weight, needed help while climbing stairs or lifting himself off the ground, and showed signs of Rheumatoid Heart Disease.

George's parents consulted several medical practitioners, but none could correctly diagnose any clinical reason behind his symptoms.

In 2007, one of George's doctors sent his muscle biopsy to USA where it was correctly diagnosed with Pompe disease. His treatment only began three years later, when he was incidentally hospitalized for respiratory failure and slipped into coma for a month.

Once his treatment began, any further deterioration of his muscles stopped. And he does not require the ventilator as often, anymore.

Thanks to the consistent and timely infusions, his health has stabilized, and his respiration has improved significantly. Though wheelchair-bound, due to George's persistence and courage, he has completed his MCA (Masters in Computer Application) successfully and received accolades for it, from the Ministry of Human Resource and Development.



WINNING
OVER FABRY

Empowered for a Better and Wholesome Future

#EveryLifeIsPrecious

#EveryLifeIsPrecious

RAKESH CHAWHAN | FABRY

YEAR WHEN THERAPY BEGAN: 2014

RAKESH CHAWHAN

Rakesh was born a normal baby in 1998. When he was in the 9th grade, his eyesight failed suddenly, and he could barely see anything written on his classroom blackboard.

His parents immediately took him to an ophthalmologist who noticed black dots in his eyes. He was referred to a geneticist, who, after running a battery of tests, and discovering that his maternal uncles had passed away due to kidney and heart failures, concluded that he was afflicted with Fabry disease. This was in June 2013.

He was pursuing his Bachelor's in Technology, but had to soon discontinue owing to poor health.

Fortunately, Rakesh started receiving his treatment just a year after his diagnosis. With regular treatment, his health started to improve. The tingling pain, predominantly in the palms of the hands and soles of the feet, reduced.

Rakesh now lives a normal life and manages his family business. His parents are happy that he hasn't met the same fate as his maternal uncles, who died due to the absence of diagnosis and timely treatment.

Rakesh wishes to make his parents proud and give them a comfortable life.

PARTHO CHAKROBORTHY

Partho lives life to the fullest; more so because he has battled a health struggle for long. Founder of a start-up, a fitness enthusiast and a father to a teenage daughter, Partho does not mince words when he says that he is alive only because of timely and regular treatment.

It all began in 2003, when he started experiencing severe pain in his right eye, but no real issue could be detected. Around the same time, one of his cousins passed away due to kidney failure.

Prior to that, a few years ago, another cousin had passed away owing to the same reason. Both cousins were males from the maternal side. This set off alarm bells for Partho.

After a battery of tests, doctors found abnormalities in his kidneys and heart. An examination of his family history and a DNA analysis confirmed, that he had Fabry disease. That is when he realized that it probably was the same disease that claimed his cousins' lives, too.

Fortunately, in 2015, he started receiving his infusions. He is thankful that he received the treatment in time as it gave him a second chance at life.

#EveryLifeIsPrecious

PARTHO CHAKROBORTHY | FABRY

YEAR WHEN THERAPY BEGAN: 2015

GEORGE AMIL | FABRY

YEAR WHEN THERAPY BEGAN: 2016

GEORGE AMIL

When one hears a seven-year-old boy complain of pain in his bones, the first thought is that he would have probably hurt himself. But what if the pain persists for several years? Adding to the woes, numerous doctors were clueless about the condition. This is merely a glimpse of what George's life was like.

For nine long years from the age of seven, George suffered misdiagnosis and inappropriate treatment. His joint pain was so severe that he could not as much as stand, and needed frequent hospitalization. With pain, he also used to develop rashes all over his body. It was recommended that he consult a clinical geneticist, and that was when he was diagnosed with Fabry disease in 2015.

Fortunately, his treatment was initiated within a year of diagnosis and his family says 'it worked wonders for George'.

Within months of receiving the enzyme replacement therapy, his condition drastically improved. There has been no further deterioration, and his episodes of pain are a thing of the past.

George is currently pursuing Master's in Computer Application and plans to complete his professional degree, in time. He aims to become successful in life and make his parents proud. George loves watching football and is a cricket enthusiast.

DR. ARVIND CHHABRA

Since childhood, Arvind faced heat intolerance, severe joint pain and got tired very easily. In 2015, when his brother suffered acute renal failure and was undergoing tests, his brother's physician decided to do genetic screening for the entire family. A series of medical tests and an analysis of his family's genetic history revealed that Arvind too, had typical clinical manifestations of Fabry disease. That is when it was discovered that like his brother, Arvind suffered from Fabry, too.

In August 2018 when he was twenty-five years old, Arvind started receiving the enzyme replacement therapy. Within 3-4 months of his treatment, his condition improved drastically. He could tolerate heat and his joint pain had also reduced.

Arvind has completed his MBBS successfully and is now Dr. Arvind Chhabra.

He has applied for a job in the Punjab State Health Department and is committed to serving the community in the space of healthcare.

BATTLING WITH **MPS TYPE I**

Beating the Odds and Winning at Life

#EveryLifeIsPrecious

LAVANYA M.

Lavanya first displayed symptoms of MPS Type I when she was just one and a half years old. With frequent bouts of common cold, fever and persistent breathing problems, her parents ran from pillar to post to find out what really was wrong with their infant.

As her symptoms worsened over the next few years, doctors recommended a detailed check-up, including blood and bone tests. Her X-ray reports revealed a deformity in the joints of her hands, fingers and legs, which confirmed that she was affected with MPS Type I disease.

Even though doctors told her parents that there was no treatment for her condition, they didn't give up. They consulted various specialists, one of whom was also a clinical geneticist and a specialist in rare diseases. She offered a ray of hope, saying Lavanya's condition is treatable.

Finally, at the age of ten, Lavanya started receiving treatment. Her condition improved, consistently. She is studying physics and aspires to be a professor of Computer Science. Also, she loves dancing, drawing and cooking.

SABRISH SHANMUGAM

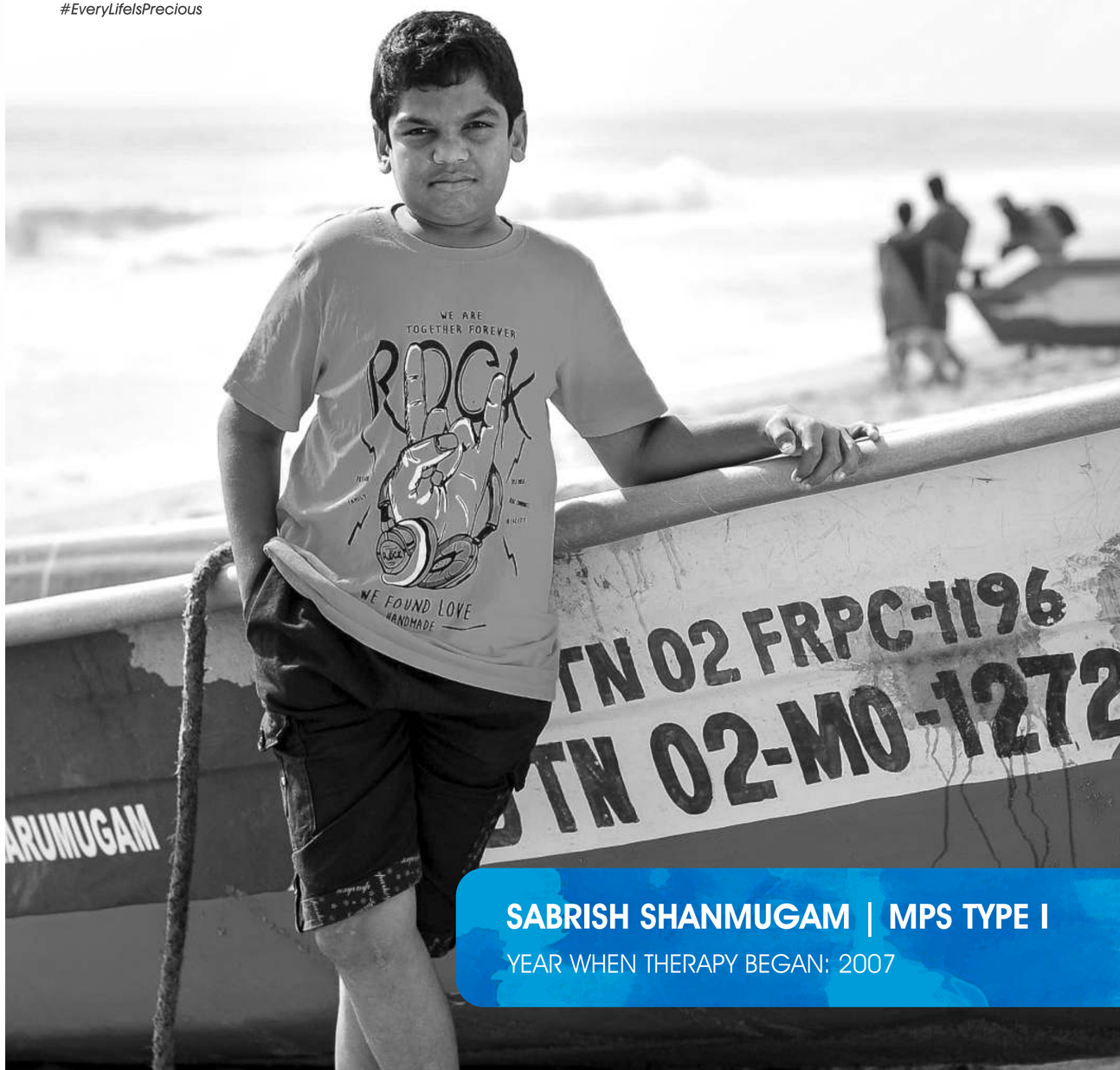
When Sabrish turned two, he was beset with medical problems. He suffered from high fever and loose motions for a long time. His head swelled up to an abnormal size. His hand and finger joints began to show deformities.

He had difficulty walking and had to undergo a surgery to correct the bone deformities. He also underwent a hernia surgery twice and got a corneal transplant for both eyes.

All these health issues prompted his family doctor to advise his parents to consult a clinical geneticist who diagnosed Sabrish with MPS Type I in 2007. Post which Sabrish's treatment began soon.

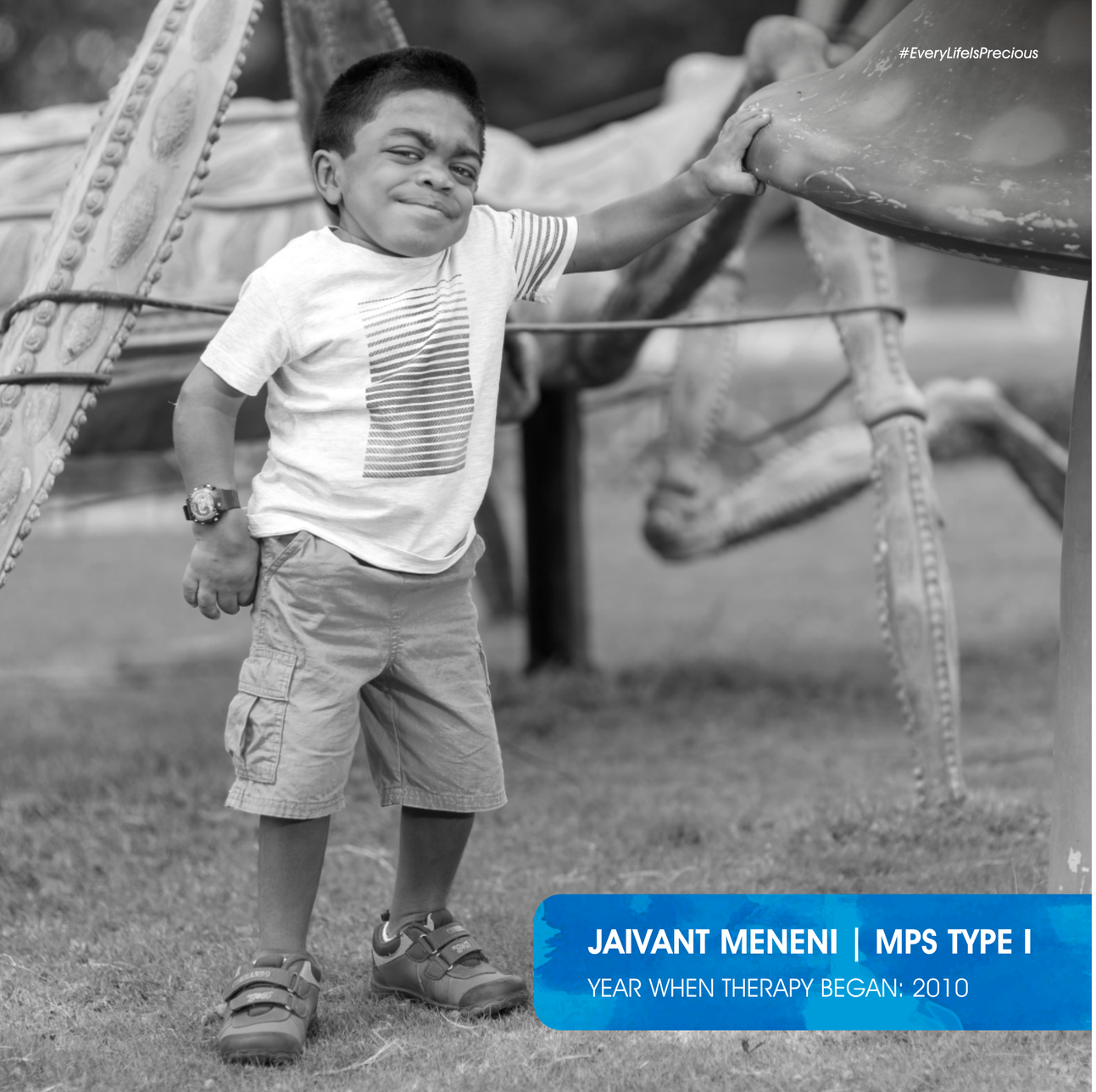
Now in his teens, Sabrish lives life to the fullest. He loves cycling, dancing and playing outdoors. When asked about his hopes for the future, he mentioned that he wants to always remain physically fit and live a fulfilling life.

#EveryLifeIsPrecious



SABRISH SHANMUGAM | MPS TYPE I

YEAR WHEN THERAPY BEGAN: 2007



JAIVANT MENENI

Jaivant was barely five months old, when he had a cloudy cornea and an enlarged liver and spleen. His uncle, an eye specialist, first noticed Jaivant's problem with his vision along with other symptoms while clicking his pictures. He was immediately recommended to a geneticist.

Jaivant's samples were sent to the UK, where he was diagnosed with MPS Type I disease. He was ten months old then.

At the age of two, Jaivant started receiving treatment.

Timely treatment has given him a chance to live a near-normal life. Since therapy began, his vision and cognitive development has been remarkable. His family whole-heartedly believes that the therapy has given them a ray of hope, when life seemed bleak.

Currently in school, he is brilliant in academics. Jaivant dreams of playing cricket for India, like his favorite cricketer - Virat Kohli.

SUMAIR ZUBAIRY

A lover of music, Sumair first displayed signs of MPS Type I disease at the age of six. His growth milestones were not like other children his age. By the time he was in his twenties, he could not fold or raise his hands fully. An award-winning drummer, Sumair soon realized that he had swelling and stiffness in his joints, because of which he could not play the drums anymore.

Sumair's life hit a low note when he underwent a major spinal surgery at twenty-two. Two years after surgery, he experienced severe pain in his limbs and could barely sleep. That is when his parents realized that the last intervention was not adequate. And he met with a clinical geneticist who initiated his therapy, in 2011.

Post therapy, he began to show remarkable improvement in his mobility and growth. There was a time before therapy when he thought that he would have to give up his passion for music, but today, he plays the piano and learns classical music. Sumair lives an independent life and hopes to marry soon.

#EveryLifeIsPrecious

SUMAIR ZUBAIRY | MPS TYPE I

YEAR WHEN THERAPY BEGAN: 2011

HARSHRAJ KRUPAL MODI | MPS TYPE I

YEAR WHEN THERAPY BEGAN: 2013

HARSHRAJ KRUPAL MODI

Hashraj was born a healthy infant, but at the age of two, when his father observed him walking on his heels with his legs twisted inwards, he sensed a serious health issue.

His father remembers the health challenges his son suffered, ever since he was very little - rough & stiff hands, umbilical hernia, vision problems and extreme fatigue - which hampered his attendance through kindergarten.

At five years, the area near his navel turned green and doctors suspected some form of a rare disease. In 2011, his blood test confirmed MPS Type I. Fortunately for him, his treatment started soon after his diagnosis, in 2013.

With regular treatment, Harshraj is now able to lead a near-normal life. His walk and vision have improved. He attends school with less fatigue and an improved heart condition. Harshraj loves spending time with his cousins. As a grown up, he wishes to be a successful businessman like his dad.

A BATTLE WORTH FIGHTING AND WINNING WITH PRIDE

Very early on in life, Dharmendra realized that there was something terribly wrong with his overall appearance. He had coarse facial features and he could neither extend his fingers nor bend his knees properly. He also noticed he was comparatively shorter than others his age and had blurred vision due to corneal clouding.

Even after visiting several hospitals and consulting many doctors, no one was able to diagnose his very unusual health complication. Several years and struggles later, he was finally diagnosed with MPS Type I in 2007 at AIIMS, New Delhi.

Even though Dharmendra comes from an economically weak background, that did not deter him from seeking his right to healthcare. He even fought a legal battle and finally won his access to treatment. But he didn't stop there as he fought for the same right to treatment for his younger brother, suffering from the same condition.

Since 2016, his therapy began and is on-course. Things are finally looking positive for Dharmendra and his family.

Currently, Dharmendra continues his work as a daily wager in Delhi and supports his family; while his younger brother studies in school.

DHARMENDRA KUMAR | MPS TYPE I

YEAR WHEN THERAPY BEGAN: 2016

VISHAL KUMAR | MPS TYPE I

YEAR WHEN THERAPY BEGAN: 2013

A BATTLE WORTH FIGHTING AND WINNING WITH PRIDE

Vishal first displayed symptoms of MPS I at the tender age of two. His elder brother Dharmendra, who also suffers from this disease, immediately noticed the symptoms. For Dharmendra and his parents, it was like history repeating itself. As he grew older, Vishal faced difficulty while walking, could not open his fingers properly, and felt that he was very different from other children his age.

After his brother fought a long-drawn legal battle for access to therapy, both Vishal and Dharmendra started receiving treatment in 2013 and 2016, respectively. Vishal was only five years old, then.

Currently, Vishal studies in school. Like children of his age, he loves to watch cricket and wishes to be able to play it too, someday.

PATIENTS ARE PEOPLE, FIRST.

WE ALL LAUGH AND CRY.

WE HOPE AND DREAM.

WE HAVE FAMILY AND FRIENDS WHO LOVE US.

WE WANT TO LEAD NORMAL LIVES.

THIS IS WHY WE DO WHAT WE DO.

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